

# **Patient terminal and self-management of cancer patients:**

**A case study of the development and implementation process of the technology in a hospital setting.**



## **Master thesis**

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Picture front page: Patient terminal, HealthBrowser, Source: Hospital IT, Oslo, Norway,  
2008.

## Summary

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Stimulation of self-management of the patient by the use of different information and communication technologies (ICTs) is a theme that has received increased attention during the last couple of years. In order to understand how novel ICTs can contribute to the facilitation of self-management of the patient, it is important to understand why and in what way the technology is designed and developed. Recently a patient-related ICT has been developed and implemented in a Norwegian hospital. The technology, the patient terminal, which consists of a computer that is connected to a white arm which again is connected to the wall, is located at the hospital bed of the patient. Norway is one of the pioneering countries in the development and introduction of this patient-related hospital ICT, although this innovative technology gradually is entering many hospitals and health care institutions in the Western world.

To understand the development and implementation process of this technology, the developers and implementers' roles, aims and image of the users, in relation to self-management of the cancer patient, will be explored. The main question for the analysis will be:

***"How are the aims of developing and implementing the patient terminal in a hospital setting related to the user and the self-management of cancer patients in hospital-care?"***

The required data to answer this question are collected by in-depth interviews with developers and implementers of the technology, by analysing the technology itself, and by the use of relevant scientific literature related to this topic. The exploratory case-study has been performed at the Cancer Centre of Ullevål University Hospital in Oslo.

Central in the analysis is the actors' image of the end-user(s) of the technology, how this is created, and reflected in the design of the technology. By the use of the Script-theory (Akrich, M. 1992 and 1995), the socio-technical analysis of the script of the technology can reveal to what extent the actors' view of the end-user is reflected in the design of the patient terminal, and in what way the technology can be used to facilitate self-management of hospitalized cancer patients.

This research shows how developers and implementers constructed images of the end-user as a diverse user-group. Diversity among users in nationality, age, interests, health condition and skills is recognized by the actors and taken into account in the design of the patient terminal. The research does also reveal the patient terminals' potential to facilitate self-management. However, the new design of the prototype of the patient terminal has more potential to contribute to this process, than the current, already implemented patient terminal at the Cancer Centre. The findings show that facilitation of self-management was not an initial aim of the developers and implementers involved. In general, this is an aim that received increased attention by all actors during the development process. However, the potential of novel ICTs, like the patient terminal, to facilitate self-management was recognized by two actors already at an early stage in the development process, the nurses and the Norwegian Cancer Society (NCS). This can possibly be explained by the nurses' hands on experience with cancer patients, as their daily caretakers, and the NCS aim to improve self-management and information services for the group they represent, the cancer patients and their families. The Script-analysis of the technology demonstrates how the new design of the patient terminal can contribute to this facilitation process in hospitalized cancer patients. Provision of information was, by the actors involved, identified as an important factor to facilitate self-management. The new design of the technology makes use of an extended information arena, where provision of information to the patient is realized, both related to the daily management

of disease and symptoms, and the personal situation of the cancer patient. The Script-analysis performed indicates that the patient terminal is designed only as an information technology to facilitate self-management and not as a communication technology.

Based on the findings, recommendations are made for future developments and for the design of the system with respect to facilitation of self-management in hospitalized cancer patients.

Furthermore, a number of recommendations are made for future scientific research related to the topic. The explorative case-study of the patient terminal can create a basis for future research projects, related to the patient terminal technology, or development and implementation of ICTs for facilitation of self-management in health care. Because of the explorative character of the research, some parts of this analysis, or certain aspects related to the topic, like the actual effect of using the technology for the purpose to facilitate self-management in cancer patients, could be examined more extensively in further research.

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Tusen takk!

Dank jullie wel!

## Chapter 1 – Introduction

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### 1.1 Introduction

The number of people with cancer or other chronic disease will increase the coming years due to demographical changes in society, like change in lifestyle and obsolescence of the population. To be able to deal with these changes, efficient use of resources to optimize the quality of health care services and the quality of life of the individuals involved, can be of importance. Facilitation of self-management of the patient, can increase the individuals' active participation in management of own health and situation, and contribute to deal with the mentioned changes in society. The participation in own health management can also be essential for the overall health of a patient, and how the patient experience the situation they are in (Barlow et al. 2002)<sup>1</sup>.

More and more innovative information- and communication technologies (ICTs) are developed and designed to deal with the changes and new demands in society and to facilitate self-management in patients. The way ICTs are developed, and how the end-user of the product is taken into account during the design process, can be of importance to understand how and to what extent the technology can contribute to facilitation of self-management of the patient.

The access to knowledge can be improved by introducing new ICT applications in the hospital. In this research I will focus on one of the ICT applications: the patient terminal. The patient terminal is an information- and communication technology (ICT) recently introduced in hospital care. The patient terminal is easy accessible for the hospitalized patient, implemented bedside of the patient. The technology has many different service possibilities for provision of information and education to the patient, which indicates that the technology possibly can contribute to the process of self-management of the patient.

When a patient is hospitalized, care is provided to the patient by professionals and other care takers. Next to the care provided, can self-management of the patient be stimulated to optimize the health outcome and the active role of the patient in relation to own disease and treatment (Turton, et. al 2002)<sup>2</sup>.

The patient terminal creates new possibilities for communication and information for the cancer patient when in hospital<sup>3</sup>. The technology has, depending on its' design, the potential to be used as mean to facilitate self-management and control reinforcement of the user, next to make the hospital stay more pleasant for the patient.

The exploration of the development and implementation process of the technology can provide knowledge about to what extent the patient terminal can be used to facilitate self-management in hospitalized cancer patients.

To increase our understanding of this design process, it is important to know why it was decided to introduce the patient terminal at the Cancer Centre in the first place, to identify the actors involved, their aims of developing the technology, and how the end-user is imaged and reflected in the design of the product.

The inclusion of multiple actors, directly or indirectly involved in the design, next to documents related to this process, and the analysis of the script of the technology, can reveal

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<sup>1</sup> Barlow, J. , Wright, C. Sheasby, J., Turner, A. , and J.Hainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. School of Health and Social Sciences, Coventry University, England, UK, Elsevier Science Ireland Ltd. Doi.10.1016/S0738-3999(02)00032-0

<sup>2</sup> Turton, P and Cooke, H. (2002) Meeting the needs of people with cancer for support and self-management. Obtained via Science Direct. Complementary Therapies in Nursing and Midwifery. Volume 6, Issue 3, aug 2000, pp.130-137

<sup>3</sup> Hospitality, product provider patient terminal. Retrieved 15th of February 2008  
<http://www.hospitality.no/index.php?cat=2906b>

important knowledge about the social shaping and design of the product. Central of the research will be the analysis of:

**"How are the aims of developing and implementing the patient terminal in a hospital setting related to the user and the self-management of cancer patients in hospital-care?"**

Sub-questions are developed related to the overall research question presented above. The sub-questions and objectives will be further described in chapter three.

## **1.2 Background and area of the research**

Within health care (Te@mwork, 2007)<sup>4</sup> and scientific research (ZonMw, 2008)<sup>5</sup>, the involvement of the users, and the use of ICTs to stimulate self-management, got increased attention the last years, as more and more novel technologies are developed to provide the user with self-management support. The patient terminal technology, which is an innovative healthcare information and communication technology, was introduced at the Cancer Centre at Ullevål University Hospital in the autumn 2006<sup>6</sup>, and is still in development. The patient terminal is a digital information and communication technology, providing the user with entertainment, communication and information<sup>7</sup>. Thus, the services provided by the patient terminal are many, and allow for provision of both general and specific disease-related information to the hospitalized cancer patient.

Different actors are involved in the development and implementation processes of the technology. To better understand this process, interviews with the different actors involved, and an analysis of the design of the technology, has been performed, as a part of a socio-technical analysis.

## **1.3 Context of the study**

There is, as mentioned, increasingly more focus on the role of the patient, managing and actively participating in the cure and care of their own disease (Kammen, et al, 2002)<sup>8</sup>. The patient does not only by Norwegian law<sup>9</sup> have the right to actively participate when health services are provided, they do also have the right for information about their own disease and treatment. The provision of information to the patient is important for the patient to actively participate, and also to support patient self-management in cure and care of disease (Barlow, et al. 2002)<sup>10</sup>. Several information and communication technologies are already in use, or being developed, as mean to stimulate aspects of the self-management process of the patient (Celler, et. al. 2003)<sup>11</sup>.

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<sup>4</sup> Te@mwork 2007 National strategy plan ICT development in Health Care by the Norwegian Directorate for Health and Social welfare. Retrieved 02.03.2008 at [http://www.shdir.no/samspill/s\\_mspill\\_2007\\_5642](http://www.shdir.no/samspill/s_mspill_2007_5642) English and Norwegian version of Te@mwork 2007 / S@mspill 2007 available. Appendix 7

<sup>5</sup> Zorgonderzoek Nederland Medische Wetenschappen, ZonMw, (Health Research Dutch Medical Science) visited in June 2008: <http://www.zonmw.nl/nl/subsidie/subsidiekalender/subsidieronde/item/diseasemanagement-chronische-ziekten/>

<sup>6</sup> Ullevål University Hospital, visited at the 15th of February 2008:

[http://www.ullevaal.no/modules/module\\_123/proxy.asp?iCategoryId=460&iInfoId=15229&iDisplayType=2](http://www.ullevaal.no/modules/module_123/proxy.asp?iCategoryId=460&iInfoId=15229&iDisplayType=2)

<sup>7</sup> Product provider Hospitality Retrieved 15th of February 2008 <http://www.hospitality.no/index.php?cat=2906b>

<sup>8</sup> Kammen, van J. (2002) Zorgtechnologie, kansen voor innovatie en gebruik. Den Haag Stichting Toekomstbeeld der Techniek / Bewton.

<sup>9</sup> Norwegian law on patient rights, Law 1999-07-02 nr 63 (Patient rights law § 3-1 and 3-2). The Norwegian Directorate for Health and Social welfare. Additional information about the law see extended literature and document review appendix 6.

<sup>10</sup> Barlow, J. , Wright, C. Sheasby, J., Turner, A. , and J.Hainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. School of Health and Social Sciences, Coventry University, England, UK, Elsevier Science Ireland Ltd. Doi.10.1016/S0738-3999(02)00032-0

<sup>11</sup> Celler, B.G, Lovell, N.H, and Basilakis, J. (2003) The Healthcare System. Using information technology to improve the management of chronic disease. The Medical Journal of Australia. Vol 179. pp.242-246



Patients with cancer are likely to experience a phase of lack control and helplessness as a result of their illness experience (Turton, et al. 2002)<sup>12</sup>. The stimulation of self-management of the patient, by providing knowledge, by the use of the patient terminal technology, can possibly stimulate the feeling of control and contribute to optimize the health of the patient, and the situation they are in.

#### ***1.4 Study purpose, generalizability and significance***

##### **1.4.1 The purpose of the study**

The purpose of this research is to understand and describe the development and implementation process of the patient terminal in a Norwegian hospital. The focus will be on the exploration of how and to what extent the end-user is taken into account in the development and implementation of the patient terminal at the Cancer Centre. The analysis also aims to explore and describe to what extent aims of developing the technology relate to facilitation of self-management in cancer patients, and to what extent the design of the technology can be used for this purpose. The study does not aim to analyse if the technology actually supports self-management, or the actual effect of using the terminal for this purpose. The research will also not aim to answer questions related to how the users themselves, the patients, their experience or use of the technology.

##### **1.4.2 Generalizability of the research**

The analysis focuses, as mentioned, on the development and implementation of the patient terminal technology at the Cancer Centre of a Norwegian hospital. Still, the research findings might be relevant for other countries where this novel technology is being developed and implemented.

The latest developments include a pilot design-project of the technology, for patients with testicular cancer. The results aim to be generalizable to other forms of cancer care or cancer types.

The knowledge about the development and implementation process of the patient terminal may also be relevant for similar technologies, or interactive means, designed to facilitate self-management of patients in hospitals, or in health care in general.

##### **1.4.3 Significance and relevance of the research**

The role of information and communication systems within an organizational context can be studied and has been studied in many different ways. Up to this point in time the patient terminal technology in regard to user-interface<sup>13</sup>, integration interface<sup>14</sup> and design<sup>15</sup> has been investigated.

To our knowledge, socio-technical aspects like the basic intentions of introducing the patient terminal in a hospital setting, focusing on the role and aims of the different actors, and to what extent the end-user is taken into account, next to in what way the patient terminal can facilitate to self-management of hospitalized cancer patients, has not yet been studied.

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<sup>12</sup> Turton, P and Cooke, H. (2002) Meeting the needs of people with cancer for support and self-management. Obtained via Science Direct. Complementary Therapies in Nursing and Midwifery. Volume 6, Issue 3, aug 2000, pp.130-137

<sup>13</sup> Markiewicz, J.K. (2005) User interface for patient terminals. Norwegian University of Science and Technology, Trondheim, Norway

<sup>14</sup> Alsos, O.A. Svanæs, D. (2006) Interaction techniques for using handhelds and PCs together in a clinical setting. Norwegian University of Science and Technology, Trondheim, Norway

<sup>15</sup> Volstad, N. (2008) Utvikling av brukergrensesnitt for pasientterminaler. Institute for product design, Norwegian University of Science and Technology, Trondheim, Norway

Thus, due to the lack of literature within this field, rapid technologic developments, and in the light of the scientific<sup>16</sup>, social and political debates within health care, and national strategy plans<sup>1718</sup> related to self-management and ICT in health care, the topic is considered to be of added value.

### **1.5 Personal motivation**

The personal motivation for choosing the subject is related to my interest of how medical technologies and innovations can contribute to optimize health care and the care for the patient.

The health care is changing, as a reaction on the demographical changes in society, due to new medical and technological developments, and due to the fact that patients in general want to actively participate more in their own health and treatment.

The centralization and activation of the patient, through patient empowerment and self-management, by the use of medical technologies and ICTs, can potentially result in better care for the patients, more efficient use of available resources and optimization of the provision of care.

Cancer is a disease that sadly enough is affecting more and more people. Based on own experience and work with patients, I think that for cancer patients, as for any individual, the management of own situation and to be a part of decision-making processes, can be crucial for how the individual deals with and experience their own situation, health and the care provided.

The patient terminal technology introduced at the Cancer Centre in Oslo, is a relatively new hospital technology for patients that possibly can be used in the facilitation of self-management, and to optimize the care for the hospitalized cancer patient.

Due to the fact that the technology already is implemented, but still under development, gives me the possibility to analyse this process, to better understand the design of the product and hopefully provide the actors involved with interesting knowledge about this process, and the possibilities to use the technology to stimulate self-management of cancer patients.

Knowledge can be revealed which hopefully can be valuable for the Cancer Centre, policy makers, health scientists and the health care in general, to optimize further technologic developments and implementation of the product, and the care for cancer patients.

### **1.6 Limitations of the study**

The study will be limited to the actors involved in the development and implementation process of the new patient terminal technology. The user themselves, the patient, will at this point in time not be included in the analysis. The study of the users own experiences, or what the patients actually use the terminal for, will be beyond the scope of this research.

One of the reasons not to include the patients is due to ethical reasons. An ethical committee must approve the inclusion of the patient, and the time constraints of this research does unfortunately not allow the estimated waiting time for this permission.

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<sup>16</sup> Nederlandse Organisatie voor Wetenschappelijk Onderzoek, NWO, (Dutch organization for scientific research) published 6th of June 2008, visited 12th of June 2008 [http://www.nwo.nl/nwohome.nsf/pages/NWOA\\_7FCBD5](http://www.nwo.nl/nwohome.nsf/pages/NWOA_7FCBD5)

<sup>17</sup> Norwegian Government National Strategy plan for cancer care a prognosis towards 2020, visited 14<sup>th</sup> of June 2008 [http://www.regjeringen.no/upload/kilde/hd/rap/2004/0010/ddd/pdfv/220645-kreftstrategi\\_endelig\\_dokument.pdf](http://www.regjeringen.no/upload/kilde/hd/rap/2004/0010/ddd/pdfv/220645-kreftstrategi_endelig_dokument.pdf), and Te@mwork 2007 National strategy plan of ICT development, by the Norwegian Directorate for Health and Social welfare. Retrieved 02.03.2008 at [http://www.shdir.no/samspill/s\\_mspill\\_2007\\_5642](http://www.shdir.no/samspill/s_mspill_2007_5642) English and Norwegian version of Te@mwork 2007 / S@mspill 2007 available.

<sup>18</sup> Dutch Government, published 13<sup>th</sup> of June 2008, visited 17<sup>th</sup> of June 2008, Chronic disease in Dutch health care [http://www.regering.nl/Actueel/Pers\\_en\\_nieuwsberichten/2008/juni/13/Kabinet\\_chronische\\_ziekten\\_terugdringen](http://www.regering.nl/Actueel/Pers_en_nieuwsberichten/2008/juni/13/Kabinet_chronische_ziekten_terugdringen)

## **Chapter 2 – Related literature**

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### **2.1 Literature review: patient terminal and self-management**

A survey of scientific literature related to the field of self-management of patients and the use and development of ICT in health care, has been studied to orientate about the subject and to obtain information for discussion of the research findings. The relevant research findings of this survey will be presented in this paragraph, as an introduction to the topic and relevant scientific debates related to ICT in health care and self-management of patients. A search strategy was developed to make specific literature searches, and to obtain relevant scientific literature. The basic criteria made, which are less strict than when a systematic literature review is made, will be presented below.

#### **2.1.1 Search for scientific literature in electronic databases**

By the use of the University library at the University of Twente, electronic databases and journals, related to the field of Health Sciences, was selected for the literature searches in: Medline, PubMed, Jstor, PiCarta, ScienceDirect, and JMIR. Articles and books from the University library were also used for finding relevant literature, next to specific searches in Google related to the topic, and political debates, national strategy and policy plans, and health care laws.

#### **2.1.2 Key terms to be used for literature searches**

The following key-terms were used, single or in combination, to obtain relevant literature: *Patient terminal, self-management, cancer patient, interactive means, health information, ICT, IT, socio-technical approach/analysis, design, development, implementation, (hospital) technology.*

#### **2.1.3 Inclusion and exclusion criteria for the scientific articles**

Articles included were published between 1990 and 2008, and related to socio-technical analysis of health care technology, patient self-management, and use and development ICT in health/hospital care.

Articles not published in English, Dutch or Norwegian, and before 1990, were excluded.

### **2.2 Presentation of relevant literature**

The presentation of relevant literature for this research is diverse in the sense that not one single investigation is found exactly related to the topic of this research. There has, by our knowledge, not been performed a socio-technical analysis of the development and implementation process of the patient terminal technology in hospitals, and its contribution to patient self-management. Because of this reason it was needed to look for literature in the broadest sense, related to information and communication technologies (ICTs) in health care in general and the stimulation of self-management.

This paragraph will conclude with a summary of the previous research results relevant for this study, and a description about what to be developed further and what to find out more about, by performing this research.

There can be many different reasons to develop and introduce ICTs in health care. According to Gawande et al. (2000)<sup>19</sup> are information- and communication technologies likely developed to allow the patient to manage, monitor and regulate their own care, and to increase the

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<sup>19</sup> Gawande, A.A. and Bates, D.W. (2000) The Use of Information Technology in Improving Medical Performance: Part II. Patient-Support Tools. *Medscape Today*, February 2000.

opportunities for medical education of the patient. The study of the patient terminal technology at the Cancer Centre will reveal reasons for introducing and developing the technology in the first place, and if these reasons confirm or oppose the reasons as mentioned in the study by Gawande et al. (2000).

Recent investigation about the use of ICTs to facilitate patient self-management, performed by Van Gemert-Pijnen et al (2007)<sup>20</sup>, demonstrates how self-management of self-limiting disease can be facilitated by the use of web-based communication system in primary care. The study shows that digital web-based tools can promote self-management in patients, especially of people with chronic disease and people that have confidence in computer generated advice. Conclusions are made that web-based consultations in primary care can promote the efficiency of the system and stimulate self-management of the patient.

In another study about the use of internet based self-management systems for asthma patients, to achieve better control of their disease (Van der Meer, V. et al. 2007)<sup>21</sup>, the results show that novel information and communication technologies can meet the needs for self-management support. Internet based self-management systems appeared to be a powerful tool to overcome limited self-efficacy of adolescents with poor asthma control. Together with an internet self-management program and a short message service system, the patients being studied demonstrated improved self-efficacy and increased self-management by the use of the technologies.

Both studies mentioned demonstrate that different types of information- and communication technologies can be used to support or facilitate self-management in patients. The study of the patient terminal will reveal knowledge about how and to what extent the script of the technology can contribute to self-management in cancer patients.

When looking at self-management as term, this can be understood and defined in different ways. According to a study of Barlow et al (2000)<sup>22</sup>, there is no golden standard definition existing of self-management. Still, several investigations try to define what self-management indicates and how it can be facilitated.

Aujolat et al. (2008)<sup>23</sup> described in their study about patient empowerment of patients with chronic illness, that increased self-efficacy and mastery of disease can lead to more effective self-management of the patient. To support effective self-management is, according to Aujolat et al. (2008), a part of the empowerment process of the patient. They base their study findings on in-depth interviews with 40 chronically ill patients.

Not only control, but also the process of behaviour change is found to be an important part of the activation process of the patient. Aujolat et al. (2008) describe the empowerment process as a dual process of 'holding on' and 'letting go'. According to their study, does the patient usually try to control their illness because of insecurity. This is described as 'holding on'. 'Letting go' is the process of acceptance, that not everything can be controlled for by the patient alone.

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<sup>20</sup> Van Gemert-Pijnen, JEW, Cranen, K, Verlinden, SSF, Boer, H, Nijland, N, Verhoeven, F, & Seydel, ER (2007) Self-management of self-limiting diseases via web-based communication system for digital triage in Primary Care. University of Twente, Roessingh Research & Development. MedNet, October 26, 2007

<sup>21</sup> Van der Meer, V, Van Stel, HF, Detmar, SB, & Otten, W. (2007) Internet-based self-management offers and opportunity to achieve better asthma control in adolescents. *Chest*, doi:10.1378/chest.06-2787

<sup>22</sup> Barlow, J , Wright, C. Sheasby, J., Turner, A , and JHainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. School of Health and Social Sciences, Coventry University, England, UK, Elsevier Science Ireland Ltd. Doi.10.1016/S0738-3999(02)00032-0

<sup>23</sup> Aujolat, I, Marcolongo, R, Bonadiman, L. and Deccache, A. (2008) Reconsidering patient empowerment in chronic illness: A critiques of models of self-efficacy and bodily control. *Social Science and Medicine*. Volume 6, Issue 5, March 2008, pp1228-1239.

