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# Table of Contents

## Articles

<b>Validation of a Health Literacy test in a Danish population - Results from a pilot study</b> <i>Lisa Emtokaer, Lars Ehlers, Ole Hejlesen</i> .....	1
<b>Using ICT training as an arena for intergenerational learning experience. A case study</b> <i>Elin Thygesen, Ragni MacQueen Leifson and Santiago Martinez</i> .....	9
<b>Methodology for Care Processes Modelling: Bringing the Health Care Complexity into Health IT Development</b> <i>Conceição Granja, Kari Dyb, Eli Larsen, Stein Roald Bollea and Gunnar Hartvigsen</i> .....	17
<b>Collaborative Process Modelling and Evaluation in E-health</b> <i>Niels Frederik Garmann-Johnsen and Øyvind Hellang</i> .....	23
<b>RIS/PACS implementation calls for changes in work processes and organizational structure</b> <i>Karsten Niss and Ole Hejlesen</i> .....	31
<b>Access Control for Electronic Health Records. A Delphi study of current challenges and highlighting of potential improvements</b> <i>Rune Hystad and Rune Fensli</i> .....	37
<b>Usability Evaluation of Electronic forms and Collaborative Assessment Report in an Inter-municipality Health Care team for Dementia Diagnose</b> <i>Berglind Smaradottir, Elisabeth Holen-Rabbersvik, Elin Thygesen, Rune Fensli and Santiago Martinez</i> .....	45
<b>End-to-End Infrastructure for Usability Evaluation of eHealth Applications and Services</b> <i>Martin Gerdes, Berglind Smaradottir and Rune Fensli</i> .....	53
<b>Need for Telecare for Home Residents with Dementia: Potential Solutions - Based on the Experiences of Close Relatives and Healthcare Professionals</b> <i>Marthe M. Fensli, Elin Thygesen, Martin W. Gerdes and Rune Fensli</i> .....	61
<b>Future Hospital Structure in Vest-Agder? Analyzing a Newspaper Debate</b> <i>Hans Olav Omland</i> .....	69
<b>Gathering Experience with Ontology and SPARQL Based Decision Support</b> <i>Jan Pettersen Nyttun, Tian Zhao, Angeliqne Mukasinea and Rune Werner Fensli</i> .....	77
<b>A Belief Rule Based (BRB) Decision Support System to Assess Clinical Asthma Suspicion</b> <i>Mohammad Shahadat Hossain, Emran Hossain, Saifuddin Khalid and Mohammad A. Haque</i> .....	83
<b>Prototyping a Diet Self-management System for People with Diabetes with Cultural Adaptable User Interface Design</b> <i>Eunji Lee, Eirik Årsand, Yoon-Hee Choi, Geir Østengen, Keiichi Sato and Gunnar Hartvigsen</i> .....	91
<b>Abstracts</b>	
<b>A Success Story about a Communication Reform in the County of Sogn &amp; Fjordane</b> <i>Hilde G. Corneliussen</i> .....	101
<b>Information Technology Managers and Critical Success Factors in Healthcare Organizations in Nordic Countries</b> <i>Hai Thi Thanh Nguyen, Tom Roar Eikebrokk, Carl Erik Moe, Rony Medaglia, Hannu Larsson and Tommi Tapanainen</i> .....	103

<b>Electronic messaging-a contribution to fulfil the Coordination reforms intentions of coherent, seamless, coordinated and safe health services?</b>	
<i>Anne Ruth Botn Bjørlo, Heidi Christensen and Rune Fensli .....</i>	<b>105</b>
<b>Design and Development of a Smartphone Application for Cue Exposure Treatment</b>	
<i>Angelina Mellentin, Ye Wu, Minghao Wang, Arne Bilberg, Elsebeth Stenager, Bent Nielsen and Fei Yu .....</i>	<b>107</b>
<b>A Usability Evaluation of a Web-Based ICT System for Quality Management</b>	
<i>Torunn Kitty Vatnøy, Grete Vabo, Mariann Fossum .....</i>	<b>109</b>
<b>PALANTE – an EU project that will demonstrate the user value of electronic patient solutions</b>	
<i>Ingrid Heitmann.....</i>	<b>111</b>
<b>Piloting the Norwegian version of the “The Measuring Instrument for Determinants of Innovations” (MIDI) - a new instrument for implementation of innovations in health care</b>	
<i>Janne Dugstad, Etty Nilsen and Hilde Eide .....</i>	<b>113</b>



# Articles



# Validation of a Health Literacy test in a Danish population – Results from a pilot study

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## Abstract

*The authors of this paper translated and adapted the original American full-length Test of Functional Health Literacy in Adults (TOFHLA) into a Danish version. As a part of a pilot study the Danish TOFHLA was validated for use in a Danish population. The purpose of the pilot study was to test and validate the Danish version of TOFHLA on 42 consecutively selected patients diagnosed with chronic obstructive pulmonary disease (COPD), and to explore tendencies and associations between health literacy and demographic characteristics, educational attainment, and mean response time. The 42 COPD patients were recruited from two different settings (the municipality of Aalborg and the municipality of Hjørring). Based on a Cronbach's alpha coefficient of 0.943, a reliable Danish TOFHLA has been successfully developed. The results of the pilot study showed no statistical significant differences between COPD patients recruited from the municipality of Aalborg and those recruited from the municipality of Hjørring. More research is needed to explore the level of health literacy among Danish COPD patients.*

**Keywords:** Denmark, chronic obstructive pulmonary disease, TOFHLA, validity, Health literacy

## Introduction

During the past decade, health literacy has become a rather vibrant area of research [1]. In spite of the rapid development in the research area, there is still no consensus regarding the definition and conceptualisation of health literacy [2]. The definitions from the Institute of Medicine [3], the WHO [4] and the American Medical Association (AMA) [5] are the ones most frequently cited in the relevant qualified literature and also the most acknowledged ones [2]. These definitions are slightly different in content, but they are very similar in terms of their emphasis on the individual ability to evaluate, access and use health-related information to make appropriate health decisions and maintain good health [2].

In recent years, health literacy has received increased attention in European legislation and politics, and also as an important area of research [6]. Research on health literacy has been carried out in the UK [7], Japan [8], Australia [9,10], Switzerland [11], Korea [12], and the Netherlands [13]. The lack of consensus regarding the conceptualisation and

definition causes disagreement about the measurement of health literacy [1]. In the literature, the *Rapid Estimate of Adult Literacy in Medicine (REALM)* [14] and the *Test of Functional Health Literacy in Adults (TOFHLA)* [15] are the screening instruments most widely used to assess health literacy, but they are only available in an English/American and Spanish version [16]. To date, there is no standardised approach to assess health literacy in most European countries [17]. Therefore, as in many European countries the research into health literacy in the Danish context is at an infant stage.

There is a higher prevalence of low health literacy among elderly people with a chronic disease like for example chronic obstructive pulmonary disease (COPD) [16]. The association between COPD and health literacy is rather unexplored, but three recent studies investigated the association between various health outcomes and health literacy among COPD patients; one study found that COPD patients with a low level of health literacy often have a poorer overall health status compared to more health-literate COPD patients [18]. The second study found that poorer health outcomes seem to be associated with a low level of health literacy among COPD patients [19]. The third study emphasizes the role of health literacy in chronic disease self-management; it states that good doctor-patient communication is important to support self-management among COPD patients [20]. The third study also points out that recognition of low health literacy as a problem, and suitable screening instruments for identifying patients with a low level of health literacy in a proper and respectful way, are required to achieve better health outcomes [20]. Baker et al. [21] have also stated the importance of identifying patients vulnerable to low health literacy, so that education efforts regarding chronic disease management and medication can be tailored according to their needs [21]. On this basis, a logical first step is the development of proper health literacy screening instruments. The full-length original American TOFHLA has been used to assess functional health literacy in various populations and health conditions. Functional health literacy, as assessed in the original American TOFHLA, comprises basic numeracy, reading and writing skills applied in a healthcare setting [15]. Functional health literacy is the foundation in the concept of health literacy [22].

As the original American TOFHLA is well described and widely used in existing literature, the authors of this paper translated and adapted the original American TOFHLA into a Danish version. As a part of a pilot study the Danish TOFHLA

was validated for use in a Danish population based on a sample of patients with COPD. The purpose of the pilot study was to test and validate the Danish version of TOFHLA on consecutively selected COPD patients from two different settings, and to explore tendencies and associations between health literacy and demographic characteristics, level of education, and mean response time.

## Materials and Methods

### Procedures

A Danish version of the original American TOFHLA was developed and evaluated for cultural equivalence for the Danish population. This cross-cultural adaptation process was conducted according to the guidelines for cross-cultural adaptation as defined by Beaton et al. [23]. In accordance with Beaton et al. [23], the Danish TOFHLA was pre-tested as a part of a pilot study, to ensure consistency and reliability of the instrument. The Danish TOFHLA was used to explore the level of functional health literacy among a sample of COPD patients in the region of Northern Jutland, Denmark.

### Participants in the pilot study

The participants in this pilot study were selected using consecutive sampling. Consecutive sampling seeks to include all accessible subjects at multiple data collection sites. In this case the consecutive sampling was carried out at the pulmonary outpatient clinic at Aalborg Hospital (the municipality of Aalborg) and the Health Centre in Hjørring (the municipality of Hjørring); it provided a sample of 42 Danish participants with COPD. The Health Centre in Hjørring and Aalborg Hospital are both located in the area of Northern Jutland, Denmark. This area represents a broad socio-demographic range, as it serves almost 45,000 people with COPD [24].

At each site, the contact with all accessible subjects was initiated by a healthcare professional. The healthcare professionals provided the subjects with a short written description (developed by the researcher), which explained the requirements of participants as well as the process should they agree to take part in the pilot study of the Danish TOFHLA. The healthcare professionals were asked to consider the following inclusion and exclusion criteria when potential subjects were invited to participate in the pilot study:

**Inclusion criteria:** Patients diagnosed with COPD (as assessed by the two healthcare professionals and afterwards the diagnosis of COPD was confirmed by self-report to the researcher), men and women, adult > 18 years, pregnant or non-pregnant, and able to read and understand Danish as judged by the researcher.

**Exclusion criteria:** Patients diagnosed with dementia (as assessed by the two healthcare professionals and afterwards this was confirmed by researcher's observation of the patient), being too ill to participate or blindness, unable to read or understand Danish as judged by the researcher, unable to understand the informed consent procedure also as judged by the researcher.

If a subject agreed to participate, the first step was to ensure that the participant was suitable for participation and inclusion in the pilot study; this was done by the researcher. The researcher also informed the participants orally about the purpose of the pilot study and about their rights to stop the interview/test and withdraw at any time. Relevant data (completion of the Danish TOFHLA and the face-to-face interview) were collected at the most convenient times for the participants either in their own homes or at the setting where they received health services. The participants were assured privacy and confidentiality conditions at all times during the pilot study.

### Data collection in the pilot study

Relevant data were collected for statistical analysis using two types of methods:

1. Each COPD patient entered a face-to-face interview to collect the following demographic data: *municipality, civil status, educational level, sex, and age*. The interviews were carried out by the researcher.
2. After the face-to-face interview, each COPD patient was asked to complete the Danish TOFHLA. The original American TOFHLA consists of a numeracy part containing 17-items and a reading comprehension part containing 50-items [15]. This structure is maintained in the Danish TOFHLA. In the Danish TOFHLA, the numeracy part concerns the participant's ability to keep a clinical appointment, understand instructions for taking medication, understand financial assistance, etc. For example, a participant could be asked to read prescription medication instructions or an appointment reminder card, and afterwards, s/he would be asked about what had been read. The reading comprehension part of the Danish TOFHLA is constructed as a modified Cloze procedure. In a Cloze procedure words are randomly deleted from a reading passage [25]. In this case of health-related reading passages, every fifth to seventh word is removed from the text, and then the participant is asked to select the most suitable word from a list of four possible words. The total health literacy scores for the Danish TOFHLA are divided into three levels: **inadequate (score: 0-59)**, **marginal (score: 60-74)** and **adequate (score 75-100)** – just like the original American TOFHLA [15].

### Data Analysis

The statistical software SPSS version 21 [26] were used to analyse the results obtained from the Danish TOFHLA and the basic demographic interview. A variety of statistics were performed on the obtained data to describe the study participants in terms of *frequency, percent, mean, standard deviations*, etc. Cronbach's alpha coefficient was used to analyse the internal consistency of the Danish TOFHLA; this was conducted as an overall analysis of the Danish TOFHLA followed by an analysis on the two subcategories (numeracy

and reading comprehension). The criteria for reliability set by Houser [27], requires a Cronbach's alpha coefficient that exceeds a value of 0.7 before an instrument is considered reliable.

Descriptive statistics were applied to explore the health literacy score by demographic characteristics, level of education, and mean response time to the Danish TOFHLA. ANOVA test and independent t-test were used to assess statistical significant differences between groups [28]. Finally, a multiple linear regression analysis was conducted to explore the association between health literacy and educational level – adjusted for age and sex.

## Results

Our sample constituted 42 Danish COPD patients); mean age was 68.7 years (range 34-86 years) with a standard deviation of 11.49. 42.9% of the participants were recruited from the municipality of Hjørring (Health Centre) and 57.1% were recruited from the municipality of Aalborg (Hospital). The basic demographics of the 42 participants are shown in *Table 1*.

*Table 1 - Basic demographics of the 42 participants*

<b>Number of participants</b>	42
<b>Age</b>	Mean = 68.7 (range 34 – 86 years)
	<b>Frequency (percent)</b>
<b>Sex</b>	
Men	20 (47.6)
Women	22 (52.4)
<b>Recruitment</b>	
Municipality of Aalborg (Hospital)	24 (57.1)
Municipality of Hjørring (Health Centre)	18 (42.9)
<b>Civil status</b>	
Married or living with a partner	23 (54.8)
Living alone	19 (45.2)
<b>Level of education</b>	
9 <sup>th</sup> or 10 <sup>th</sup> grade or less (some only completed 7 <sup>th</sup> grade)	18 (42.8)
High school	6 (14.3)
Higher education	2 (4.8)
Skilled worker (trade, industry, office etc.)	16 (38.1)

<b>Correct answer to question about COPD stage.</b>	4 (9.5)
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The basic demographics of the 42 COPD patients are fairly balanced with 20 men and 22 women, 23 reported having a partner and 19 participants reported not having a partner. The distribution of educational attainment is skewed as only approximately 19% of the participants had a higher education or completed high school. It should be noted that only four of the 42 participants could provide a correct answer when they were asked about their COPD stage.

In the Danish TOFHLA, the internal consistency was determined to 0.943 by the Cronbach's alpha coefficient. A Cronbach's alpha coefficient of 0.943 indicates that the Danish TOFHLA fulfils the criterion for reliability (> 0.7 as set by Houser [27]). When the Cronbach's alpha coefficient was calculated for the two sub-categories, the following reliabilities were observed: reading comprehension  $\alpha_{\text{com}} = 0.940$  and numeracy  $\alpha_{\text{num}} = 0.750$ .

The health literacy score was explored among the 42 COPD patients. The distribution of the health literacy score by health literacy category, various demographics and educational level are shown in *Table 2*.

*Table 2 - Distribution of health literacy (HL) score*

	Obs (n)	Mean	Std. Dev.	Min	Max
<b>Overall HL score</b>	42	72.43	18.14	29	95
<b>HL score by health literacy category</b>					
Inadequate	11	47.09	8.84	29	59
Marginal	8	67.38	3.54	62	73
Adequate	23	86.30	6.47	76	95
<b>HL score by civil status *</b>					
Married or living with a partner	23	75.39	17.77	40	95
Living alone	19	68.84	18.39	29	94
<b>HL score by gender *</b>					
Men	20	76.05	17.48	40	95
Women	22	69.14	18.49	29	95
<b>HL score by educational level *</b>					
9 <sup>th</sup> or 10 <sup>th</sup> grade or less (some only completed 7 <sup>th</sup> grade)	18	71.61	19.37	29	95
High school	6	71.67	21.45	40	95
Higher education	2	75	11.31	67	83
Skilled worker (trade, industry,	16	73.31	17.58	41	94

office etc.)					
<b>HL score by recruitment site *</b>					
Municipality of Aalborg (Hospital)	24	70.75	19.15	40	95
Municipality of Hjørring (Health Centre)	18	74.67	16.96	29	95

\*No statistical significant differences were observed in health literacy score.

As seen in *Table 2*, 23 COPD patients were categorised as having an adequate level of health literacy with an average health literacy score of 86.30, 8 were categorised as having a marginal level of health literacy with an average health literacy score of 67.38, and 11 were categorised as having an inadequate level of health literacy with an average health literacy score of 47.09. Those living alone had an average health literacy score of 68.84 ± 18.39, whereas those living with a partner had an average health literacy score of 75.39 ± 17.77. The average health literacy score among the 20 male COPD patients was 76.05 ± 17.48, and 69.14 ± 18.49 among the 22 female COPD patients. An average health literacy score of 75 ± 11.31 was observed among COPD patients, whose highest educational attainment was higher education, and an average health literacy score of 71.61 ± 19.37 was observed among those, whose highest educational attainment was 9<sup>th</sup> or 10<sup>th</sup> grade or less. COPD patients recruited from the municipality of Hjørring had an average health literacy score of 74.67 ± 16.96 and those recruited from the municipality of Aalborg had an average health literacy score of 70.75 ± 19.15.

The mean response time to the entire Danish TOFHLA was explored; it was explored if educational level or health literacy category affected the mean response time; results are summarised in *Table 3*.

*Table 3 – Mean response time*

	Obs (n)	Mean	Std. Dev.	Min	Max
<b>Mean response time</b>	42	18.38 (18 min 23 sec)	2.93	10	22
<b>Mean response time by health literacy category **</b>					
Inadequate	11	20.18 (20 min 11 sec)	1.99	17	22
Marginal	8	19.88 (19 min 53 sec)	1.89	17	22
Adequate	23	17 (17 min)	2.94	10	21
<b>Mean response time by recruitment site *</b>					
Municipality of Aalborg (Hospital)	24	18.21 (18 min 13 sec)	3.18	10	22
Municipality of Hjørring	18	18.61 (18 min 37 sec)	2.64	13	22

(Health Centre)		sec)			
<b>Mean response time by educational level *</b>					
9 <sup>th</sup> or 10 <sup>th</sup> grade or less (some only completed 7 <sup>th</sup> grade)	18	18.17 (18 min 10 sec)	3.13	12	22
High school	6	19.33 (19 min 20 sec)	2.16	17	22
Higher education	2	18.5 (18 min 30 sec)	2.12	17	20
Skilled worker (trade, industry, office etc.)	16	18.25 (18 min 15 sec)	3.17	10	22

\*No statistical significant differences were observed in mean response time.

\*\* Statistical significant difference was observed in mean response time between groups (Sig. = 0.002).

The mean response time for the completion of the entire Danish TOFHLA was 18 minutes and 23 seconds (95% CI: 17 min 28 sec; 19 min 18 sec). COPD patients in the lowest health literacy category (inadequate) had a mean response time of 20.18 ± 1.99 and COPD patients in the highest category had a mean response time of 17 ± 2.94. The mean response time among COPD patients recruited from the municipality of Aalborg was 18.21 ± 3.18 and 18.61 ± 2.64 among those recruited from the municipality of Hjørring. A mean response time of 18.5 ± 2.12 was observed among COPD patients, who had a higher education, and a mean response time of 18.17 ± 3.13 was observed among those, whose highest educational attainment was 9<sup>th</sup> or 10<sup>th</sup> grade or less. It should be noted that no difference was observed between genders in response time to the entire Danish TOFHLA.

A multiple regression analysis was conducted to explore the association between health literacy score and level of education – adjusted for sex and age; results of this analysis is presented in *Table 4*.

*Table 4 – Multiple regression analysis*

Model	B	Std. Err.	Beta	t	Sig.
(Constant)	115.09	21.17		5.4	0.00
Level of education	-0.99	2.39	-0.08	-0.4	0.68
Age	-0.42	0.24	-0.27	-1.7	0.09
Sex	-7.59	6.53	-0.21	-1.2	0.25

The multiple regression analysis provided a Sig. value of 0.68 (> 0.05) between health literacy score and level of education - adjusted for sex and age.

## Discussion

As the American TOFHLA is one of the screening instruments primarily used to measure health literacy in existing literature, the authors chose to translate and adapt it for use in a Danish population instead of developing a new screening instrument. It is easier to validate a Danish version of the original American TOFHLA on the assumption that it has a sufficient level of validity and reliability. Additionally, it will be possible to make more accurate comparisons of the results in the literature with the results obtained with the Danish TOFHLA. However, the original American TOFHLA could not just be directly translated into a Danish version, as the American healthcare system is very different from the Danish healthcare system. Therefore, to make sense in the Danish context, some of the questions in the original American TOFHLA were modified in the translation and adaptation process, after being discussed carefully by the expert panel (stage IV as defined by Beaton et al. [23]). If modifications of the original instrument are made without changing the original intent of the questions and the criterion for internal consistency of the new instrument is fulfilled, then it is reasonable to assume that a relatively reliable instrument has been developed. In the Danish TOFHLA, the internal consistency was determined to 0.943 by the Cronbach's alpha coefficient. A Cronbach's alpha coefficient of 0.943 indicates that the Danish TOFHLA fulfils the criterion for reliability ( $> 0.7$  as set by Houser [27]). On this basis, a reliable Danish version of the original American TOFHLA has been developed.

In this pilot study more than 50% of the 42 COPD patients were categorised as having an adequate level of health literacy; a result that seems to contradict observations in existing literature where elderly people with a chronic disease like for instance COPD are considered at risk of low health literacy [29]. No statistical significant differences were observed between COPD patients recruited from the municipality of Aalborg and those recruited from the municipality of Hjørring; both the average health literacy score and the mean response time were very similar among COPD patients at the two recruitment sites.

Educational attainment did not influence the average health literacy score and the mean response time, as no statistical significant differences were observed between the four education groups; this was not expected as educational attainment has been known to play a predictably strong role in health literacy – people with lower education are more likely to have a low level of health literacy [16]. Additionally, the multiple regression analysis, conducted in this pilot study, provided a Sig. value of 0.68 ( $> 0.05$ ) between health literacy score and level of education -indicating no association.