To stimulate this behaviour change and the coping style of the patient, the patient needs help to increase their knowledge about disease and treatment. Knowledge is found important to be able to influence the patients' feeling that the disease is manageable. When not being knowledgeable this can actually lead to the feeling of helplessness. The access to knowledge is, because of this reason, seen as an important aspect of the empowerment process, and can lead to better self-management of the patient (Aujolat et al, 2008).

The findings of Aujolat et al. support earlier investigation by Barlow et al. (2002).

In their study<sup>24</sup> of self-management approaches and its' effectiveness, the access to information is found to be an important component to carry out self-management tasks by the individual patient. Self-management is by Barlow et al. (2002) referring to an individuals' ability to effectively take care of oneself and to learn how to do so, to be able to daily manage symptoms, treatment, and the physical and psychological consequences of the individuals' chronic disease. Barlow et al. (2002) refers to this self-management process as a dynamic and continuous process, where lifestyle- and behaviour change is needed. Improved self-management cannot only lead to increased control of the individuals' personal situation and disease, but also influence self-efficacy and mastery of disease. They describe a trend that management of care gradually is shifting from the professional to the individual, as a result of demographic changes and developments in society, and that the patients in general want to play a more active role. They identified important self-management components to be provision of information, drug management, symptom management, dealing with psycho-social consequences, life style, social support and communication (Barlow et al, 2002).

When looking at the different self-management approaches provided, these are in general found to be effective in increasing participants' knowledge, symptom management, use of self-management behaviours, and self-efficacy, and can influence aspects of the health status of the patient (e.g. depression) (Barlow, 2002).

Most of the self-management approaches were found to be provided in a clinical setting or in the home setting of the patient, either group-based or individual, often in combination, or together, with other types of interventions like computer package, telephone, videotapes or written material. According to their research, will self-management strategies provided to the patient, be most effective when there is a combination of different methods used (Barlow et al. 2002). A multi-component strategy, of both disease specific and general interventions should, according to Barlow et al. (2002), be provided to the patient.

In the research of the patient terminal one focus will be on the actors' view on facilitation of self-management of the cancer patient in a clinical setting by the use of the patient terminal technology. By analysing the script of the technology, knowledge will be revealed about how and to what extent their view is reflected in the design of the patient terminal, and to what extent the technology can be used to facilitate self-management in cancer patients.

In a study by Turton et al (2002)<sup>25</sup>, about the provision of information and communication to meet the cancer patients' needs for self-management support, the findings confirm some of the research findings just presented.

The access to information is, by Turton et al. (2002), found to be an essential component to increase cancer patients' knowledge about disease and treatment, and to support self-management.

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<sup>24</sup> Barlow, J. Wright, C. Sheasby, J., Turner, A. , and JHainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. School of Health and Social Sciences, Coventry University, England, UK, Elsevier Science Ireland Ltd. Doi.10.1016/S0738-3999(02)00032-0

<sup>25</sup> Turton, P and Cooke, H. (2002) Meeting the needs of people with cancer for support and self-management. Obtained via Science Direct. Complementary Therapies in Nursing and Midwifery. Volume 6, Issue 3, aug 2000, pp130-137

There is a growing awareness that the feeling of helplessness and lack of control may adversely affect the health outcomes of the treatment of the patient. Turton et al (2002) describes different ways to support the cancer patient to stimulate self-management, as a part of the empowerment process. The distribution of information about the disease and treatment plays a central role. By increased knowledge, the active role of the patient will increase, and can influence the sense of control and ability to manage their disease. Cancer patients level of satisfaction did also show to be related to the degree of involvement in decisions about own care.

Not only information, but also a broader approach to stimulate self-management is presented in the investigation by Turton et al. (2002), about how to meet the needs of cancer patients for self-management support. As people with cancer go through an identity shift during the progress of their disease, people will at certain moments not only require information, but also additional emotional and psychological support. This is important to be able to increase cancer patients' sense of control and self-management of disease.

The research by Turton et al. (2002) demonstrates aspects important to facilitate self-management support of cancer patients. The investigation of the patient terminal can not only reveal knowledge about the actors' view of using the technology for self-management support, but will also reveal knowledge about the actors' image of the cancer patients and their need for self-management support.

When looking at the use of ICTs for the expansion of medical knowledge, there is some recognition for that this will contribute to empower the patient (Henwood et al, 2003)<sup>26</sup>, but that individual differences among patients can be of influence in this process. According to Henwood et al. is it important to recognize that individual and cultural differences among patients, in interest, age, literacy level, mental and physical condition, can influence the extent and level of information that can be given to, and absorbed by the patient, and can influence the level of patient self-management.

Henwood et al (2003) base their study findings on the information practice of 32 mid-life women in a decision-making process for taking hormone replacement therapy, and the use of internet.

The provision of relevant quality information, which is appropriately targeted, is found to be central as a part of the empowerment process of the patient (Henwood et al, 2003).

When the provision of information lead to increased knowledge about the patients' disease and treatment, this can contribute to empower the patient. This process may, according to Henwood et al (2003), also stimulate and support the self-management of the patient.

There is in literature support for that medical knowledge not necessarily must be distributed face-to-face or by folders, but also can be distributed by the use of new information technologies like the internet (Henwood et al, 2003). When using information technologies patients can actively participate in collecting information about their disease and treatment.

The potential of the new media in the development of new services is though widely discussed (Henwood et al, 2003). Individual differences like literacy (computer and health) level, the medium used and the quality of the information provided can be of influence in the process of facilitation of self-management.

This study demonstrates that individual characteristics of the end-user may play a role when using ICTs for the provision of medical knowledge and facilitation of self-management, but also for the individuals' ability to self-manage. The information provided to the user will also

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<sup>26</sup> Henwood, F. Wyatt, S. Hart, A. and Smit, J. (2003) 'Ignorance is bliss sometimes': Constraints of the emergence of the "informed patient" in the changing landscape of health information. *Sociology of Health and Illness*. Vol.25, no6, pp.589-607.

be of relevance, as this, according to Henwood et al., must be of good quality and appropriately targeted.

The actors' picture of the end-user and how this is reflected in the design of the patient terminal, can demonstrate if the technology is designed with respect to individual differences among patients, and to what extent the technology can be used to distribute information of good quality as a part of the facilitation process of self-management among cancer patients.

The scientific literature presented, focus on different ways to facilitate and stimulate the active role of the patient and self-management. To stimulate the feeling of control and self-efficacy of the patient<sup>27</sup>, and to facilitate the patients active involvement and daily management of own disease and treatment<sup>28</sup>, are important aspects mentioned in relation to facilitation of patient self-management.

Self-management can be stimulated, not only by provision of quality information and knowledge about how to deal with day-to-day situations regarding the patients' disease and health, but also by provision of information about both the patients personal situation and relevant socio-psychological aspects.

Increased knowledge is found to be essential to stimulate the feeling of control among patients, and for the patient to be able to independently perform self-management tasks. To be able to make the behavioural change needed to manage own disease and situation, is recognized as crucial for the patient to perform self-management tasks.

There is in literature some support for developing medical technologies and ICTs for the purpose to facilitate self-management in patients and to distribute information. Still, effectiveness and efficiency of these approaches are being discussed. Another point of discussion is the individual differences among patients using the technologies for this purpose, which can influence the patients' level and ability to self-manage their health and situation.

In the discussion of the findings and conclusions, chapter six, literature findings presented in this chapter will be viewed in the light of the research results of the development and implementation process of the patient terminal.

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<sup>27</sup> Aujolat, I. Marcolongo, R. Bonadiman, L. and Deccache, A. (2008) Reconsidering patient empowerment in chronic illness: A critiques of models of self-efficacy and bodily control. *Social Science and Medicine*. Volume 6, Issue 5, March 2008, pp1228-1239.

<sup>28</sup> Turton, P and Cooke, H. (2002) Meeting the needs of people with cancer for support and self-management. Obtained via Science Direct. *Complementary Therapies in Nursing and Midwifery*. Volume 6, Issue 3, aug 2000, pp130-137

## Chapter 3 – Research questions and objectives

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### 3.1 Overall research question and sub-questions

New innovations and novel technologies might have different origins and might be developed for different purposes and reasons. Some products have been designed in reaction to specific demands or to solve specific problems (technology pull), other products are developed because designers want to experiment with different technological possibilities to create new markets (technology push)<sup>29</sup>.

Why a technology was introduced, and the aims and roles of the actors participating in the development process, next to the actors' picture of the end-user, can reveal important knowledge about the design and development of the technology, and to what extent it can be used to facilitate self-management in hospitalized patients.

The study aim to answer the following research questions:

#### 3.1.1 Overall research question:

The overall research question is defined to identify the topic and area to be studied, and is overarching the problem selected. The following overall research question is defined for the purpose of this investigation, and will be answered in this paper based on the research findings:

**"How are the aims of developing and implementing the patient terminal in a hospital setting related to the user and the self-management of cancer patients in hospital-care?"**

#### 3.1.2 Sub-questions and research objectives:

The open character of the research question leads to some specific sub-questions to be investigated, to specify the focus of this research, which is the development and implementation of the patient terminal in relation to facilitation of self-management in hospitalized cancer patients.

The sub-questions will aim to identify and describe reasons to introduce the patient terminal at the Cancer Centre, the actors' aims of developing and implementing the technology and how this relates to self-management of cancer patients. Secondly, sub-questions and objectives focus on revealing the actors' involvement, their picture of the end-user, and how this is created and reflected in the design of the technology.

The actors' view on facilitation of self-management in cancer patients by the use of the technology, and whether the script of the technology can contribute to facilitation of self-management in hospitalized cancer patients, will also be described, as a central objective, in the analysis, chapter five.

The following sub-questions will be answered separately, but will also be used to answer the overall research question defined above:

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<sup>29</sup> Oudshoorn, N., Brouns, M. and Oost, E. van. (2003) Diversity and Distributed Agency in the Design and Use of Medical Video-Communication Technologies. *Inside the Politics of Technology*.



1. Why was it decided to implement the patient terminal at the Cancer Centre in the first place?
2. What was the involvement of the actors and what kind of image do the developers and implementers have of the users of the patient terminal?
3. What are the aims of the developers and implementers of the patient terminal in a hospital setting?
4. How and to what extent does the script of the technology contribute to facilitate self-management of cancer patients in hospital-care?

### **3.2    *Unit of analysis***

The unit of analysis indicates “what” or “whom” being studied in the research.

As in much social science research the unit of analysis is individual people<sup>30</sup>. In this case the actors, developers and implementers, participating in the design of the patient terminal technology will be studied.

Their role, aims, image of the user, and their opinion on the technologies possibility to facilitate patient self-management is investigated. In addition, the script of the patient terminal will be analysed.

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<sup>30</sup> Online encyclopaedia visited May 2008 [http://en.wikipedia.org/wiki/Unit\\_of\\_analysis](http://en.wikipedia.org/wiki/Unit_of_analysis)

## Chapter 4 – Theories and methods

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This chapter presents the conceptual framework of the analysis, theories and methods used in the study of the patient terminal technology.

### 4.1 *Conceptual framework*

The “Script” method by Madeleine Akrich (1992, 1995) has been used and creates the conceptual framework in the study and socio-technical analysis of the development and implementation process of the patient terminal technology. The French socio-technologist Madeleine Akrich introduced the concept “Script” to better understand the development of a technology in relation to its user.

When designing, developing and implementing information and communication technologies, like the patient terminal technology, choices are made in the design process and its functionality depends on its script. The script is the outcome of the design process, and can be studied to understand the interaction between the actors better, the role of the user and to which extent the user is taken into account when designing the technology.

Madeleine Akrich describes the designing of technical objects as the work of innovators “inscribing” the vision of (or prediction about) the world in the technical content of the new object. The end-product of this work Madeleine Akrich calls a “script” or a “scenario”<sup>31</sup>.

Like a script of a movie or musical play decides how an actor must act, the script of a technology indicates what is possible to do or not to do for the user, and how, for the very specific technology. Human action of a specific technology can be revealed by analysing its script.

Different actors, human and non-human, influence the development and design of technologies. This can also be the case in the development and design of the patient terminal technology.

An analysis of the actors involved, how the aims of the actors and their expectations are reflected in the design script of the technology, by constantly moving between the technical and social, can reveal knowledge about the shaping and design of the technology.

According to Akrich, technical objects have political strength; they can change social relations, but also be translated into other media or be socially shaped by its users. The success and failure of innovations frequently depends on this interaction, and depends on developers’ ability to cope with diverse users (Akrich, M. 1995)<sup>32</sup>. Innovators are, according to Akrich, M. (1995) constantly interested in their future users. They construct many different representations of these users, and objectify these representations in technical objects.

Akrich describes different techniques for producing user-representation. These techniques are explicit techniques and implicit techniques. The explicit techniques are formal, more direct representation techniques, based on specific methods of defining or interpreting consumer representations. Examples of explicit techniques are market surveys, user-feedback and involvement, or consumer testing of a technical object.

The implicit techniques are informal, more indirect representation techniques, relying on statements made on behalf of the users. The implicit techniques have in common that they actually address the “real” users, but rely on spokespersons for the users, like the designers, the expert consultants, and other actors related to the user. Implicit methods seem, according to Akrich, M. (1995), to be more powerful than explicit once.

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<sup>31</sup> Akrich, M. (1992) The De-Description of technical objects

<sup>32</sup> Akrich, M. (1995), ‘User Representations: Practices, Methods and Sociology’. In: Rip, A, Misa, T.J., Schot, J. *Managing Technology in Society*. Cenegage Learning, 167-184.

The I-methodology, which is considered to be an inadequate design methodology, excluding the perspectives and needs of people with other demographic characteristics than the designer<sup>33</sup>, is an implicit technique, and more common than at first site. By using the I-methodology the designer relies on personal experience and represents the opinion of the layman in the design process<sup>34</sup>. This method can be used when it is not possible to bring the end-user into the design process, or organizational constraints like time and money are at issue.

The process of identifying the user is fully concentrated in the design phase. The role of the designer in the design phase, shaping the functions and meanings of the technical object, does also involve risks. Risks of ending up with a kind of “technological monster” extremely sophisticated, but finally ineffectual because it is unable to attract the users for whom it was intended (Akrich, M. 1995).

Methods used for bringing the end-user into the design process vary. Akrich, M. describes that the problem of successful design is how to deal with the proliferation of “users”. When analysing the interaction between the actors and the technology involved, next to how the actors’ create their user-image, the script-framework can help to interpret this interaction process, and understand the development and possibilities of the technology in relation to its user and the facilitation of self-management of cancer patients. The de-scription of the technical object, which is the opposite movement of the in-scription of the technology by the engineer, inventor, designer or other actors involved, will be central for this analysis. The de-scription will reveal knowledge about how the developers and implementers in-scribe their vision and aims designing the technology, and how the script reflects the expectations of the actors involved in this process.

Different scientific literature makes use of the conceptual framework of Akrich indicating how this concept can be used to analyse design and development practice of technologies in relation to its’ social context.

In socio-technical analysis, in the study of design and use of technologies, heterogeneous actors usually participate in the design process. The needs of the end-user of a technology are often demonstrated to be diverse.

When looking at a study about how to design information- and communication technologies for “everyone”, constraints can be met. In the study by Oudshoorn, N. et al (2004)<sup>35</sup> looking at how to configure the user as “everybody”, the use of the “I-methodology” is demonstrated to actually be an important constraint in the development of technologies which aim to reach diverse users. According to Oudshoorn et al. (2004), “user-centered design” and “design for all” are frequently used by designers and policy-makers, interested in questions of equal access to new technologies, especially new ICTs.

Even though there has been a shift in design paradigm, towards the user-oriented approach, users seem hardly to be involved in the design process of ICT, especially within small companies. The speed of production is one barrier found in this design method (Oudshoorn et al, 2004).

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<sup>33</sup> Oudshoorn, N & Somers, A. (2006) Constructing the digital patient: Patient organization and the development of health websites. University of Twente, The Netherlands. Information, Communication & Society, Volume 9, Issue 5 October 2006 , pages 657 - 675

<sup>34</sup> Akrich, M. (1995), ‘User Representations: Practices, Methods and Sociology’. In: Rip, A, Misa, T.J., Schot, J. *Managing Technology in Society*. Cenegage Learning, 167-184.

<sup>35</sup> Oudshoorn, N. Rommes, E. and Stienstra, M. (2004) Configuring the user as Everybody: Gender and Design Cultures in Infomraion and Communication Technologies. Jstor: Science, Technology & Human Values, Vol. 29. No. 1 (Winter, 2004) pp.30-63

In this study and script-analysis of the design of two different virtual cities, configuring the user as “everybody” was found an inadequate strategy to deal with the diversity of the users. Both design practices showed to have a big gap between the objective to design for everybody, and the actual design strategy, as they did not take care for adjusting for differences in interests and skills among users. Because of the lack of differentiation and the use of the I-methodology, the design of the virtual cities was primarily designed for men. Although this conclusion is made, it is emphasized that users do not always adopt the scripts as created by the designer, but might slightly or drastically, transform or reject them, and create new meanings of the objects as users or nonusers of the technology.

In another research performed by Oudshoorn et al (2003)<sup>36</sup> the meaning and power of non-users in design of technologies is recognized and demonstrated. The analysis is about the underlying processes of designing technologies for multiple users, and illustrates how innovators represent the users shaping the technology designed – the babywatch. The study demonstrates that the first design process of the babywatch relies on informal and indirect methods, while the second design phase relied on different methods, due to the influence of the non-users. By not recognizing the different interests of the users, especially the needs of the nurses and the parents, resulted in a re-design of the product after developing the first prototype. By the use of the I-methodology the engineers initially developed a system which they thought the users wanted.

With respect to the image send to the parents, by the use of the babywatch, and the inflexibility of the system experienced by the nurses, the study shows that a re-design of the technology was needed.

Different actors participated in the process of design of the babywatch, except for the parents and the babies. The nurses, involved in both design phases, did not have much influence on the design despite their participation. Although parents were defined as the actual end-user, the requirements and demands were set by the hospital management, and reflected in the design of the first prototype.

A reaction on this design resulted in that the parents became non-users, which again resulted in re-design of the product – demonstrating the power of nonusers in the design of technological artefacts (Oudshoorn et al., 2003).

As demonstrated in these two investigations, Oudshoorn et al (2003) and Oudshoorn et al (2004), the involvement of an actor not necessarily lead to a reflection of their wishes in the design of the technology<sup>37</sup>, and the I-methodology and informal techniques are methods often being used for designing ICTs in health care<sup>38</sup>.

The research and case-analysis of the patient terminal, will investigate aspects related to the involvement of heterogeneous actors and the aims of the actors developing the technology. By analysing the script of the technology conclusions can be made if these aims are equally reflected in the design of the technology, based on the role and involvement of the actors in the development process of the technology.

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<sup>36</sup> Oudshoorn, N. Brouns, M. & van Oost, E. (2003) Diversity and Distribution Agency in the Design and use of Medical Video-Communication Technologies. University of Twente. Inside the Politics of Technology. Hans Harbers (ed) Amsterdam University Press, 2005

<sup>37</sup> Oudshoorn, N. Brouns, M. & van Oost, E. (2003) Diversity and Distribution Agency in the Design and use of Medical Video-Communication Technologies. University of Twente. Inside the Politics of Technology. Hans Harbers (ed) Amsterdam University Press, 2005

<sup>38</sup> Oudshoorn, N. Rommes, E. and Stienstra, M. (2004) Configuring the user as Everybody: Gender and Design Cultures in Infomraion and Communication Technologies. Jstor: Science, Technology & Human Values, Vol. 29. No. 1 (Winter, 2004) pp.30-63

The study will also aim to develop knowledge about the representation techniques used by the actors', the actors' image of the end-user, and how this is reflected in the design. The design strategy used, in configuring the user as "everybody"<sup>39</sup>, demonstrated to be an inadequate way to deal with the diversity among users in the design of ICTs, as designers often fail to design a technology adjusted for difference in interests and skills among users.

Knowledge about the representation techniques used for the purpose to identify the users of the patient terminal, and how this is reflected in the design of the technology, can reveal important knowledge about the design practice related to the development of the patient terminal technology. As the individual needs of the user, and the perceived problems of the patient, is found important to identify for the development of self-management programs<sup>40</sup>, the representation techniques used and the image of the patient can be important for the design of the product, and to what extent the technology can be used for facilitation of self-management in cancer patients.

#### **4.2 Script - operationalization**

The script framework by Akrich (1992, 1995) will, as mentioned, be used as conceptual framework for the analysis, in chapter five, with the purpose to analyse if the actors' expectations and user-image are reflected in the design of the technology (in-scription). By moving through the social and the technical, by performing in-depth interviews with the actors involved, and by analysing the design of technology itself, knowledge about how and to what extent the patient terminal can facilitate self-management of the cancer patient, and how this relates to the actors' aims, views on self-management, and their image of the end-user, will be revealed. The de-scription of the technical object and the representation techniques used by the actors involved, will attempt to improve understanding of the interaction between the social and technical in the development and design process of the patient terminal technology, and in what way the technology can contribute to facilitate self-management in cancer patients.

#### **4.3 Self-management - operationalization**

The operationalization of self-management as term is based on the scientific literature related to self-management (Aujolat et al. (2008), Barlow et al. (2002) and Turton et al. (2002)). Self-management is about individually chosen approaches to optimize living and the illness situation of the patient, where the individual is more responsible, and learn how to actively and effectively manage daily situations regarding medical and psychosocial aspects of their disease.

Self-management relates to different components, like the daily management, problem-solving and decision-making, regarding the patients' health and private situation. Examples of specific self-management components can be taking medication, making health care appointments, deal with symptoms, seek health care help when acute unwell, manage financial or private situation, and to be able to make a lifestyle change if needed related to aspects like nutrition and exercise. By increased self-management the individuals' feeling of safety, self-efficacy and control can increase. Increased feeling of control and self-efficacy can again lead to more effective self-management, which indicate a dynamic and continuous process, where the individual gradually undertakes control or reduce impact of disease on physical health status.

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<sup>39</sup> Oudshoorn, N. Rommes, E. and Stienstra, M. (2004) Configuring the user as Everybody: Gender and Design Cultures in Information and Communication Technologies. *Jstor: Science, Technology & Human Values*, Vol. 29. No. 1 (Winter, 2004) pp.30-63

<sup>40</sup> Lorig, K. & Halsted Holman, MD (2003) Self-management education: context, definition, and outcomes and mechanisms. *Stanford University School of Medicine. Pubmed* 2003, Aug; 26(1): 1-7

#### **4.4 Choice of research method**

In this chapter the choice of research method for this study will be described. The case study will be presented, together with a short introduction of the technology and the actors taking part in the research.

##### **4.4.1 Case study:**

The case study is in this research characterized by an in-depth examination of a single instance<sup>41</sup>.

The choice of research method, to focus on one single case, is due to the examination of a relatively new hospital technology, recently implemented, and still under development. This research method allows exploring the topic further, to acquire better understanding of the topic.

##### **4.4.2 The case:**

The case study focuses on the development and implementation process of the patient-related hospital technology, the patient terminal, and the technologies contributions to cancer patient self-management.

The case will be limited to the development and implementation of this ICT in a Norwegian hospital at the cancer department of the hospital. The recent developments of the technology, which is limited to the cancer patients with testicular cancer at the hospital, make this category of patients the main focus of the study.

The analysis of the technologies contribution to patient self-management will focus on hospitalized cancer patients in general, based on the concept developed for patients with testicular cancer.

##### **4.4.3 The location of the study: The Cancer Centre, Ullevål University Hospital**

Ullevål University Hospital is one of the biggest hospitals in Norway with in total 9.000 employed<sup>42</sup>. The Cancer Centre at Ullevål University Hospital is the regional cancer department for the eastern part of Norway. In the autumn 2006 the new Cancer Centre opened at their present location in a completely new building. A research- and development department is also located at the centre.

The Cancer Centre has four different departments and provides patients with cancer with different forms of treatment, like radiation therapy, cytostatica and other pain-relieving and treating forms of therapies.

Next to specialist knowledge in cancer, the centre offers services like course offers, silence room, relaxing room, art, a centre for learning and self-management, and different types of ICT facilities for patients and their family and friends, next to visitors and health care personnel at the Cancer Centre. The patient terminal is one of the new ICT facilities at the centre. The Cancer Centre is the only building, at the Ullevål University hospital, where the patient terminal technology is implemented. The Cancer Centre is the location of the case to be studied for the purpose of this research.

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<sup>41</sup> Babbie, E. (2007) *The practice of social research*. Pp. 298-299 Eleventh edition. Thompson Wadsworth. And Swanborn, P.G. (1996). *Case-study's: wat, wanneer, hoe?* (Case Studies: Everything You Need to Know). Amsterdam/Meppel: Boom.

<sup>42</sup> Ullevål University Hospital Internet site. Visited April 2008: <http://ic3.intbuilder.com/hospitality/kanal.aspx?kanal=42114>



*Illustration 4.4.3a: Krefstenteret, Ullevål Universitetssykehus, Oslo, Norway.<sup>43</sup>*

#### **4.4.4 Presentation of the actors and product information**

Several actors have participated in the process of design and development of the patient terminal at the Cancer Centre. The actors included in this case study will be presented below.

##### **The product provider**

The product provider of the patient terminal, Hospital IT (or Hospitality), is a Norwegian company with head office located in Oslo, and with different partners represented throughout the whole country<sup>44</sup>.

Hospital IT is an information technology (IT) company, which strategy focus on delivering information solutions for the Scandinavian health market<sup>45</sup>. The company has provided Norwegian hospitals with different innovative solutions for information and communication technology (ICT) the last years, and has participated in several different projects providing and managing digital services used in hospitals<sup>46</sup>.

The product portfolio of the company includes patient related ICT, like the patient terminal, information touch-screens and big screens, meant to be used for health information and communication.

##### **The Product Designer**

The product designer (N.Volstad) of the new information arena at the patient terminal participated in these developments as a part of her master education in Industrial Design Engineering at NTNU (Norsk Teknisk Naturvitenskapelig Universitet), located in Trondheim, Norway. The development resulted in a prototype of the new design of the patient terminal. The product designer worked for the product provider during this design and development phase. The product designer focused on re-designing a new user-interface on the patient terminal, by developing the information architecture, interaction design, next to the graphical and visual design at the new extended information arena on the patient terminal.

##### **The management**

The management that participated in the development and implementation process consists of different types of managers. Both former and present managers, at the Cancer Centre, departments and units. Most of the managers have a dual function, working both with management tasks and cancer patients.

The former manager of the Cancer Centre, which currently is the manager of the Research- and development department at the Cancer Centre, was included. Other managers included, was the current department manager of one of the day-units, and the current manager of the Radiation department at the Cancer Centre.

<sup>43</sup> Source Picture Hospital IT: <http://www.hospitality.no/cparticle7469-2950b.html>

<sup>44</sup> Hospitality internet site Visited April 2008: [www.hospitality.no](http://www.hospitality.no)

<sup>45</sup> Information folder Hospital IT

<sup>46</sup> Hospitality internet site Visited April 2008: [www.hospitality.no](http://www.hospitality.no)

### **The medical specialists**

The medical specialists included in the analysis are both working with cancer patients. One is specialists in oncology and one is a general surgeon. Both actors have participated in the development and implementation of the patient terminal at the Cancer Centre. One actor in the early phase of implementing the technology, and the other actor, related to the latest developments of the terminal.

### **The nurses**

Two nurses, working at the Cancer Centre, with a nursing and administrative background were interviewed. They both have many years of experience working with cancer patients, and do currently have a dual function at the Cancer Centre in combination with daily contact with patients. One of the nurses did also work for the Norwegian Cancer Society, and has participated in the development and implementation of other ICTs at the Cancer Centre.

### **The patient terminal project group**

Two different project groups have been actively involved in the development and implementation of the patient terminal. One group was involved in relation to the first development phase, when the patient terminal was introduced at the Cancer Centre. A second project group was involved in relation to the second development phase, including the current and latest developments of the technology. Characteristic of both project groups is that they have been multi-disciplinary.

The project coordinator of the second project group is included in the research representing the latest patient terminal project group.

### **The Norwegian Cancer Society (NCS) (Den Norske Kreftforening)**

The Norwegian Cancer Society (NCS) is a nation wide, non-profit voluntary organisation divided in four departments<sup>47</sup>. The Cancer Society's work, focus on the reduction of cancer incidences, increase of the recovery rate of cancer and to improve the quality of life for people affected by cancer. The main activities of NCS contain patient services, research, prevention activities through education and awareness programmes, advocacy and international activities where they support international social and health programmes. Information and communication about cancer, available for all, for the purpose of preventing, treating and to improve the situation for affected persons with cancer, is part of the central strategy plan of the society for 2008-2011<sup>48</sup>.

The society origins from a cancer association, that started already in 1938. This indicates that NCS have a long tradition to act as a represent of the cancer patients' and their families' needs, with the aim to improve their situation as good as possible. The last years there have been increasingly focus on digitalization of health information and digitalization of services within the society.

The represent of the NCS is an advisor at the society, and was, in 2007, the project leader of the project related to the development and implementation of the information touch-screen technology which is located in the halls of the Cancer Centre. For the latest developments of the patient terminal technology he was also involved.

### **The patient terminal technology – product information**

The patient terminal technology itself has already existed for a couple of years, and is already implemented in five Norwegian hospitals. Still, new applications and area of use are

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<sup>47</sup> The Norwegian Cancer Society/Den Norske Kreftforeningen internet site. Visited April 2008: [www.kreftforeningen.no](http://www.kreftforeningen.no)

<sup>48</sup> The Norwegian Cancer Society/Den Norske Kreftforeningen internet site. Visited April 2008: [www.kreftforeningen.no](http://www.kreftforeningen.no)



developed, which makes the technology in continuous development. The patient terminal to be studied is developed and produced by Hospital IT.

The patient terminal technology consists of a white 12, 1 inch LCD touch-screen connected to a white arm which again is connected to the wall<sup>49</sup> (Illustration 4.4.4a). In this way the terminal is secured to the hospital wall by a stationary system. The technology is located close to the bed of the patient and can be moved manually into the wished position. HealthCarrier is the patient terminal hardware, and the software is called HealthBrowser<sup>50</sup>.



*Illustration 4.4.4a: The patient terminal technology<sup>51</sup>*

The keyboard is integrated in the computer touch-screen at the terminal. The product provider offers a pen to make the touch more specific. Due to the few external buttons and attributes, integrated keyboard and a flat screen, the terminal is easy to clean for the hospital personnel. This can be important for hygienic reasons in a hospital. The terminal can next to hospitals, be suited for nursing homes and other health care centers, or potentially, in the future, in the patients' home or interactive communities.

Sound is provided through a head-phone which is connected to the terminal. The services of the terminal can be controlled for directly via the touch-screen function of the system. To turn the terminal off there is a specific button, and any pressure on the screen will make the terminal go on again. A requirement to use the terminal is that it is provided with electricity. If the patient occupies a room, the electricity is normally on. The patient terminal arena is organized in four sub-areas: information, communication, entertainment and specific applications.

#### **4.5 The research method**

The research methodology chosen and used for the study was a qualitative case study, with an explorative character, which include descriptive elements. This research method allows the exploration of the topic to obtain knowledge about the development process of a technology, where, based on our knowledge, relatively few publications exist. A possible shortcoming of the study is related to representativeness, and issues like reliability (Babbie, 2007)<sup>52</sup>.

An advantage of the method used is that the exploratory study, can serve as basis for more extensive studies or to develop methods to be studied in the future (Babbie, 2007). The qualitative research method can give insight about, and allow to study, sociotechnical relations and interaction during the development and implementation of the technology. Tables, overviews and pictures are presented as a part of the assignment and will be referred to in the text. Actors involved in the research will be quoted and referred to by the use of footnotes at the bottom of the respective page. Reference to scientific, or other relevant

<sup>49</sup> Interview and product information folder, Hospital IT, 2008.

<sup>50</sup> Interview and product information folder, Hospital IT, 2008.

<sup>51</sup> Source Picture: Hospital IT/N.Volstad

<sup>52</sup> Babbie, E. (2007) *The practice of social research*. Eleventh edition. Thompson Wadsworth.

literature, will also be marked in the text with footnotes and presented in an alphabetic overview in the reference list at the end of the report. Additional overviews and documents will be included in the appendices.

#### **4.6 Data collection**

The following empirical data creates the basis of the research:

- I. Interviews of the different actors and experts involved in the development and implantation process of the patient terminals at the Cancer Centre.
- II. Product information and design information of the patient terminal, next to other relevant documents from the actors or material related to the development and implementation process.
- III. Analysis of the technology will be used to perform the script-analysis by Akrich (1992, 1995).

#### **4.7 Actor selection and inclusion**

An overview chart over possible actors that participated in the development and implementation process was made for identification purposes (Appendix 1 and 2). Based on this chart and information from the hospital, the actors participating in this process, presented in paragraph 4.4, were contacted by e-mail and asked to participate in this research. The development and design process of the patient terminal has lasted for already three to four years. The actor selection and inclusion was made to make sure the whole period would be represented, based on the actors that have been involved during the whole process. Possible is that some actors have been involved, but are not included in the research. To prevent this, every actor was asked during the interview what their role had been in the development process and which actors they cooperated with during this process.

#### **4.8 Interview method**

The empirical data was obtained by qualitative semi-structured interviews, with a flexible open-ended design<sup>53</sup>, of in total 11 actors. Interview questions were actor specific and prepared in advance. The interview was performed face-to-face and recorded, by permission of the individual actor. One interview was performed by telephone, due to practical reasons. To prevent interview bias a recorder was used during the interviews. The actors included were participating voluntarily. Respondents got the right for anonymity. The interviews were obtained in the actors' natural work setting. An advantage of the interview method chosen, above questionnaires, is to minimize incomplete answers from the actor, misunderstanding or wrong interpretation of a question (Babbie, 2007). Also social processes related to the topic, like nuances in difference of opinion and attitude could be observed, an advantage above questionnaires. An important aspect in the development of the interview questions was the obtaining of objectivity. By not formulating suggestive questions, to prevent bias in the answering of the respondent, the questions were limited to the topics to be studied and the research questions.

Compared to surveys and experiments, the qualitative research method chosen, have in general higher level of validity, but less degree of reliability<sup>54</sup>. Because of this reason, statistical descriptions and causal explanations will not be applied to the empirical material obtained.

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<sup>53</sup> Babbie, E. (2007) The practice of social research. Pp. 305-312 Eleventh edition. Thompson Wadsworth, and Baarda, D.B, M.P.M. de Goede, A.G.E. van der Meer-Middelburg. (1996). Basisboek Open Interviewen (Beginners' Guide to Open Interviews). Houten: Stenfert-Kroese.

<sup>54</sup> Babbie, E. (2007) The practice of social research. Pp.312-314 Eleventh edition. Thompson Wadsworth.

#### **4.9     *Ethical issues - Access and participant protection***

Access to material and contact with the actors was provided by the contact persons and assistant supervisor(s) at the Cancer Centre. By using contact person(s) within the hospital organization when approaching the actors to be interviewed, facilitated the access to the actors. All actors are referred to in the text by the actor-group they belong to. For the access and use of illustrations and pictures, permission was obtained by the product provider, Hospital IT, and the product design developer. All images used in this report, related to the technology, originate from the product provider, and the latest design development of the product.

## Chapter 5 – Research results and discussion

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This chapter will present the research results per research sub-question, based on the interview findings and the script-analysis of the patient terminal. The overall research question, with respect to the findings and scientific literature, next to discussion and conclusions, will be presented in the following and last chapter, chapter number six.

### ***5.1 Sub-question 1: Why was it decided to introduce the patient terminal at the Cancer Centre at the first place?***

The interviews with the different actors revealed the actors own view, why the patient terminal technology was introduced at the Cancer Centre in 2006. A short presentation will reveal the results.

#### **5.1.1 The product provider - Hospital IT**

There are, according to the product provider, two main reasons why the patient terminal technology was introduced at the Cancer Centre in 2006.

First of all, the patient terminal technology, which was developed in 2003-2004, was already known within the hospital sector when it was decided to introduce the technology at the Cancer Centre.

The patient terminal, which was originally developed to satisfy a technology demand of a hospital in the South-Eastern part of Norway, was a new technology that included multiple services to satisfy the patients' demands when staying in hospital. The patient terminal was introduced at the Cancer Centre to fulfil these needs, both hospital and patient related-needs of service.

Another reason for introducing the product at the Cancer Centre was that several other development and implementation projects in Norwegian hospitals were already ongoing. This could, according to the product provider, probably have influenced this decision-making process of the hospital, next to that the product provider themselves were actively involved marketing the product.

“Due to hard lobbying from our side and strong internal forces within the hospital, it was decided by the hospital that this technology we need to have.”<sup>55</sup>

According to the product provider, the wish to introduce one single technology, with several functions and services integrated into one single product, was still the main reason why the technology was introduced at the Cancer Centre in Oslo in 2006.

#### **5.1.2. The product designer**

The product designer of the new information arena was not involved in the early introduction of the patient terminal at the Cancer Centre in Oslo. Because of this reason, the actual reason for introducing the product is based on experience and knowledge from her involvement at a later stage.

Like the product provider, the product designer, think the hospital was first of all interested in a technology that offered multiple functions. The fact that one product, an interactive personal screen placed by every individual hospital bed, offers entertainment, information and

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<sup>55</sup> Interview, Hospital IT, 2008

communication to the individual patient, could be one of the main-reasons why the technology was introduced at the Cancer Centre in 2006<sup>56</sup>.

### **5.1.3 The Management**

There were, according to the management, several reasons to introduce the patient terminal at the Cancer Centre in 2006. One reason was, as already mentioned by the other actors, to introduce one system which could meet the patients' needs for information, communication and entertainment, and to hopefully create the possibility to make a log access to the patients' own medical journal and patient information.

Another important reason to introduce the technology was that the new Cancer Centre wanted to profile itself as modern Centre, equipped with the latest medical and information- and communication-technologies to satisfy the needs of its clients.

“..the idea was that the Cancer Centre was going to become very modern, with a lot of different new technologies to meet the needs of the patient.”<sup>57</sup>

In the planning phase of the new Cancer Centre the technology was already there, and the hope of the management was that the technology would be further developed and good enough to fulfil all their demands and wishes when the new building of the Cancer Centre was finished, in 2006.

### **5.1.4 The medical specialists**

The medical specialists confirm earlier indicated reasons for introducing the technology at the Cancer Centre in Oslo. The patient terminal was, according to this actor, introduced as an “all-in-one product” to offer the patients better services for entertainment and communication, but also to integrate these functions, and a signal function, into one single product. The reason for this is that less technologic equipments would be needed if one system could contribute with multiple services.

“An advantage of the patient terminal is that the patient only has one technology to relate to.”<sup>58</sup>

The opinion of the medical specialist, participating in the building project of the new centre, is that every bed in any hospital should be equipped with a patient terminal. According to the medical specialists, the patients of today demand these services, and do also have the right for these offers when in hospital. The reason why the patient terminal was chosen, as the technology to offer these services and fulfil the demands of the Cancer Centre, was that the technology was being evaluated as a mature and well-functioning technology for this purpose at the time of the introduction in 2006.

“The patient terminal was introduced to satisfy the patients' needs of service. The patient terminal is a part of the services offered to the patient.”<sup>59</sup>

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<sup>56</sup> Interview, Product Designer, 2008

<sup>57</sup> Interview, Management, 2008

<sup>58</sup> Interview, Medical specialist, 2008

<sup>59</sup> Interview, Medical specialist, 2008

### **5.1.5 The nurses**

According to the nurses, the patient terminal was introduced to provide the patients with a service offer, where entertainment and information were the most important ingredients. This reflects and confirms the view of the medical specialists and the management at the centre. At the out-door department five mobile patient terminals were introduced, to share between the 21 beds which are available at this department. The rest of the Cancer Centre got equipped with one patient terminal placed bedside at every hospital bed at the centre.

### **5.1.6 The patient terminal product group**

When the decision was made to introduce the patient terminal at the Cancer Centre, the current project coordinator of the patient terminal project group, did not work at the centre yet. Other participants of the project group are represented by the management. Still, the opinion of the project coordinator, based on the last years experience with the technology, is that the patient terminal first of all was meant as a service-offer for the patients, with television, telephone, internet and information. This confirms reasons to introduce the system as described earlier. New opportunities for the system have, according to the project coordinator, been discovered through the development process after the introduction of the technology at the Cancer Centre.

### **5.1.7 The Norwegian Cancer Society (NCS)**

The Norwegian Cancer Society was not involved in the introduction of the patient terminal at the Cancer Centre in 2006, and cannot give an answer to this question.

In relation to the recently developed and implemented information- and communication technologies at the Cancer Centre, the big screen and information touch-screen technology, the NCS was involved from 2007 on. One reason to introduce these information technologies, which the NCS invested in and is responsible for, was to give the patients and their relatives' easy access to relevant information of good quality, and to facilitate self-management of cancer patients. Another reason for the introduction of the touch-technology was to emphasize the cooperation between the Cancer Centre and the Norwegian Cancer Society.

### **5.1.8 Summary of the reasons to introduce the patient terminal at the Cancer Centre.**

It is obvious that the main reasons to introduce the patient terminal technology at the Cancer Centre in Oslo in 2006, was related to the need to introduce one single technology with several different services, and not directly related to the facilitation of self-management in cancer patients.

All actors agreed on this point, that this was the main reason why the technology was introduced at the Cancer Centre in the first place.

With the introduction of an "all-in-one" product, the needs of the hospital and cancer patients for multiple services could be met. In this way fewer technologies would be needed and the patients would only have one technology to relate to.

Important to recognize is the medical specialists' view on this matter, indicating that the patients demands and needs actually must be seen as the patients' rights during hospitalization. This indicates that the medical specialists actually act as spokespersons for the patients during the phase of introduction, reflecting what they think are the patients' needs and rights when in hospitals.

Another important point to recognize is that the Norwegian Cancer Society, which was involved in the introduction of other ICT at the Centre at a later stage, is the only actor indicating the technologies contribution to self-management as reason to introduce different ICTs at the centre.

The access to relevant information of good quality and stimulation of self-management, are important reasons to introduce the ICTs according to the NCS.

Reasons to stimulate patient self-management, by introducing the patient terminal technology at the Cancer Centre, was not recognized by management or medical specialists at the point of introduction.

## ***5.2 Sub-question 2: What was the involvement of the actors and what kind of image do the developers and implementers have of the users of the patient terminal?***

In the process of design, development and implementation of the patient terminal at the Cancer Centre in Oslo multiple actors have been involved, at different phases through this process. Their role and actual influence might have been related to the actors' involvement, their image of the user, and to what extent their expectations are reflected in the design.

### **5.2.1 Summary of the actors' involvement**

Many actors participated in the development and implementation of the patient terminal technology at the Cancer Centre. This development and design process has involved an interaction between many heterogeneous actors. The table below (5.2.1a) summarizes the different actors' involvement during this process.

The development process of the technology has been continuous, but is still characterized by, and can be divided into, two main phases.

The first phase started before the patient terminal was introduced at the Cancer Centre in 2006, and involved the first developments and implementation of the terminal at the centre.

The second development phase started in the autumn 2007, and is still ongoing. The new developments involve a re-design of the user-interface of the already existing patient terminal technology at the centre, and the design and development of an extended information arena.

The new developments are planned to be implemented at the centre during 2008.

ACTORS	INVOLVEMENT			
	First phase		Second phase	
	Direct	Indirect	Direct	Indirect
The product provider	X	-	X	-
The product designer	-	-	X	-
The management*	X	-	-	X
The medical specialists*	-	X	-	X
The nurses	-	X	-	X
The project group I	X	-	-	-
The project group II	-	-	X	-
The NCS**	-	-	-	X

Table 5.2.1a: Actor involvement indicated by 'X'.

\* represented in the patient terminal project group I

\*\* represented in the patient terminal project group II

Some actors have participated directly and been actively involved in the development and implementation process. Others have participated in the design and development more indirectly. Important to notice is that the actors' direct and indirect involvement is different for the two development phases.

The product provider of the technology is the only actor that has been equally involved in both development phases.

The patient terminal project group, which has been two different multi-disciplinary project groups, has also been an important actor during both phases, but represented by different people.

The management was actively involved in the decision-making process around the implementation of the technology at the Cancer Centre. The management was also active involved during the second phase, but mainly in relation to the financial resources which have been made available for the latest development and design of the technology.

The product designer, of the latest developments, has also been actively involved in re-designing the overall design of the user-interface and the new information arena at the technology. The medical specialists were equally active in both phases, but more active in relation to the content during the second development phase. The nurses, as the table indicates, have been indirectly involved, providing input during both development periods. Important to recognize is that the multidisciplinary project groups, which have been actively involved during both phases, has contained people working at the hospital with different type of work, background and interest. Also including medical personnel, like nurses and oncologists. This indicate that a heterogeneous network of actors have participated in the development and implementation of the technology at the Cancer Centre.