The mean response time was significantly influenced by health literacy category (Sig. = 0.002). The greatest difference in mean response time between groups was observed between COPD patients with adequate health literacy and those with inadequate health literacy (difference: 3 min 11 sec). An ANOVA test was used to explore if the difference between the three (health literacy category) groups was significant; an ANOVA test only tells you there is a difference between

groups, but not exactly between which groups [28], so we cannot be sure between which of the three health literacy category groups there is a significant difference in mean response time.

A limitation to this pilot study is the sample size of only 42 COPD patients; it is a rather small sample size at least when compared to other international studies that also assesses health literacy [9,30].

## Conclusion

In this pilot study, the Danish TOFHLA demonstrates strong consistency with the original American TOFHLA. Based on a Cronbach's alpha coefficient of 0.943, a reliable Danish version of the original American TOFHLA has been successfully developed. As the cultures, languages, and the structure of healthcare systems are quite similar within Scandinavia, it should be easier to develop an instrument to assess health literacy in other Scandinavian populations.

The results of the pilot study showed no statistical significant differences between COPD patients recruited from the municipality of Aalborg and those recruited from the municipality of Hjørring. Educational attainment did not affect the average health literacy score and mean response time in this pilot study. A statistical significant difference was observed in mean response time between the three health literacy category groups. Hence, the health literacy score seem to influence the mean response time in this pilot study.

This is a small pilot study including 42 COPD patients, and more research is needed to explore the level of health literacy among Danish COPD patients.

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# Using ICT training as an arena for intergenerational learning experience. A case study

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## Abstract

*In Norway, municipalities administer selected electronic health information services. These institutions face the challenge of educating to use these health systems and the responsibility for their citizens' e-inclusion. In the case of ICT-illiterate people, the questions about what is the necessary ICT knowledge for basic use and how this content should be pedagogically delivered arose. This paper presents a pioneer intergenerational model for ICT education, in which young generations teach the basics of ICT use to elderly people without ICT experience. A qualitative evaluation of the piloted model in a Norwegian municipality was carried out using semi-structured interviews. The findings highlighted the fundamental role of the young people as experienced ICT users and teachers but also as a decisive factor for course participation for many elderly students. The outcome of the course was noticeable in both directions: most of the elderly attendees acquired basic ICT skills at the same time that young teachers had the opportunity to develop qualitative social values such as goal achievement and social responsibility.*

**Keywords:** *teaching, e-inclusion, educational model, intergenerational relations, social responsibility, future generations*

## Introduction

Most of European countries' populations are involved in a general demographic aging process. These demographic changes will affect the pension system, health care services and labour market in the coming years, being defined as one of the main challenges Europe will face (European 2020 Strategy [1]). Technology can make a significant contribution to quality of life in old age [2] and, in the North Sea region, policy makers have the responsibility to review the way they respond to aged citizens' needs via innovative and ease-to-use technologies. This scenario creates an increasing demand for new products and services that potentially could empower elderly population within those geographical areas. Use of technology presents a unique opportunity to socialise and establish social networks that can alleviate loneliness and alienation, making the access to information an essential part for health improvement and independent living. In the context where everyday more information is becoming digitally available, governments should guarantee the right of equal and granted access to information to their citizens through e-inclusion policies. However, ICT and Internet use have historically presented obstacles among ICT-illiterate population. Technology adoption is a complex issue and elderly people have more problems in deal-

ing with it than younger people, which means that older adults may be less able to benefit from innovations in technology.

Studies show that computer and Internet use seems to contribute to elderly adults' well-being and sense of empowerment by affecting their interpersonal interactions, promoting their cognitive functioning and contributing to their experience of control and independence [2][3]. Raising awareness of ICT use and developing efficient training programs for such use have been demonstrated to be an incentive among potential users [2][4]. At present, ubiquity of technology expands the range of such potential users in age (from early to old life), technology experience (from professionals with long experience to occasional users without IT skills) and health conditions (increase in technology use by healthy and ill patients). However, there is evidence of barriers in ICT use for inexperienced users. Examples of commonly reported barriers are lack of perceived benefit, lack of interest or motivation and lack of knowledge [5]. In this line, European Framework Programs (EU FP) promote the e-inclusion of citizens through the development and satisfactory use of ICT technologies. For instance, in Norway, electronic health information and services are among those only accessible via a national internet portal (i.e., [www.helsenorge.no](http://www.helsenorge.no)). Therefore developing ICT-use training tailored to the needs of users without experience is a necessary challenge for the e-inclusion of traditionally digitally excluded population. This ICT training, coupled with the awareness of its benefits can empower citizens for daily life tasks (e.g., online shopping), human communication (e.g., social networks and videoconference) and personal autonomy (e.g., access to wider sources of information). The overall aim of this study is to present the learning experiences gathered through an intergenerational model for ICT education taking advantage of the natural technology skills acquisition of young people to instruct inexperienced elderly people in the basics of ICT use.

## Project research background

The background of this study is based on a contemporary research project, "iAge", an Interreg IVB North Sea Region (NSR) European project whose main aim is to promote e-inclusion among European areas in decline that are affected by an ageing population through promoting and increasing economic and social e-inclusion. The NSR region may benefit from a growing market where public institutions, private companies and entrepreneurs can help to develop dynamic and successful communities. The "iAge" project acknowledges the importance of new technologies for economic activity and new ways of delivering services. In the "iAge"-project, partners from 6 countries of the NSR cooperate and work to transnationally develop new approaches

in service delivery and economic restructuring through joint development of ICT innovation. This joint implementation to increase the use of ICT among the aged population, aims to keep them active and facilitating their participation in social and work life. The project pursues an inclusive growth, made by modernising the labour market by palliating psychosocial aging changes through ICT skill training and acquisition. The development of policies and strategies are built around the end-users as part of the inclusive approach. "iAge" promotes a useful use of ICT through the instruction of inexperienced elderly users in relevant tasks for their lives, such as Internet browsing and basic computer skills. This learning aims at improving employment opportunities, quality of life and social participation overall. In addition, the transnational activities and joint analyses carried out in the project creates an economy of scale to allow positive achievements towards the European 2020 Strategy [1] innovation and employment objectives and enables regions to improve the quality of results.

### **"Grandma on web"**

Related with the iAge project, another second project, "Grandma on web", was developed to create educational programs in ICT to instruct elderly users in Southern Norway municipalities. This project was based on the fact that, in Norway, the municipalities are in charge of the e-inclusion of their local people. At the same time, younger generations have traditionally quickly acquired ICT skills that could be effectively transferred to elderly people inexperienced with the use of ICT [6]. The "Grandma on web"- project is an inter-municipal cooperation between local municipalities in the Kristiansand region (Knutepunkt Sørlandet) and the Centre for eHealth and Healthcare Technology at the University of Agder in Norway. The aim is to design, implement and evaluate educational programs in ICT to instruct elderly users. In the period 2012 to 2014, three ICT courses for elderly were run by the "Grandma on the web" – project. This study comprises the evaluation of this educational program using semi-structured interviews. The purposes of the study were threefold: firstly, the evaluation of the courses; secondly, to inform the development of a model for implementation of ICT training for an elderly population; thirdly, to create a gateway of learning experiences between generations. The results from the evaluation will form the basis for this paper and will be described in subsequent sections.

### **Research Questions**

RQ1 How can elderly people be instructed in the use of ICT required to be e-included in the society?

RQ2 How can ICT training be used as an intergenerational learning experience?

## **Materials and Methods**

### **An intergenerational teaching model**

#### **Course design**

The courses for elderly people were used to instruct them in ICT use and also to facilitate a learning experience gateway between different generations. The teaching model consisted of a program that combined ICT training for elderly people with an educational program on a school. Teachers were Scandinavian Conference on Health Informatics, August 21-22, 2014, Grimstad, Norway

schoolchildren (14 years old) who organized ICT-courses for their grandparents and other elderly people in the community. The course formed part of an elective work-life training program at a middle school, specifically designed for pupils who want more practical subjects at school. Grandparents and other elderly people in the community were invited into the school for a two-hour course per week throughout during a total of six weeks. An experienced teacher coordinated the program. In the courses, school children worked as teachers and each pupil was responsible for instructing one elderly person throughout the course. The teachers (pupils) sat beside the elderly students to instruct them. An easy-to-read simplified user manual in lay Norwegian language created in collaboration with volunteers from a volunteer center in the municipality was available for each student during the lesson. The manual included didactical explanations of basic ICT functionalities, such as how to start up the PC, how to access to online email system or using applications such as *Google* search, online newspapers, *Facebook* and *Skype*. Navigating through travel sites and checking out how to book tickets was also part of the program. Three free courses were arranged at a small-middle size school in a rural area in Southern Norway between 2012 and 2014.

### **Recruitment of Courses' Attendees**

29 elderly people participated as students in the three courses, whereas 14 of them contributed to the evaluation of the courses. Course participants were invited either by the schoolchildren (teachers) or by a representative from the municipality. In addition, the courses were advertised in the local newspaper. Another 29 young people were recruited as teachers. Every course had one adult person working as a supervisor.

### **Evaluation of the courses**

#### **Design**

The study had a qualitative, descriptive and exploratory design using semi-structured interviews for the attendees, teachers and the coordinator of the courses.

#### **Data collections**

Data were gathered through 6 semi-structured interviews following an interview-guide consisting of 10 open-ended questions, three individual interviews and three group interviews. All interviews were conducted in the training facilities, three group interviews and one individual interview immediately after the last course section, while two individual interviews were conducted four weeks after course completion. The average duration of the individual interviews was 30 minutes and of the group interviews was 35 minutes. The interviews were carried out between April 2012 and April 2014. All interviews were audio-recorded and then verbatim transcribed.

#### **Participants**

Fourteen elderly participants of the 3 ICT-courses were interviewed, 12 women and 2 men. There were 5 teachers in total: 4 young teachers (all girls, 14 years old) participating in the last course and 1 adult, who worked as a coordinator and as a supervisor, in the last the course (woman, 55 years old). Recruitment of participants was made in cooperation with a contact person from the municipality who gave the participants written and oral information about the study. All participants signed informed consent before the interviews.

## Data analysis

The interviews were analyzed and interpreted according to Kvale's [7] three levels: *self-understanding*, *common sense* and *theoretical understanding*. The analysis consisted of three differentiated steps. In the first step, the researchers condensed the informants' statements in meaning units. In the second step, an initial, thematic framework was presented. In the third step, a theoretical discussion was conducted on the basis of the findings. Interpretations from the steps one and two are presented in the results section, and from the step three in the discussion section.

## Ethical considerations

Prior to each interview, all participants received written and oral information about the project. Each participant was informed about their data confidentiality, that participation was voluntary and that they had the right to withdraw at any time without reason. According to the Norwegian regulations for ethical approval, the research project was not required to be registered with the Norwegian Research Ethics Committee (REK), but was authorized in compliance with the privacy protection of Norwegian Social Science Services (NSD), reference number 33519.

## Results

The main goal of this study was to pilot an intergenerational teaching model in ICT for elderly people. The experiences gathered from the students and teachers of pilot courses' were identified through interviews and are next presented. The information gathered in the different interviews was categorized in two groups, "factors external to the course" and "factors internal to the course".

### Factors external to the course

The first category of the data analysis includes factors external to the course, such as the ICT background of the participants and the motivation for participation in the course.

#### Former ICT experience

The majority of the participants did not have any or had very little experience with computers, even though most of them had a computer at home. One participant said: *"Now the machine has been there for twenty years because my husband used it for work purposes. It is a very long time without using it."* Another participant, who was invited by his granddaughter, said: *"I have never had anything to do with computers. I barely knew what they looked like"*.

#### Motivation for Participation in the Course

The interviewees were asked about their motivation for attending the course. Several of them were not initially motivated and did not previously have the intention of learning how to use computers. However, they joined the course because they were invited, and sometimes convinced, by their grandchildren or by the contact person from the municipality. One participant said: *"I just tell to myself that this was quite a coincidence that all this happened. I had never imagined that I would use computers [laughs]. I had not done it unless someone younger or someone else had persuaded me to do it."* Another participant was invited by a young teacher that she had previously babysitted: *"[...] and then she said that she would not partici-*

*pate in the project unless I went there"*. Besides of being pushed by grandchildren or relatives, another reason for course attendance was the desire to become self-reliant: *"[...] to avoid having to disturb the rest of the family"*. Other participants were motivated by specific needs, such as learning to manage photos, seek information on the Internet or communicating via email.

### Factors internal to the course

The second category comprises the identified factors related to the ICT courses, such as the general evaluation of the course, pedagogic approach of course instructions, learning output and intergenerational experience.

#### General evaluation of the course

Participants were unanimously satisfied with the course. One participant told that, at the beginning, she was skeptical and reluctant to attend: *"[...] I would not attend, just because I saw all the time they spent on it, so I would never do it"*. She finally attended because she felt persuaded: *"I had never done it unless someone had come and asked me. I had never voluntarily gone to just learn data"*. At the end of the course, she was finally happy to have participated: *"[...] but I am very happy about it"*. The young teachers gave slightly different feedback on how they felt about the course. Those who have brought with them their grandparents were the most satisfied. They expressed that teaching was challenging because it was difficult to find enough tasks to do with the elderly students: *"It was hard because we run out of tasks"*. In addition, the coordinator of the course expressed that the course was very successful, especially for those who have been with the people they know: *"The best thing is that they have their own grandparents or other relative with them. It is great"*.

#### Pedagogic approach of course instruction

The ICT course was organized with a combination of demonstration and one-to-one instruction methods. The participants argued that this type of teaching worked best for the lessons, especially including first a short demonstration using a projector to let all students simultaneously see it: *"[...] you learn more by sitting one-to-one"*. Some participants felt that a possible incentive would be if they could choose by themselves what they would do on the computers: *"[...] then you pick out what you want"*, although others wanted more structured contents with freedom for own tasks: *"Maybe it could have been a bit more structured, but in a way that one can still work with things one is interested in"*. The supervisor believed that it was good that the course allowed up to participants to decide for themselves what they wanted to learn: *"It has been very opened and they have controlled themselves. I think they liked it"*.

The diversity of students' and teachers' ICT-level presented a challenge for the developing of an effective and pedagogical teaching program. For instance, there were cases where the students did not have any previous experience with computers, others with some experience and others with long experience using specific software in conjunction with previous work. Actually, there were also great variations in the teachers ICT competence, and in some cases teachers had a different expertise than the students sought. In this context, most of the students believed that it was positive to have a guide of what to do. Some thought that they might like to have even more tasks and a more structured course, while others preferred the ability to choose by them what they would do. The elderly students

found that, overall, there was a suitable number of lessons, but, however, the young teachers commented that the course was extensive because it made the learning process too demanding in a way that the students had difficulty in defining their needs: *"They do not know what they will learn. They do not know anything about the Internet"*. Teachers quickly run out of ideas and did not know what to do. A recommendation for a future course was to include more free-choice tasks.

The participants pointed out that the presence of the supervisor throughout the course was an important factor to monitor the development of the course and, especially, to monitor if the young teachers needed any help: *"It has been good because their supervisor is also there. I think it is a bit dependent on her"*. The teachers were young and with different type of ICT experience and personal skills, so it helped that an adult was present and in charge of the students.

### **Learning output**

The participants were asked about how the course had influenced their ICT daily use. Many participants answered that a positive outcome of the course was that they had become more confident in the ICT use, which lead them to try new things out on their own: *"I learned a lot, and then I came back a little into it again"*, *"...so I learned actually more things than what I had previously thought"*. A woman told that she had become less afraid of making mistakes: *"[...] and I am no longer so afraid of doing something wrong"*, and another woman meant that it was not as frightening as she might have thought. In addition, it triggered students' curiosity about what opportunities existed around computers. The course inspired them to want to learn more and attend future courses. Some have invested in new computers or tablets and some of the participants told that they, through *Facebook*, had created contact with old acquaintances and relatives, and that they had enjoyed on doing it.

### **Intergenerational experience**

One of the main goals of the course plan was to develop a model that combined training of ICT for elderly people with contact between generations. The elderly students who had grandchildren as teachers were most satisfied, but also many of the other students thought that it was very positive to have young teachers.

Most participants thought it was very pleasant to spend time with the youth. One of the participants said: *"And I think it is great fun that it is the children who teach us. It is absolutely amazing. Suddenly they are wiser than us. Otherwise, it is usually us who are wiser than them."* In this way, it was the young teachers who had the useful knowledge, which gave them a sense of empowerment: *"They master it in a different way. I think that is good for them."* In that way, the ICT knowledge that most of the young teachers was useful for teaching elderly students: *"I think they are very good. The kids are absolutely amazing in what they do."* One of the participants said: *"I cannot praise enough her who was my teacher."* However, some pointed out that there were noticeable differences between the students: *"I changed a student along the way. The first student knew a lot and I did a very good teaching, but then I got another one that really was not"*. It was also commented a disparity between what knowledge the students were interested in and teachers' competence. A woman stated: *"[...] often she had no knowledge of what I asked about, and then she simply answered - I do not know"*. Several of the elderly students reported that some of the young teachers were shy and that made them to feel sorry for the stu-

dents: *"[...] and she was very shy, so I felt so sorry for her"*, and the students felt responsible to make the situation more comfortable: *"After a while, we got very good contact, so she talked to me at the end of the course, but at first she did not"*. Some of the students lacked initiative. Therefore, it was sometimes difficult to know for the teacher in what to work next. A woman told: *"I had a student who did not say anything [...] I was a little indecisive at the end: what should I do now?"* The supervisor stated that the program contributed to the contact between generations: *"It is so much fun when the relationship between young and elderly works. Some of them get closer in their communication with their grandparents. They are delighted when they sat there and looked at pictures together with their grandparents"*. She was keen to continue to build on the relational aspect of the program: *"If we are going to do it again, I think we should put a little more effort into getting more senior students who have some close relationships to the children"*. However, the young teachers gave slightly different feedback on how they experienced the contact with the elderly. Some thought it was very nice, while others believed that it was embarrassing. Those who taught previously known elderly students were the most positive. When asked about what they had learned by delivering the course, they replied that they had learned the importance of patience: *"It was hard to keep your patience"*.

During the courses, the act of socializing was also emphasized. Sometimes it was the young teachers, together with the supervisor, who initiated it, while other times there were some of the students who initiated it, e.g., bringing food: *"[...] and so we had coffee break, and I had made some cake"*. Other time was a general event arranged which included all the participants and students, such as in the aftermath of one of the courses where a social evening with food was organized.

## **Discussion**

There were relevant findings in the two categories of factors gathered through the semi-structured interviews. Inside the first category, "factors external to the course", the motivation for participation in the course resulted to be a relevant component for the attendance of the course. The inexperience with ICT usually carries out the unawareness of ICT use benefits, an important factor for promoting ICT use [5]. Therefore, the fact that several students were initially not sufficiently motivated to attend the course could have been influenced by their none or very little experience with ICT that impeded their awareness of the course benefits. Studies have revealed the importance of elderly people's attitudes towards technology before using computers [4][8]. Students who are unaware of the things they could, need or want to learn are more reluctant to participate in the course. Then, a key part of the courses was to educate the elderly students about the benefits of ICT use. This reinforces the idea of creating a detailed learning plan for the course, where teachers are previously instructed of the range of tasks that should be included in the course. In addition, informing the students in advance of what are the benefits and possibilities of ICT use can ease the learning process. In this line, often positive attitude changes are found once elderly people use computers. When they understand the potential, they start to use it [4][8].

One of the key elements found in the model was the role that the young students played as an informant of the course and as an incentive for such attendance. Many of the attendees commented in the interview that the main reason for their attendance was that young people persuaded or helped them to

change their mind for attending the course. The relationship between the young teachers and the elderly students, e.g., relatives or acquaintances, increased the overall student's satisfaction with the course. The ability to have a good relationship with their grandchildren was an important motivating factor for many of the students. According to gerontology theories of motivation, social relatedness is a significant factor in later life [9].

The course was created with a combination of demonstrative one-to-one instruction methods. However, the students sometimes had too little things to do. In some cases, students successfully finished the content of the course sooner than the class was finished and they did not have more things to do or learn, losing their interest. In these situations it was difficult for young teachers to instruct them with new unplanned tasks. Therefore, a structured content would have given the students a route map to follow. However, a right learning curve and a balanced amount of planned tasks should be found to not accidentally overload the students with too many or too new ICT tasks, covering at the same time a diverse background of ICT skills and experience among the students. An alternative approach could give the students freedom to decide what they want to learn. However, this could attach a potential trade-off of deciding their own tasks, which could overload students with too many decisions to make without actually having enough experience for it. Therefore, a combined approach is proposed, where a planned course structure is made at the same time that students are given the option to decide what to do. In this line, studies suggested that it would be better for elderly people to have more time or self-paced practice to master learning content [10]. At the same time, using aid devices, such as writing materials for taking notes or printed instructions, can be advantageous for elderly. Such additional material must be easy-to-read with large fonts and simple graphic illustrations [10].

Another potential problem is the wide range of ICT experience and knowledge that students might present. This challenges the preparation of the teachers who should be able to fill the gap between students with different backgrounds and experiences. A possible way to solve the gap is to send a questionnaire in advance to future students asking questions about ICT experience, motivation for participation, what they would like to learn, interests/hobbies, etc., because elderly people usually prefer interesting and engaging material [11]. Providing the teachers with this information can contribute to the course program planning and improve teachers' preparation to cover adult students' needs. This will give useful information about the elderly needs in general (e.g., what sort of information can facilitate independent living), and specifically related with the course (e.g., health portals, internet banking). According to [2], preparing Internet programs for the elderly require special attention to various factors characterizing this population. Studies showed that because of age-related changes in cognitive and physical functions, elderly people are usually slow, make more errors, and are less likely to have self-confidence in their computer-using abilities [8]. Therefore, it is important to develop learning material that best fit elderly people and specific individuals' characteristics [11][8]. However, the implementation of these recommendations might be difficult to put into practice at once. Therefore, the supervisor/s should play a key role in the continuous development of the learning program and especially on young teachers' instruction adapted to the local particularities and needs of the elderly students.

The evaluation showed that ICT use learning was an arena for an intergenerational experience. For instance, the one-to-one teaching approach provided a closer contact between teacher

and student that reinforced the link between elderly student and the young teacher. However, not everybody has old or young relatives, which can make difficult the ideal one-to-one teaching approach between young and old relatives. The obvious solution for these cases, to randomly couple a young teacher with an old student, did not always resulted in a satisfactory learning process in the situations where two people do not know each other and have to collaborate in the course. Therefore a planned program can provide a starting point of collaboration between teacher and student even if they do not have many things in common. Once the first barrier of ICT use is removed, a range of applications is available for the elderly students that can cognitively and physically stimulate them, such as playing games and social contact. There were cases where people who would never go to a course by themselves went only because they were asked by a person they knew (young teacher relative or acquaintance), and thank to that could have social interaction and get to know other people. The evaluation also showed that the elderly students felt that they had a positive learning outcome from the course. For many of them, the course was a door opener for further exploration of the Internet's possibilities and many of them had particularly great pleasure of discovering the opportunity to have contact with friends and family through social media. It is precisely in this area that the use of technology can have a great potential in relation to elderly people in future. In this line, social isolation is one of the biggest health challenges facing the elderly today. The social capital tends to decrease with age due to impaired function and increased risk of loss of partner and friends [12]. Research has shown that by providing elderly people social activities and strengthening their social network, depressive symptoms will decrease and quality of life will be improved [13]. For the elderly, the use of Internet can help establish or maintain their social network despite health deterioration.

### *Questions and answers course creation guide*

Several questions and some answers are next presented in order to provide a brief guideline for a similar ICT course creation.

#### *Who is the course addressed to?*

It is important to have a notion of students' background. To improve the adequacy and relevance of the course for the students, it is recommended to individually ask several key questions to students, such as:

“How many years of experience do you have with computers?”

“Do you have a computer at home?”

“Is there anything specific you would like to learn?”

“Do you have any special interests or hobbies?”

#### *Who is going to teach it?*

In this case young teachers are recommended because ICT teaching is used as an arena for an intergenerational experience of learning. There is a need for an adult supervisor with teaching and ICT experience to help in any problem. Teachers should be equipped with strategies specifically designed to assist older adults.

#### *What should be the course content?*

One of the most important goal of designing ICT courses for elderly people should be to increase their computer self-efficacy. The course program preparation should be based on the answers previously gathered from the students and should also include a core curriculum for the students to learn the

benefits of ICT for social participation. The program content should be tailored to students' needs, their current level of ICT use and the one to achieve. However, it is especially relevant for the teachers' preparation to be aware about age cognitive and physical decline that elderly students may have. In addition, developers of programs should bear in mind the barriers that elderly people have for computer use, in particular the perceived lack of benefit and lack of motivation. Thus, teachers should be trained to highlight benefits of ICT use and motivation for use.

It is recommended to have a manual per student for basic ICT use where they can search by themselves for information related to the course. Future content of the manual could include information sources about relevant general topics customized for the students, such as health portals, local organisations and activities.

Another lesson learned from the course experience is that to have a projector with a large screen could be used as an additional tool for showing specific applications or solve general problems, where all students can see the same content at the same time (e.g., how to log in to Skype for videoconference or how to set up the computer video camera).

#### *What should be the course structure?*

The course was delivered in sessions of two hours per week over a period of six weeks. The key is to spread the course through a series of weeks to create a routine, but without an excessive number of hours per session that could risk in tiring the students, and also teachers. It is recommended to have structured pre-made tasks to present the students having the teachers the solutions at hand. At the same time, include free choice tasks where students ask for specific problems or skills they would like to learn. In this latter case, a list of possible choices would be useful to have teachers aware and prepared of potential tasks to present to students.

## Conclusions

A qualitative evaluation of a piloted model using ICT training as an arena for intergenerational learning experience in a Norwegian municipality was carried out using semi-structured interviews. The course was designed to teach elderly students inexperienced in ICT use. The teachers were young pupils of 14-years-old supervised by an experienced teacher. The course formed part of an elective work-life training program at a middle school, specifically designed for pupils who want more practical subjects at school. An easy-to-read simplified user manual in lay Norwegian language created in collaboration with volunteers from a volunteer centre in the municipality was available for each student during the lesson. Three free courses were arranged at a small-middle size school in a rural area in Southern Norway between 2012 and 2014.

The findings highlighted the fundamental role of the young people as experienced ICT users and teachers but also as a decisive factor for course participation for many elderly students. The outcome of the course was noticeable in both directions: most of the elderly attendees acquired basic ICT skills at the same time that young teachers had the opportunity to develop qualitative social values such as goal achievement and responsibility (see Fig. 1).

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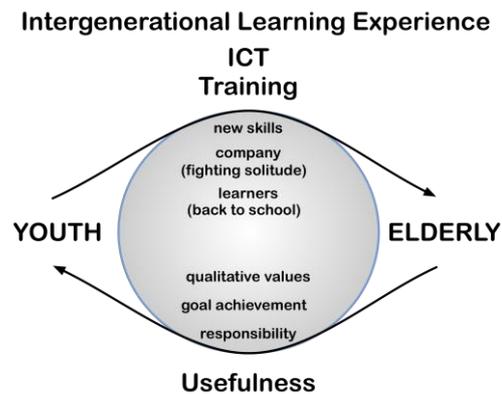


Figure 1- Scheme of the intergenerational learning experience in the ICT courses

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# Methodology for Health Care Process Modelling:

## Bringing the Health Care Complexity into Health IT System Development

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### Abstract

Health Information Technology is recognized as a solution to manage health care and improve the quality of care. However, health IT has only proven its full potential and benefits in specific fields. The aim of this paper is to propose a methodology to comprehensively model health care processes in order to define health IT system requirements. The proposed methodology was successfully implemented in a University Hospital in Norway. By applying the suggested three-stage methodology, it was possible to identify the cause for elective surgery cancellations at this hospital. Additionally, the preoperative planning process was modelled, and its complexity described. Based on the conducted work, it is concluded that the design of health IT systems should not be done by computer scientist alone. An interdisciplinary team is required to tackle the idiosyncrasies of care processes.

### Keywords:

Methodology, Interdisciplinary Studies, Health Information Systems, Workflow, Physicians, Nurses, Secretaries

### Introduction

Surgical departments are simultaneously the major source of investment, and the greatest source of revenue for most hospitals [1, 2]. However, the cancellation rate of elective surgeries is high, especially in the public sector [3, 4]. It is reported that between 10 and 40 % of elective surgeries are cancelled [1, 5-7]. Surgery cancellations increase costs, reduce productivity and efficiency, increase waiting lists, and directly affect the patients [5, 8, 9].

In order to reduce cancellations of elective surgeries, hospital managers make a considerable investment on operating theatres and on having surgeons and theatre staff available on the agreed schedule [1, 10]. At the department level, health care workers make huge efforts in planning and scheduling surgeries to allocate the necessary resources. However, studies show that up to 20 % of elective surgeries are cancelled on the day of surgery [9, 11, 12]. Furthermore, it has been shown that 50 % of these cancellations might be avoided [1, 3, 13].

Health Information Technology (IT) is recognized as a solution to manage health care and improve the quality of care. In the national strategy plan for electronic collaboration in health and care services, the Norwegian Ministry of Health and Care Services identified IT as a cornerstone to improve the quality of health care [14]. However, health IT has only proven its full potential and benefits in specific fields [15-19]. A contributing factor for the slow diffusion of health IT may be found on its

focus on improving individual tasks, rather than supporting value added care processes. In this paper it is argued that this is replicating the individualistic work patterns inherent to paper based care processes, as observed in the case study.

Health IT orientation to individual tasks reflects the focus of health care itself. The majority of clinical departments behaves as discrete and independent sets of physicians, nurses, and other health personnel instead of a single team. [20]. Partly due to the autonomy of most clinical departments, few health care processes have been modelled comprehensively enough to provide a basis for specifying system requirements to health IT designers. Alternatively, health IT system developers have focused on supporting the work of individual care team members by taking existing paper-based tools, as their models. The result is that most health IT does little to support care teams [21].

The causes for elective surgery cancellation are classified in two major categories, according to who took the underlying decision to cancel [22]: (a) hospital, and (b) patient related reasons. Hospital related reasons can be further divided in planning and medical causes. At our site of research, the University Hospital of North Norway (UNN), the causes for elective surgery cancellations are mainly related to the hospital category, as demonstrated in Figure 1, in the results section. The hospital has reported that more than 50 % of all cancellations at UNN are related to inadequate pre-operative planning [23]. However, the planning tool on the surgical module in the EHR system has been recognized as an unused resource by FIKS (from the Norwegian *Felles innføring kliniske systemer*, translating as *Common Introduction of Clinical Systems*; a project initiated by the Northern Norway Regional Health Authority (Helse-Nord), who invested € 62.5 million to develop the electronic health record for the future) [24]. The same conclusion was also drawn by the Lean Project which was initiated by the management at UNN as an internal project to reduce the cancellations rate. For further reference on the Lean process refer to [22].

In this paper, the elective surgery cancellation problem, in a University Hospital in Norway, is addressed. Foremost, the reasons for cancellations at UNN were explored. The workflow was observed and modelled at different departments. Based on the modelling results one department was chosen for an in-depth study. In-depth and semi-structured interviews with different health care workers involved in the process were conducted. The preoperative process was modelled taking into consideration the perspectives from the physicians, nurses and secretaries involved in the preoperative planning process.

The aim of the work presented herein, is to propose a method on how to comprehensively model care processes to establish a basis to health IT requirements. It is argued the necessity of

health IT designers to understand the complexity of care processes, and their dynamic relation with the environment in which it is accomplished. Given the idiosyncrasy of care processes, it is recognized that this cannot be a solo work, an interdisciplinary team is required.

This paper is divided in four sections. In the first section, the approached problem is introduced, and the case study is described. Data collection methodologies, with which the results were obtained, are presented and explained in the second section. The results are disclosed and interpreted in sections three and four. In the last section conclusions about the results are drawn, and some indicators of future work in the area foreseen.

## Materials and Methods

The data presented in this paper was collected based on a three stages methodology, as follows:

- Stage 1 - Analyses of historical data on the number of cancellations and the reported reason, provided by the Lean project at the hospital;
- Stage 2 - Fieldwork, including observation and interviews with health care workers at the hospital;
- Stage 3 - In-depth interviews with health care workers at a specific department.

In Stage 1, the number of cancellations and their reported reason by department, shown in Table 1, indicated that there is a great discrepancy in the number of cancellations between different departments. However, the data did not evidence a clear pattern for cancellations within the different departments. Thus, the need to obtain further knowledge on the preoperative planning workflow at each department was identified.

In order to obtain this knowledge, three weeks of fieldwork at the Surgery and Intensive care clinic was carried out as Stage 2, conducting observations and unstructured interviews while following an anaesthesiologist and an anaesthetist nurse – which provide care services at all surgical departments – in their daily work. In addition, thirteen structured interviews with physicians, nurses and administrative personnel were conducted.

Based on the fieldwork, the preoperative planning workflow was modelled at the different departments. From the initial results it was concluded that the discrepancy in the number of cancellations are related to the heterogeneity of work patterns observed. It also raised the hypothesis that the variations in the number of cancellations may not be related to structural, or organizational, differences at the department level. It may rather be related to the fact that, in order to complete the daily schedule, health care workers need to use empirical and personal knowledge. To be able to get an in-depth understanding, on what are the real needs of health care workers in the preoperative planning process, the fieldwork observations were narrowed to a single department in Stage 3.

During the observations, and the interviews, two departments at the hospital were described to be more efficient. However, the departments still evidenced a representative number of cancellations. From these, one department was chosen to proceed with the in-depth study. The choice was based on the need to gather knowledge about the preoperative planning process and reduce local, contextual and department specific complexity, without losing the general challenges in the process. The chosen department is not revealed due to ethical reasons.

In Stage 3, physicians, nurses and secretaries, at the chosen department, were interviewed. The interviews were semi structured, done at the workplace and lasted between one to two hours.

## Results

In this section, the results from each stage of the methodology proposed in the Materials and Methods section are reported. In Stage 1, the historical data on the number and causes for elective surgery cancellations (Table 1), was analysed. From the analysis it is evident that the decisions to cancel elective surgeries are mainly taken based on reasons related to the hospital, as shown in Figure 1.

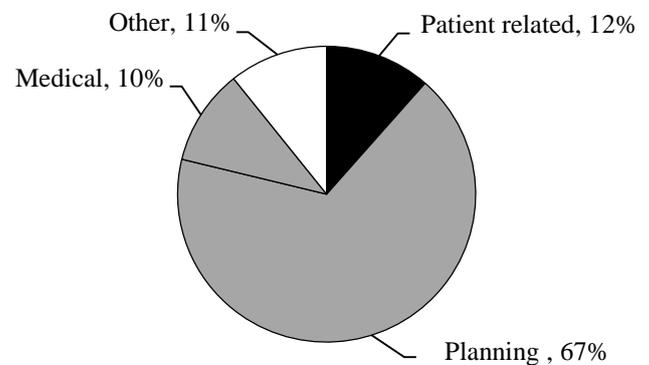


Figure 1- Fractional number distribution of the reasons for day of surgery cancellation at UNN.

■ Patient related reasons ■ Hospital related reasons.

The historical data also indicated that there is a great discrepancy in the number of cancellations between different departments, as shown in Figure 2. The results obtained from the analysis of the historical data were used to define the requirements for Stage 2.

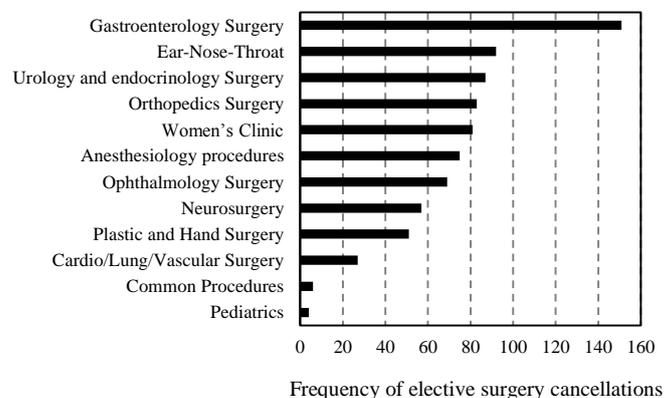


Figure 2 – Number of elective surgery cancellations by department.

In Stage 2, the preoperative planning workflow at the different departments was investigated and modelled. The workflow models revealed heterogeneous work patterns. The sequence of the activities required to complete the preoperative planning process was not consistent among the different departments. Furthermore, the preoperative planning process for different patients had different professionals executing the same activity. Additionally, the professional responsible for the activity varied. Based on these results, as well as the empirical nature of the daily running at the departments, it was recognized the need to narrow the fieldwork to a single department. The focus on a single department should facilitate the identification of the real needs of health care workers in the preoperative planning process, in Stage 3.

Table 1 - Number of cancellations and their reported reason by department.

Reason for cancellation Department	Other acute medical condition	Lack of capacity - Anesthesia nurse	Lack of capacity - Anesthesiologist	Lack of capacity - Surgeon	Lack of capacity - Surgery nurse	Lack of capacity - Intensive care	Lack of capacity - Recovery	Lack of capacity - Ward beds	Missing equipment	Insufficient surgery indications	Overbooking	Patient no-show	Incomplete study	Patient will	Emergency surgery	Higher duration of previous surgeries	Unknown/Other	Total
	Anesthesiology procedures	4								2	22	3	21	2	4	1		16
Gastroenterology Surgery	10	3		2	22				2	16	34	10	6	1	11	28	6	151
Cardio/Lung/Vascular Surgery	3	2			2		1			3			3	2	7	3	1	27
Urology and endocrinology Surgery	8	5			8				3	13	19	4	8	1	4	7	7	87
Pediatrics	1									1		1	1					4
Felles koder	2									3		1						6
Women's Clinic	5	4		1	19					7	13	4	3	3	4	12	6	81
Neurosurgery	2	6		1	7	1	2			4	3		1	1	12	10	7	57
Orthopedics Surgery	14	1		4	18		2	5	1	10	1	7	2	3	4	3	8	83
Plastic and Hand Surgery	1	5		5	9		1		1	6		1	2	2	5	7	6	51
Ear-Nose-Throat	20	3	1	1	10				2	15		7	5	3	2	13	10	92
Ophthalmology Surgery	12	1	1	1	1				1	16	1	8	2	6	2		17	69
Total	82	30	2	15	96	1	6	5	12	116	74	64	35	26	52	83	84	783

In Stage 3, the interviews with physicians, nurses and secretaries showed that the diversity of work patterns is also evident on the professional group level. An example of such heterogeneity is evident right in the beginning of the process, when the surgery referral is received by the hospital. The physicians have a holistic overview of this part of the process. The administrative activities on how the referral is handled, and the patients' pathway prior to surgery are not always clear to physicians. Nurses are more focused on practical activities and the daily running of the department. This part of the process is not of their responsibility, hence, they are not aware of the details on how referrals are processed. Secretaries work patterns evidenced a clear focus on avoiding elective surgery cancellations. They perform most of the operational planning work. Being the only professional group transversal to the preoperative planning process, they make a huge effort to make the patient move forward in the process and avoid cancellations. This might also be explained by the fact that they are the first line of communication with the patient.

It is our understanding that, in the preoperative planning process, the professionals that reveal more engagement in avoiding cancellations are nurses and secretaries. However, the information required for the patient to proceed in the process is generated by the physicians. In the next section, will be discussed on how this in-depth knowledge of the process is of great importance when defining the requirements for health IT system design.

## Discussion

The preoperative planning is a complicated process that takes place in a dynamic environment, where numerous pieces of information are generated in multiple sources, shared by providers, and reviewed by various health care workers. The heterogeneity of work patterns influences the IT systems' usefulness in healthcare. This is exemplified by the low usage of the existing planning tool on the surgical module at the hospital, as communicated in the Introduction section. This was underlined, by a nurse, during one of the conducted interviews: *"I prefer the system on paper. The information is too dispersed and it takes too long to track it, and it is more difficult to take notes."*

An IT system should, in principle, only support one care process at a time. It is not efficient or functional to have different versions of an IT system for different departments, and surely not for different individuals. To define the requirements for health IT systems, IT system designers need to work with a standard process. The problem must be object of a thorough analysis to identify its real cause. The holistic overview that is supporting health IT system design until now is not always sufficient to reveal underlying causes of the problem. Moreover, there might exist more than one cause to the problem. Stage 1 of the proposed methodology allows the characterization of the problem and its causes according to their nature, and relate it to the structure of the organization.

To be able to define the requirements for health IT systems, designers need to be fully acquainted with: the purpose of the care process; the activities required to accomplish the process; who performs the activities; and who is responsible for them. This was the aim of Stage 2. Not all these objectives were accomplished during the fieldwork. However, from a methodological perspective this stage should not be eliminated as it revealed the complexity and the multiplicity of care processes at the department level.

The knowledge gathered during Stage 2 was not sufficient to answer the questions required for IT system development. Therefore, the study was extended through Stage 3 where in-

depth knowledge on the care process was acquired. In this stage the required resources for each activity, and who is responsible for the activity, were identified. However, it was evident that the different professionals that are involved in preoperative planning have distinct views of the process.

The three stages methodology enabled the modelling of the complexity and multiplicity in the health care process. This was only possible since the fieldwork, and the analysis of the care processes, was done by an interdisciplinary team, composed of a computer scientist, a social scientist and health care workers.

## Conclusion

The implementation of the proposed three-stage methodology permitted the modelling of the preoperative planning process, and to describe its complexity. Furthermore, the proposed methodology made it possible to identify the cause for elective surgery cancellations at UNN. This will facilitate the development of a standard preoperative planning process, as future work. Processes that are re-engineered having a full understanding of: what they are meant to do; how resources act on it, e.g. their responsibilities and competences; how information is generated and required; and how they interact with other processes, provide the necessary knowledge for health IT to reduce inefficiencies and manage complexity.

Process re-engineering may require new activities and reorganization of the existing activities. This is a sensitive job that has impact on the whole organization. It is concluded that the design of health IT systems should not be a solo work done by software engineers or technical personnel. It is necessary to engage with the health care sector as an empirical field, and an interdisciplinary team is required to tackle the idiosyncrasies of health care processes.

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# Collaborative Process Modelling and Evaluation in E-health

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## Abstract

There is a gap in Design Research literature regarding context and methodologies for Evaluation. The Evaluation stage is the bridge between Design (or procurement), and Benefit management. Taking a constructive approach to the many challenges this poses, we propose a framework for e-health design research evaluation. We perform a systematic literature review for the use of process modelling notation in e-health. This is a prerequisite for process and service co-creation and evaluation. We further assess these, as they are applied in the literature, for cognitive efficiency in communication between receiver and sender.

## Keywords:

Design Research, Process Modelling Notation, Business - IT alignment, E-health, Evaluation.

## Introduction

In many highly industrialized countries, the increase in elderly citizens in need of care is growing. We see rising quality expectations for the provided care with the increase in the level of welfare. Service innovation and process improvement is needed to close the gap between the workforce that will be needed with today's processes, and the available future workforce. Unfortunately, e-health innovation is still especially challenging (1, 2).

The public, or semi-public context, of e-health in Norway, means that there are several stakeholder categories to consider. System development is potentially costly, and the innovation risk is high. Ex-ante evaluation of problem statements and design objectives of an emergent solution can help mitigate this risk.

## Stakeholder expectations in e-health

The public context of the e-health domain in many countries often leads to different stakeholders in the role as users and buyers of services. In general, new e-health artefacts (e.g. Methods, Processes, Performance indicators, Information systems, Organization models, and Business models) risk failing to meet their objectives because they fail to meet all the stakeholders' expectations and requirements. A possible

taxonomy of stakeholders in e-health could be based on four groups (fig. 1):

- E-health acceptors (e.g. patients, patients next-of-kind, patient-groups, and -unions)
- E-health providers (e.g. primary care, hospitals, and medication-suppliers),
- E-health supporters (e.g. IT vendors and universities),
- E-health controllers (e.g. government, legislators, financiers, and insurance companies) (3).

An example of failing to meet all stakeholders' expectations and requirements is Google Health (4). Among the reasons for its failure is that they largely ignored the requirements and expectations from both doctors and insurance companies.