The figure below (Figure 5.2.1b) illustrates the three main actors involved in the development of the patient terminal in relation to the other actors involved. The lines indicate which actors that cooperated and provided input for the design and development.

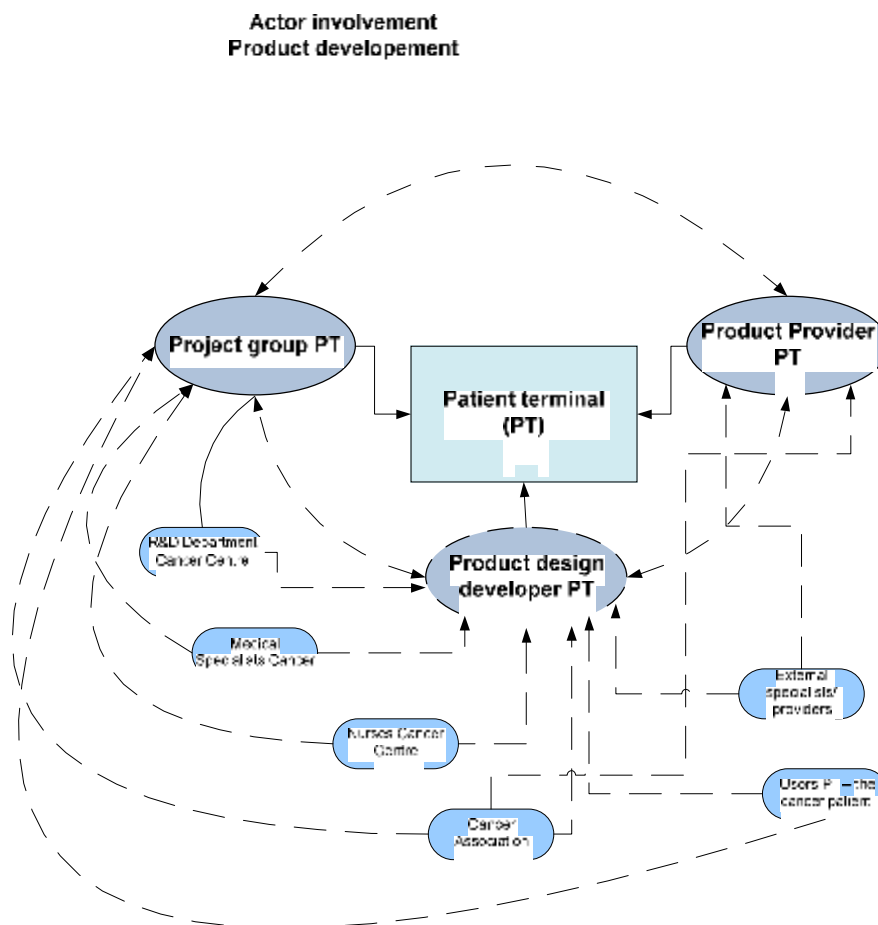


Figure 5.2.1b: Actor involvement patient terminal development



As illustrated in the figure of the actor involvement, the product provider, the project group, and, for the latest developments of the terminal, the product designer, were the main actors in this process. The product designer and the project group got input from different actors, and cooperate closely with the product provider. The product provider got input mainly from the product designer and the project group, next to cooperating with other technical specialists or providers and the Norwegian Cancer Society.

### **5.2.2 Summary of the actors' representation techniques**

Different representation techniques have been used by the actors participating in the development and design of the product. The table below indicates the different representation techniques used.

The table (table 5.2.2a) shows that the implicit techniques were the most frequently used techniques during the development and design process of the patient terminal.

ACTORS	REPRESENTATION TECHNIQUES		
	Implicit	Explicit	I-methodology
The product provider	X	-	X
The product designer	X	X	(X)
The management*	X	(X)	-
The medical specialists*	X	(X)	-
The nurses	X	(X)	-
The project group I	X	-	-
The project group II	X	(X)	-
The NCS**	X	(X)	-

Table 5.2.2a: Actors' representation techniques indicated by 'X'.

\* represented in the patient terminal project group I

\*\* represented in the patient terminal project group II

When analysing the design practice of one of the main actors, the product provider, they emphasized that it is important to develop their technological solutions together with their customers within health care, and together with other important actors involved. Up to this point in time the product provider got information about the users by the use of implicit representation techniques. Through conversations with health care personnel or the project group, which again were in contact with the main users, the patients, the product provider got information about the future end-users of the technology.

“People working with patients every day, health care personnel, see a lot of different patients, and have good experience with what the patients ask about and need. They can indirectly be used as spokespersons. In this way we usually get knowledge about the user.”<sup>60</sup>

The product provider did first of all rely on these informal techniques, next to their own experience and expertise, the I-methodology, in the design and development of the product. No formal techniques to assess the user needs during the design and development phase of the technology have been used until now.

<sup>60</sup> Interview, Product provider, 2008

The product provider relies mainly on in-house experience in relation to design and development of the technology, but cooperates closely with the purchaser or other experts about the content on the terminal, like medical professionals or other actors with relevant knowledge. For the technical solutions and developments of the product they also rely on, and cooperate with, other technical providers and partners.

The product designer made use of both implicit and explicit techniques during the latest design and development of the technology.

The representation techniques used have mainly been implicit, relying on expert opinion from oncologists at the Cancer Centre, next to other medical specialist, the NCS, and the product provider itself. Some explicit, formal techniques have been used, early in the design process, by performing interviews with cancer patients. Only a limited amount of cancer patients at the Cancer Centre were involved, to identify their needs in relation to information services in general and in relation to the patient terminal.

“User involvement is very important, and the development would have had no value if the users were not involved.”<sup>61</sup>

One patient organization and the NCS were also involved, and used as spokespersons for the patients, delivering input to the designer. Both the patient organization and NCS have long experience of representing the patients and their interests, as their spokespersons. The involvement of these organizations can be viewed as an explicit representation technique used for the purpose of identifying the user needs.

“Patient- and user-organizations can be used to get information about the user. Most of the people in the patient organizations have experience with cancer, which can be used and give valuable information about the users and their needs.”<sup>62</sup>

All other actors involved, the medical specialists, the nurses, the project group, and the NCS, are all in direct and indirect contact with patients. Some actors daily, others less frequent. They all emphasize the need and importance to integrate the users in the design and development of the system, and at several points during the development process of the technology.

“The patients, as a user-group, are important to include in a development process, because they know where the shoe pinches.”<sup>63</sup>

The general opinion of these actors is that it is important to make use of formal techniques in the design phase. A questionnaire could be used to obtain the experience and opinion of the main-users of the technology, to get an impression of the needs of the patients, and to be able to develop an optimal system for the user.

“It is important to get information from patients, their relatives and health care personnel, to know if the system lacks anything, how they experience the technology and so on..”<sup>64</sup>

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<sup>61</sup> Interview, Design developer, 2008

<sup>62</sup> Interview, The Norwegian Cancer Society, 2008

<sup>63</sup> Interview, The Norwegian Cancer Society, 2008

<sup>64</sup> Interview, Project group, 2008

Still, no explicit techniques have been performed by the hospital until now, except for the use of spokespersons, like medical personnel, the NCS and patient organizations for input in the design of the technology.

Important to recognize is that many of the patients at the Cancer Centre in general are very ill. This is mentioned as one of the reasons why the actors' picture of the end-user mainly is based on informal, implicit techniques, and not formal representation techniques. The design developer was, as mentioned, the only actor including the patients in the design process.

"I did only have one meeting with patients. I understand that these are in a difficult situation, and they cannot be used too frequent in the development of the design."<sup>65</sup>

The close cooperation with the Norwegian Cancer Society (NCS) and the Cancer Centre can though be said to partly cover the explicit techniques during the development and design of the patient terminal technology. The NCS have many years of experience with cancer patients, as they represent, and through their work with different patient organization. It can be assumed that they can be used as spokespersons for the patients, as an explicit technique, to form the picture of the group they represent.

### **5.2.3 Summary of the actors' picture of the end-user**

All actors, directly and indirectly involved in the patient terminal development and implementation process, identified and imaged the hospitalized cancer patients as the end- and main-user of the patient terminal technology. The hospitalized cancer patient is characterized as a heterogeneous user-group.

"Cancer patients are not one homogenous group, but a very heterogeneous group it is important to take care of. There is not "one picture" of a cancer patient."<sup>66</sup>

"There are just as many pictures of the user as there are patients."<sup>67</sup>

The image of the end-user as the cancer patient, usually hospitalized for a longer period, is mainly based on the actors own experience, what they see and what they hear.

"...the patients are from 35 to 90 years old, some are dying, and some are in the hospital for a new treatment, but will live for years after. Then we have a group that we will cure, which will go home after treatment and live luckily for many more years after. It is quite a complex user-group."<sup>68</sup>

The out-door patients are patients staying in hospital for only a short period. According to some actors, this is also a user-group that will use the technology, but to less extent than the hospitalized patients.

The actors' view, that the hospitalized patient is the main-user, is based on assumptions that other needs are present when staying in hospital for a longer period than for a short period. More and more patients are being treated at home. Because of this reason, the medical personnel image the patient at home as a potential user as well, if the new developments will be made available online.

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<sup>65</sup> Interview, Design developer, 2008

<sup>66</sup> Interview, Manager, 2008

<sup>67</sup> Interview, Medical specialist, 2008

<sup>68</sup> Interview, Manager, 2008

Next to defining the user as a heterogeneous user-group with many diverse needs, it is important to notice that also other images of the user are present among the actors (see table 5.2.3a). The product designer images users of the patient terminal as primary and secondary users. The primary users refer to the described picture of the end-user, the hospitalized patient, and their relatives. The secondary users are imaged as the health care personnel providing care and treatment to the patient. This secondary user-group will, according to the product designer, mainly use the technology together with the patient, as support in communication and information sharing. The product designer do also considered the primary user as a person with a certain level of computer literacy. This is inherent with the image of developing a universal product for a heterogeneous user-group, since certain skills are to be expected from the user to be able to use the technology.

A user description<sup>69</sup> was defined for this design purpose, and was, according to the designer, made as broad as possible, with the actual purpose to include all kind of users.

“The rule is that the more specific the user-group the more successful the product will be. In this project this was not possible. Anyone could end up in hospital.”<sup>70</sup>

ACTORS	PICTURE OF THE END-USER							
	Primary secondary users	Heterogeneous Diversity	Active patient	Computer literacy	Mental/ physical condition	Hospitalized patients	Patients at home	Out-door patients
The product provider	-	X	X	-	-	X	-	X
The product designer	X	X	-	X	X	X	X	-
The management	-	X	X	-	X	X	-	-
The medical specialists	-	X	-	X	X	X	X	X
The nurses	-	X	X	X	X	X	X	X
The project group	-	X	-	X	-	X	-	-
The NCS	-	X	-	-	-	X	-	-

Table 5.2.3a: Actors' picture of the end-user indicated by 'X'.

The image of the patient as a person with some degree of computer literacy is also shared by other actors indirectly involved in the design of the technology.

Not all users will be able to use the patient terminal or the new information arena independently, according to some of the actors. The level of computer literacy and the health condition of the patient is thought to be of influence (see table 5.2.3a). Both medical personnel, like oncologists and nurses, the product designer and the management, anticipated that the user, from time to time, would be in such a bad physical and mental condition, that it would be difficult for them to use the terminal.

“Some of our patients are very ill, and I am not sure to what extent they will use the terminal.”<sup>71</sup>

<sup>69</sup> Volstad, N (2008) Utvikling av brukergrensesnitt for pasientterminaler. Institutt for Produktdesign, NTNU.

<sup>70</sup> Interview, Product designer, 2008

<sup>71</sup> Interview, Manager, 2008

“People that are very ill, will, from time to time, have good periods where they probably will be able to use the terminal.”<sup>72</sup>

Some actors did emphasize that their image of the user-group in the future probably will change. Not only will more and more people have experience with computers, and a certain level of computer literacy, but also technological developments can result in a change including a bigger user-group.

“When the terminal will be integrated with other systems, the secondary user-group will probably explode. An example of this is if the patient terminal will be integrated with pharmacies, electronic patient journals and so on.”<sup>73</sup>

“The patient terminal is a patient-related product, but we think that in the future it will be both patients and health care personnel using the system.”<sup>74</sup>

#### **5.2.4 User images and user representation – script analysis**

A network of actors, both human and non-human, has been involved in the development and implementation of the patient terminal, a process of inclusion and exclusion of actors with different kind of background, experience and relationship to the patient. As we have seen described before, all actors created different images of the users.

In the script-analysis presented in this section I will analyse how and the extent to which the actors' picture of the end-user is reflected in the design of the technology.

There is, as indicated earlier, not “one picture” of the end-user defined by the actors. The design of technology does also not reflect the picture of “one” user, but is designed in a way to appeal and be used by a broader and diverse user-group.

#### **Diversity of users**

As indicated in table 5.2.3a, all actors that participated in the patient terminal development constructed the user as a heterogeneous group, where diversity is characteristic for this group. A cancer patient could, according to the product designer, be “anyone”, reflecting the actors' picture that anyone could actually end up in hospital, and also use the terminal. The diversity among patients is characterized as difference in age, gender, nationality, interest, health condition and stage and type of disease (Illustration 5.2.4a).



*Illustration 5.2.4a Different type of users<sup>75</sup>*

<sup>72</sup> Interview, Nurses, 2008

<sup>73</sup> Interview, Product designer, 2008

<sup>74</sup> Interview, Product provider, 2008

The design of the current patient terminal at the Cancer Centre (5.2.4b) and the new design of the user-interface at the terminal (5.2.4c), both take diversity among user-groups into account. In the first menu at the terminal the user is offered the option to choose between three user-profiles (Illustration 5.2.4b and c): “Child”, “Adult” or “English”. The English user-profile will lead the user to an English version of the adult user-profile.



Illustration 5.2.4b current version.



Illustration 5.2.4c new prototype

The design of the user-interface under development will, as indicated above (Illustration 5.2.4c) look different with respect to design. There is also a difference in design between the current child and adult user-profile regarding lay-out. The design of the user-profile for children is in general more colourful, with different animations and with different symbols for the arenas to enter compared to the adult user-profile.

The child profile does also contain more services compared to the adult version with several games, sound-books, quiz, and drawing programs. The entertainment for the adult is limited to television, radio and the internet, but any user is of course free to access and use the child-profile if wanted.

The image of heterogeneity among users related to the nationality of the user is to some extent reflected in the design. There is an electronic user manual available, which can provide the user with instructions about how the terminal works. This user manual is accessible by pressing the question mark “?” at the row of buttons below in the second menu at the terminal (Illustration 5.2.4d).



Illustration 5.2.4d: Access user-manual<sup>76</sup>

The electronic user manual or help function is available in five different languages: Norwegian, English, Russian, Arabic and Urdu. The user manual gives an electronic instruction about how the patient terminal works and information about the most important buttons and symbols controlling the patient terminal and how to navigate through the available menus. The actors’ picture of the end-user, as diverse in nationality, is partly reflected in the design, as the help-function at the system is developed for multiple nationalities. The rest of the terminal is developed for users understanding Norwegian or English. For the design of the new prototype only users understanding Norwegian is taken

<sup>75</sup> Source Picture: Hospital IT/N.Volstad

<sup>76</sup> Source Picture 5.2.4b/c/d: Hospital IT/N.Volstad

into account. Diversity in nationality is, because of this, partly realized in the new design of the technology.

This indicates that diversity, with respect to nationality, is less developed in the new user-interface than in the initial design of the product.

The actors' image of the end-user as diverse in needs and interest is also reflected in the design. Both the current and the new version of the patient terminal, allow the user to choose between different arenas for entertainment, communication or information.

The user can also decide independently which applications to access, as there is one terminal available at every hospital bed. Sound is provided through the head-phones, which means that the users do not disturb each other if they actually are in the same room. Another example where heterogeneity is taken into account is with respect to the use of the radio. The screen can be made black if the users want this, a function which can be preferred in the evening or at night time.

The new design of the information arena is improved compared to the earlier technology, with respect to diversity in information, both for general and specific information.

Users are, in the new design of the information arena, allowed to choose the disease or "problem" they are interested in. The choice can, in the new design, be made between ten different groups or types of diseases or problems, like: head, arm/leg, stomach/pelvic, breast/chest, hormone disturbance, pain/joint pain, varicose veins, cancer, infections, others. This illustrates diversity in interest related to disease type or problem among possible users. The problem or disease area can be accessed by pressing the animation figure to the left on the illustration below (5.2.4e) or by pressing one of the menus.



*Illustration 5.2.4e: Screenshot prototype<sup>77</sup>*

To be able to meet the needs of a broad and diverse user group, user-friendliness of the design of the new user-interface at the terminal, has been an important point of attention in the design process<sup>78</sup>. Decisions were made during the development process to form the design criteria, based on a balance of user-needs related to the actors' picture of "diverse users", and user-friendliness.

There are some restrictions both in the current and new design of the terminal related to diversity of interests in users. Both designs do not allow pop-ups or upload/download of documents in relation to the internet function, as this can result in more system failures, and again affect the user-friendliness of the technology.

<sup>77</sup> Source Picture: Hospital IT

<sup>78</sup> Volstad, N (2008) Utvikling av brukergrensesnitt for pasientterminaler. Institutt for Produktdesign, NTNU.



When these actions are made not possible in the design of the technology, certain users are being excluded, like for example business people which want to do their work from the hospital bed and want to upload or download documents.

Again, by letting the users perform these activities to meet possible user-demands, the product provider and the hospital can expect higher maintenance costs of the system, since this can result in more maintenance, which can result in higher costs for the purchaser.

The use of an external keyboard, which would allow for blind-typing, can also result in more maintenance costs, loss or more equipment breakage. Choices have been made in the design in relation to these points, as an integrated key board function, which is available at the terminal, have other advantages. An integrated key board function is more hygienically and can lower infection risks for the user of the technology.

In general, the new design of the terminal is consistent and made more predictable, as the basic design of the terminal is the same for every menu. Users with limited sight, but also colour blind are taken into account, as a general research-based guideline has been used in this process<sup>79</sup>, reflecting the image of the diverse users. A standardized guideline for developing user-friendly web pages for seniors was chosen. This guideline was used to fulfil requirements to realize a user-friendly design for a broad user group, where both young as well as old people, next to people with limited sight, are included. To meet the needs of colour blind users, all colour pictures were developed in a black-and white print. The purpose of this was to analyse if the design and contrasts of the pictures were good enough for this type of users and people with less good sight. The design aimed to make the system easy-to-use for “everyone”, designing logical and predictable solutions for navigation within the menus (Illustration 5.2.4f).

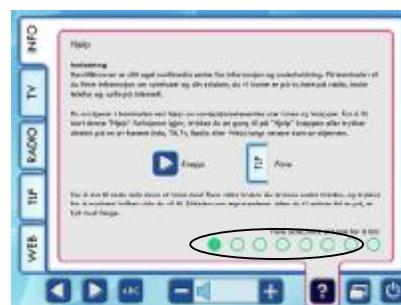


Illustration 5.2.4f Prototype navigation<sup>80</sup>

At the current patient terminal at the Cancer Centre, the navigation between the menus is less obvious, which can make the user navigate wrong when looking for information or operating the menus at the terminal. The new design is an improvement of this function.

### **The user as hospitalized patient.**

Another image of the end-user, next to the image of a diverse user-group, is the actors' image of the user as a “hospitalized patient”. Important to notice is that also this image was identified by all actors (table 5.2.4a).

This image is reflected in the way the patient terminal hardware is designed, and that the technology actually is implemented at the Cancer Centre. Every hospitalized cancer patient has the access to the technology from their bed. The fact that the patient terminal is installed

<sup>79</sup> Research-Based Web Design and Usability Guidelines, by the U.S. Department of Health and Human Services: [www.usability.gov/guidelines](http://www.usability.gov/guidelines)

<sup>80</sup> Source Picture: Hospital IT/N. Volstad



at the bedside of the patient also indicates that the system is to be used by the hospitalized patient or visitors of the patients' room (picture 5.2.4a).

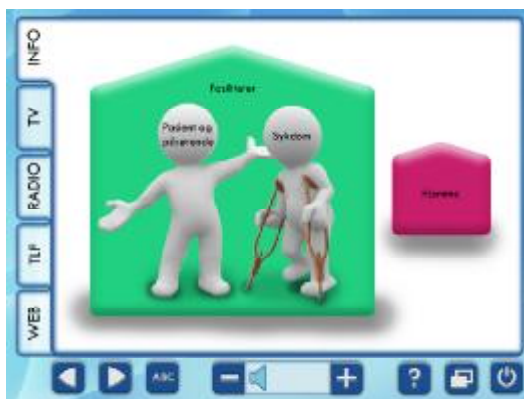
The "day-time patients", also imaged as a user by the product provider, nurses and medical specialists, visiting the out-door department at the centre, can make use of the five mobile terminals available at this department. This indicates that some of the actors' image of the users as "out-door patients" is taken care for, as also this group of patients can use the technology when visiting the Cancer Centre.

The picture of the end-user as a "hospitalized patient" or "out-door patient" is reflected in the information provided at both the current and new design of the terminals, as the information can be relevant for both user-groups.

The product designer, as the only actor, did also image the users as "primary or secondary users". The primary user was, as mentioned, next to the hospitalized patient, identified to be the patient and its family or friends. This is reflected in the new design of the user-interface at the patient terminal information arena.

As illustrated at the picture below marked with a circle, both the patients and their relatives got an "own button" for accessing information (Illustration 5.2.4g).

With respect to the secondary users (nurses or doctors, Illustration 5.2.4h), as defined by the product designer, they are not represented with their "own button" in the design of the terminal. This user group is expected to enter the same "buttons" as the patient and their relatives.



*Illustration 5.2.4g: Prototype information arena*



*Illustration 5.2.4h Primary and secondary users<sup>81</sup>*

### **Computer literacy of users.**

Another image of the users by the product designer, the medical specialists, the nurses and the project group was that the users, making use of all the offers at the patient terminal, probably have some degree of "computer literacy".

For users that have earlier experience with computer technologies, the patient terminal should be possible to handle without any instructions. By designing menus and sub-menus, divided into families, and by using easy symbols and words, next to the user-manual which is available at the terminal, the developers have tried to take the user into account with respect to difference in level of computer literacy.

Users with no experience with computers or with low levels of computer literacy, might be afraid to use the terminal, or do not understand how to use it. If this is the case, the patient can get additional instructions by the nurses, how to use the patient terminal.

<sup>81</sup> Source Picture 5.2.4g/h: Hospital IT/N.Volstad

The user-manual developed, seems to meet the needs of users with lower level of computer literacy or with little experience of computers, as the manual easy explains how to operate the technology. Still, users must of course be able to understand how to access this manual.