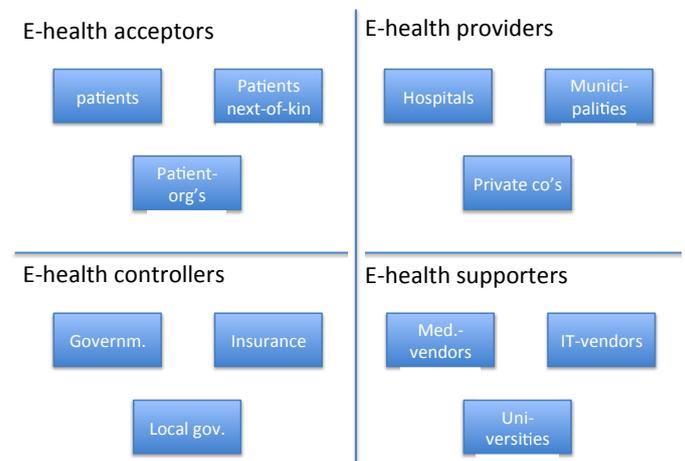


Fig. 1 The Multi-actors of e-health. After (3).

A possible taxonomy for the main elements of value propositions for new processes and services can be found in design literature (5-7):

- Feasibility - Can it be done?
- Viability - Does it make sense, economically or does it provide enough benefits vs. its cost. Other factors might be price, tax, insurance etc.
- Desirability - Do the intended users want this?

As healthcare is both a public and private/individual domain, the latter could be subdivided into a public subdomain e.g. survival rates, increased average living years, and a private subdomain, e.g. Quality of Life (Q.o.L.) and Quality of WorkLife (Q.o.W.L.). These domains combined with the mapping of main stakeholder groups provide an Evaluation scoreboard that can serve as a framework for evaluation of new e-health process improvement initiatives, see fig. 2.

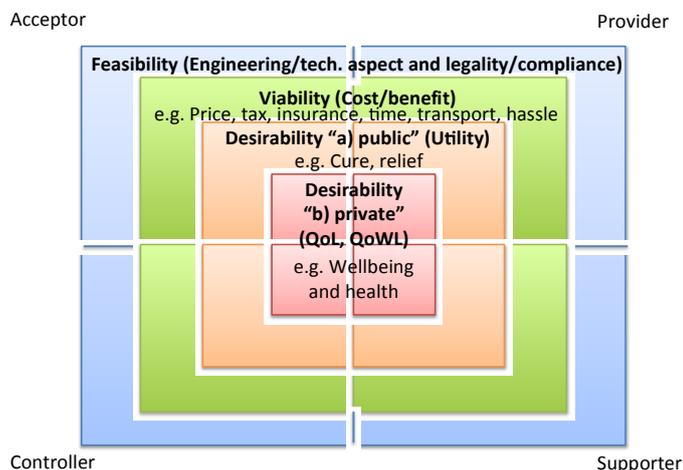


Fig. 2. Framework for e-health process evaluation. After (3, 5-7).

## Methodologies for Design Research

Design research is a growing area of interest. There is a call for Information systems (IS) research to return to exploring the underlying IT (Information Technology) engineering and its domain-knowledge premises in IS (8). The epistemology and ontology of design research has been debated (9, 10). An emergent consensus in the debate seems to be that although design research can reflect any epistemological stance, it embodies a pragmatic nature. Design research can revolve around human artefacts that can't be "true" in the positivistic ontological sense of the word, but rather more or less useful (11). There also seems to be a consensus that regardless of stance, research needs to be done in both a relevant and rigorous manner (12).

To help us perform design research, in a both relevant and rigorous manner, different frameworks methodologies have been devised such as Design Science Research (13) and Action Design Research (ADR), see fig. 3 (14, 15).

The different design research methodologies share many of the same main activities, but emphasize different activities. ADR (15) main characteristic is the Action-role of the researcher. Through intervention the researcher works in a team with practitioners and users. Here special attention given

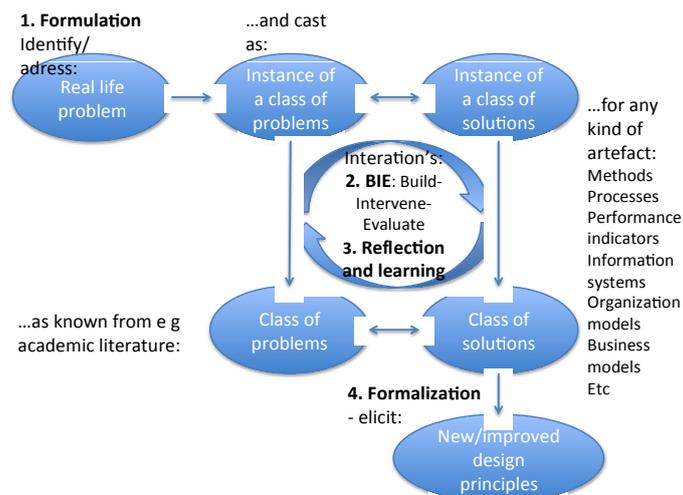


Fig. 3. Action design research activities. After (15).

to the classification of problems and solutions with regards to the research state-of-art. Peffers and colleagues emphasize the "Build" or design phase. We can illustrate this focus with the corresponding design research opportunities in parentis in the following process (16):

1. Identify a problem [or purpose] and motivate a new solution (Problem centred initiation)
2. Define the objectives of the solution (Objectives centred initiation)
3. Design and development of the artefact (Design and development centred initiation)
4. Demonstration (Client/context centred initiation)
5. Evaluation
6. Communication

The process should be iterated if necessary. See the illustration below (Fig. 4). We see that Evaluation is not assigned any research opportunity in this model.

Evaluation criteria and methods are left to choice as to how the testing and Evaluation of new solutions should be performed (13, 16).

This paper proposes a framework for evaluation in the e-health context. This paper also provides an overview over some commonly used process modelling notations and techniques in e-health. These models and notations are then evaluated for suitability in collaborative process co-creation based on a framework for assessing cognitive efficiency in communication between sender and receiver (18, 19), see table 1.

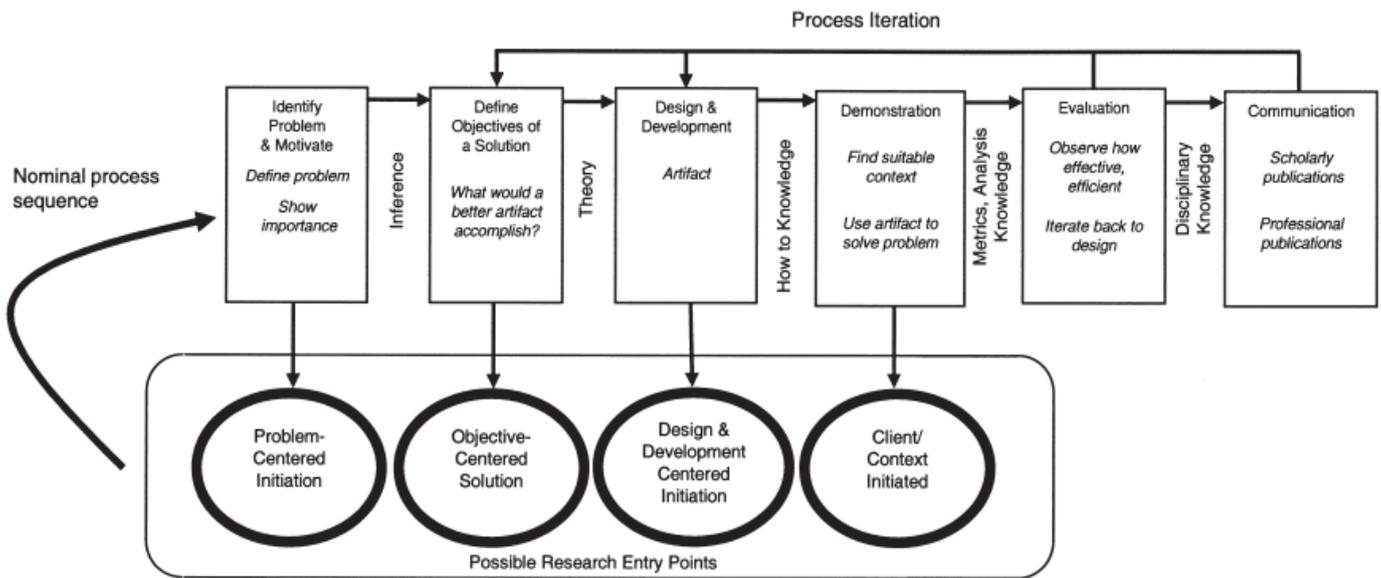


Fig. 4. Design Research Model. After (16)

Table 1. A framework for cognitive efficiency. After (18, 19).

Concept	Explanation
Semiotic Clarity	A 1:1 correspondence between semantic constructs and graphical symbols
Perceptual Discriminability	Different symbols should be clearly distinguishable from each other
Semantic Transparency	Use visual representations whose appearance suggests their meaning e.g. "Rich pictures"
Complexity Management	Include explicit mechanisms for dealing with complexity: Avoid overloading the human mind, e.g. Hierarchical organization: Abstraction-summarization vs Decomposition-refinement
Cognitive Integration	Include explicit mechanisms to support integration of information from different diagrams e.g. Contextualization: each diagram should include its surrounding context to show how it fits into the system as a whole
Visual Expressiveness	Use the full range and capacities of visual variables (Visual freedom)
Dual Coding	Use text to complement coding
Graphic Economy	The number of different graphical symbols should be cognitively manageable
Cognitive Fit	Use different visual dialects for different tasks and audiences e.g. novice perception problems

This framework aims to achieve cognitive efficiency in communication between sender and receiver. Cognitive fit is especially important in e-health, as co-creation involving patient groups require that a joint perception is possible. The principles may enhance or weaken one another, e.g. Visual Expressiveness may be in conflict with Graphic Economy, so different solutions represent a trade-off.

E-health innovation often entails inter-organizational process collaboration. Garmann-Johnsen and Eikebrokk (2) performed a literature review showing current knowledge according to literature on the antecedents of success in such collaborations. 11 of the 50 revised papers entailed cases of relevance to e-health.

We re-analysed this in depth to look for patterns for success in e-health innovation. We found very few clear examples of success stories, but the ones we found can in general be summarized as describing stories about successful alliance forming and management. When re-examining the data we also saw that success was recorded as seen from a particular perspective. Successful alliance management and beneficial (Action) Design Research thus dictate that all relevant groups are represented and become "co-creators" of new services (20).

A prerequisite for this collaboration is the ability to share a joint representation of such an intangible artefact as a process- or service-improvement. Modelling notation can serve as a boundary object, "physical objects such as design drawings, maps, contracts, learning materials, etc. that are used to facilitate cooperation while allowing diversity in interpretation" (21, p. 3). Several methods for modelling have been applied in e-health such as Business Process Modelling Notation (BPM-N) and a variety of Unified Markup Language (UML) diagram types. These are often used in combination. The next section provides a summary of a systematic literature review, mapping the use of modelling methods. We also provide an evaluation based on the cognitive efficiency of the examples of use given in the reviewed papers. This evaluation

of use of methods is based on the compliance with the principles listed in table 1.

## Literature review

We performed a systematic literature search to establish state-of-art for process modeling and notation in the healthcare contexts that are of relevance to IS-research. The literature search covered the academic databases that we deemed as likely to cover the most relevant subjects (cf. Table 2). EBSCOhost was used to search several databases for interdisciplinary journal articles.

In addition, a more refined search in ProQuest was conducted in order to search for possible secondary papers not found in the first search. We refined the second search based on experiences from the first. In total we found 435 articles, reduced for duplicate findings. We used truncations like ‘\*process\*’, ‘\*modelling\*’, ‘\*notation\*’ and ‘\*health\* (OR) hospital\*’ in the two searches, to cover the area of ‘service robotics’ in clinical support systems and the Boolean operator ‘OR’ giving ‘e-health’, ‘healthcare’ and ‘hospital’/‘hospitals’.

## Screening the search results

As our search was concerned with services and work processes we excluded articles dealing with Biology, Biochemistry, Biotechnology, Medical trials, Ecology, BioInformatics, Statistics, Medical ontologies, Demography, Research methods and other non-related themes.

The screening done by one of the authors was pair-reviewed and revised by the other. Thus we elicited 38 articles containing relevant knowledge.

Table 2. Literature review search strategy

Date	Database	Search string	F1	F2	F3
28/04/14	EBSCOhost all databases	(*process* OR *modelling *) AND *notation* AND *health*	101	81	22
29/04/14	ABI/Inform (ProQuest), all databases	*process* AND *modelling * AND *notation* AND *health* NOT ...	358	354	16
<b>SUM</b>			<b>435</b>		<b>38</b>

Note: F1 = Total number of articles, F2 = Articles reduced for duplicates, F3 = Articles containing relevant knowledge for this study.

The 38 articles found and deemed relevant for our area of interest was:

EBSCOhost; (22), (23), (24), (25), (26), (27), (28), (29), (30), (31), (32), (33), (34), (35), (36), (37), (38), (39), (40), (41), (42) and (43)

ProQuest; (44), (45), (46), (47), (48), (49), (50), (51), (52), (20), (53), (54), (55), (56), (57) and (58) (contact first author for detailed table overview).

## Findings

Our analysis of these relevant articles found 45 different concepts of modelling. 36 of these could be described as graphical notation systems, where some articles applied a combination of two or more notational systems. While finding many different notational systems there were still 9 out of the 38 articles with no reference to any graphical notation system. 13 articles contained notational systems only found in a single instance.

The most often used graphic notational systems were (see fig. 5). :

1. Diagrams associated with Unified Markup Language (UML); Use case diagrams, sequence diagrams and flowchart or activity diagrams.
2. Business Process Modelling Notation (BPM-N).
3. User Requirement Notation (URN). This system consists of two complementary sub-languages called Goaloriented Requirement Language for goal modelling, and Use Case Maps for scenario modelling(36).

We also rated the articles using graphic notation systems in process modelling, for Overall Cognitive Efficiency Rate, giving 1 point for every criterion in Moody and colleagues’ framework being met (see table 1). We found that the most used notation systems usually met many of the listed criteria. The highest score was given to articles using the URN notation system. The notation systems used in single articles meet few of these criteria. Some candidate design principles for use of graphic notational systems in process modelling could be elicited from this rating:

1. Articles that used more than one type of notational system in combination achieved a higher Cognitive Efficiency Rate, especially the Complexity Management criteria and Cognitive fit.
2. To supplement the more formal diagrams with more informal “Rich pictures” provide better Cognitive fit and Semantic transparency.
3. UML flowcharts or activity programs could improve their Cognitive Efficiency Rate by adopting the “swimlanes” symbol from BPM-N thus clarifying responsibilities for different stages in a process.

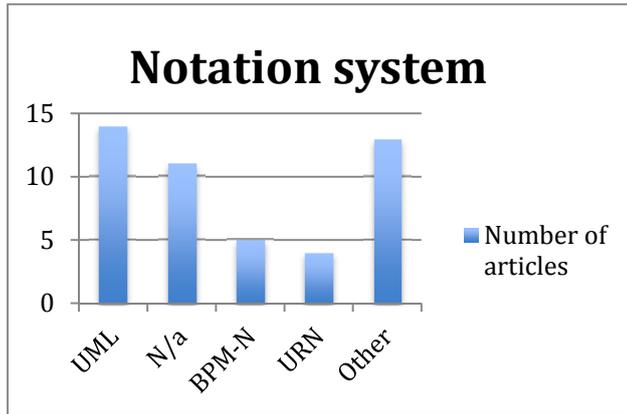


Fig. 5. Notation system per articles

Some articles (23, 25, 31, 32, 35, and 37) where no formal graphic notational system was reported used did contain what could be described as meta-models. These articles used alternative models to provide a background or a richer understanding of the problem in question. This could be theoretical lenses, political programs or other paradigm that describes the antecedents of problem solving and provides methods for understanding problems. One example could be the social model of disability that is recognized by disabled people and groups as an alternative to traditional models. This new model provides an alternative understanding expanding on individualized disability to also include social, political and cultural factors (46). Seeing disability as a broader “social, political and cultural” challenge will make action design researchers and practitioners look for other types of solutions than when seeing it as primarily an individual challenge.

## Discussion

There is a research gap in design research literature regarding the Evaluation phase. This is a challenge that needs to be addressed. A multiple stakeholder perspective should be taken into consideration when designing or implementing a new e-health process change. High assumption innovations are associated with high risk for failure. Asking a representative selection of stakeholders based on what problem needs addressing can mitigate this risk.

As we have shown, graphic notation systems used in a combination that meets the requirements for cognitive effectiveness in communication (18, 19), can enable the discourse between stakeholder groups when evaluating proposed new process or service. Agreeing on a joint holistic understanding of the problem area of concern in each respective context will ease the discourse between stakeholders, as shown earlier in the Social vs. the Individual Model of Disability (46). Decisions often need to be a pragmatic compromise, as society’s collective economy puts restraints on what levels of utility and quality is achievable (viable).

### Enabling co-creation

This is an area of growing concern. The interest in especially eliciting the users and the general public’s requirements for service innovation in public sector and e-health is growing.

Research has provided honed methods for collection of data. Surveys and quantitative analysis, qualitative analysis using coding and aggregation of statements into concepts, and Q-sorting (59, 60) can be used to form inter-subjective user requirements for new more efficient healthcare processes and services.

Graphic notational systems as enablers of the co-creative design process are still developing. In addition to the applied notation systems our review has shown, new systems are emerging. One example is the User Experience Modeling notation where the patients take active part in the modeling process (61).

### A coherent framework for e-health process modelling and evaluation

We see a need to involve stakeholders when evaluating e-health initiatives and a need for cognitive efficiency when involving stakeholder groups. Based on these findings we have defined six propositions that constitute a framework for evaluating new e-health processes:

1. Identify stakeholders and pick or recruit representative informants
2. Clarify the problem-perception between all stakeholder groups
3. Formulate problem and viable classes of solutions
4. Invite competing alternatives for (instances of) solutions
5. Evaluate and prioritize, using the E-health Process Evaluation Board (fig. 2.)
6. Elicit design principles for classes of solutions

#### 1. Identify stakeholders and pick or recruit representative informants

Figures 1 and 2 contain four main- stakeholder categories (acceptor, controllers, providers, and supporters) and a few examples of subcategories. Relevant stakeholders in each applied case, depends on the specific context. Often a new process has an impact beyond first users, so all individuals or groups that are influenced directly or indirectly should be considered stakeholders. The sample size of a representative group of stakeholders depends on the method used for data collection (i.e. large scale experiments with control-groups (13), surveys, Delphi-methods, interviews, focus-groups, Q-sorting (59))

#### 2. Clarify the problem-perception between all stakeholder groups

How problems are classified, or what theoretical lenses are used for problem elicitation, influence which solutions are sought (46). Discussing and clarifying problem perceptions and theoretical lenses for a discourse with stakeholder representatives will help focus the hunt for the best solutions, as seen from a multi-stakeholder perspective. E-health researchers can facilitate such discourses for the general public by representing relevant models and scenarios using

“Rich picture” notation (18). Allowing for ambiguity of perspectives in this stage can be beneficial, as the different categories of stakeholders or even subcategories should be allowed to hold subjective opinions.

### 3. Formulate problem and viable classes of solutions

Defining which class of solutions each specific solution belongs to will facilitate a better evaluation of competing solutions. Each class of solutions must address the defined problem or problem area (class of problems). Again one should allow for a certain ambiguity as to problem definitions and appropriate avenues for solution. The solutions should be presented for the stakeholder-representative group using the same graphic notation system and diagrams, making a comparison by the stakeholder representatives possible. At least one of the diagram types used should be suited for discourse with the general public, providing a “Cognitive fit” (18).

### 4. Invite competing alternatives for (instances of) solutions

A human artifact, such as an e-health method or process, will not be “true” in a natural science sense (10). It can only be found better or worse than some chosen alternative according to some chosen criteria. Such criteria might be within the aspects of feasibility, viability and desirability (public and private). Choosing a good solution, necessitates a completion with amongst more than one viable solution.

### 5. Evaluate and prioritize, using the E-health Process Evaluation Board (fig. 2.)

Formulate questions for the test and rating of feasibility, viability and desirability (public and private), for each stakeholder-category (acceptors, providers, supporters and controllers). The test can be adapted to each stakeholder-category, but should be controllable in the sense that it’s the same for each solution alternative. The scale used should be the same for all stakeholder categories and solution alternatives, giving the possibility to facilitate decision-making by having comparable scores (indicators).

### 6. Elicit design principles for classes of solutions

In a range of competing solutions, it would be possible to identify and elicit which factors differentiate the best-ranked solutions from the worst. . These factors can again be cast as design principles reflecting existing or new theory. These design principles can be tested for any other instance of the defined class of problems.

### Contribution/implication for Research/Practice

Our paper contributes to the literature on design research by detailing a practical way of eliciting new design principles through stakeholder evaluation. We also contribute a practical methodology and rationale for the use of comparable process modeling notation, to facilitate co-creation. This facilitates collaborative iterations in Building, Intervening and Evaluating solutions (15).

Our propositions for an evaluation framework can produce a baseline for indicators that can be utilized in process management and benefit management in public sector. This

framework might also facilitate public-private collaboration where the choice of the better solution is based on a holistic view of the alternatives and not solely on price-competition between standardized and un-innovative solutions.

### Further research

Further research for this proposed framework for evaluation of e-health processes would entail applying it in different case studies covering different classes of problems. The applicability of the framework in other fields of research in the public sector might also be explored.

### Limitations

Our proposal does not cover all aspects of evaluation in design research. Nor does it concern other related aspects as system development, business models, or project management.

The literature review on process modelling and notation in e-health cannot give an exhaustive picture of the state of art here, as our search strategy or screening may have its limitations.

### Conclusion

We have provided a proposal for a framework for evaluation of new e-health process and services that supplement existing literature on design research and e-health research.

We have shown that our propositions may have an impact for both research and practise. Further research will be to apply this framework to case studies in the e-health context or other related public sector contexts.

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# RIS/PACS implementation calls for changes in work processes and organizational structure

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## Abstract

*A Readiness for Change survey was conducted in a radiology department at large Danish University Hospital's in connection with the implementation of RIS/PACS in 2005. The survey was part of a research project concerning organizational factors in the implementation of RIS/PACS and aimed to evaluate the preparedness for the new system and obtain staff members' assessments of co-operation in and among professional groups.*

*A follow-up survey conducted in May 2014 shows that nine years after the RIS/PACS implementation, users continue to call for changes in system functionality and work processes, and point out organizational shortcomings. Co-operation in and among professional groups was assessed at the same level as in 2005. The new survey corroborates the 2005 respondents' expectations for change in work processes and organizational structure in as far as their retrospective assessment of the significance of work processes and organizational structure when implementing RIS/PACS remain unchanged.*

*It is concluded that the implementation of RIS/PACS involves not only technological issues but also affects tasks, actors and structure in the department, as predicted by Leavitt.*

## Keywords:

Organizational change, radiology information system, PACS (radiology), evaluation studies, Aalborg University

## Introduction

When in 2004 Aalborg University Hospital implemented a radiology information system and picture archiving and communication system (RIS/PACS) a decision was taken to initiate an action research project concerning organizational factors in relation to the implementation of the system. As work progressed, the limited focus on RIS/PACS was abandoned for a more general orientation towards organizational development. The primary result of the research project was the formulation of a shared vision for the radiology department with an action plan listing 35 initiatives. The action plan targeted a wide range of improvements, such as better signposting and floor markings for traffic guidance and the preparation of guidelines

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for examinations. Efforts to establish a new culture in the department to help secure general respect and recognition of individuals and professions exemplify ideas of greater scope. Only five of the action plan initiatives were connected directly to the RIS/PACS implementation.

As a first step in the action research project, a Readiness for Change Survey (RCS) was conducted in early 2005 to assess the department's preparedness for the implementation of RIS/PACS. In May 2014, a follow-up survey was done to understand the extent and nature of changes over the nine years since the first RCS. A shorter version of the 2005 RCS questionnaire was used.

This paper reviews those aspects of the study that relate to RIS/PACS, partly by comparing responses from 2005 and 2014, partly by examining respondents' suggestions for changes.

## Materials and methods

The questionnaire used for the 2005 RCS was an adapted version of the questionnaire for studying the implementation of electronic medical records described in Høstgaard and Nøhr [1], whose terms were substituted by terms relevant to radiology and RIS/PACS.

In 2014 an abbreviated version of the 2005 questionnaire was used, as items relating to staff expectations for the implementation were removed. Other questions were changed to introduce the retrospective perspective that would enable comparison with responses in 2005.

The quantitative analyses of the paper-based 2005 questionnaire were performed using Microsoft Excel statistical software. In 2014 SurveyXact software was used both for the electronic distribution of the questionnaire and the quantitative analysis. For the qualitative analysis, data were reduced via meaning condensation – in 2014 supported by the NVivo analysis software.

In both surveys the questionnaire was sent to all employees in the department. Responses were obtained from 47 % (90 of 191) and 45 % (91 of 202) in 2005 and 2014, respectively.

As shown in Table 1 the response rates for individual professional groups ranged from 35 % to 57 % in 2005 and from 29 to 51 % in 2014 (Table 2).

Table 1 – 2005. Staff numbers and response rates, by profession

Profession	n	%
Radiologists	39	36
Carers <sup>1</sup>	98	55
Secretaries	40	35
Various	14	57
<b>Total</b>	<b>191</b>	<b>47</b>

Table 2 – 2014. Staff numbers and response rates, by profession

Profession	n	%
Radiologists	52	29
Carers	110	51
Secretaries	40	50
Various <sup>2</sup>	0	0
<b>Total</b>	<b>202</b>	<b>45</b>

The relatively low response rates for radiologists is unsurprising as physicians' response rates are typically 10 percentage point below average for all professional groups, according to Bowling [2]. The secretaries' exceptionally low response rate in 2005 was understood to stem from their recent experience that survey responses were used to identify candidates for a subsequent round of layoffs.

## Results

### Use of PC

The recorded increase in computer/PC experience from 2005 to 2014 is unsurprising. The proportion of respondents in the department who assessed themselves as super users rose from 6 % to 11 % while the category of highly experienced increased from 34 % to 63 %. Thus, almost three fourths assessed themselves to be *Highly experienced* or *Super users*.

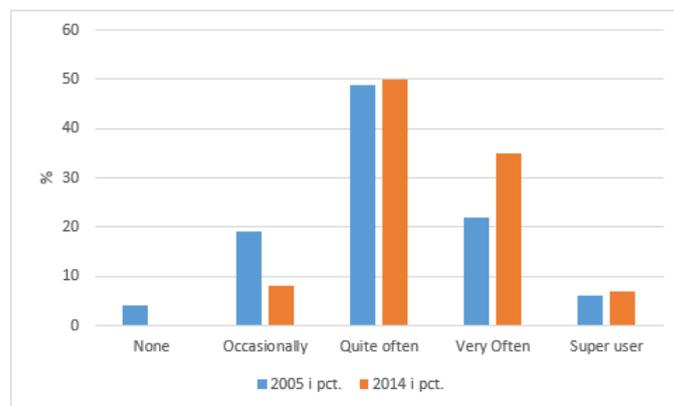


Figure 1 - Experience working with computer/PC

### Perceived need for changes before/after RIS/PACS

The 2005 survey asked staff members to assess the need for changes in organizational structure and work processes in the forthcoming implementation of RIS/PACS. In 2014 those 64 % of the 2005 respondents who were still employed in the department were asked to assess the necessity of changes in structure and processes in connection with the implementation of RIS/PACS. Figure 2 below gives responses for organizational structure and work processes as perceived in 2005 and 2014, respectively.

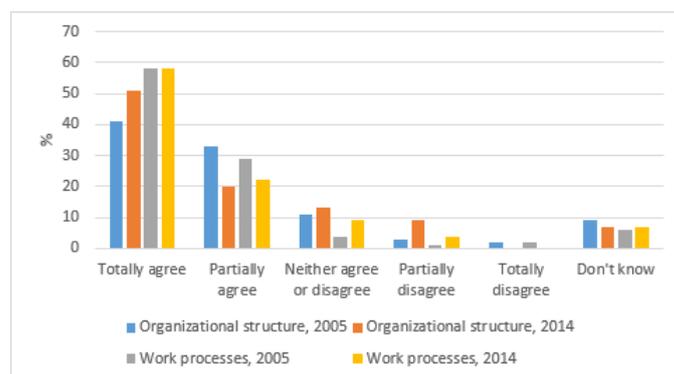


Figure 2 – Perceived need for changes in organizational structure and work processes assessed before/after RIS/PACS

The distribution of responses concerning the need for changes in organizational structure were slightly more dispersed in 2014, while the proportion of responses indicating total agreement rose from 41 % in 2005 to 51 % in 2014. Regarding work processes, the percentage of those who declare themselves in total agreement was unchanged, whereas the *Neither agree nor disagree* category went from 4 % to 9 % while the *Partially agree* category rose by 3 % to 4 %.

### Improvement of RIS/PACS via changes in organizational structure and work processes

In 2014 57% of responses ticked either the *Agree* or *Partially agree* button to indicate their view that the use of RIS/PACS would gain from changes in organizational structure while 22 % offered concrete suggestions for helpful changes.

<sup>1</sup> Primarily radiographers and nurses.

<sup>2</sup> In 2014 part of the other tree professions.

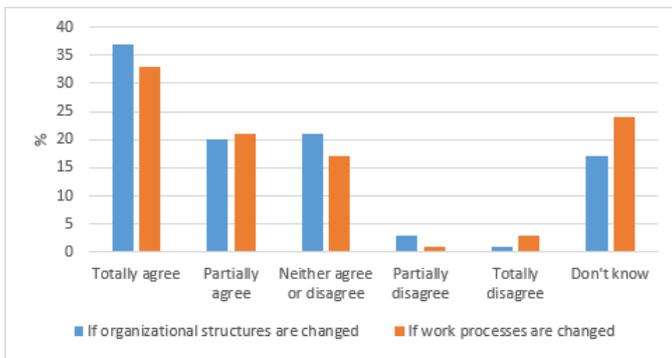


Figure 3 – The outcome from using RIS/PACS could be improved if organizational structures and work processes were changed

With regard to changes in work processes, 54 % of responses indicated either *Total agreement* or *Partial agreement* with statements concerning changes, with 21 % offering concrete suggestions for change. The distribution of responses appears from Figure 3.

The concrete suggestions for change generated by the above questions may be categorized under four headings: functionality, organization and management, training, and support. The suggestions for each of the four categories are discussed below.

#### Systems functionality:

- shortcut keys needed to avoid excessive clicking of computer mouse
- improved functionality for secretaries' hanging protocol task (image displays)
- improved integration with other systems and modalities, e.g. by:
  - removing the need for simultaneous operation of up to five IT systems
  - securing earlier appearance of referral documents from general practitioners
  - securing automatic transferral of to do lists to all modalities
- integration of systems for digital dictation, speech recognition, and spelling control
- improved overview of patients' previous examinations and the information communicated to them
- modernized/improved user interface and customization options
- optimized examination coding function

#### Organization and management:

- ensuring correct referrals of patients to examinations and rooms
- proper work stations in adequate numbers
- discontinuation of autonomy and individual rules

- avoiding process duplication in RIS/PACS
- improved management insight into staff members' job tasks

#### Training:

- time for RIS/PACS user-training
- training to avoid process duplication

#### Support:

- improved access to IT support as the department depends on RIS/PACS for essential functions such as examination reporting

#### Co-operation in and among professional groups

In 2005 as well as in 2014, respondents assessed co-operation in their own professional group as better than among professional groups in the department. The assessment of intragroup co-operation increased marginally over the years whereas inter-group co-operation was rated slight lower in 2014. Nevertheless, 90 % and 91 % stated that *co-operation is good* in 2005 and 2014, respectively. Figure 4 also shows that only a very small percentage regarded co-operation as *poor*.

A large majority of respondents indicated, however, that internal co-operation in their professional group offered room for improvement (76 % in 2005 against 88 % in 2014), 39% of those also offered comments or concrete suggestions. A similar picture emerges for co-operation among professional groups, with 92 % in 2014 indicating that co-operation might be improved (77 % in 2005). Comments or concrete suggestions were given by 32 %.

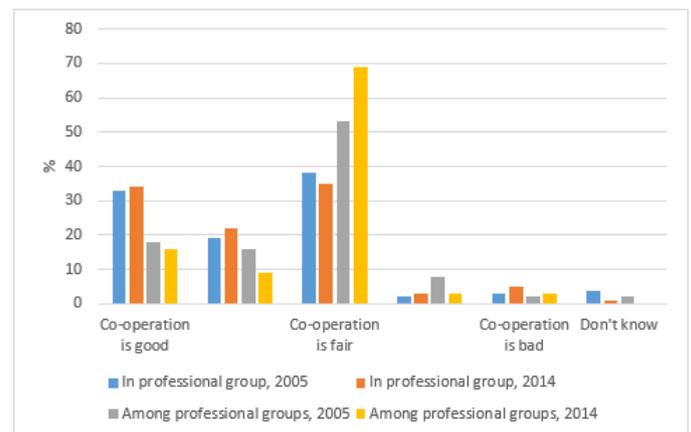


Figure 4 - Co-operation in and among professional groups

Figure 5 shows the relative distribution of all comments concerning co-operation in and among professional groups. Between 2005 and 2014 the greatest increase is seen for *Organization* and *Management*, while issues concerning *Meetings* and *Respect* attracted fewer comments in 2014. Comments on *Communication/information* and *Education* saw little change.

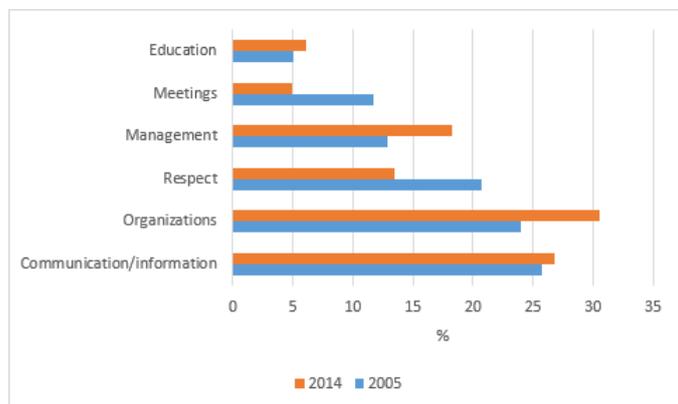


Figure 5 - Comments on co-operation

With respect to comments of relevance to RIS/PACS, several respondents mentioned the working environment, lack of team spirit, and the department's stressful work atmosphere. A shortfall of staff caused by recruiting problems for vacant consultant positions leaves little energy for helping others and scarce opportunity for concentration. Another typical comment concerned the wish for changes in work routines and the department's social culture. There seems to be an understanding that the stressful workday in combination with apprehensions about changes prevents this. Other comments concerned management, for example in calls for a stronger contribution to the formulation of clear guidelines for work in the department.

## Discussion

The decision taken in 2004 to implement RIS/PACS at North Jutland hospitals – including the radiology department at Aalborg University Hospital – may be seen as a paradigmatic shift in that paper and film were replaced by the digital RIS/PACS system. In addition to using IT for patient-related information, the department now employs advanced technology for radiological examinations. It follows naturally that today's respondents assess themselves as considerably more experienced computer users. The fact that three fourths of current respondents categorize themselves as *Highly experienced* or *Super users* only serves to emphasize that production and work routines in the department are based on the use of advanced information technology.

The initiation of an action research project focusing on organizational issues (among others: structure, work flow, cooperation, communication, and culture) reflected the recognition that apart from being an IT project, the implementation of RIS/PACS was also a question of adapting organizational conditions and work processes, as pointed out by several authors at the time. [3-7]

A high-profile speaker at a 1998 conference on computer-based patient records, Reed Gardner, is quoted as saying:

"...the success of a project is perhaps 80 percent dependent on the development of the social and political interaction skills of the developer and 20 percent or less on the implementation of the hardware and software technology!" [4, 7, 8]

The controversial statement on the distribution of organizational and technological issues in successful instances of IT system implementations was often cited in the field.

A comparison of responses concerning the need for changes in organizational structure and work processes shows the foresight of the early respondents' assessment of the need for changes. The gain since 2005 in the perceived need for changes in organizational structure may indicate that while many at the time saw a change of work processes as required, they were less inclined to see the importance of changes in organizational structure. The course of events has affirmed this need. Further indication is evident from the responses to the question concerning improvements in the future use of RIS/PACS. Such a need is not only acknowledged – in fact, respondents in 2014 prioritized changes in organizational structure over changes in work processes.

The system model developed by Leavitt clearly shows that when changes are implemented in one realm of an organization, whether they involve technology, tasks, actors, or structure, the other three realms are bound to be affected [9, 10]. The high scores for perceived need of changes in organizational structure and work processes provide support for the aforementioned 80/20 rule (in figure 2 and figure 3). Also Lorenzi and Riley [5, 6] and Berg [7] have focused on organizational factors in the implementation of IT systems in healthcare.

Respondents' assessment that changes in organizational structure and work processes can improve the use of RIS/PACS may be taken either as an expression that the department still has some way to go before its goals are met or that its staff recognize that the implementation and subsequent application of RIS/PACS is a continuing process.

Considering that the questionnaire items concerned organizational structure and work processes, it seems surprising that a relatively large proportion of suggestions for improvements related to functionality instead. A possible explanation may be that respondents equate the concrete functions in RIS/PACS with work processes, or that they took the survey as an opportunity to communicate their demands for improvements in functionality. It is easy to see how functionality and work processes can be confused as the former is intended to support the latter, but it cannot be ruled out that functionality is a limiting factor for the development and adaptation of work processes in RIS/PACS. Alternatively, work processes may have changed without subsequent adjustment of RIS/PACS functionality.

Apart from ideas for changes in functionality, respondents suggested several concrete changes that would immediately facilitate their use of the system. They mentioned more time for training, better support, and adequate access to proper work stations. Improvements in these areas would support the

department's execution of routine tasks which is strongly dependent on the proper functioning of RIS/PACS. However, all of these suggestions would incur immediate costs.

Other suggestions could be implemented without immediate costs; for example that management become more involved in staff members' responsibilities and work processes. Such issues concerned e.g. process duplication in RIS/PACS, the quality of referrals, and putting an end to certain colleagues' adherence to own rules and procedures.

Generally speaking, the majority of suggestions from respondents, for example in relation to functionality, organization, and management, and to training and support would be considered as management responsibilities as far as their implementation is a question of resource allocation. But a number of responses seem to reflect that the department is pressed for resources and understaffed as a result of a lack of qualified applicants for vacant positions. This impression is furthermore supported by the fact that many comments concerning co-operation, whether inside or among professional groups, appear to indicate working conditions in which staff are struggling to keep up.

### Discussion of method

In the nine years that have elapsed between the two surveys the health sector has seen numerous changes. A few are listed below:

- The Municipal Reform of 1 January 2007 in which 14 counties were abolished to make way for five regions. In the reform a number of municipalities were merged, diminishing their number from 271 to 98, and changing the distribution of responsibilities between local government tiers [11]. For example, the municipalities were charged with several new healthcare tasks, calling for increased collaboration among them.
- Implementation of the cancer packages guaranteeing patients an effective examination and treatment programme. The majority of cancer diagnoses require radiology departments to perform at least one examination.
- The entitlement to early diagnostic examination, implemented in September 2013, requiring that referred patients be examined within 30 days, places a heavy load on diagnostic departments.
- Increased focus on quality in healthcare. The health service quality and accreditation institute IKAS (Institut for Kvalitet og Akkreditering i Sundhedsvæsenet) was established in 2005 and the first version of the Danish quality model DDKM (Den Danske Kvalitetsmodel) for hospitals was ready in 2009. Today, the accreditation procedure follows the second version of DDKM.
- Regions (supported by the governmental grants) have decided to build new acute hospitals (erroneously referred to as super hospitals by the media) [12].

### Conclusion

Overall, a comparison of the results of the 2005 and 2014 readiness for change surveys reveals only minor differences. The evidence supports Leavitt's model of change predicting that technological change will spark the reconsideration and adjustment of tasks, actors and structures in the organization. The 2014 respondents offered many suggestions for change of functionality, but several of them are judged to concern the adjustment of organizational structure and work processes in the department. While the present study did not intend to determine whether the case provides an example of the mentioned 80/20 distribution between organizational and technical conditions, it clearly indicates that the implementation of RIS/PACS involves many other factors apart from technological ones.

Almost a decade after RIS/PACS was introduced in Aalborg University Hospital's radiology department, the 2014 survey offers an occasion for taking stock. It should be encouraging that respondents continue to offer constructive suggestions for optimizing the everyday use of RIS/PACS. On the other hand, their responses also give evidence that their struggle to cope with day-to-day responsibilities may in part be the very source of their creativity.

### Acknowledgments

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# Access Control for Electronic Health Records

## A Delphi study of current challenges and highlighting of potential improvements

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### Abstract

*Access control is an essential function in electronic health records (EHR) to maintain the duality between patient safety and patient privacy by ensuring that authorized personnel are allowed access to health records. In the Norwegian secondary care, access control in EHR must be given on the basis of decisions about health care, so called decision based access. There is however no empirical data on experiences with the use and setup of decision based access. A Delphi survey was therefore undertaken to identify what end users and system administrators consider to be important challenges, and ways to improve the access control. The survey shows that challenges identified in previous studies are still present. Access control is not sufficiently tailored to treatment processes, and there is extensive use of exception mechanisms, which creates long event records that are not followed up systematically and therefore may go at the expense of patient privacy. Possible improvements include more education, standardization of access control, easier use of exception mechanisms and a more process oriented access control.*

**Keywords:** Access control, Electronic health records, security measures, patient safety, Delphi Technique

### Introduction

Access control is an important feature of EHR, and deals with enforcing laws and policies to ensure that only authorized users gain access to confidential information. In health care, this means protecting patient privacy, while patient safety. This method requires that healthcare professionals have access to the information they need to make the most informed decisions about care and treatment of the patient [1]. Treatment Processes may be unpredictable, making it difficult to implement strict rules for access control, which adequately protects both privacy, by minimizing the possibility of misappropriation of confidential information (snooping), and patient safety.

There are many models for access control, but there is little published research regarding the health services requirements for access control. Literature shows that most models for access control in healthcare are studies or prototypes where health professionals have not participated in the development of either policies, models or mechanisms for access control [2].

Decision based access, which is a further development of traditional role-based access control is in use in much of the Norwegian secondary healths EHR systems. On the basis of Scandinavian Conference on Health Informatics, August 21-22, 2014, Grimstad, Norway

legislation concretized through the EHR-standard [3], and standards for information security in the health care and social sector [4] are required to use this. Within a few years the decision controlled access is likely to be introduced in all regional health enterprises, each with a set of standardized principles for access control. There is, however, little empirical evidence about this model among those who daily work with it; end users and system managers.

This paper has sought to identify what the end users and system administrators consider important challenges and possible improvements of access control, through a Delphi study and data from an EMR database.

### Materials and Methods

#### Delphi survey

The survey was conducted with end users from one health enterprise, and system administrators from several health enterprises and regional system administrators. This study used the Delphi method as described by Schmidt [5] to identify and rank important challenges and possible improvements with regard to access control. Data were collected via SurveyXact online survey program.

#### Expert panels

End users and system managers were allocated to each their panel, and the selection of experts was partially based on Okoli and Pawloski's [6] recommendations of the preparation of a knowledge resource nomination worksheet (KRNW). The end users were recruited from Sørlandet Hospital health enterprise (SSHF). Criteria for inclusion was that the end users as far as possible should use exception mechanisms, i.e. cases where regular access control does not cover the need for access. To identify relevant categories of end users, data on the use of actualization mechanisms were extracted from the EHR-database. In addition, nurses were invited as they are the largest user group, and feedback from them was therefore considered important. There was also a criterion that end users should have received additional training in, and having been involved in testing decision based access when this was introduced at SSHF. The latter criterion was set to increase the likelihood that end users in the study were aware of concepts like decision based access and related concepts and issues that would come up during the questionnaires in the survey. The

author got help from the IT dept. in SSHF to get an overview of which users met these criteria, and on this basis a KRNW was prepared.

The system administrators were recruited from different regional health enterprises. To ensure a variety in the group, experts with expertise in both direct management of EHR (local system managers at each health authorities, and regional system managers), and individuals with expertise in policy and legislation related to access control were nominated.

A total of 35 end users, and 20 system administrators were then invited to participate in the survey, to account for non-response and attrition, so that after the last round would be left with between 10 to 18 respondents, as this is a recommended number [6].

The study was conducted as a four-round study. SurveyXact was used to distribute questions and collect data. An e-mail was sent to the experts with a link to the questionnaire. Response time was set to three working days, with a reminder the fourth working day. Analysis was conducted in 1-3 working days, and then returned to the experts. It took five weeks between the distribution of the first round, and the last was analyzed. The language used in the study was Norwegian, and answers were translated to English by the main author, and validated by the coauthor. Table 1 shows the participation in the rounds.