#### **The health condition of the users.**

Some users are imaged by the actors as being too ill, physically and/or mentally, to be able to use the terminal. For this group user-friendliness of design can be of importance, so not too much effort is needed to use the technology. Both the initial and the new design of the user-interface at the terminal, is designed with respect to user-friendliness. Still, changes are being made in the new design to meet the needs of patients within this user-group. An example of a change made in the design of the user-interface at the new prototype is illustrated below (Illustration 5.2.4i/j). The buttons and symbols are made bigger, which makes the new design of the patient terminal even easier to operate and use both for users with a less good medical condition, less visibility or lower level of computer literacy.



*Illustration 5.2.4i: Current version*



*Illustration 5.2.4j: Prototype<sup>82</sup>*

The product provider, the management, and the nurses' image of the user as "the active patient", is also reflected in the design of the technology. The patient terminal is an interactive product, which reacts on the input from the user. The fact that the user controls the technology already refers to an active role of the user to be able to use the system. The user can independently access the patient terminal, with power supply as the one criterion to actually use the technology. Referring to the actors' image that the users of the terminal want to participate in their own health and management of care, the technology is designed in a way that users actively can look for information about their disease on the internet if wanted. While the current version of the patient terminal have some, but not much, information available at the terminal, to stimulate the active role of the patient, the new prototype of the information arena is designed in a way that the user easy can access a lot of different information when lying in the hospital bed.

The image of the "active patient" is more reflected in the design of the new prototype than in the current version available at the Cancer Centre.

Both with respect to the user image "diversity" and "active patient", the user of the new prototype of the information arena can choose from much more informative and educative material, like movies, illustrations and animations, and texts, than earlier versions of the technology.

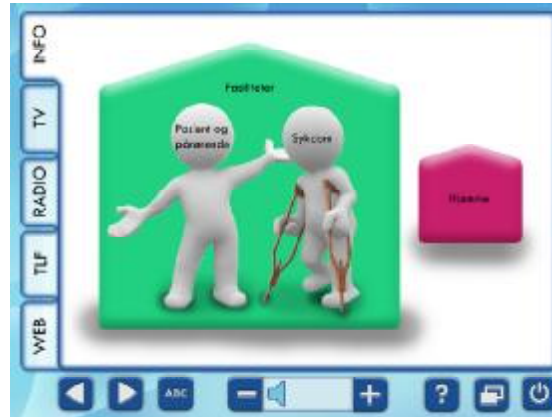
The "old" design is less challenging for the active patient, as this image to less degree is reflected in the design, except for the access to the internet facilities.

The new developments reflect the "active patient", as a lot of new information is integrated at the information arena, stimulating the active patient role, by providing information about what patients can do themselves to influence their own situation and health (see overview illustration patient terminal, Appendix 3,4,5).

<sup>82</sup> Source Picture 5.2.4i/j: Hospital IT/N.Volstad

### **The patients at home.**

Another image, identified by the nurses and the medical specialists, is the image of the user as a “home-patient”. As indicated at the illustration on the following page this is also taken care for in the new design of the information arena (Illustration 5.2.4k).



*Illustration 5.2.4k Prototype “Home” function<sup>83</sup>*

The “home” function explains the users how to access the information arena from home. This opens up for a new user group, compared to the earlier design of the patient terminal. Both the medical specialists, as well as the nurses, imaged the user as a patient being treated at home, due to the fact that more and more patients actually are being treated at home<sup>84</sup>. In the new design of the technology, their image is reflected in the design, as users can access the information arena via the internet, and not necessarily from the terminal in a hospital situation. Two criteria that must be met for this user-group, is that the user know how to access this “home-arena” and that they have access to a computer with internet facilities in their home situation.

As mentioned in the earlier paragraph did many types of actors interact and participate in the development and implementation of the technology, like the purchaser, owners, primary and secondary users, innovators, designer, technicians, IT-department, health care personnel and specialists, the hospital R&D department, project group, management, patient organizations and societies.

The product provider and designer in the development of the technology did not have any direct contact with the primary users of the technology, the patient, except for a couple of patient interviews in the beginning of the second development phase of the new prototype.

For the identification of user needs the interaction with purchaser and spokespersons of the user were involved, as informal representation techniques, to identify the needs of the user. Since all actors participating, shared the image of the users of the technology as being diverse, and as the hospitalized patient, the actors’ participation in the design, direct or indirect, did not influence the design with respect to reflection of these images. Both the views of indirect and direct actors involved in this process can be said to be taken care for, especially in the design of the new user-interface of the patient terminal technology.

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<sup>83</sup> Source Picture: Hospital IT/N.Volstad

<sup>84</sup> Interview, Nurse, 2008

### ***5.3 Sub-question 3: What are the aims of the actors of developing and implementing the patient terminal technology in a hospital setting?***

All the actors involved in the development and implementation of the patient terminal technology have different aims of developing the technology. Some of the aims are short term, and other aims are long term. Some aims are related to the hardware, but most of the aims are related to the software.

A systematic analysis of the individual actors' most important aims of developing the technology revealed important knowledge about the design choices made during this phase, and brought knowledge about the actor's aims in relation to patient self-management, and differences in aims among the actors.

#### **5.3.1 Summary aims actors**

When analysing the different actors' aims of developing and implementing the patient terminal technology, the aims are many and quite different. As indicated in the tables at the following pages (5.3.1 a to d), the actors share some aims, but there are also some actor specific aims. These aims can be said to characterize the individual actor.

When studying the aims of the product provider, their aims are first of all general aims related to development and design of a user-friendly technology for the health care sector as a whole.

“The technology is basically an empty arena where many smart things can be developed.”<sup>85</sup>

The aims of the product designer are first of all related to the latest design of the new user-interface of the information arena at the terminal.

“The goal has actually been to help the health care sector to develop an information technology for the patient. There is little IT for the patient within a hospital.”<sup>86</sup>

Management aims are related to long term strategic hospital goals, like decrease the amount of paper by electronic services, and the aim to use the system as efficient and cost-effective as possible.

“It is a technology of mass consumption, so the design should be developed in a way that time and costs used on the terminal are minimal.”<sup>87</sup>

Aims of the medical specialists are first of all related to the care of patients and aims to improve their working processes and interaction with the patients.

The nurses are first of all interested in optimizing the care of the patient, by improving the continuity of the treatment process.

“Patients feel safer if continuity in the treatment process is stimulated. It is positive if the patients know which team works with the individual patient. This can be presented at the patient terminal...the team cooperates to deliver optimal treatment to the patient.”<sup>88</sup>

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<sup>85</sup> Interview, Hospital IT, 2008

<sup>86</sup> Interview, Product designer, 2008

<sup>87</sup> Interview, Manager, 2008

<sup>88</sup> Interview, Nurse, 2008

As the only actor, the nurses indicate that stimulation of patient self-management is one of the most important aims of the technologic developments of the information sites at the patient terminal. The project groups' aim is to get maximal output of the investments in the product, due to limited resources. As the management of the Cancer Centre, the project group finds it important that there is made efficient use of the available resources and that many different services are integrated at the terminal for optimal use.

The Norwegian Cancer Society does, as the management, have organizational aims.

Characteristic for the NCS is that their aims are related to their own organization, by the wish to use the technology as a 'channel' to reach the cancer patients and to promote their offers.

The NCS is also an actor, next to the nurses, which thinks an aim to develop and implement the terminal must be to facilitate cancer patient self-management.

The following two tables (5.3.1a and b) indicate the aims of the different actors related to the development and design of the product. Some of these aims can be said to be common aims of the different actors. Important to notice is that all actors want to develop and implement "one tool" or one technology with multiple functions, an important reason to implement the terminal in the first place. The digitalization of already available hospital services, like electronic patient record and digital forms for patient information and registration, is another important aim recognized by all actors. Aims related to the internal and external communication and entertainment are also important aims to mention, as these are other aims common for several actors.

ACTORS	AIMS									
	Modern Centre	Continuity treat. process	New design user-interface	Pleasant hospital stay patients	External communication	One tool multiple functions	Fulfil customer needs/demands	Fulfil patient needs/demands	User-friendly product	Digitalization of services*
The product provider	-	-	-	-	X	X	X	X	X	X
The product designer	-	-	X	-	-	X	-	-	X	X
The management	X	-	-	-	X	X	-	X	-	X
The medical specialists	X	-	-	-	X	X	-	X	-	X
The nurses	-	X	-	X	-	X	-	X	-	X
The project group	-	-	-	X	X	X	-	-	-	X
The NCS	-	X	-	-	X	X	-	X	X	X

Table 5.3.1a: Actors' aims indicated by 'X'

\*Electronic Patient Record, X-rays, agenda, medication/symptom curves.

ACTORS	AIMS									
	Signal function	Universal product	Internal Communication	Research	Digital archive	Paper-less hospital	Cost-effective	Entertainment offer	Multiple foreign language	Hygienic product
The product provider	-	-	X	-	-	-	-	X	-	X
The product designer	-	X	-	-	-	-	-	-	-	-
The management	-	-	X	X	-	X	X	X	X	-
The medical specialists	X	-	X	-	-	-	-	X	-	-
The nurses	-	-	-	-	-	-	-	X	-	-
The project group	-	-	-	X	X	X	X	X	X	-
The NCS	-	-	X	-	-	-	-	-	-	-

Table 5.3.1b: Actors' aims indicated by 'X'

The aim to develop information at the patient terminal is also a common goal for all actors. The following table (table 5.3.1c) indicates which aspects of these information aims the individual actors find most important.

“We wanted to develop a chronological and well-presented information arena.”<sup>89</sup>

Timely information of good quality, both in relation to general and specific hospital and disease related information, are the aims that most actors priorities.

“We know that the information the patient gets in hospitals fast can be forgotten. The situation the patient is in, can affect how much information the patient can obtain at the moment the information is provided.. Because of this it is important that information is easy available for the patient.”<sup>90</sup>

Several actors want to visualize the information in different ways. In relation to these developments the NCS is the only actor which aims to develop information which is pedagogically right. Although, other actors mentioned that an aim must be to secure the quality of the content, the NCS is the only actor which mentioned the pedagogic aim as a specific aim of these developments.

“The technology must be developed in a way that it does not create more fear, but takes care for the patient in a good way.”<sup>91</sup>

ACTORS	AIMS									
	Pedagogic right information	Equal info all patients	IT	Extended info arena (general+ disease spec.info)	Info online	Visualization of information	Information of good quality (EBM)**	Timely information	Syst. registration patient info	Interactive medium
The product provider	-	-	X	-	-	X	X	X	-	X
The product designer	-	X	X	X	-	X	X	X	-	X
The management	-	-	X	X	-	-	X	X	X	X
The medical specialists	-	-	X	X	-	-	X	-	-	-
The nurses	-	X	X	X	X	-	X	-	-	-
The project group	-	-	X	X	-	X	X	X	X	X
The NCS	X	-	X	-	X	X	X	X	-	-

Table 5.3.1c: Actors' aims indicated by 'X'

\*\* Evidence Based Medicine

The aim to develop a user-friendly product is first of all an aim of the product provider and product designer, next to the NCS. All these actors have design experience of ICT which can be a reason why this is an important aim of these actors. The NCS, which have many years of experience representing the patients, might reflect the needs of the patients of a user-friendly technology.

<sup>89</sup> Interview, Product designer, 2008

<sup>90</sup> Interview NCS, 2008

<sup>91</sup> Interview, Norwegian Cancer Society, 2008

“It is important that the technology is easy to use, so people dear to try..”<sup>92</sup>

One goal, quite different from the rest, is the management and medical specialists’ aim to profile the Cancer Centre as a modern Centre. This is more a commercial goal, reflecting the wish of the actors about creating a Centre where the latest technologies and services are available and used.

Some of the aims, indicated in the tables above, are, as mentioned, actor specific.

Aims to develop a product with signal function, which is universal, hygienic, has a digital archive, fulfil customer needs, have a new design user-interface, and is pedagogic right, are all examples of aims which are actor specific, and which can be aims required to compete with other hospitals or to make efficient use of the technology.

When looking at the aims related to self-management of the patient, the table below (table 5.2.1d) indicates which actors aim to stimulate or support patient self-management by the use of the technology.

The nurses are, as mentioned, the only actor which emphasized aims to develop the technology as a self-management tool. The management, the project group and the NCS are other actors which aim to use the technology for this purpose.

The design developer of the information arena does also have explicit goals to facilitate patient self-management, even though this is not a primary goal of the developments set by the designer herself. Her primary goal of developing the new information arena at the patient terminal was to increase the knowledge spiral of the patient, an aim which can facilitate patient self-management.

All actors can be said to have aims related to the facilitation of self-management of the patient. The aim to increase the knowledge spiral of the patients is shared by several actors. This is an aim which, as mentioned, possibly can lead to facilitation or stimulation of self-management in patients. Next to this aim there are aims to improve the patient control, the patients’ active role, and patient empowerment (table 5.3.1a), which are aims set by the different actors involved.

“I think that the system can contribute to empower the patients.”<sup>93</sup>

ACTORS	AIMS										
	Patient self-manag-ement	Improve patient control/safety	Increase knowledge spiral of patients	Active role patient	Patient empower-ment	Channel to reach patients	Patient feel less isolated	Secure zone – smart card function	Not replace human contact	Little maint-enance	Improve efficiency
The product provider	-	-	-	X	X	-	-	-	-	X	X
The product designer	-	X	X	-	-	-	-	-	-	-	-
The management	X	-	X	-	-	-	-	X	X	X	X
The medical specialists	-	-	X	-	-	-	X	-	X	-	-
The nurses	X	X	X	-	-	-	X	-	X	-	-
The project group	X	-	X	X	X	-	X	-	-	-	X
The NCS	X	X	X	X	-	X	-	-	-	-	-

Table 5.3.1d: Actors’ aims indicated by ‘X’

<sup>92</sup> Interview, Norwegian Cancer Society, 2008

<sup>93</sup> Interview, Project group, 2008



#### ***5.4 Sub-question 4: How and to what extent does the script of the technology contribute to facilitate self-management of cancer patients in hospital-care?***

This paragraph will analyse the actors view on facilitation of self-management and the use of the patient terminal for this purpose in hospitalized cancer patients. An overview of the actors' view on facilitation of self-management in relation to the user, and how and to what extent their vision on facilitation of self-management is in-scribed in the design of the technology, will be presented.

##### **5.4.1 Actors' view on facilitation of self-management and the use of the patient terminal**

When analysing the actors' view on facilitation of self-management in cancer patients, by the use of the patient terminal, interesting knowledge was revealed.

The following citations indicate some of the actors' view on facilitation of self-management in hospitalized cancer patients:

"Self-management is important for all, especially when one is in an existential crisis..."<sup>94</sup>

"Self-management is important for all, especially for the patient. Self-management is the feeling of having control and being able to deal with every day in the best possible way. Cancer patients are in a difficult situation, the feeling of having control over this situation, can contribute to manage disease and the situation the patient is in..."<sup>95</sup>

"Self-management is how a person deals with a threat. A way to deal with a crisis is to search information, to get a balance, and rest, by having overview over the problems..."<sup>96</sup>

"Self-management makes the patient feel of being in control... a feeling of control to be able to manage their situation in a better way..."<sup>97</sup>

"Self-management is the possibility to influence the situation you are in. To take personal control over or to get a better understanding of something..."<sup>98</sup>

"Increased self-management can make the patient experience their illness differently..."<sup>99</sup>

"It is documented in literature that patients are more capable to deal with their disease if self-management is stimulated. The actual effect of self-management is not know..."<sup>100</sup>

"More and more patients wish to be active during their illness process and treatment. Others do not wish this, which is something that must be respected..."<sup>101</sup>

As indicated, there are different views on self-management among the actors, although all actors find it important to facilitate self-management among hospitalized cancer patients. Self-management components recognized by the actors were the ability to daily manage symptoms and disease, the ability to deal with emotions and the personal situation the patient is in, next the ability to active participate in decision-making process regarding their disease and treatment.

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<sup>94</sup> Interview, Nurse, 2008

<sup>95</sup> Interview, Management, 2008

<sup>96</sup> Interview, Nurse, 2008

<sup>97</sup> Interview, Nurse, 2008

<sup>98</sup> Interview, NCS, 2008

<sup>99</sup> Interview, NCS, 2008

<sup>100</sup> interview, Medical specialist, 2008

<sup>101</sup> Interview, Nurse, 2008



When the individual is able to deal with these self-management components, the actors' think that this can contribute to the feeling of control and independence, and give the patient better understanding of the situation they are in. Some actors think that the cancer patients, by improved self-management, probably will experience their disease differently, and as less difficult to deal with (Illustration 5.4.1 a/b). The tables below indicate what facilitation of self-management can lead to, and are related to the self-management components just mentioned.

ACTORS	FACILITATION OF SELF-MANAGEMENT							
	Manage own situation	Manage own feelings	Be able to be part of discussion	Decision making process	Active participant/patient	Deal with uncertainty	Deal with existential crisis	Disease management
The product provider	-	X	X	X	X	-	-	-
The product designer	-	-	-	-	-	-	-	-
The management	X	X	-	X	X	X	X	-
The medical specialists	-	-	X	-	-	-	X	X
The nurses	X	X	X	-	-	X	X	X
The project group	X	X	-	-	-	-	-	X
The NCS	X	X	X	X	X	-	-	X

Table 5.4.1a: Actors' view on facilitation of self-management indicated by 'X'

ACTORS	FACILITATION OF SELF-MANAGEMENT							
	Increase self-conscious	Less worried/Afraid	Increase independence	Feeling of control	Increase knowledge spiral	Safety feeling	Improved illness experience	To get a balance/overview problem
The product provider	-	-	-	X	X	-	-	-
The product designer	-	-	-	-	X	X	X	-
The management	-	X	-	X	X	X	-	-
The medical specialists	-	X	-	-	X	X	X	-
The nurses	-	X	-	X	X	X	-	X
The project group	-	-	X	X	X	-	-	-
The NCS	X	-	X	X	X	-	X	-

Table 5.4.1b: Actors' view on facilitation of self-management indicated by 'X'

All actors, except for one medical specialist, think that the patient terminal technology can contribute to facilitate self-management in hospitalized cancer patients, mainly by the provision of information. The actors do though not think that the patient terminal can have a direct medical effect on the disease, only the way the patient deals with and experience the situation they are in. When looking at the table below (table 5.4.1c) the view of the actors in relation to facilitation of self-management of the cancer patient, by the use of the technology, is indicated. The use of the technology alone, for the purpose of facilitating the self-management of the cancer patient when in hospital, is though not recognized by any actor.

ACTORS	FACILITATION OF SELF-MANAGEMENT BY THE PATIENT TERMINAL						
	PT do facilitate self-management	PT do not stimulate self-management	Cannot replace self-management groups	Self-management tool/medium	No replacement human contact	Provision of information self-management offers	Educational purposes
The product provider	X	-	-	X	-	X	-
The product designer	X	-	-	X	-	X	-
The management	X	-	-	X	X	X	-
The medical specialists	-	X	X	(X)	-	X	X
The nurses	X	-	X	X	X	X	X
The project group	X	-	-	X	-	X	-
The NCS	X	-	-	X	-	X	-

**Table 5.4.1c: Actors' view on facilitation of self-management by the patient terminal (PT) indicated by 'X'**

All actors think that the patient terminal can be used to increase the knowledge spiral of the patient by providing information. To have information and being knowledgeable is, according to the actors, important to perform self-management tasks. Both medical and socio-psychological information is recognized as important information to provide to the patient, next to information about daily management of disease and symptoms to facilitate self-management:

"When patients get increased information about own disease or diagnose, advice and support, patients get knowledge which can contribute to increased self-management, self-conscious, and the feeling of being able to influence."<sup>102</sup>

"Information about disease and learning about self-management contribute to increase self-management of the patient. The patient can learn methods of managing different feelings, like fear, and learn ways to manage a situation if they would get problems."<sup>103</sup>

"The information sites can contribute to increase the knowledge spiral of the patient. All external links and information on the information arena are of good quality. The patient can actually be empowered in this way, and not make them insecure in any way. The patient terminal is a supplement, and can contribute in the self-management process."

"My opinion and experience is that people that have more information are less afraid and worried."<sup>104</sup>

"By visualizing investigation and treatment, like investigation by a CT-scanner, the patient will know and get familiar with the situation before actually going through it. This can help the patient and their relatives to prepare and manage their situation..."<sup>105</sup>

By providing information to the cancer patient, by the use of the patient terminal, this will, according to most actors, influence the ability to manage own disease, situation, and feelings, which again can lead to increased control, feeling of safety, and improved ability to deal with uncertainties (table 5.4.1a/b).

All actors involved in the design of the technology, think that the patient terminal can contribute to complete the offers at the Cancer Centre, facilitating and stimulating cancer patients' self-management process by providing information or education to the patient (table

<sup>102</sup> Interview, NCS, 2008

<sup>103</sup> Interview, Medical specialist, 2008

<sup>104</sup> Interview, Management, 2008

<sup>105</sup> Interview, Project group, 2008

5.4.1c). The management and the medical specialists find it important that the use of the technology will not replace human contact, as they think human contact is essential for the cancer patient going through a difficult process. They do also think that human contact is important for the learning of methods to deal with emotions and disease specific or personal problems related to the individual patient.

The actors think that the patient terminal can contribute to complete the self-management offers at the centre, and make them more available and visible for the cancer patient, next to contribute to meet the needs of the active patients wanting to participate in own health and management of cure and care of disease.

As cancer patients often go through an existential crisis, the management, medical specialists and the nurses, think that self-management is especially important to stimulate among this group of patients.

The facilitation of self-management in cancer patients is also identified by the actors to be important for the individual to be able to take part in decision-making process regarding their disease and treatment, as well as being able to manage their own situation and disease, like medication and symptoms, on a daily basis.

#### **5.4.2 The patient terminal and facilitation of self-management – script analysis**

In this part I will describe how and the extent in which the actors' visions on self-management and facilitation of self-management by the use of the technology is reflected in the design.

The current and new design of the patient terminal both contain information which users can access on the terminal at any time. All actors involved in the design of the patient terminal think, that the technology can be used for the purpose of providing the patient with information. The provision of information is by all actors recognized as an important part of the facilitation of self-management of the cancer patient, whereas being knowledgeable is recognized as important for the individual to self-manage.

When looking at the current design of the patient terminal, the user can access general and specific information by using the internet site of the hospital. The user can get information about specific disease-related information or self-management when accessing the link of the Norwegian Cancer Society at the start-page up page of the internet. The way in which the current patient terminal implemented at the Cancer Centre is designed, the information available is limited and might be difficult to access by the user.