Table 1- Participation

	End users	System administrators	Total
Round one (%)	18 (100)	17 (100)	35 (100)
Round two (%)	18 (100)	17 (100)	35 (100)
Round three (%)	16 (89)	16 (94)	32 (91)
Round four (%)	13 (72)	15 (88)	28 (80)

## Analysis

A qualitative content analysis of the first round of questionnaires was done, where it was chosen to use Directed Content Analysis, described by Hsieh and Shannon [7], which assumes that one has a theoretical framework as a basis for coding statements. The Extended InfoSec model [8] for information security in healthcare was used as the theoretical foundation. The model is developed with the purpose to describe in a simple manner what information security presents, and can express the problems and needs in information security. In this paper the model is used to highlight areas in which respondents' factors of challenges and improvements in access control can be placed. The model is shown in figure 1.

Respondents' statements were therefore shortened and categorized according to the predefined categories in the InfoSec model. In the fourth round, the statements average rating was calculated, and the degree of consensus was analyzed in SPSS by calculating Kendall's W.

### Round 1

In the first round, the experts answered the following questions:

Question 1: *What challenges do you experience related to decision based access (the access control in DIPS)? You*

*should mention point wise (in brief) at least five challenges you can think of*

Question 2: *How can access control in DIPS in your opinion be improved? You should mention point wise (in brief) at least five factors you can think of.*

The qualitative data were then consolidated so that the answers with equal meaning were merged, and answers were sorted under the overarching theme, and a number of replies were reformulated to clarify the challenge or improvement suggestion.

Based on question 1, a total of 56 unique challenges were identified after the consolidation of similar answers.

Based on question 2, a total of 44 unique ideas for improvement were identified after the consolidation of similar answers.

### Round 2

After answering the first round, the experts automatically received an e-mail with the answers they had given, and in the second round they were asked the following requests related to the questions from the first round:

Question 1: I asked: What challenges do you experience related to decision based access (the access control in DIPS)? You should mention point wise (in brief) at least five challenges you can think of. The answers that came in are summarized below (but not necessarily verbatim). Look through the list and if you cannot find your answer, write it down in the field below, in brief.

Question 2: I asked: How can access control in DIPS in your opinion be improved? You should mention point wise (in brief) at least five challenges you can think of. The answers that came in are summarized below (but not necessarily verbatim). Look through the list and if you cannot find your answer, write it down in the field below, in brief.

Three of the respondents came with feedback in this round, and as a result, three new factors in Question 1 were included in round three, and it was made an addition to one of the factors in Question 2.

### Round 3

In the third round, the experts were treated as two independent panels, and asked to select at least ten of the most important statements/factors associated with each of the two initial questions. The statements/factors were arranged in random order to avoid bias, due to context effects.

Question 1: Select at least 10 statements/factors that you think are important challenges to decision based access. Your answers should be based on the expertise you have in your position. The challenges do not have to relate to your own experiences.

Question 2: Select at least 10 statements/factors that you think are important factors for improving the access control. Your answers should be based on the expertise you have in

your position. Improvement proposals do not have to relate to your own experiences.

For the panel with end users, the statements/factors which were selected by over 30 % of the experts were retained, while it for the system manager panel was set a cut- off point of 35% for question one and 40 % for question two. This was done to reduce the list to a manageable size of about 10 factors, while ensuring that important factors were not rejected in this round.

#### Round 4

In the fourth round, the experts were asked to rate statements/factors from the reduced list after the previous round, related to each question. The statements/factors were arranged in random order to avoid bias due to context effects. In addition, the experts could post comments to explain or justify their rankings.

Question 1: To what extent do you consider the following statements/factors as challenges in access control?

Below is a list of the most important factors you have chosen, and now I want you to rank them by typing a number from 1 to 10 in the small pane by the factor. You must use all the numbers from 1 to 10, where 1 = most important.

If you want to explain the rankings, you can type this into the text field to the right.

Question 2: To what extent do you think the following statements/factors can improve the access control?

Below is a list of the most important factors you have chosen, and now I want you to rank them by typing a number from 1 to 9 in the small pane by the factor. You must use all the numbers from 1-9, where 1 = most important.

If you want to explain the rankings, you can type this into the text field to the right.

Degree of consensus among the experts were then analyzed using Kendall's W in IBM SPSS Statistics 19.

In addition, the scale was inverted for readability upon presentation of the results, and the average rating for each factor was calculated.

Kendall's W was <0.3 for all the questions, indicating weak agreement [5]. The survey was still ended for practical reasons, and not to waste the panel members' time, when it was believed that more rounds would not lead to strong agreement among the experts. Dissensus, or lack of agreement can also be a valid findings of a Delphi study [9]. The panels agreed on the key factors, lack of strong consensus was on the ranking of these factors.

## Results

In round one and two, the aim was for the experts to identify and validate statements concerning challenges and possible improvements of access control. A total of 56 challenges, and 44 suggestions for improvement were identified. The results of the fourth and final round are here presented. The respondents were asked to rank the most important factors from the previous round. In the tables, the scale is inverted for easier viewing, with the highest ranking factors on top.

Table 2 - Ranking question 1, end users

Factor	Average ranking (inverted)
1. Insufficient number of/covering implicit decision templates	7
2. Missing/too few appropriate explicit decision templates in relation to real reason for opening the journal	6,92
3. User may choose a wrong decision template	6,31
4. Lack of clarity regarding use of the free text field when deciding access	6
5. One must too often decide for access, for example when checking test results, printing to general practitioner, ended contact etc.	5,69
6. Insufficient education in access control	5,62
7. Users lack understanding of decision based access	5,46
8. It requires too many keystrokes to decide access	4,46
9. Having to decide access gives a feeling of doing something illegal, and to be mistrusted and monitored	3,92
10. When deciding access, you automatically only have access for one day	3,62

Kendall's W = 0,150

Table 3 - Ranking question 2 end users

Factor	Average ranking (inverted)
1. Upon referral from psychiatric to somatic department, one should have access to the referral	6,31
2. The screen for deciding access should appear at once you try to open a patient journal you do not have access too	5,92
3. The possibility to create custom decision templates	5,85
4. Ability to choose what you get access to when deciding access	5,85
5. Ability to choose what you get access to when deciding access	5,31
6. Ability to select a default decision template that applies to all medical records	4,77
7. Provide examples for grounds in the text field for deciding access	3,77
8. Reduce the number of clicks needed to decide access	3,62
9. The decision for access should automatically last more than one day	3,62

Kendall's W = 0,158

Table 4 - Ranking question 1 system administrators

Factor	Average ranking (inverted)
1. The interface of the administrator section of DIPS is too little intuitive and transparent	6,47
2. The access control is not integrated with the personnel system	5,67
3. Defining the correct access profiles	5,2
4. Little standardization of access control across health enterprises	5
5. It is impossible/difficult to quickly get an overview of what access rights a particular user has	5
6. There is insufficient support for log analysis	4,87
7. Procedures for ordering and/or termination of access are not complied	4,87
8. Insufficient functionality for blocking access to journals	4,4
9. Adaptations to special permissions are challenging for system administrators	3,53

Kendall's W = 0,086

Table 5 - Ranking question 2 system administrators

Factor	Average ranking (inverted)
1. Simplify the process of creating and terminating access in the administrative section of DIPS	5,13
2. Clearer guidelines from national authorities on how access control is to be organized	5,07
3. The access control should be integrated with personnel system so that access is automatically generated	5,07
4. Common guidelines for access control at regional or national level	4,93
5. Logic for access control should be done nationally and linked to patient care/referral periods	4,4
6. Better overview of everything a user has access to	4,4
7. The screen to decide access should come up instantly when you try to enter a journal you do not have access to	3,73
8. Active use of the access log for quality assurance	3,27

Kendall's W = 0,080

### Summary of challenges and suggestions for improvement

Figure 1 shows the InfoSec model with the assembled factors for challenges and improvements of access control. Letter and number codes in the figure are listed according to the expert panel, questions and factor, where A = end user, B = system administrator (eg. code A2-4 refers to the panel with end users, question 2, factor 4).

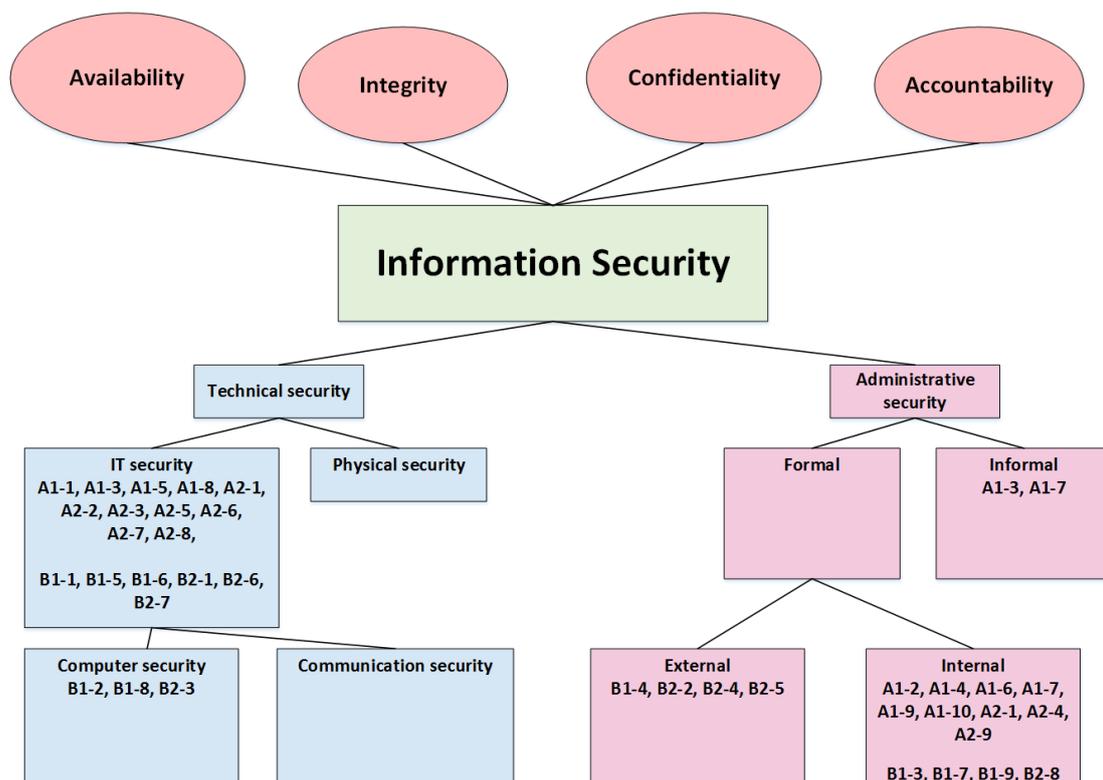


Figure 1 – The Extended InfoSec model with assembled factors

Table 6 - Average number of actualizations per position for the period 01.08.13-30.09.13

Position	Number
Skilled worker (n=19)	47,1
Consultant (n=115)	43
Audiologist (n=16)	27,4
Medical student with license (n=5)	21
Secretary (n=588)	19,9
Other position (n=1)	17
Adviser (n=23)	13
Unit manager (n=131)	11,4
Senior physician (n=452)	7,6
Physician (n=278)	7
Engineer/technical position (n=4)	6,3
Head of Department (n=32)	5,7

Table 7 - Number of record lookup per decision template

Decision template	Count
Internal control / quality assurance	10031
Request from the patient's physician	6733
Supplementary work	4844
Order of documents from government and legal agencies and insurance companies	4375
Request from patient	3091
Reported patient	1410
External test results/notes for review	1315
Supervision in other departments	591
Request from the patient's relatives	512
Research	362
Emergency access	180
Patient access to information	91
IT system work	42
Total	33577

## Discussion

### Challenges

#### End users

Among the main challenges end users arrived at, the first half were placed in the general category of IT security, and the second half in administrative security, of which the majority was Internal, under Formal administrative security.

The two highest ranked challenges concerned the lack of appropriate implicit and explicit decision templates. Missing implicit templates are placed in the category Technical safety, as they are set by the vendor as default for all customers, while the challenge of too few explicit templates are placed in the category Internal, as new explicit templates can be ordered by the customer (health enterprise). These two challenges are logically connected, as lack of relevant implicit decision templates means that you do not automatically get access to the records you need, and thus must use exception mechanisms. When you try to get access via the exception mechanism named "greenlight access", you get a list of decision templates,

but based on respondents' answers, there should have been more decision templates, as the real reason for opening the records are not always found in the list they have access to. These challenges have thus consequences both for end users, who must spend time using exception mechanisms to bypass normal access control, and system managers, who review the logs for the use of the exception mechanisms. End users also think that it is an important challenge that you have to decide access too often. This suggests that the access control is not sufficiently tailored to adhere to treatment processes, which is seen in previous studies [1]. Exception mechanisms were used 33 577 times over a period of two months in the end users health enterprise, as shown in table 7. This number indicates that it must be difficult to follow up event logs, which corresponds to an interview survey [10] where it appears that the use of exception mechanisms is too large to be systematically followed up. If you also cannot rely on the decision template that is used to correctly indicate reason for opening the record, it seems at best unclear what value a log of this has. These challenges are previously described by Røstad [1] who analyzed an event log from Siemens DocuLive EHR, from eight hospitals in central Norway. Røstad also revealed a lack of predefined reasons for deciding access, and came with a recommendation for six new templates:

- Physician referrals.
- Hand over patient information to other hospital/health personnel on request.
- Request for information from a patient or next of kin.
- Release information to other external entity: insurance, legal, complaints.
- Out-patient clinic patient encounters.
- Patient not registered correctly in admin system (results in access denied, even though patient is physically present at ward).

In DIPS, decision templates with similar reason to the top four of these are included as standard for all health enterprises with decision based access, but there is still a need for more, according to the end users. If the Health enterprise defines a need, more templates can be ordered. The challenge, and a possible solution with regard to explicit decision templates, is therefore placed in the internal formal level.

When exception mechanisms are used extensively, the process of using them to gain access should therefore be simple and fast. Based on the factor A1-8 "It requires too many keystrokes to decide access" it may seem that this is not the case. It should be further investigated how many keystrokes is needed, and if this is something the vendor can reduce. End users' perception that exception mechanisms for access control occupy too much time and can be "annoying" is also described in previous studies [11].

The last factor directly linked to decision templates is factor A1-3; "User may choose wrong decision template". This is included in the category Informal. Wrong template may be used by mistake, lack of knowledge about which template is correct, or it can be a culture to select a random template, even if the user knows that the template does not match the cause for opening of the journal. The factor is also included in the category Computer security, as it ideally should be impossible for users to open a record, and choose a reason that is not correct, as this result in poor data quality in relation to monitoring of the event register.

The five remaining factors are placed in the category Internal, and are considered challenges that the health enterprise itself may influence, as they relate to education, or lack of such of end users. The relevant factors in ranked order are:

- Lack of clarity regarding the use of free text field when deciding access
- Insufficient education in access control
- Users lack understanding of decision based access
- Having to decide access gives a feeling of doing something illegal, and to be mistrusted and monitored
- When deciding access, you automatically only have access for one day

When one decides access, you must firstly choose a decision template you have access to, and then you may insert a justification in free text. This can be useful as an elaboration of the reason why you opened the record. It does not appear that it has been communicated to the end user how and in which cases this field should be used. The next three factors indicate that end users perceive that they have too little knowledge of access control, and therefore lack understanding of the use of decision based access, and the legislation that requires this to ensure patient privacy, which is a challenge identified in an earlier study [8]. The last of the formal internal factors "When deciding access, you automatically only have access for one day" can also be attributed to lack of training and/or knowledge, when how many days one has access can be adjusted by the end user himself.

The seemingly lack of education in access control, coincides with an earlier study of information security in the health service in Norway, Finland and England, which points out that the most neglected area around information security, is user education [8].

Four factors; A1-1, A1-5 A1-8, and A1-10, indicates that increased time spent because of access control mechanisms are considered an important challenge for end users, and is consistent with previous studies [1,8,11].

### **System Managers**

Among the key challenges system managers came up with, five are related to technical security, and four to administrative security, and most concerned challenges to the administration of user access.

Of the challenges related to technical security, we find the highest rated factor: "The interface of the administrator section of DIPS is too little intuitive and transparent" That the user interface is not perceived as sufficiently intuitive and straightforward, together with factor B1-5; "It is impossible/difficult to quickly get an overview of what access rights a particular user has" may affect both patient privacy and confidentiality if wrong permissions are granted, and you do not have an overview of what access a user is actually assigned.

It also seems as though system managers consider the granting of access rights involves many manual procedures, as the second highest ranked challenge is that access control is not integrated with the personnel system. Such an integration could be thought to reduce, if not eliminate, manual administration of user access, thus reducing human error related to granting and maintaining access.

System managers believe that there is insufficient support for log analysis. The event registers may contain a high volume of entries. It is therefore generally only taken random samples, or

access logs for profiled personalities such as celebrities are reviewed, or access logs are printed at the request of the patient [10,12]. Without a systematic approach for log analysis you cannot effectively achieve adequate privacy when widespread use of exception mechanisms exists [8]. Software for pattern recognition may be used as a tool to analyze event logs to identify possible violations of patient privacy, and the use of this will clearly be an improvement from the current situation where there apparently is no automaticity in this.

The last factor under technical security is "Insufficient functionality for blocking access to journals". Patients have a legal right to blocking of their medical record. If a patient objects to extradition of information, this must result in a denial of the relevant information in the EHR so that access control can take into account the patient's wishes. In what way functionality is insufficient is not evident in this study and should be investigated further, as a denial of access to records can result in a risk of errors in patient care if the end user does not have access to the necessary information, or violation of patient privacy, if the information is not in sufficiently inhibited [8].

Of the challenges that can be categorized under administrative security, system managers came up with three factors among the nine regarded most important:

- Defining the correct access profiles
- Little standardization of access control across health enterprises
- Adaptations to special permissions are challenging for system administrators

Defining the correct access profiles is mainly to set up the default permissions users may be given. As stated by the InfoSec model, one must deal with internal and external constraints, in the form of laws, rules and regulations, and internal policies for access control. The challenge here is to deal with all these guidelines, and simultaneously create default permissions that protect end user needs for access to information to ensure patient safety, while patients' privacy is protected. Norwegian laws and regulations and the EHR standard applies to all hospitals in Norway, but these provide only general guidelines for access control. Each health enterprise is responsible for its own access control. For system managers who manage access control across several health enterprises, it is therefore clear that there can be a challenge to deal with each health enterprises distinctive layout and guidelines for access control.

It is also clear that not everything can be standardized, either nationally, regionally or locally, and the goal of access control is not doing the job easy for system administrators to manage this, but to protect patients' privacy. There may be cases where local adaptations need to be made, and special permissions must be granted to individual employees who have a need for this in their work. The last factor, "Adaptations to special permissions are challenging for system administrators" puts the spotlight on this. This is a factor that may be useful to investigate in further studies, to clarify what factors make it difficult to adapt to special permissions, be it administrative and/or technical challenges.

### **Potential improvements**

#### **End Users**

Of the possible improvements end users deem most important, the majority were categorized under technical security. The highest ranked factor is: "Upon referral from psychiatric to

somatic department, one should have access to the referral" The underlying problem is that record documents in DIPS are associated with electronic referrals, and employees of somatic departments do not have access to psychiatric documents. Therefore, end user can open the electronic referral, but not an associated document. The routine today is that documents are manually sent electronically to the recipient, so that an implicit decision template is activated and the recipient can access the document, even if the end user initially do not have access to this type of document. Giving access to psychiatric documents in general will solve the problem, but may not be a solution that protects patient privacy. This factor shows that the definition of rules and policies may be more complex than the design of technical solutions [8]. It is the author's opinion that the vendor and customer together should arrive at a solution so that both privacy and safety are protected.

The remaining factors under technical security are mainly related to ease of use, and can be characterized as a response to the previously mentioned challenges. This applies to, for example, reduction of clicks needed to decide access, and include examples of the use of free text fields when manually deciding access. One factor it may be interesting to note is A2-5; "Ability to choose what you get access to when deciding access". It would appear that end users demand an even more granulated access control. This could conceivably be relevant if for example an end user receive a request from the patients' general practitioner about what medicines he or she currently is using, and the end user can then decide access to only the patient's medication. Such functionality will safeguard patient privacy at a deeper level than the current access control enables.

### ***System Managers***

Of potential improvements system managers deem most important, one half were categorized under technical security, and the other under administrative security. Under technical security, two factors (B2-1 and B2-6) are related to a desire to increase usability regarding the administration of access control. This may influence both patient privacy and safety if the user interface can be made easier and more transparent to possibly reduce human errors when administrating access control. Factor B2-3; "The access control should be integrated with personnel system so that access is automatically generated " may even further reduce human error when creating user access, when all default permissions can be granted automatically when the end users managers registers the employee in the personnel system. Such a solution is scheduled to be operational in OUS, autumn 2014 [15]. Hopefully this can simplify user administration, and thus conceivably have a positive effect on both patient safety and privacy.

Of the four improvement proposals categorized under administrative security, three of the four factors (B2-2, B2-4 and B2-5) are in the category formal external, and these factors show that system managers clearly want a more general regional and national management of how the access control should be set up. These factors can be seen as a response to factor B1-4 "Little standardization of access control across health enterprises". Several of the regional health authorities aim to consolidate EHR databases, so that there is one database per regional health authority [16], [17].

The last factor, B2-8; "Active use of the access log for quality assurance" show that system managers are concerned about

patient privacy, while also seeing that it is appropriate to improve the use of logs to ensure that end users do not abuse the trust they are given by unlawfully acquire confidential information.

### **Comparison of the panels and general discussion**

The two panels have an almost equal distribution of factors under administrative and technical security, but the further distribution of the subcategories show obvious differences. Only end users have informal factors, and only system managers have external factor. Furthermore, only system managers have factors that according to the InfoSec model can be categorized as data security. This shows that both end users and system administrators are primarily concerned with factors that affect them on a daily basis. End users are experts in the use of access control, while the system managers are experts in the administration of it. For access control to work there should be good communication between these two groups on a local, regional and national level [8]. This is especially important to keep in mind when entering a period of increased focus on standardization of EHR, including access control at a regional and possibly national level.