The design of the new prototype of the patient terminal is changed, both with respect to general and specific information, related to practical information, disease, interventions, treatment, and self-management.

The design of the new information arena is easy accessible for the user, as the information available is organized in different menu-options depending on the needs of the user (Illustration overview map Appendix 3/4/5).

The knowledge spiral of the patient, which all actors' found important to stimulate as a part of the facilitation of self-management, can increase by using the 'new' information arena. The new design of the information arena contains a lot of different information which can contribute to this process.

The design of the new information arena is divided into four main menus: "patient/family", "facilities", "disease" and "home". The first the main menu "patient/family" does, as the name of the menu indicates, not only contain information for the patients, but also to their relatives.

Information about the cancer association and other patient organizations, how to deal with alternative treatment, different self-management strategies and offers, information about patient rights, medication, work, personal economy, social services and how to act as a relative is presented (Illustration 5.4.2a), are sub-menus to be found within this menu.

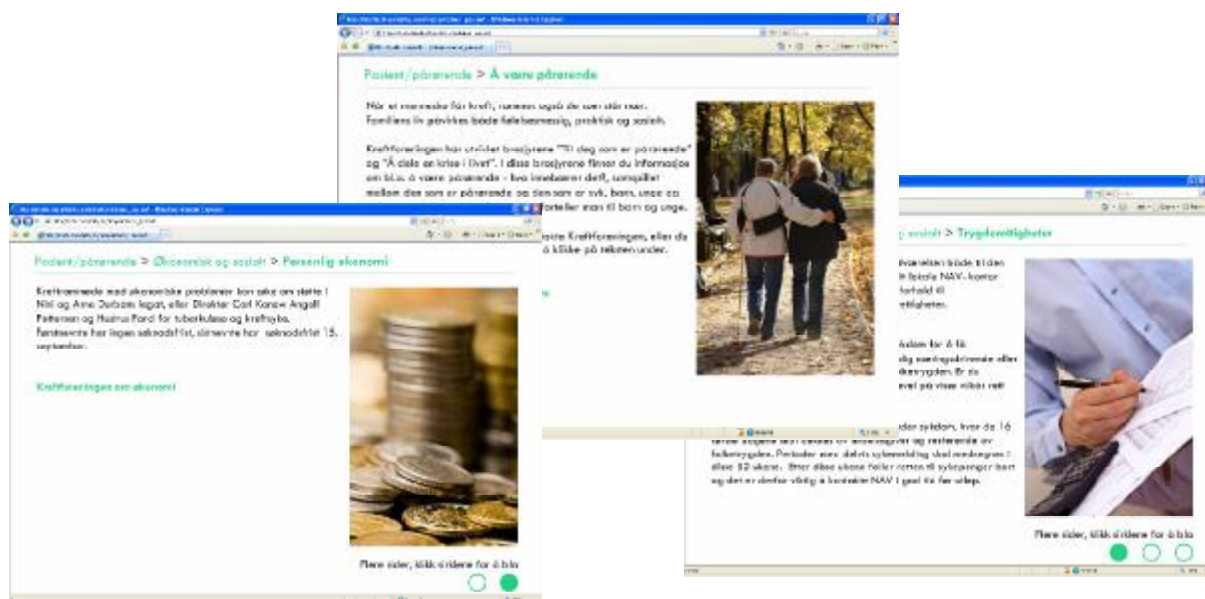


Illustration 5.4.2a Screenshot prototype: Economy, to be a relative, social rights

In the second main menu “facilities”, information about the hospital and Cancer Centre in general, its location, departments and facilities, like hotel, stores, library and more, can be accessed by the user (Illustration 5.4.2b).

The way the new information arena is designed makes the patient and its relatives less dependent on other people to get the information they need in relation to their personal situation, but also about the hospital and other information in general.



Illustration 5.4.2b Screenshot prototype: Location facilities<sup>106</sup>

When looking at the disease specific information that can contribute to increasing the knowledge spiral of the user, information about the disease itself, prevalence and prognosis, interventions and treatment, can be provided to the user of the technology by accessing the main menu “disease” (Illustration 5.4.2c).

The actors’ opinion that the patient terminal can be used for providing information to the patients to stimulate self-management is less reflected in the current design of the technology, but is reflected in the re-design of the product. As illustrated (illustration 5.4.2c) the user of

<sup>106</sup> Source Picture 5.4.2a/b: Hospital IT

the new information arena can access information about several subjects. The information is presented by the use of sound, pictures, video, animations and text. The illustrative pictures and text can contribute to better understanding and knowledge about both the disease and treatment of the patient and may as such increase knowledge to stimulate self-management of the cancer patient.

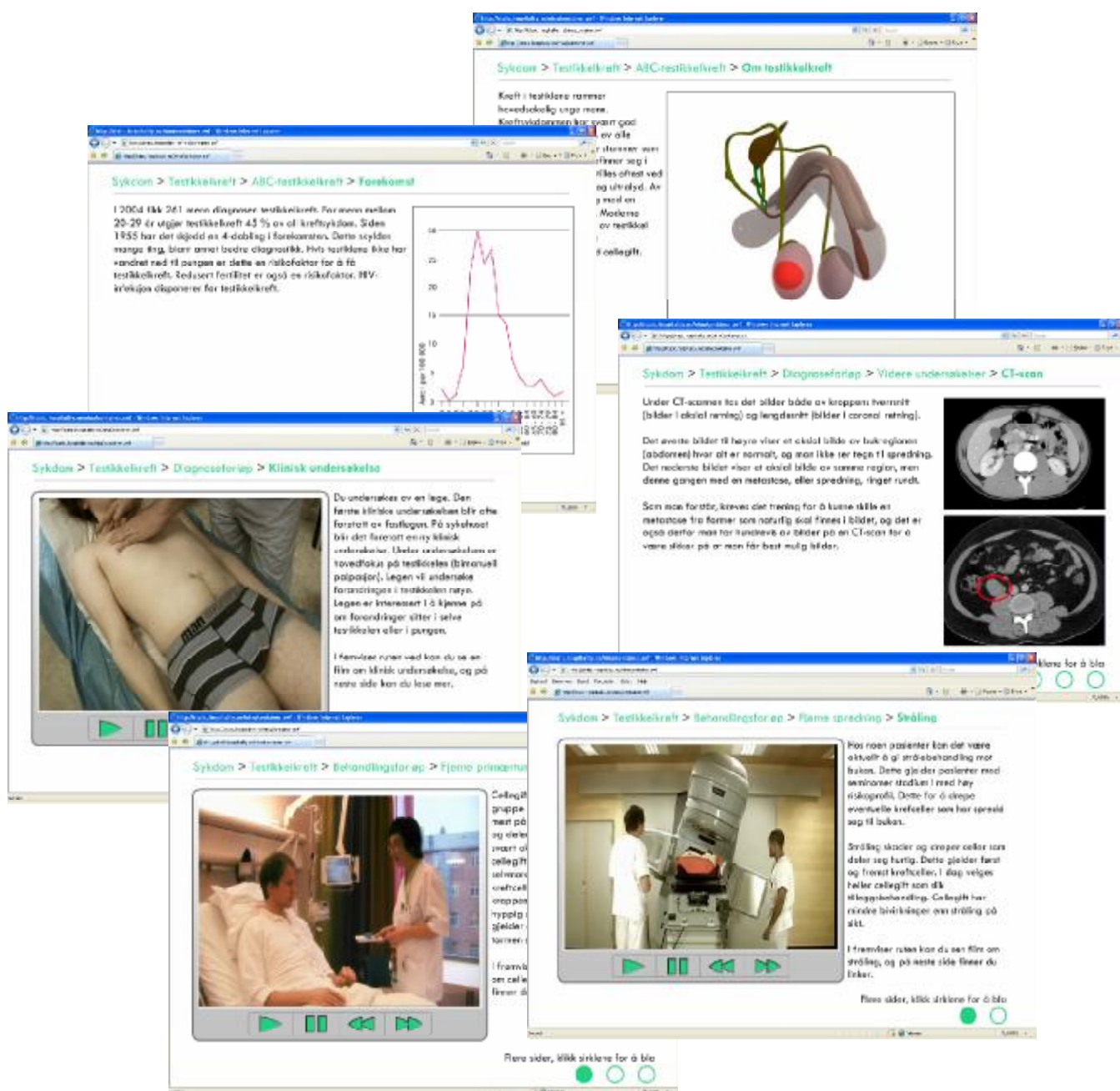


Illustration 5.4.2c Screenshot prototype: Disease, prevalence, investigation, interventions, treatment for testicular cancer<sup>107</sup>

Almost all actors think the technology can contribute to self-management and can be used as a self-management tool or medium to stimulate this.

<sup>107</sup> Source Pictures 5.4.2c: Hospital IT

When looking at the design of the terminal in relation to specific self-management offers available at the terminal, the current patient terminal is not designed to provide the user with information about this. Although the user can make use of internet links to access this type of information, the current design of the patient terminal does not indicate that this is taken into account during the development process.

The design of the new prototype is different with respect to this point (Illustration 5.4.2d). The design of the new information arena allows the user to access different information related to self-management. Offers, like self-management courses and conversations, and information about self-management strategies is included as an own part of the arena. In this way the self-management offers at the Cancer Centre are made more easily available and visible for the user, than in the earlier design of the technology.

The specific information about self-management is divided into two menus. As the illustration below indicates (5.4.2d), does one menu gives information about “different self-management”, a menu which informs the user about different coping styles, reactions and self-management strategies.

The second menu informs the user about different “self-management offers”, which refers to self-management offers available at the hospital in general and the Cancer Centre, like courses and the ‘learning- and self-management centre’, and offers externally.



*Illustration 5.4.2d Screenshot prototype: Self-management approaches and offers<sup>108</sup>*

The ‘self-management offers’ available at the prototype of the terminal are divided into eight groups. The eight groups refer to: Child & adolescent, breathing room, silence room, course offers, groups, cancer line, learning- and self-management centre, nutrition expert. This gives the user the possibility to choose the information they want, also related to the self-management offers of the Norwegian Cancer Society as well as information about psychology services at the hospital.

Not only information about self-management approaches and offers for the patients are to be found, but also for their relatives. The illustration on the following page shows an example of this, providing information about self-management offers for children of seriously ill parents (Illustration 5.4.2e). This reflects the nurses’ view on self-management that both patient and

<sup>108</sup> Source Picture: Hospital IT



their family must be taken into account, and get information about self-management and the self-management offers available.



Illustration 5.4.2e Screenshot prototype:  
Self-management offers family<sup>109</sup>

The content of the new design of the information arena is also changed with respect to information about daily management of own disease and situation.

The management, the nurses, the project group at the Cancer Centre and the NCS think that the patient terminal can be used for the purpose to inform the patient about how to manage their disease and situation in a better way.

The new prototype of the terminal does allow the users and the patients to get information about these aspects.

As illustrated below (Figure 5.4.2f) can the future user of the new information arena get information about how to manage different symptoms related to cancer or the medication provided, like nausea, dry mouth and bad appetite. Users can also get information how to deal with aspects related to their health and private situation, like nutrition, physical activity and sexuality. This means that the actors' vision of self-management and self-management components, as being able to daily manage own health and situation, is reflected and taken into account in the new design of the technology.

The current patient terminal technology at the Cancer Centre does not reflect this vision in the design of the product in various ways.

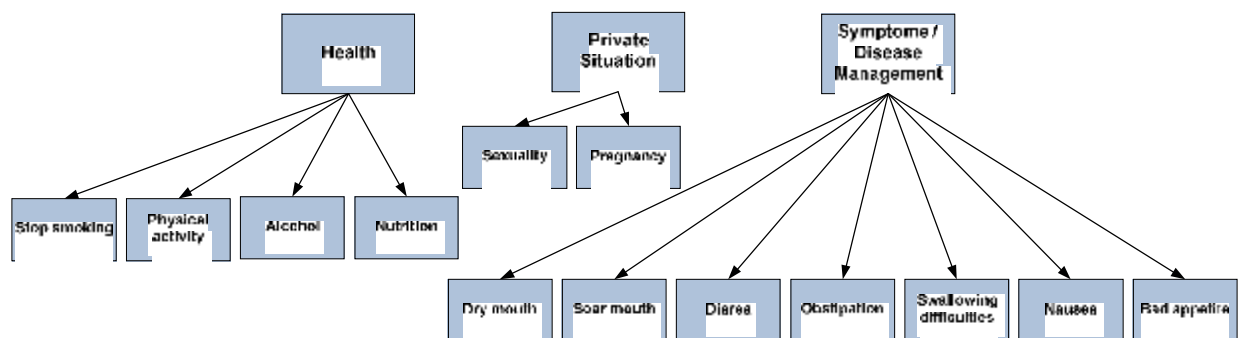


Figure 5.4.2f Overview design prototype: Information arena, self- management cancer patients: own health, symptoms and disease, and private situation

<sup>109</sup> Source Picture: Hospital IT

The management and the nurses did also find it important that the patient terminal was not developed and implemented to replace human contact, as human contact is an important part of facilitating and supporting self-management in cancer patients.

As the current and new user-interface of the patient terminal is designed, the technology does not give the user any form of human support or contact, like internal or external communication, to stimulate patient self-management. Telephone and the use of internet to communicate, is the only exception, as the user in principle is free to phone any regular line and use the internet if wanted. Still, there is no cancer line or support network developed specifically for the purpose to support self-management. No psychological or emotional contact or support can be provided by human actors by the use of the current or the re-design of the technology. Because of this reason the product can also not replace the human contact, as hospital services and offers available related to self-management of cancer patients. Future design and developments of the product, with respect to new functionalities, can possibly open for other types of stimulation of self-management, also by human actors. This can also be the case if the patient can use the technology as a communication aid to express opinions, feelings or ask questions in relation to daily management, and allow for individual support.

The product provider, the management and the NCS shared the same view of facilitation of self-management in relation to stimulation of the active role of the patient, in the decision-making process. The actors' vision is that by participating in the decision-making process regarding disease and treatment, the self-management abilities of the cancer patient will increase.

As the current patient terminal at the Cancer Centre is designed, no specific information about cancer, investigation or treatment can be obtained by the user, restricting the users' ability to actively participate in the decision-making process by the use of the current technology.

The new design of the patient terminal, which contains a lot of disease specific information about cancer, can to a bigger extent facilitate and stimulate the active role of the patient in this process.

All actors think that the management of own feelings, the feeling of control and safety, is an important part of self-management of cancer patients. Cancer patients can from time to time be in a difficult situation or go through an existential crisis. Because of this reasons the actors think that stimulation of self-management among this patient group can be essential for how the patient experience their disease and deal with the situation they are in.

The new design of the technology can, though facilitation of self-management and support by human actors is not available, provide cancer patients with different types of knowledge, which possibly can contribute to the feeling of control and safety. Being knowledgeable can influence the way cancer patients and their relatives manage their daily life and disease, and can help to get an overview over problems or a balance in their situation.

According to the NCS, which have many years of experience providing self-management offers to cancer patients, facilitation and stimulation of self-management can increase the feeling of independence and self-consciousness of the patient. According to the NCS, the self-management of the cancer patient will increase even more if specific patient-related information would be available on the terminal in the future, like the electronic patient record, to provide the patient with lab results and treatment plan.

"Through this, the ownership of the patient increases and stimulates self-management in relation to their own situation."<sup>110</sup>

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<sup>110</sup> Interview, The Norwegian Cancer Society, 2008



The patient terminal technology can, as earlier mentioned, be accessed independently by the user. Although the electronic patient record is not yet available at the patient terminal, the user is less dependant on other people to access general and specific information. Because of this reason the patient terminal can possibly contribute to the self-management process of the patient regarding the feeling of independence, and stimulation of their active role.

## Chapter 6 – Conclusion

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In this chapter the conclusion of the research findings will be presented with respect to the research questions in paragraph 6.1 to 6.5. In paragraph 6.6 to 6.8 the research results and method used will be discussed and reflected on and recommendations for further research will be made.

### **6.1 Conclusion – Overall research question**

*“How are the aims of developing and implementing the patient terminal in hospital setting related to the user and the self-management of cancer patients in hospital-care?”*

The case-study of the patient terminal technology revealed important insights into aims of developing and implementing the technology in a hospital setting, in relation to the actors' image of the end-users and facilitation of self-management in cancer patients.

The aims of the different developers and implementers participating in the development and implementation process are diverse. In general the aims of the actors involved were related to the main-user of the technology, the hospitalized cancer patient, and secondly the hospital organization itself. The initial aims of developing the technology were to meet the needs of the cancer patients, for an information and communication service, and entertainment when staying in the hospital. The initial aims were not related to facilitation of self-management of the hospitalized cancer patients. The aim to develop the technology as a tool to facilitate self-management of cancer patients got increased attention during the latest development phase and re-design of the technology.

The nurses at the Cancer Centre and the Norwegian Cancer Society (NCS) were the two actors that recognized facilitation of self-management, by the use of the technology, as an important development aim for the patient terminal.

Almost all actors involved in the design process of the technology, wanted to develop and implement the system as an important source for quality information to the hospitalized cancer patient. This is a goal which can be said to relate to facilitation of self-management in cancer patients. To provide information is found to be an important ingredient to facilitate the self-management process in cancer patients, whereas being knowledgeable is recognized to be an important factor to be able to self-manage the disease and situation a patient is in.

With respect to the actors' image of the users, the primary user was defined to be the hospitalized cancer patients. This user-group, as defined by the actors, is characterized as a diverse group, with many different individual needs. Because of the diverse needs among the hospitalized cancer patients, the actors' opinion is that self-management must be facilitated in many different ways to meet the diverse needs of the patients.

The actors think that the patient terminal can be used as one, of many, tools to facilitate self-management, and that the technology can contribute to complete the self-management offers available at the Cancer Centre. Several self-management offers must, according to the actors, be made available to meet the needs of the cancer patients in hospitals.

The actors' diverse image of the hospitalized cancer patient, as the main-user of the technology, indicates that not all patients will use or benefit from using the terminal to stimulate or increase self-management, but that this also will be based on the individual patient. The ability to actually make use of the technology, and to self-manage disease and the situation the patient is in, will vary depending on individual factors, like the health and computer literacy of the user, the medical condition of the patient, age, behaviour and coping

strategy of the individual, and not only the self-management possibilities of the patient terminal.

As the current and 'new' user-interface of the patient terminal is designed, the script-analysis of the technology revealed that it primarily can be used as an information technology to stimulate self-management. There is little self-management support integrated in the new prototype of the patient terminal making use of the system as a communication technology. Information is available and communicated by the system to the patient, but no communication between humans is possible related to self-management. The need for emotional and psychological support among cancer patients, as a part of the facilitation of self-management, can probably not be met by the system alone in the way the technology currently is designed.

The use of communication services at the patient terminal by humans, like medical personal and psychologists would have had the potential to facilitate self-management of the cancer patient even more, next to the information which is made available. As the hospital organization has no wish or aim to replace human contact by implementing the patient terminal, these services are also not a part of the current technology at the Cancer Centre. An electronic communication service to facilitate self-management, provided by professionals, would maybe also be more beneficial and useful for the cancer patient being treated at home, by the use of other ICT functionalities next to the information arena.

If future developments will integrate and include the patients electronic medical journal, these are other functionalities that possibly can contribute to even more control and self-management of the cancer patients, as the patient can be in control over own health care data,. This will also allow increased control of own health. When these services are made available, confidentiality and privacy aspect of patient specific information must be taken into account. Future research of the users and actual use of the system is needed to reveal knowledge about the cancer patients as users or nonusers of the technology, and the actual effect of using the system to facilitate self-management in hospitalized cancer patients. The needs of the users and their opinion of the technology can be crucial for effective self-management of cancer patients by the use of the system, and for future technological developments. More specific recommendations are made in paragraph 6.8.

## **6.2 Conclusion – Sub-question 1**

*Why was it decided to implement the patient terminal at the Cancer Centre at the first place?*

The most important reason to introduce the patient terminal technology at the Cancer Centre in the first place, was related to the need to introduce one single technology with several different services, and was, as mentioned, not related to facilitation of self-management of the cancer patient. All actors agreed that this was the actual reason to introduce the technology at the Cancer Centre in the first place.

By introducing "one tool", with multiple applications integrated, the needs of the hospital and the cancer patient for information and communication services and entertainment could be met. In this way fewer technologies would be needed in the individual patients' room, and the patients would only have one technology to relate to. Important to recognize is that the medical specialists actually acts as spokespersons for the patients during the phase of introduction. The medical specialists indicated that the patients' demands and needs for information and communication services actually must be seen as the patients' right during hospitalization.

Some actor specific wishes, demands and expectations were involved at the point of introduction with respect to the multi-functionalities the system could offer. Some actors had higher expectations related to the integrated functions available at the terminal, than actually was realized in the design at the point of introduction.

Reasons to introduce the technology in the first place was, according to some actors, also related to the integration of an internal hospital communication system, between health care personnel and patients, and the integration of existing hospital technologies with the patient terminal, like the electronic patient journals.

The actors involved at the point of introduction realized that these functionalities would not be possible to implement at first instant, with respect to security and confidentiality aspects and the economic resources available. This would be functionalities that potentially could be developed in the future.

The initial reason for introducing the technology was, as mentioned, not related to the support of self-management of cancer patients, as this was not recognized by the actors involved at the point of introduction.

To support self-management of the cancer patient, by the use of the technology, has got more attention in the later development phases of the technology.

The Norwegian Cancer Society, which did not participate at the time of the introduction, was the only actor recognizing the self-management possibilities of novel communication and information technologies, as a reason to introduce the technology in the first place.

### **6.3 Conclusion – Sub-question 2**

*What was the involvement of the actors and what kind of image do the developers and implementers have of the users of the patient terminal?*

With respect to the second sub-question the analysis revealed important knowledge about which actors that actually were involved in the development and implementation of the technology at the Cancer Centre, the representation techniques used in the design of the terminal, and to what extent the actors' picture of the end-user is reflected in the design of the product.

First of all the design process, with respect to the actor involvement, can be characterized as a process of two main phases, where many heterogeneous actors have been involved developing and implementing the technology. The first phase was related to the initial development and implementation of the product in 2006. The second development phase was related to the latest developments of the technology, which started in 2007, and is still ongoing.

During both phases the product provider acted as the main actor, and both the I-methodology and other implicit representation techniques were used to create an image of the user. The most frequently used informal technique, was the use of spokespersons of the patient, like medical personal and the cancer organization.

The second development phase is different from the first phase, as even more actors are actively participating and explicit representation techniques are being used. Some patients and patient organizations were involved during this phase, providing input regarding the needs and image of the user, next to the involvement of a different designer of the new user-interface, than during the first development phase of the product.