End users regarded the lack of decision templates as an important factor, but system managers did not. It appears that the lack of templates have not been communicated to system managers. This seems unfortunate as it results in users in certain situations have to register false reasons for opening records, when it in DIPS does not exist a decision template for "other reasons ", as it does in other EHR's [1]. End users in the Delphi survey wanted the ability to create custom decision templates (factor A2-3). Although the goal should be minimal use of exception mechanisms, such an alternative may be useful, and the system managers or others in the health enterprise may log its use. The log can be reviewed and one may be able to be proactive and ensure that frequently used reasons can be ordered as a new template.

Over a period of two months, exception mechanisms were used 33,397 times. Amongst these, only 180 were stated as emergency access. In addition, none of the major factors are related to directly hampering patient care as a result of limited access, and none of the experts believe that too wide permissions are the main challenges of access control. It is possible that this is due to the end users by using the green light access, and deciding access, basically have access to what they need.

### **Conclusion**

This is a study of access control in the dominant EHR used in specialist health care in Norway. To carry out this study of existing access control was needed to understand the weaknesses of, and possible improvements in how decision based access is implemented and in use today, seen from both end users and system administrators' viewpoints.

Decision based access is implemented in a number of the country's health enterprises, and will soon be introduced in all, but challenges that have been identified in previous studies, are still present.

The Delphi survey also revealed factors that previous studies have not shown. To better protect patient safety and patient privacy, the interface for both end users and system administrators need to become more user friendly.

On the basis of the Delphi survey and extractions from the EHR database, the following administrative and technical challenges and possible improvements have been highlighted according to the two main categories of administrative and technical security from the extended InfoSec model:

#### **Administrative Security Problems:**

- Insufficient knowledge and understanding of access control
- Procedures for ordering and closing of user accesses are not complied
- Lack of communication of the need for new decision templates
- Access control is different in each health enterprise

#### **Technical Security Problems:**

- The access control is not sufficiently tailored to patient care
- Time consuming and cumbersome to decide access
- Excessive use of the exception mechanisms

#### **Administrative Security Improvements:**

- Education of end users on access control
- Communication between end users and system administrators to clarify the need for new decision templates
- Standardization of access control at regional and national level

#### **Technical Security Improvements:**

- The access control should be tailored to treatment processes by developing more implicit decision templates
- Systematic monitoring of event logs, possibly by using pattern recognition
- Simpler interface for end users using exception mechanisms
- Simpler interface for system administrators monitor for administration of access control
- Integration between personnel systems and EHR for automatic creation and closing of user access

The Extended InfoSec model has been useful to visualize the areas in which challenges and improvements of access control can be placed, showing that both administrative and technical challenges exist. It is according to the InfoSec model essential that all parts of the model where challenges have been identified must be followed up in order to obtain information security in the EHR. Administrative actions both inside and outside the organization that utilizes an EHR must be designed in a workable way, and they must also be complied with by well-functioning technical security measures.

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# Usability Evaluation of Electronic forms and Collaborative Assessment Report in an Inter-municipality Health Care team for Dementia Diagnose

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## Abstract

Despite that paper-based medical procedures have historically been the most common way of registering and exchanging patient data, it does not avoid the potential risks of unauthenticated access, unregistered data loss, legibility and difficulty to share the data with third parties. The Coordination Reform 2009 (Samhandlingsreformen) has demanded from municipalities to implement health services for citizens based on electronic messaging that eases the access to and sharing of patient data. In the context of the Research project "Collaboration without borders" (Samhandling uten grenser), in this study electronic forms and collaborative assessment report by videoconference have been usability tested in order to evaluate the potential application of these electronic tools in an inter-municipality workflow of dementia assessment. The results showed that electronic forms helped to reduce the paper load of the process, allowing repeated access to the forms for retrospective amendments and reviews. The videoconference with document sharing was reported to be a very effective and satisfactory tool to cooperatively work on the final report of the assessment between the members of the dementia team.

**Keywords:** eHealth, dementia, health care team, health information technology, videoconference, collaboration

## Introduction

The Norwegian Coordination Reform [1] demanded from municipality health care services to implement structural changes and facilitate the increasing use of ICT solutions to improve collaboration and coordination services. In addition, the Norwegian Association of Local and Regional Authorities (KS) [2] pointed out the need for effectively coordinated services that combine medical expertise with the experience from other sectors such as technology, research and innovation. In this context, the research project *Collaboration without borders* (Samhandling uten grenser), aimed to evaluate new opportunities for interaction and development of technological solutions that facilitates electronic sharing of information between the municipal care service professionals, users and relatives. One of the objectives of the project was to investigate whether the introduction of electronic communication through the establishment of inter-municipal professional teams required changes at an organizational level. Thus, the introduction of electronic communication presents inherent challenges for municipality health professionals who are used to work on paper-based procedures. The intrinsic benefits of the progressive transformation of physical documentation into digital docu-

ments that are electronically available have to be validated from a usability, operation and satisfaction perspective of the health professionals and patients involved.

This usability evaluation is preceded by a qualitative case study [3], which analysed work procedures and workflow regarding documentation practices in inter-organizational care teams in four small municipalities in Southern Norway. In that study, the workflow of a Dementia team was analysed (see Fig. 1) and revealed a need for improving communication processes, especially those paper-based, which lack of secure data storage and limited availability. The study specified user requirements and proposed the use of electronic tools that could support access and exchange of medical information of inter-municipality care teams.

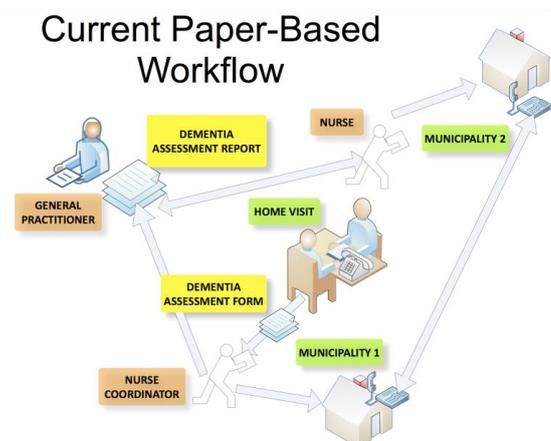


Figure 1- Scheme of the current paper-based workflow in the inter-municipality dementia team in Southern Norway

This paper presents the usability testing of two electronic communication tools, electronic dementia assessment forms and videoconference with shared document visualisation, to support the assessment of potential dementia patients, reduce the paper-based load and introduce digitally stored documents in their workflow. The research questions of this study were:

*Does the replacement of paper-based dementia assessment evaluation forms by electronic versions impact on clinical practice and workflow in inter-municipality dementia teams?*

*Does a collaborative tool such as videoconference with a shared visualisation document impact on the*

## Research Background

Underdiagnose of dementia has been demonstrated in research [4][5][6][7][8][9], with as few as 50% of dementia cases being diagnosed by physicians [10]. From there, the importance of early assessment and diagnose mechanisms that could improve the medical detection on patients, with evidence of increasing case finding [5][7][11][12]. However, negative attitude towards assessment and diagnose and, especially, added visit time, still represent barriers for physicians to efficiently diagnose cognitive impairment [4][10]. During their patient visit, physicians document and store the information related with dementia assessment and diagnose with a great variance in their methods: from personally written or dictated paper notes to templates with fill in boxes [13]. After the information collection, physicians have to work in collaboration with other staff members to summarise, evaluate and enter patient data from paper charts into final assessment reports [13]. Workflow improvements in the information gathering and/or the collaborative final assessment could produce tangible benefits such as productivity increase, reduced paper usage, time saved and quick completion time [14]. Usability improvements in any of these processes could also produce intangible benefits such as increased user satisfaction, e.g., on physician, ease of use and improved institutional image [14].

## Materials and Methods

### Method

The usability evaluation was carried out as a follow up of the research project *Collaboration without borders*. In the evaluation, end-users performed representative tasks related to dementia assessment. The test included two scenarios: 1) a visit to a patient's home to conduct a dementia assessment using electronic dementia assessment form replicating existing paper forms provided by the National Expertise Service for Ageing and Health (*Aldring og Helse Nasjonalt Kompetansesenter*) and Directorate of Health (*Helsedirektoratet*) [15]; 2) a collaborative writing of the dementia assessment report supported by videoconference with shared document visualisation. A post-evaluation group interview was conducted to qualitatively analyse the output of the test.

### Test environment settings

The usability evaluation was run in the Centre for eHealth and Healthcare Technology of the University of Agder, Norway. The facilities were the Usability Laboratory and the Smarthouse. The Usability Laboratory had two rooms: the Test room and the Observation room, connected through one-way mirror (visualisation from the Observation room towards the Test room). The Smarthouse was a large room that simulated firstly a potential patient's home and secondly a municipality office. The test was run in two separated days in May 2014, Day 1 and Day 2.

### Participant selection

Four people formed the Dementia team: one nurse coordinator and three nurses. They were one male and three female participants aged from 26 to 58, with a mean of 45 years. They had an average of 10.5 years of experience using clinical systems.

All had experience using laptop, and using tablet and videoconference for working purposes.

The patient and patient's relative were healthy elderly people (average age of 79 years), who acted as patient and relative. The acting was merely figurative, meaning that their answers and behaviours were freely decided. The use of actors was based on the recommendations of usability evaluation in clinical settings where the tests were run as role-plays with multiple stakeholders as participants, e.g. physicians, nurses, and patients [16]. Their role was relevant for the simulation process because the Dementia team had somebody similarly aged to a real dementia patient to direct the questions to.

### The Research Team

Four members, two with health professional background and two with health and ICT background formed the Research team. All had experience in working in health and technological environments with real patients.

### Test procedure

The test plan for the usability evaluation was adapted to the workflow description of an inter-municipality dementia team in Southern Norway collected in a series of workshops in April and May 2013. The usability evaluation was run in three sessions. Each session started giving information to participants about the subsequent test and filling in a pre-test questionnaire (with questions about computer skills, experience with specific technological devices and videoconference systems). Each session followed the same test plan running on an average total duration of 120 minutes. A total of three sessions were run across two days, one session in Day 1 and two sessions in Day 2. For each session, two members of the Dementia team (the coordinator alternating one different nurse at a time) went through the two evaluation scenarios: patient's home dementia team visit and videoconference with shared dementia assessment report. A group interview was conducted at the end of each day as a part of the evaluation method of the two scenarios.

The sequence of the two scenarios, participants involved and the distribution of the rooms used are described in Table 1. Both scenarios were performed in each session of the test and audio-visually recorded in the Observation room. The nurse of the Dementia team was replaced across the sessions and the nurse coordinator participated in all of them. The three rooms were used in a realistic way, replicating the part of the dementia team workflow where they interacted with the patient, relative and technology (i.e., patient's home visit), and the final writing of the dementia assessment report with communication between long-distance municipality offices.

The Scenario 1 represented a home visit by the Dementia team to assess the potential dementia of a patient. The home visit was simulated in the Smarthouse as a dementia patient's home. Two elderly people played the roles, one as the dementia patient and the other as the patient's relative. During the home visit, the Dementia team represented by a nurse coordinator and a nurse alternatively used a laptop and a tablet to fill in the electronic version of the dementia assessment forms (see Materials section for more details on the specific forms).

The Dementia team had not used or seen the electronic version of the dementia assessment forms before.

Table 1 – Usability Testing Settings

Scenario	Task	Participants	Input Device	Room <sup>1</sup>
Dementia team visit to patient's home	Dementia assessment form filling in for patient	Nurse coordinator, Nurse, Patient	Laptop	Patient's Home
Dementia team visit to patient's home	Dementia assessment form filling in for relative	Nurse coordinator, Nurse, Relative	Tablet	Patient's Home
Dementia team Videoconference with shared document visualisation	Dementia assessment report writing	Nurse coordinator and Nurse	Laptop	Municipality offices

A member of the Dementia team interviewed the patient reading the questions of the electronic forms in a tablet, while the other team member filled in the questionnaire answers in a laptop (see Table 2).

Table 2 – Scenario 1 Dementia team interactions during patient's home visit

Electronic Dementia Form	Nurse Coordinator Activity / Device	Nurse Activity / Device	Actor
Mini Mental State Examination (MMSE)	Filling in form answers / Laptop	Reading out loud form questions / Tablet	Patient
Dementia Patient's Relative Questionnaire	Reading out loud form questions / Tablet	Filling in form answers / Tablet	Relative

In the next step of the same scenario, roles were swapped within the Dementia team so a member asked questions to the patient's relative reading from the tablet and the other member was writing the answers in a tablet too. Therefore, two types of input device were used: laptop and tablet. The average time of the Scenario 1 was 45 minutes. There was a moderator present from the Research team whose role was to guide throughout the scenario, reminding the way of proceeding when necessary.

In the Scenario 2, the same two members of the Dementia team from the Scenario 1 wrote a dementia assessment report based on the answers gathered during the patient's home visit. The report writing was performed in a simulated environment, where the participants had a long-distance collaboration, such as between two municipalities. In Scenario 2, the Smarthouse

and the Test room represented Dementia team members' offices in different municipalities (see Table 3). A videoconference communication system (see Materials section for further details) was used together with a shared document visualisation of the dementia assessment report simultaneously seen on both offices' screens. The dementia assessment report was written in a MS Word 2010 template provided in advance by the Dementia team. The visualisation of the screen from the Dementia team member in charge of writing the dementia assessment report was directly recorded in the Observation room through the Desktop Presenter software. This screen was also shared with the other Dementia team member office (Smarthouse) via the same software. The average time of the Scenario 2 was 40 minutes. There were moderators in the Smarthouse and in the Test room.

Table 3 – Scenario 2 Dementia team videoconference with shared document visualisation

Participant	Activity	Device	Room
Member 1 of Dementia team	Writing dementia assessment template report	Laptop	Municipality office <sup>2</sup>
Member 2 of Dementia team	Reading dementia assessment template report writing by nurse coordinator	Monitor	Municipality office <sup>3</sup>

In the group interview at the end of Day 1 and Day 2, the Dementia team was asked to give feedback of the two scenarios of each test session: the interaction with the electronic dementia assessment forms and the videoconference with shared document visualisation as a supportive tool for collaboration. The group interview followed the steps defined in an interview guide. The guide included questions relative to the benefits and disadvantages of bringing electronic forms into the home visit stage of the dementia assessment workflow. In addition, questions relative to use of the videoconference with shared document visualisation, as a collaborative tool for writing the dementia assessment report, were included. Finally, questions about usability and graphic User-Interface Design were made during the interview. Suggestions from the Dementia team about further development of the electronic dementia assessment forms were also annotated. Two group interviews were performed with the average time of 35 minutes and moderated by members of the Research team.

### Material

For replicability and information purposes, the technological material used during the study is presented below grouped by rooms.

#### Smarthouse:

- PC: HP Compact Elite 8300 ultra-slim desktop.
- Monitor: 46" Samsung 460tsn-2.
- Laptop: HP EliteBook 8440p, Intel Core i7 CPU @ 2.67GHz, 4GB RAM, Windows 7 Enterprise SP1 64 bit.

<sup>1</sup> The Smarthouse first simulated a patient and relative's home, afterwards the municipality office and at the end the meeting room for the interview group; the Test room only simulated the municipality office.

<sup>2</sup> The Test room simulated the municipality office for the report writing.

<sup>3</sup> The Smarthouse simulated the municipality office for the report reading.

- Tablet: 2x Elite Pad 900, Intel Atom @1.80GHz, 2GB RAM, Windows 8 32 bits.
- Tablet keyboard: HP ElitePad Case H4R88AA.
- Camera: SONY BRCZ330 HD 1/3 1CMOS P/T/Z 18x Optical Zoom (72x with Digital Zoom) Colour Video Camera.

#### Observation room:

- PC: HP Z220 CMT Workstation, Intel Core i7-3770. CPU@3.4 GHZ, 24GB RAM, Windows 7 Professional SP1 64 bit.
- Monitor: 3x HP Compaq LA2405x.
- Remote controller: SONY IP Remote Controller RM-IP10.
- Streaming: 2x Teradek RX Cube-455 TCP/IP 1080p H.264.
- Software Wirecast 4.3.1.

#### Test room:

- Laptop: HP EliteBook 8460p, Intel Core i7 CPU @ 2.70GHz, 4GB RAM, Windows 7 Enterprise SP1 64 bit.
- Monitor: 19" Dell 1908 FPT.
- Tablet: Elite Pad 900, Intel Atom @1.80GHz, 2GB RAM, Windows 8 32 bits.
- Camera: SONY BRCZ330 HD 1/3 1CMOS P/T/Z 18x Optical Zoom (72x with Digital Zoom) Colour Video Camera.
- Software Cisco Jabber v9.7.1.
- Software Telestream Desktop presenter v2.0.4.

For the electronic dementia assessment forms creation, the software packages Adobe Acrobat X Pro 10.0.1 and Adobe InDesign CS6 8.0.2 were used. These electronic forms replicated the standardized dementia's assessment A4 paper-based form versions from standardized dementia's assessment A4 paper-based form versions [15]: Mini Mental State Examination (MMSE) (*Mini Mental Status Evaluering*) and Dementia Patient's Relative Questionnaire (*Spørsmål Til Pårørende*). The electronic forms were designed and electronically made at the University of Agder, Norway.

#### Data collection

Scenarios 1 and 2 (3 sessions x 2 scenarios) and the two group interviews were all audio-visually recorded in the Observation room of the Usability Laboratory, resulting in 8 data recordings in total. Annotations of the recording visualizations by the Research team were included in the analysis. The group interview recordings were transcribed verbatim. Pre-test questionnaire participants' answers and notes from the Research team were also included. The analysis was based on qualitative content analysis [17] and made with the software QSR NVIVO 10 [18].

#### Ethical considerations

This study was approved by the Norwegian Social Science Data Services [19] (NSD), project number 37920. All participants received oral and written information about the project, informed that participation was voluntary and the data collection, storage and access was confidential. All participants signed a written informed consent before the evaluation.

## Results

The results were obtained from the annotations, observations and transcripts of the audio-visually recorded data. To ease the reading, the results of each scenario are separately presented.

### Scenario 1: Dementia team visit to Patient's Home

The Dementia team argued that the use of electronic forms did not substantially save time for the dementia assessment form filling. The time consumed in information input to the devices (via physical keyboard or touch screen), based on the Dementia team answers, did not improve when compared with the traditional pen and paper.

The use of a device with a vertical screen and physical keyboard (e.g., laptop or tablet with external keyboard) resulted in a physical barrier that interfered in the communication between Dementia team members and the patient. When filling in the questions, it was found more appealing by the Dementia team to have the tablet in the lap covered by the table they were sitting around, removing any technological device from the visual field of the interviewed and reducing distractions. This resulted in a unanimous preference for tablet built-in keyboard input than through an external one.

The primary outcome of the electronic form evaluation was the immediate paper load reduction of the process. Instead of having to carry out and store the dementia assessment forms, the answers were electronically kept in the tablet, occupying no extra physical space nor introducing potential problems related with data loss or uncontrolled access.

The most highlighted benefit of the electronic form use was its impact in the Dementia team workflow after the home visit. It allowed repeated access to the forms for retrospective amendments and reviews. In addition, it introduced the possibility of electronically sharing the form answers with other professional colleagues, with a potential systematic treatment of the data.

The usability of the electronic assessment forms was subjectively evaluated as "clear, self-explained and little need for user training". The text size was sufficient in term of legibility, although there were some problems with the page scrolling.

Several errors were found during the test relative to the form filling. Initially, the arrow keys were used to navigate through the questions. However, once a question was answered, the arrow keys changed their functionality for question answer navigation, which impeded the normal navigation across questions and could potentially affect the final answer of a question (e.g., changing from *Yes* to *No*, instead of jumping to the next question). Another critical error was the miscalculation of the summarisation of the form answers, making the Dementia team members to manually summarise the question answers. The last main error was an occasional problem with storing the electronic form after filling in. This required having the tablet permanently switched on until the dementia assessment report was filled in.

The disadvantages were referred to the amount of visualisation of information on the form. It was stated that in the device, the information at one glance was smaller than when compared to the paper version form. The navigation through the document also presented some problems. For the Dementia team members, it was easier to physically navigate through the document pages than to scroll one by one the pages in the device. This also affected the notion of where the user was in the document at a given time, point especially relevant when they wanted to

check out answers or information from other questions than the one currently visualised. It was expressed a fear of unexpected technology failure (e.g., device run out of battery before or in the middle of the form fill in, fatal error of device Operative System or unable to open/save document form), which reinforced the idea of having the paper-based form at hand as a back up. In the hypothetical scenario of technology failure and having to fill in the paper-based form, the presumed benefit of paper load reduction would not apply.

The Dementia team members suggested that an automatic summarisation and result transfer into the dementia assessment report in order to reduce human errors in manually calculating and transferring the data from the forms to the report. In addition, the possibility of making comments for each question (e.g., in a text box beside the answer options), instead of only in one section at the end of the form, would help to refine the assessment and reflect the nuances of the answers (e.g., if a potential patient wrongly answers to the question of “What is today’s date?” with years of difference instead of days, then it would worsen the evaluation of that answer compared with the current case where the only accepted answers are *right* or *wrong*). In this context, one nurse of the Dementia team asked for the possibility of using a stylus to insert the answer by hand in the device using text boxes.

Other suggestions were made related to link the filled form with patient’s health history; the document should be seamlessly stored in the patient’s electronic Health Record (EHR) directly from the device, and allowing temporary and final versions of the document. This interoperability feature will ensure the long-term impact in the Dementia team workflow.

## **Scenario 2: Collaborative Dementia Assessment Report Writing**

The use of a videoconference system with a shared document visualisation was evaluated as positive way of collaborative work by the Dementia team. In terms of work efficiency, sharing the report document visualisation allowed to see and collaboratively work on the same document by Dementia team members working from long-distance municipalities. The ability of finishing the document in one session, instead of requiring several sessions that would require additional tasks such as physically printing out the report, sending it by post or communicating the information through phone call to the other colleague, as it was stated in one of the group interviews:

*The videoconference with shared document was a positive experience today. It functioned quite well. My colleague sees what I write at once, instead of me having to read aloud what I have written*

In addition, a good sound quality was found more important for communication than the on-screen visualisation of the other Dementia team member. The average duration of the Scenario 2 was 40 minutes.

Several potential disadvantages were described by the participants that might affect the collaborative work, such as bad sound quality or difficulties to establish the communication between the two remote systems.