The main-user of the technology is, by all actors, identified to be the hospitalized patients. Some actors think that future developments of new applications at the terminal can create more and new user-groups of the technology. Both out-door patients, home-patients, the relatives of the patient and medical personal, are other possible user-groups, as defined by the actors.

One of the strongest findings of this case study is that all actors imaged the user as “diverse” and “heterogeneous”, a user-image which also can be said to be reflected in the design of the technology. The possibility to select user profile, different language and different types of services is created, and guidelines are used to design a product, user-friendly for a broad user-group.

Both the initial and new design of the user-interface of the patient terminal technology reflects the actors’ picture of the end-user as a diverse user-group. Diversity among the users with respect to difference in nationality, computer literacy, health, age and interest is reflected in the design of the patient terminal.

The re-design of the user-interface at the patient terminal, has shown to even more reflect this picture, as revealed by the script-analysis of the latest design of the technology. The new design is improved compared to earlier design except for one aspect. The script of the new prototype does not yet take difference in nationality into account in the design, as the new prototype of the information arena is only developed in Norwegian.

An improvement of the new design, which makes the re-design of the product even more reflecting the actors’ picture of the end-user as diverse, than the already implemented product, is that difference in interests for information, and skills among users, to a bigger extent is taken into account.

#### **6.4 Conclusion – Sub-question 3**

*What are the aims of the developers and implementers of the patient terminal in a hospital setting?*

Several goals and aims are initiated by the actors of developing and implementing the technology at the Cancer Centre. Some of the goals are common of all actors, while other goals are actor-specific.

Goals like an internal communication system, the availability of the electronic patient journal at the terminal, and the integration of electronic forms for registration of patient information and research, are some important goals, mentioned by several actors, not realized in the design yet.

The mentioned aims are aims the actors wish to realize and implement on long term, to integrate the technology even more into current hospital services, and to make more cost-effective and efficient use of the system.

The most important reason for not reaching these aims is, as mentioned, related to the availability of budgets, security reasons, confidentiality and privacy aspects of patient-related information when making this available at the patient terminal.

The aim of the recent developments of the patient terminal was to improve the general and specific information facilities available at the technology. The script-analysis revealed that the design of the new prototype of the technology reflects the actors’ expectations in relation to the development of an extended information arena at the patient terminal. The new information arena at the patient terminal contains a lot of different information about disease, treatment, the hospital, and the patients’ private and personal situation.

With respect to self-management, this was an important aim of two of the actors involved, the nurses and the NCS. They both emphasize the possibilities to support self-management of cancer patients by the use of the technology. A reason why the nurse defined this as an aim can possibly be explained by the actors “hands on” experience with cancer patients, as their daily care takers. The NCS, as the “daily represents” of the cancer patients and their family, are continuously interested in developing optimal self-management offers for the group they represent.

The designer developer, of the new prototype of the information arena, had explicit goals related to facilitation of self-management, even though this was not a primary goal, defined by the designer herself. Her primary goal was to increase the “knowledge spiral” of the hospitalized cancer patient, an aim which can influence and facilitate self-management of the patient. The goal of the product provider, which aims to design a system which empowers the users within health care, did also want to develop a tool providing knowledge to the users.

To conclude, all actors have aims related to self-management of the cancer patient, even though this was not the initial aim of developing and implementing the system. They all aim to increase the knowledge spiral of the patient, by providing the patient with appropriately targeted, quality information, which is evidence based and up-to-date. Next to the aim about an improved information service, was important aims of the developers and implementers, to stimulate the cancer patients’ active role in own disease and treatment, to improve patient control, and to stimulate patient empowerment.

#### **6.5 Conclusion – Sub-question 4**

*How and to what extent does the script of the technology contribute to facilitate self-management of cancer patients in hospital-care?*

The actors’ opinion of facilitation of self-management in cancer patients and their view of using the technology for this purpose, next to what extent their view is in-scribed in the design of the technology, will be presented in this paragraph.

Cancer patients can, according to the actors, from time to time be in a difficult situation where facilitation of self-management and the ability to self-manage is important to stimulate to increase the feeling of control and safety. The patient terminal, as a technology to facilitate self-management, is recognized by all, except for one actor. The de-scription of the design of the technology, illustrates that the actors’ vision of the technologies’ contribution to the self-management process in cancer patients, is reflected in the design of the new prototype of the information arena. The fact that the new design of the patient terminal have a bigger potential to facilitate self-management than the current version of the technology available at the centre, can possibly be explained by the increased attention for the use of ICTs within the hospital organization to stimulate self-management. Another reason can be the involvement of more and new actors during the second development phase, and the more active involvement, and close cooperation between the patient terminal project group and the Norwegian Cancer Society. Thirdly, there was another designer involved designing the new user-interface of the patient terminal prototype, with an explicit goal to facilitate self-management, using different representation techniques to define the needs of the patients, working closely with medical specialists and other actors for developing the product.

As recognized by the actors involved in the design and implementation process, increased information about cancer as disease, treatment and how to daily manage disease, symptoms, and personal situation can lead to facilitation and increased self-management of the cancer patient. Information about these self-management components are reflected in the new design of the prototype of the patient terminal. Especially the information about disease, intervention and treatment is extensively presented at the new information arena, but also general information about how to deal with socio-psychological aspects of disease. Methods for dealing with emotions and goal-setting to facilitate self-management and increase self-efficacy, is to less extent reflected in the design of the technology. The script-analysis performed of the new design of the patient terminal indicates that the technology primarily can be used as an information technology, to provide the cancer patient with knowledge to facilitate self-management.

The way the technology is designed and developed, it can probably facilitate the self-management process of the hospitalized cancer patient, completing the offers available at the Cancer Centre and make them more visible for the patient. Human contact is recognized by the actors as an important aspect of facilitation of self-management, to support the cancer patient with dealing with emotions and individual goal-setting. Human contact cannot be provided to the patient by the use of the system, which indicates that the current design of the system cannot replace all self-management offers available at the Cancer Centre. Future development and design of the technology, aims and use of the system, will decide if the patient terminal mainly can be used as an IT to facilitate self-management in cancer patients or as an ICT.

### ***6.6 Comparison with literature***

In chapter two and three relevant literature about the topic and socio-technical analysis was presented. In this paragraph a summary of the results of this research, will demonstrate how the results relate to earlier findings, confirm or contradict results previously reported in scientific research.

Within the field of social studies of technology several researches has indicated that the study of the interaction between the human and non-human, the social and the technical, can lead to better understanding of the design and introduction of information communication technology (ICT) in health care<sup>111</sup>. The research of the patient terminal demonstrated this, as important knowledge is revealed to understand the development and implementation process of this patient-related information and communication technology in a hospital setting.

The study of the patient terminal at the Cancer Centre indicates that there are several aims of developing and implementing the technology, both on short and long-term. According to Gawande et al. (2000), the aims of patient-related ICT often includes the support of management of own care. The initial reason for developing the patient terminal was not related to this goal, disconfirming the findings of Gawande et. al. The facilitation of self-management of the patient has become a more important goal of the hospital, and the developers, during the last couple of years, and is reflected in the latest prototype of the terminal. The study reflects how the technology possibly can be used to facilitate self-management in cancer patients.

Recent investigation has demonstrated that there is increased attention to use novel ICTs to stimulate self-management in patients (Van der Meer, et al. 2007)<sup>112</sup>, (Van Gemert-Pijnen, et al. 2007)<sup>113</sup>. When looking at the patient terminal as a patient-related information- and communication technology, it is first of all designed to be used as an information technology to stimulate self-management, and to less degree designed to be used as communication technology for this purpose. Since no effect is studied of the technologies' actual contribution to self-management, this research cannot confirm or disconfirm theories about using this novel ICT for this purpose (Van der Meer, et al. 2007).

The feeling of being in control, the ability to learn to manage emotions, disease and own situation, to create a balance, is recognized, by the actors in the development and implementation process of the patient terminal, to be important to facilitate in cancer patients.

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<sup>111</sup> Akrich, M. (1992), 'The De-scription of Technical Objects'. In: W.E. Bijker en J. Law, *Shaping Technology / Building Society*. Cambridge: MIT Press, 205-224.

<sup>112</sup> Van Gemert-Pijnen, JEWC, Cranen, K, Verlinden, SSF, Boer, H, Nijland, N, Verhoeven, F. & Seydel, ER (2007) Self-management of self-limiting disease via web-based communication systems for digital triage in Primary Care. University of Twente, Roessingh Research & Development, MedNet, October 26, 2007

<sup>113</sup> Van der Meer, V, Van Stel, HF, Detmar, SB, & Otten, W. (2007) Internet-based self-management offers and opportunity to achieve better asthma control in adolescents. *Chest*, doi:10.1378/chest.06-2787

This confirms the theory of Aujolat et al. (2008)<sup>114</sup> that self-management is a dual process of “holding on” and “letting go”, characterized by the feeling of control and behaviour change. The research revealed the actors’ opinion on how to facilitate self-management in hospitalized cancer patients. Knowledge, by providing information to the cancer patient, is recognized as an important source to stimulate self-management, confirming earlier research findings (Barlow, et al. 2002)<sup>115</sup>, (Aujolat, et al. 2008).

By becoming more knowledgeable, the patient can be able to get an overview over the possible problems experienced, and can be able to find a balance in their situation. Cancer patients are seen as individuals with special needs for care and self-management, as many patients are going through difficult processes of existential crisis. According to Barlow et al. (2002) important self-management components include: providing information about drug management, symptom management, how to deal with psycho-social consequences, life style, and the available social support system. When looking at the different self-management components presented by Barlow et al. (2002) these are also recognized by the actors involved, and to some degree reflected in the design of the new prototype of the information arena at the patient terminal. The design of the patient terminal allows the patient to get information about the different self-management components as mentioned by Barlow et al., but do not allow for individual support by human actors.

According to Barlow et al. (2002) the most effective approach to facilitate self-management is to offer a combination of different interventions. Like individual and group conversations, in combination with written materials and the use of technologies. The way the patient terminal is designed it can, as mentioned, contribute to complete the offers at the Cancer Centre, and meet the individual needs of the cancer patients for self-management support. In this way the patient terminal cannot only function as a ‘door opener’ to the self-management offers available at the centre by presenting these at the technology, but it can also optimize the offers available, as a multi-component approach is facilitated, and possibly stimulate more effective self-management of the cancer patient. According to the developers and implementers of the patient terminal, the technology is part of a broader and more complete approach of self-management offers to meet the needs of cancer patients for self-management support at the Cancer Centre.

In the study by Turton et al. (2002)<sup>116</sup>, how to meet the needs of the cancer patients for self-management support, the provision of information is again identified as an important part of this process. Both information about the disease and treatment of the patient, is found important to provide, to stimulate the patients’ active role and sense of control. The recent developments of the patient terminal have, as mentioned, an extended information arena, where both medical and socio-psychological information can be provided to the patient. In this context the patient terminal has the potential to be a part of a self-management support system, contributing, completing and creating new offers to the cancer patients at the Cancer Centre, and has the potential to be used to facilitate self-management of the cancer patient, mainly as an information technology.

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<sup>114</sup> Aujolat, I. Marcolongo, R. Bonadiman, L. and Deccache, A. (2008) Reconsidering patient empowerment in chronic illness: A critiques of models of self-efficacy and bodily control. *Social Science and Medicine*. Volume 6, Issue 5, March 2008, pp1228-1239.

<sup>115</sup> Barlow, J., Wright, C, Sheasby, J, Turner, A. & Hainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. School of Health and Social Sciences, Coventry University, England, UK, Elsevier Science, Ireland, Ltd Doi.10.1016/S0738-3999(02)00032-0

<sup>116</sup> Turton, P and Cooke, H. (2002) Meeting the needs of people with cancer for support and self-management. Obtained via Science Direct. *Complementary Therapies in Nursing and Midwifery*. Volume 6, Issue 3, aug 2000, pp130-137



As earlier discussed in this paper, and described in scientific research (Henwood et al., 2003)<sup>117</sup>, individual needs and differences among patients can influence the use of the technology for facilitation of self-management.

The actors' image of the cancer patients as a diverse user-group, is, as earlier described, reflected in the design of the technology. Both difference in skills and interests, by designing a user-friendly technology with text and pictures to provide information, are taken into account when developing the technology for a diverse user-group. Still, it is recognized by developers and implementers of the patient terminal, that cancer patients' age, health condition and literacy level, probably will influence the use of the technology, and the extent in which the individual patient will benefit from using the technology in facilitation of self-management. The actors' view reflect earlier presented research findings by Henwood et al (2003), that using ICT for the expansion of medical knowledge probably can be used to facilitate self-management, but that individual differences among patients can influence this process.

When looking at the theory of Akrich (1992, 1995), and earlier research findings related to socio-technical research, it is indicated that the development process of ICTs often include multiple-heterogeneous actors (Oudshoorn et al. 2004)<sup>118</sup>. There is usually a continuous interaction between the social and the technical in the design process of ICTs. The development of the patient terminal also involves a heterogeneous network of professional actors, as both technical experts, patient organizations and medical personnel are among some of the actors involved in this process.

According to Akrich, the success and failure of the design and end-use of technologies often depends on the developer's ability to deal with diverse users<sup>119</sup>. With respect to the representation techniques used to create an image of the end-user in the design of the patient terminal, the implicit representation techniques are the most frequently used techniques. The "I-methodology", earlier demonstrated to be an inadequate technique in designing products for diverse user-groups<sup>120</sup>, is used together with other implicit representation techniques, involving patient organizations and medical personal, which usually are in close contact with cancer patients. According to Oudshoorn et al. (2004), confirming the theory of Akrich, the designer often fails to deal with diversity among users. The script-analysis of the patient terminal indicates the opposite in this case. The diversity among users is taken into account in the design of the patient terminal. By including different actors and using different representation techniques, the aim to create a product for a broad, diverse user-group is reflected in the design of the patient terminal. Differentiation in health condition, skills, nationality, age and interests is taken into account. Diversity among possible users has become an increasingly more important part of the design practice and development of the technology, as this even is more reflected in the latest design of the prototype of the patient terminal, with one exception, with respect to nationality. As there is almost no information available about the primary users of the technology, the hospitalized cancer patients, or the

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<sup>117</sup>Henwood, F. Wyatt, S. Hart, A. and Smit, J. (2003) 'Ignorance is bliss sometimes': Constraints of the emergence of the "informed patient" in the changing landscape of health information. *Sociology of Health and Illness*. Vol.25, no6, pp.589-607.

<sup>118</sup> Oudshoorn, N. Rommes, E. and Stienstra, M. (2004) Configuring the user as Everybody: Gender and Design Cultures in Infomraion and Communication Technologies. *Jstor: Science, Technology & Human Values*, Vol. 29. No. 1 (Winter, 2004) pp.30-63

<sup>119</sup> Akrich, M. (1995), 'User Representations: Practices, Methods and Sociology'. In: Rip, A, Misa, T.J., Schot, J. *Managing Technology in Society*. Cenegage Learning, 167-184.

<sup>120</sup> Oudshoorn, N. Rommes, E. and Stienstra, M. (2004) Configuring the user as Everybody: Gender and Design Cultures in Infomraion and Communication Technologies. *Jstor: Science, Technology & Human Values*, Vol. 29. No. 1 (Winter, 2004) pp.30-63

actual use of the technology, the role of the users or nonusers of the technology, cannot be described in these results.

With respect to earlier investigation, by Oudshoorn et al (2003), knowledge about this user-group and the actual use of the system, is shown to be important for the further design, implementation and use of technological artefacts<sup>121</sup>. This is a point of attention future research can bring light to.

### ***6.7 Reflection on the research method used, process and results***

As in many qualitative studies there are advantages, but also some limitations of the research method used, as no hard conclusions can be made. Some critics can be made related to the actor selection method, representativeness and generalizability of the case study made.

The actors participating in the research were selected based on information obtained from contact persons at the Cancer Centre, and by asking the developers and implementers which actors they cooperated with during this process. There is no guarantee that the limited amount of actors involved, represents other participants in this process. Another point, due to the relatively small group of participants that were interviewed, is that the research results probably cannot represent all similar groups or situations. There is because of this, no guarantee that the research findings of this study will be identical or equal applicable for other situations, which means that generalizing the results can be difficult.

A shortcoming of exploratory studies in general, is that they seldom provide definite answers to research questions<sup>122</sup>. Exploratory research however, has the advantage that it can give in-depth knowledge about processes, and indicate questions for further research.

Another question that can be raised about the research method used is related to the reliability of the research. As the study has an explorative character, with the purpose to explore the topic further and create a basis for more research about the topic, issues related to reliability are less important.

The research method used can provide advantages related to validity, allowing to study, and better understand the processes involved in the development and implementation of the technology, and the technologies' possible contribution to facilitation of self-management in cancer patients.

The inclusion of interviews with the patients, as one of the users of the technology studied, would have provided interesting knowledge about this user-group and their needs. Due to restrictions in access because of anonymity protection of patients and their health condition, permission of ethical committees must be obtained to include this group in research. Time restrictions resulted in exclusion of this user-group. The plan to include logs to analyse the actual use of the system could also not be included, as the novelty of the technology did not allow making use of these log-transcripts yet.

### ***6.8 Implications of the research for people working within the field of the study***

The introduction and use of the patient terminal in hospital care can lead to important changes with respect to the work processes within the hospital and the organization around the patient. When the patient terminal technology actually will be used for the purpose to provide the patient with information and to facilitate self-management of the cancer patient, this can influence the work of the medical personal within the hospital, and the quality of life of the hospitalized patient. Provision of folders and oral information might be less needed, and can

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<sup>121</sup> Oudshoorn, N. Brouns, M. & van Oost, E. (2003) Diversity and Distribution Agency in the Design and use of Medical Video-Communication Technologies. University of Twente. Inside the Politics of Technology. Hans Harbers (ed) Amsterdam University Press, 2005

<sup>122</sup> Babbie, E. (2007) The practise of Social Research. Eleventh edition. Thomsom Wadsworth

lead to more cost-effective and efficient use of the resources available at the hospital. This can require that medical personal must stimulate an active use the technology, as the patients in hospitals by law have the right for information, and need to know where to find this. It is also important that the information available at the terminal stays up-to-date, relevant and correct. This means that responsibilities must be clear, within the hospital, and between the product provider and the hospital, about who will be responsible for the quality of the content on the information sites available at the terminal.

Another scenario is that patients, by using the new information arena, actually will ask more questions, or more specific questions, as information is made easy accessible at the terminal. This can lead to more discussion and influence the time needed during consultation hour with the patient. The cancer patients may also want to make more use of the self-management offers at the Cancer Centre as increased information about this is made available, which can result in an increased need for offers, like psychological services or self-management groups and courses. By increased self-management among patients this can possibly also influence and reduce the time needed to stay in the hospital, and again lead to more cost-effective use of hospital resources. The patients might by increased responsibility and involvement, be able to spend more time at home during the treatment of their disease. The online information arena can in this case serve as a tool to facilitate self-management in the home-setting of the patient. The involvement of different actors in the development and implementation process of the patient terminal can influence the attention the technology receives within the hospital organization, increase awareness for, and the possibilities to use the technology for facilitation of self-management, and influence the further developments and implementation of the system.

The outcomes of this study can be used for evaluative purposes to optimize the system, or for ideas for future development and implementation of the patient terminal. If future technologic developments and implementation of the patient terminal will result in integration with other technologies and the availability of more applications and services, like an internal communication system, the access to the electronic patient journal or the use of electronic forms which again can be used for research, the system will not only require more involvement of the user(s), and create more user-groups, but will possible also become more integrated, and to a bigger extent, part of hospital delivery and services. A change, which will have even bigger implications for the organization, the work process, and the users of the system, than until now has been the case. The dependency and use of ICTs within hospitals for different purposes have not only increased the last years, but is also something the hospital organization relies on and need in their daily work. Standardization and common hospital solutions of ICTs, like the patient terminal, can not only be important to make cost-effective and efficient use of hospital resources, but possibly demand a different kind of cooperation between not only actors related to one hospital, but also actors within the region or on national level to be able to reach not only self-management aims, but also national, regional and hospital specific goals and strategies.

### ***6.9 Recommendations and future research***

Further research is needed to identify the actual use of the technology. The possibilities to make logs of the use of the patient terminal can be used to analyse how the users interact with the system anonymously, without involving the user. With respect to the health condition of the users, this could be a preferred method to provide general knowledge about user patterns of the whole user population. Interesting to know, in relation to the use of the technology, is whether users of the patient terminal make use of the information arena provided at the system, or make own searches on the internet to get the information they want and need. This

knowledge can be used to improve the system and further develop the information services available at the patient terminal.

There is also made no extensive research about the actual needs of the end-users of the patient terminal, except for some orientating interviews with a limited amount of cancer patients. To identify the needs of the cancer patients when in hospitals, related to the technology and self-management, formal techniques, like a questionnaire and user investigation, could be performed. An evaluation of the user-needs could provide information about whether the design of the technology actually meets the demands of the users, which possibly can contribute to improve the system and future developments of the technology. Increased user-involvement can contribute to optimize the system and the health care services provided, and possibly lead to more cost-effective and efficient development and use of the technology. Up to this point in time, no studies have been conducted to analyse the effect of using the patient terminal technology to facilitate self-management in cancer patients. A study about the technologies' actual effect on facilitation of self-management could reveal interesting knowledge regarding the technologies' contribution to this process in hospitalized cancer patients.

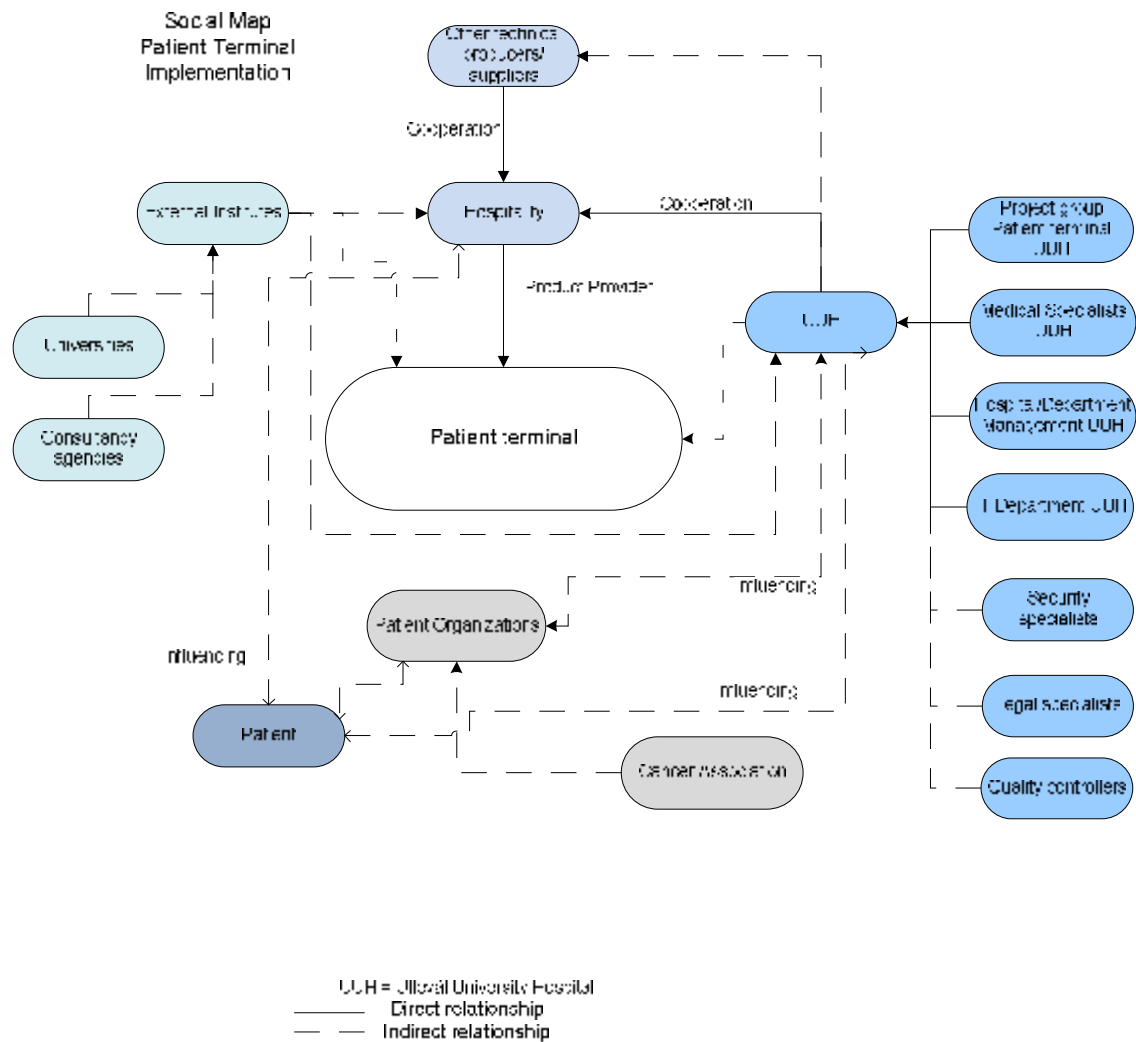
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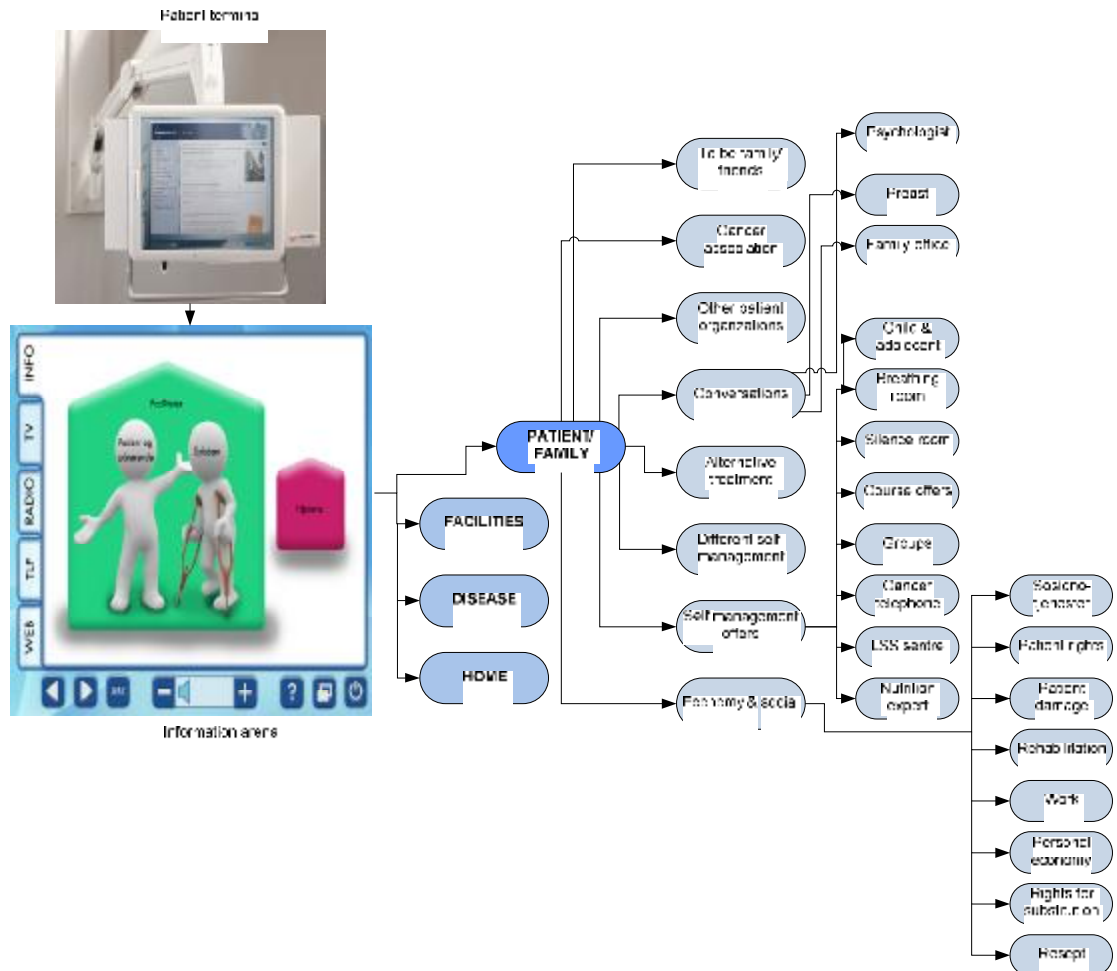
The overview chart of the implementation phase indicates that more or less the same actors are involved, with a couple of exceptions. The main actors during this phase were still the product provider and actors at the Cancer Centre.





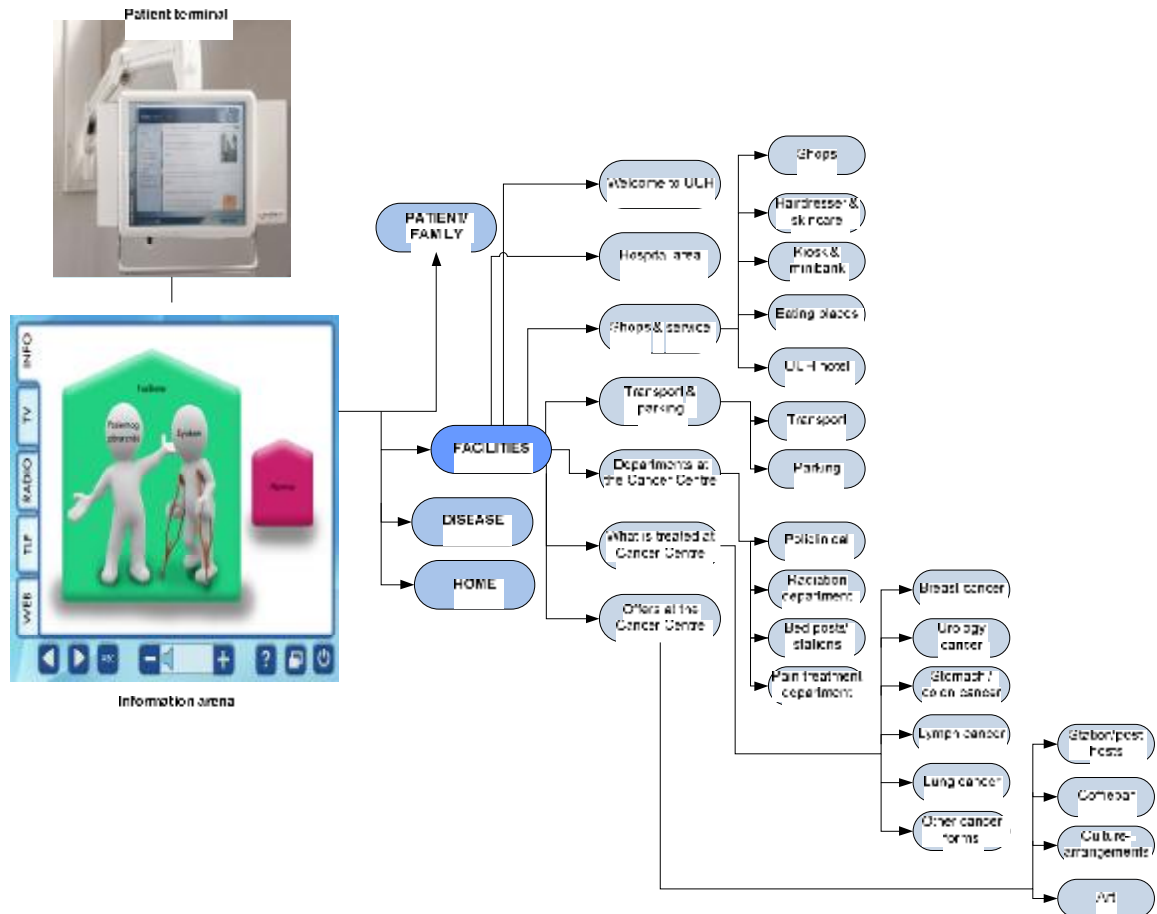
### Appendix 3 Overview information arena: Patient/family – sub-menus

The overview of the information arena below, indicate the content available on the prototype of the new information arena at the patient terminal. The different 'boxes' indicates the different sub-menus available, under the main-menu, in this case 'patient/family'.



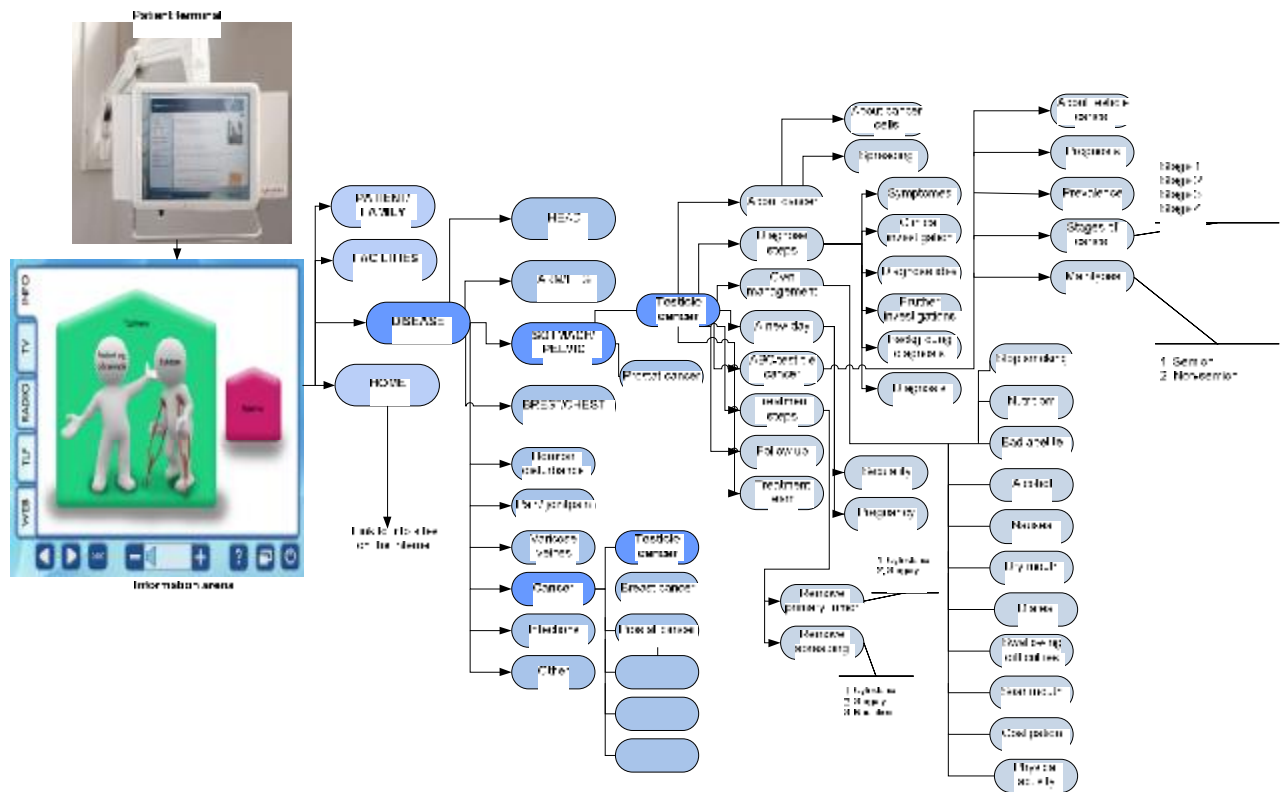
## Appendix 4 Overview information arena: Facilities – sub-menus

The following overview of the information arena indicates the sub-menus related to the main-menu ‘facilities’. The chart illustrates how these menus are divided into ‘families’ at the prototype under development.



## Appendix 5 Overview information arena: Disease – sub-menus

The last overview if one of the main-menus, 'disease', contains information about disease, intervention and treatment of cancer, and daily management of symptoms, disease and private situation. The last main menu, 'home', do only contains one sub-menu, indicating how to enter the information arena from home by the use of the internet.



## Appendix 6 Norwegian Law on Patient rights

### § Norwegian Law on Patientrights by The Norwegian Directorate for Health and Social welfare



#### Law 1999-07-02 nr 63 (last changed 21-12-2007)

The rights of the patients are primarily regulated by the patient right law. Patientrightlaw of 2<sup>nd</sup> of July 1999 nr is to contribute and secure that all patients have the same right for health of good quality. The law is one out of several laws, and must be seen together with other health laws regulating health services, health personal, mental health and other health related fields.

CHAP3. The right to participate and information

#### 3.1. The patients right to participate (Patientrightslaw § 3-1)

A patient has the right to active participate when health services are provided. The right to participate indicate that there must be cooperation between health personnel and the patient. Within this element, the patient also must take own initiative and responsibility for this participation. The patient can decide him/herself to what degree the patient is involved.

The patient has the right to participate and has influence of the decisions to take for what has to be done and in which way. According to the law, the right to participate influence all aspects of health help, prevention, intervention, examination, diagnosis, cure, treatment and rehabilitation.

The degree of participation will vary related to practical aspects and the degree of complexity. With high degree of competence needed, the less the patient will participate in decision making. In what way the patient participate must be adapted to the patients own capabilities.

The right to participate is closely related to the rights for information and the right to agree/disagree to health help.

#### 3.2. The patients right for information (Patientrightslaw § 3-2)

##### 3.2.1. What kind of information has the patient right to get?

The patient has the right to receive information about his/her health condition and information about the health help to receive, this include information about treatment, cure, diagnosis, or examination. The patient must also be informed about possible risks and side effects related to the health help provided.

The information must be good enough that the patient can participate and make decisions about own health and must be adapted to the patient based on his/her age, maturity, experience, culture and language. What is expected of the content and the extent of the information will depend on the situation. This means that the same demands of information cannot be required when acute situations, in comparison with a long-term care situation.

##### 3.2.2. Who should give information?

The health personnel that are in contact with the patient have the duty to give information to the patient and answer questions. One person within the health institution is responsible that the patient actually receive information and that the information is good enough. The patient can contact this health person for the overall information.

##### 3.2.3. If the patient does not want to receive information

Some patients do not wish to receive information or do only want limited information. This must be respected. Health persons must in some cases still inform the patient if needed to prevent damage for the patient or others, or when it is needed due to chances of infection.

##### 3.2.4. Circumstances where the patient is not to be informed

In special cases is the health personnel not suppose to inform the patient. Information can be held back if this is otherwise the patient's life is threatened or it is clearly not advised by persons closely related with the patient. If the patient wants to be informed there must still be very special circumstances still not to do this.

Source: The Norwegian Directorate for Health and Social welfare;

<http://www.shdir.no/vp/multimedia/hunk/pasientrettigheter/>

## Appendix 7 Te@mwork 2007 – National strategy plan ICT development Norwegian Health Care



Sosial- og helsedirektoratet

### Te@mwork 2007 - Electronic Interaction in the Health and Social Sector

Te@mwork 2007 is the national strategy for ICT development in the health and social sector for the period 2004-2007 in Norway. The strategy gives direction and continuity to ICT development in the sector. The vision of the work is that patients and clients shall experience continuity of care when using the services. Realizing this vision entails considerable development and change in the way that this interaction and other performance tasks take place in the sector.

Te@mwork 2007 gives higher priority to certain challenges than to others. The fundamental idea behind the strategy is that things shall be done properly rather than halfway. Therefore the national strategy will have two main priority areas:

The first main priority area involves improving the flow of information in the sector. This presupposes working with infrastructure, information structure, information security, electronic patient records, exchange of electronic messages and access to professional support.

The second main priority area involves greater inclusion of new actors in electronic interaction in the sector. So far electronic interaction has mainly been developed between health enterprises, general practitioners and the National Insurance Service. Patients, clients and relatives, pharmacies and municipal health and social services are actors that must be included more closely in the interaction.

Source: The Norwegian Directorate for Health and Social welfare:

[http://www.sklir.no/sunspill/sunspill\\_2007\\_5612](http://www.sklir.no/sunspill/sunspill_2007_5612)

## Appendix 8 Overview relevant key terms used in the report

### ***Information and communication technology:***

Information and communication technology (ICT) is an umbrella term that includes all technologies for the communication of information.<sup>123</sup> When this term is used in the report it refers to ICT in the broadest sense.

### ***The patient terminal:***

The patient terminal is a technology that can be categorized as an information and communication technology (ICT). The patient terminal refers to the screen situated bedside of the individual patient. The following definition of a patient terminal, by Knutslien<sup>124</sup>, will be used: "A patient terminal is a combination of the terminal hardware and the patient portal software that provides the user with a graphical user interface."<sup>125</sup> When we talk about hardware this refers to the actual screen, buttons, and framework, like the arm for connecting the screen to the wall. The software refers to the applications which can be viewed at the screen. Hospital IT is the product provider of the technology, cooperating with other providers, delivering both the software and hardware.

### ***Touch-screen***

Touch-screen refers to a screen, where the user use his or her finger or a special pen to provide the screen with input. The input, provided by a touch, is detected by the screen within the screen area, and makes the user able to interact with the content of the screen<sup>126</sup>.

### ***User-interface***

The user-interface is the area or interface where the user interacts with the system. The user gives input to the system and is provided with feedback from the system which cause the interaction. The input allows the users to manipulate the system, and output allows the system to produce the effects of the users' manipulation<sup>127</sup>.

Related to software the user-interface often refers to the graphical user-interface (GUI) which is the graphical image provided at the screen<sup>128</sup>. The screen is then the area or interface between the user and the system.

### ***Arena***

An arena refers to the area or a specific field of application at the patient terminal, which the technology is divided into. An example of arena is for television, radio or information. The information arena, which refers to the arena of information, is the arena which frequently will be referred to in this report, as this is the arena which currently is under development.

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<sup>123</sup> Definition retrieved from Wikipedia May 2008: [http://en.wikipedia.org/wiki/Information\\_Communication\\_technology](http://en.wikipedia.org/wiki/Information_Communication_technology)

<sup>124</sup> Knutslien, S.A. (2002) Pasientterminal: Et informasjons-, kommunikasjons-, og underholdningstilbud for pasienter. Norwegian University of Science and Technology, Trondheim, Norway

<sup>125</sup> Knutslien, S.A. (2002) Pasientterminal: Et informasjons-, kommunikasjons-, og underholdningstilbud for pasienter. Norwegian University of Science and Technology, Trondheim, Norway

<sup>126</sup> Based of the definition at the online encyclopaedia Wikipedia. Visited May 2008: <http://en.wikipedia.org/wiki/Touchscreen>

<sup>127</sup> Based of the definition at the online encyclopaedia. Wikipedia. Visited May 2008: <http://en.wikipedia.org/wiki/User-interface>

<sup>128</sup> Volstad, N. (2008) Utvikling av brukergrensensnitt for pasientterminaler. Institute for product design, Norwegian University of Science and Technology, Trondheim, Norway

### ***Actor***

What is meant by an actor for the purpose of this research is the following:

“An actor is one that takes part, a participant.”<sup>129</sup> The term actor will refer to a participant in the development and implementation process of the patient terminal, a developer, designer and/or implementer.

### ***Self-management***

There are different views and many different ways to define self-management. In a study made by Barlow et al (2002) about self-management interventions and components, the conclusion is made that no golden standard definition actually exists for self-management. Self-management can refer to interventions, training, and skills by which patients with a chronic condition, disability, or disease can effectively take care of them selves or learn how to do so.”<sup>130</sup> Self-management, as the term indicates, means that oneself can manage or influence the disease or the situation an individual is in.

### ***Socio-technical systems theory/approach***

Socio-technical system theory is theory about social aspects of people and society and the technical aspects of machines and technology<sup>131</sup>. The socio-technical analysis or approach refers to the study of the interaction between the technology and its social environment, through the analysis of its design, development and/or use.

### ***Script***

The script-analysis of Akrich (1992)<sup>132</sup> is a method, and socio-technical approach, to analyse and describe the interaction between technologies and humans. Akrich (1992) introduced the script concept to better understand the development and design of technologies.

The de-description of objects, usually made by the analyst, is the opposite movement of the inscription by the engineer, inventor, manufacturer, or designer<sup>133</sup>.

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<sup>129</sup> Definition of the an actor according to Online Dictionary: <http://www.thefreedictionary.com/actor> Visited at 8th of February 2008

<sup>130</sup> Online encyclopedia, visited February 2008: <http://encyclopedia.thefreedictionary.com/Self-management>

<sup>131</sup> Online encyclopaedia visited May 2008 [http://en.wikipedia.org/wiki/Sociotechnical\\_systems\\_theory](http://en.wikipedia.org/wiki/Sociotechnical_systems_theory)

<sup>132</sup> Akrich, M. (1992), ‘The De-scription of Technical Objects’. In: W.E. Bijker en J. Law, Shaping Technology / Building Society. Cambridge: MIT Press, 205-224.

<sup>133</sup> Akrich, M and Latour, B. A (1992) Shaping technology/Building society: Studies in sociotechnical change. Ch.9, p. 259-264: Summary of a convenient vocabulary of the semiotics of human and nonhuman assemblies