## **Discussion**

### **Use of electronic dementia assessment forms**

The use of electronic dementia assessment forms generally received favourable comments from the Dementia team members. Scandinavian Conference on Health Informatics, August 21-22, 2014, Grimstad, Norway

bers in all the sessions. When comparing the electronic functionality of the form in the tablet with the traditional paper form filling in, the result was evenly ranked. However, the digital form offered several features that the paper form lacked. For instance, the electronic form gave the opportunity to retrospectively amend the results filled in by the professionals, which sometimes needed to be revisited. In addition, they reduced the amount of paper produced in each visit and the wide availability of the electronic format (i.e., PDF), made potentially easier to digitally interoperate with other electronic systems (e.g., EHR). These advantages confirmed the findings of the project *Collaboration without borders* that revealed a need for improving communication processes, especially those paper-based. The use of electronically stored data improves the availability of the data, reduces the hand-made transference of data between sources (e.g., from paper to EHR) and can automatically summarise the results. In addition, the use of devices with external keyboard was unanimously seen as a non-optimal, because the Dementia team members argued that the device’s vertical screen could create a physical barrier in the communication with the patient and relative.

There were some additional non-tested features that were suggested by the Dementia team members and could easily be incorporated in the electronic form fill in that could enhance the interaction and the home visit outcome. For instance, the possibility of writing comments for each question would help to refine the information used for the dementia assessment outcome. The use of a stylus was also suggested for handwriting device input, as a more natural way of interacting with the technology.

In conclusion, the use of electronic dementia assessment forms could impact the workflow home-visit stage of an inter-municipality team when compared with traditional paper-based procedures. The main impact are benefits after the home visit, where added functionalities such as paper-load reduction, retrospective access for amendments and reviews and electronic availability and storage, are now included.

### **Videoconference with shared document visualisation**

The videoconference with shared dementia assessment report visualisation also received positive evaluations from the Dementia team members. The tested system no longer relied on manual procedures that lacked optimal visualisation and sound quality for the collaboration. It allowed collaboratively completing the dementia assessment report in one operation in contrast with the paper-based workflow where printed forms sent by post and/or physical meetings are used for mutual agreement between the Dementia team members in the dementia assessment report writing. This collaborative component can save time to the team members involved in the report writing and provide information at earlier stage to the other professionals included in the next step of the workflow, such as General Practitioner.

Limitations of the study are related with the reduced number of participants (one nurse coordinator, three nurses and two actors), which might influence the generalisability of the findings. However, in qualitative usability studies a small number of participants can be sufficient for having valid results (e.g., 3 users from each category if testing three or more groups of users [20]). Another limitation could be that the electronic assessment forms were not completely operative which impeded the full exploration of the form functionalities. However, their operativeness provided a satisfactory simulation of how they could work in a real scenario.

## Conclusions

The study presented is a follow up of the project *Collaboration without borders*, which specified user requirements and proposed the use of electronic tools that could support access and exchange of medical information of inter-municipality care teams. Two electronic tools have been usability tested, in order to evaluate their impact in an inter-municipality workflow of dementia assessment. The evaluation was carried out in realistic clinical settings: patient's home for the interaction with the electronic version of dementia assessment paper-based forms; municipalities' offices for collaborative writing of a dementia assessment report; and role-play with multiple stakeholders such as nurse coordinator, nurse, potential dementia patient and patient's relative.

The main findings reported several benefits of the use of electronic forms, such as digital storage that allowed a later access for reviewing the written information and reduced paper load. These results are congruent with the use of electronic tools to facilitate efficient, accurate and controlled information flow, in a wide range of scenarios such as emergency care [21], medical homes [22] and for sharing data with patients, professionals, providers and government [23]. Research evidence shows that identified communication process gaps can be partly or fully covered by the use of effective electronic tools [22] and workflow operational improvements [24]. The potential of electronic forms for data collection has been demonstrated in data sharing and reporting quality measures between multiple actors [23].

The evaluation of a videoconference system with shared document visualisation provided a synchronization component to the workflow, where both professionals of the Dementia team could collaboratively work on the same dementia assessment report. Based on the findings of this simulation, a new dementia assessment workflow is proposed below as an alternative for the current paper-based one (see Fig. 2).

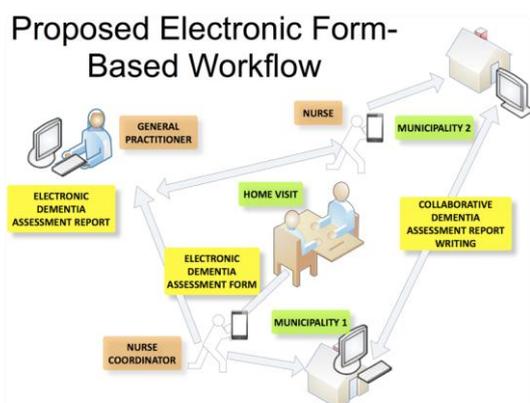


Figure 2 – Scheme of the proposed electronic form-based workflow for an inter-municipality dementia team

Future work would include usability evaluation of the implementation of fully operative electronic dementia assessment form and its interoperability with other electronic health services, such as the Electronic Health Record within simulated and real clinical settings.

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# End-to-End Infrastructure for Usability Evaluation of eHealth Applications and Services

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## Abstract

*eHealth technologies are widely used in collaborative health care services involving multiple different user groups. A very important aspect of the design and development of such applications is the ease-of-use and user-friendliness of the user interface for the end-users. Usability testing is performed in a simulation or real environment to ensure that the system is adapted to the specific needs of the different end-users and to evaluate the interaction between users and system.*

*The aim of this paper is to present an infrastructure for end-to-end usability testing of eHealth technologies in a controlled environment simulating both the Point-of-Care and the Health and Care Service Provider. The primary focus is on the requirements and technical aspects of the test infrastructure itself, but on top of that also a trial project is presented where the proposed usability testing infrastructure has been used and validated.*

## Keywords:

eHealth, health informatics, usability evaluation, end-to-end test infrastructure, point-of-care, user centered design

## Introduction

eHealth applications and services are designed for the exchange of information between different collaborating user groups of the same system, utilizing certain information and communication technologies (ICT) [1].

The reference system that sets the framework for the usability evaluation system discussed in this paper is illustrated in Figure 1. One of the major aspects is the collaboration between a patient in his point-of-care environment (e.g. his private home) and certain health and care service providers (as e.g. a specialized nurse in a telemedical central, a general practitioner, or a medical specialist in a hospital). Collaboration means in this context, that certain information about the medical and health status of the patient as well as about his current living context is made available to the health and care service providers via dedicated eHealth installations, applications and services. For that the information has to be transmitted through communication and health information system (HIS) infrastructures by means of information and communication technology (ICT). In turn this information shall enable the health and care service providers to provide optimal health and care support to the patient in an efficient and cost effective manner. For that the same eHealth infrastructure is utilized to get in contact with the patient, and to assist him with information, general sup-

port, and with dedicated treatment recommendations as e.g. medication changes.

The most important requirement on such a collaborative eHealth system should be the *usability* of the system for all involved user groups. In order to support the patient to derive the health and care related information required by the staff in the telemedical central, the design of all involved eHealth devices and user interfaces of applications have for example to consider physical and mental limitations of the patient. On the other side it has to be taken into account that health and care personnel have to take care for many individual patients. Consequently, the design of the user interfaces of the eHealth services used by the health and care service providers have to consider for example an intuitive and optimal presentation of relevant and important information.

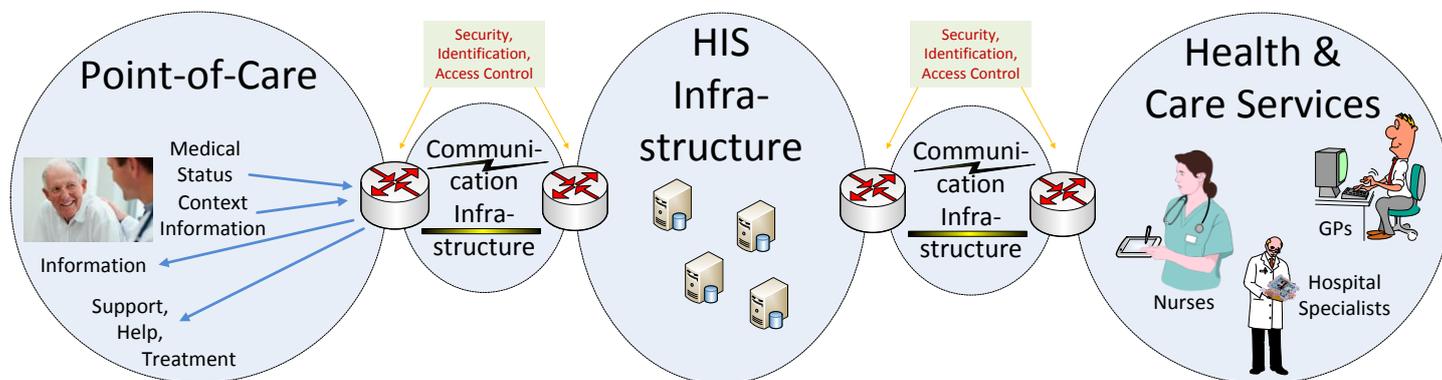
In this paper we present a usability test infrastructure addressing this utmost important requirement. It consists of an environment simulating both a point-of-care and a typical health and care service provider, and it allows performing end-to-end usability tests of applications and services for all involved user groups through a controlled health and care information system. The primary scope is on the technical aspects of the usability test infrastructure, from a health informatics and ICT perspective.

Following this introduction, a rough overview of the *state-of-the-art* of related usability testing infrastructures will be given. The section on *end-to-end infrastructure for usability evaluation* discusses first the identified requirements on the targeted usability testing infrastructure, and presents then the details of the different parts of the proposed infrastructure. Subsequently a trial system for the realization and verification of the proposed usability testing infrastructure is presented. That system was developed under the umbrella of the 3-year European funded project United4Health [2] for the usability evaluation of eHealth technologies.

## State-of-the-art

eHealth applications and services have multiple user groups, and there is a need for systems supporting collaborative work across organizational borders of health care services. However, the development of such systems is a complex process.

The overall objective of usability evaluation is to improve both the interaction design between all involved users as well as the user interfaces of eHealth applications and services [3-5].



**Figure 1: Reference System for Tele-Health and Tele-Care Services**

User-centered design methods, where real end-users are involved in all steps of the development of eHealth applications and services, are used to collect users' needs and to understand the context of use, in particular the clinical workflows and their impact of on the requirements on support applications and service. Applying user-centered design methods is the basis for the adaption of the eHealth applications and services to the users' needs [3, 6, 7].

The main benefits of systems with a high level of usability are increased productivity, reduced errors, less needs for user training and support, and an overall improved acceptance by the users [5].

With the focus on bringing a human-centered perspective to the formulation of system requirements and the configuration of effective user interfaces, Samaras presents a systems engineering method providing a framework for incorporating human factors (ergonomics) knowledge and integrating ergonomists in the interdisciplinary development of health information systems [8]. Validation and verification testing is an essential part of the presented iterative systems engineering lifecycle model.

User-based evaluation means that users participate in the evaluation. They are asked to do typical tasks or to explore a system, while being observed and recorded. The goal is to identify flaws that cause errors or difficulties in the use of the system. Measurements are performed on time for solving a task, on numbers of completed tasks, and on numbers and types of errors. The aim is to provide a better understanding of the interaction between the user groups and the graphical user interfaces provided by the collaborative eHealth services [3].

Usability evaluation can be performed in laboratory settings or natural environments such as the home of the patient or the work place of a health or care service provider. The strength of a laboratory setting is the controlled environment for the test, but it can also influence the behavior of the test participants. The unfamiliar environment and the knowledge of being observed and recorded can impact on the problem solving, which is also known as the Hawthorne Effect [7]. Natural settings are often easiest for test participants, but can be a challenge for the research team.

Usability evaluation can usually not be performed in real clinical environments because of the legal, ethical and privacy regulations to protect patients. Therefore simulation of the health care services environment is important to create a realistic test scenario for the user groups [9, 10].

In their paper on *Teleevaluation* Kushniruk et al [11] describe an integrated approach for distance evaluation for assessing Web-based clinical information systems. The development of methods for assessing the effectiveness and usability of such systems is identified as a critical issue.

Kaufman et al [12] present an approach to usability evaluation of computer-based health care systems designed for patients use in their homes. Their approach incorporates a cognitive walkthrough usability evaluation and methods for usability testing that can be conducted in the patient's homes. Based on the usability evaluation, they stress the importance of a multi-faceted usability approach. However, an integrated usability testing framework is not presented.

The ALFA toolkit [13] offers support for the observation of computer mediated consultations of patients at a doctor. The Activity Log File Aggregation (ALFA) serves as basis to provide an analysable overview of the Clinician-Computer-Patient interactions.

## End-to-end usability evaluation infrastructure

In this section we describe an end-to-end infrastructure for the usability testing of tele-health and tele-care services corresponding to the reference system introduced above. In the following the underlying requirements towards the usability testing infrastructure are discussed.

### Requirements on the usability testing infrastructure

The requirements on the infrastructure for the usability testing (including hardware components and software solutions) are determined by the main service scenarios that shall be tested.

#### Guiding service scenarios for usability tests

The usability test infrastructure shall support the evaluation of the following basic scenarios, which correspond to the reference architecture in Figure 1 for collaborative services.

1. Measurements of medical values

Patients at the point-of-care shall measure certain data about their medical status, using corresponding measurement devices (as Personal Medical Devices, PMD). The measurement process shall be supported by dedicated patient services and applications that provide a user interface with information and instructions showing the progress of the measurement scenario. This shall for example include information regarding the transmission of the measured data to the health and

care service providers via the Health Information Services (HIS) infrastructure, and shall provide instructions in certain possible error cases.

The measurements shall in turn be made available to the health care professionals in their health and care services environment. Dedicated health care services and applications shall process and present the data in dedicated user interfaces that support an optimal and efficient support for the corresponding patient.

2. Questionnaires

The patient shall provide subjective information about his health status by answering specific questionnaires, which shall be made available to the health care specialists. Corresponding user interfaces of the patient services and applications shall support the patient through the process of answering the questions and with the delivery of the data through the HIS infrastructure to the health care professionals.

Dedicated computer services and applications for the health and care service providers shall then process the answers and present the (processed) questionnaire results to the health and care staff. The corresponding user interfaces shall support the utilization of the results for an optimal and most efficient patient support.

3. Video consultation

The services and applications of both the patient and the health and care specialists shall include means to

establish an audio-video communication session between each other. The user interface for the patient shall make it easy to establish an on-demand-video-call with their dedicated health and care service provider, and to accept an incoming audio-video-call. The user interface for the health and care service provider shall give optimal support to establish a video call with a selected patient (out of all patients the service provider has to take care for) following e.g. a timetable of appointments, or to initiate an immediate on-demand session as reaction on a critical situation determined by certain measurements or questionnaire outcomes.

*Joint testing of collaborating user groups*

One of the main requirements of the usability testing and evaluation of interactive and collaborative services is the study of interactions and dependencies between different user groups of the same system. For that it must be possible to monitor and study different user groups independently from each other, while they use interactive and collaborative applications and services (via certain equipment and user interfaces). The main aspect of interaction and collaboration is that each user group has to react on actions that the respectively other user group is carrying out.

*User-group specific tasks for usability tests*

The usability test infrastructure shall allow studying arbitrary test cases of each user group involved in a collaborative service. For that it is required that specific usability test tasks can be specified independently for each involved user group.

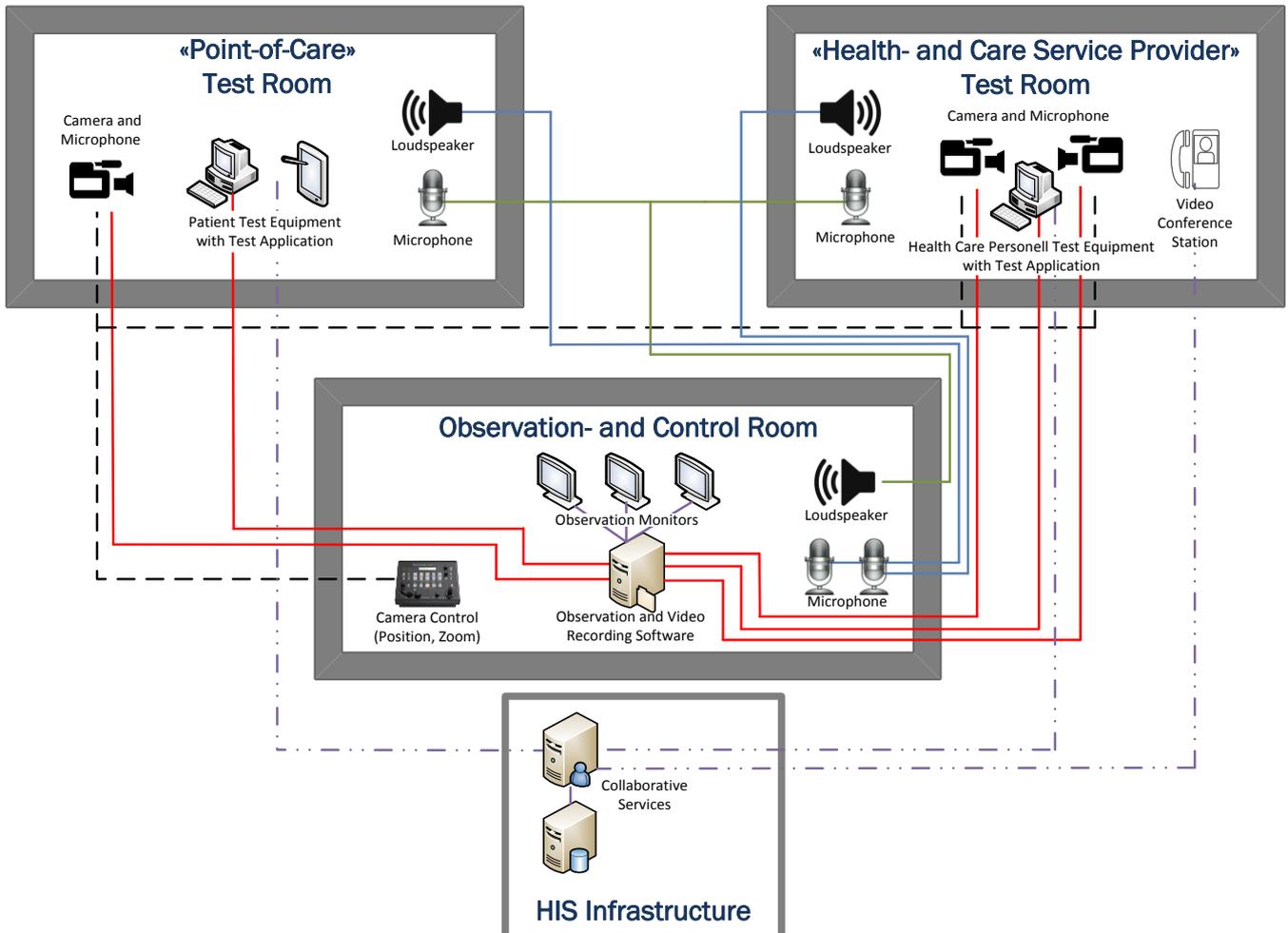


Figure 2: E2E Usability Test Infrastructure

### **Full control over specific actions and events**

The usability evaluation of certain specific test tasks for one individual user group might require full control of specific actions and reactions of the system they interact with. That means that the system should allow that the counter-part of the tested user group is either fully simulated (i.e. it carries out specific actions and re-actions according to a defined test process), or that the actions and re-actions are carried out by the usability test staff according to a defined test plan.

### **Further general requirements**

A few further aspects have to be considered regarding the usability test configuration and the infrastructure and technologies for the observation of the test persons.

- The users of all user groups (i.e. both “test-patients” and “test-health-service-providers”) shall be able to focus on the user interfaces of the applications and service components they typically interact with in order to utilize a certain function or service of the tested system. Hence, the distraction by any test-specific device or functionality (e.g. for observation purposes) should be minimized.
- The interaction of the user with the tested applications and services should be recorded during the tests in terms of video and audio, covering as many aspects as required for future evaluation.

### **End-to-end usability test infrastructure**

Considering the requirements presented above, an end-to-end infrastructure for usability tests is proposed as illustrated in Figure 2. The infrastructure is distributed over three interconnected rooms: a Point-of-Care Test Room, a Health- and Care Service Provider Test Room, and an Observation and Control Room.

#### **Point-of-Care Test Room**

The Point-of-Care Test Room contains all equipment needed to carry out the usability tests of the user group representing the “patient”.

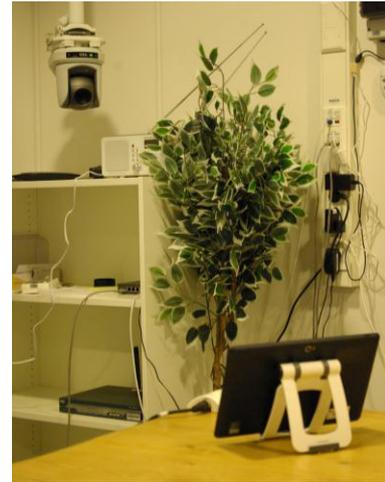
The patient test equipment should be similar or optimally the same equipment a patient would use in a real point-of-care to carry out the activities that are subject of the usability tests. That equipment runs the corresponding point-of-care services and applications, which are connected to the collaborative services in the Health Information Services (HIS) infrastructure, and provide the user interfaces to be tested. Besides the services and applications that are subject to the usability tests, the test equipment might also contain certain software to support the observation during a test session (refer to description of the Health- and Care Service Provider Test Room below).

For the observation of the test person during the test session a video camera with microphone is installed. Both the video and audio signals are digitized using an embedded capture device, and transmitted to the Observation- and Control Room via the LAN. The camera can be remotely controlled from the Observation- and Control Room in terms of observation direction and zoom.

Besides the test and observation equipment, there’s also a simple microphone and loudspeaker installed in the Point-of-Care Test Room. This allows communicating between the test persons and the test staff in the Observation- and Control

Room independently from an ongoing observation and recording session.

An example Point-of-Care Test Room setup as deployed at the University of Agder is shown in Figure 3.



**Figure 3: Video Observation of Point-of-Care**

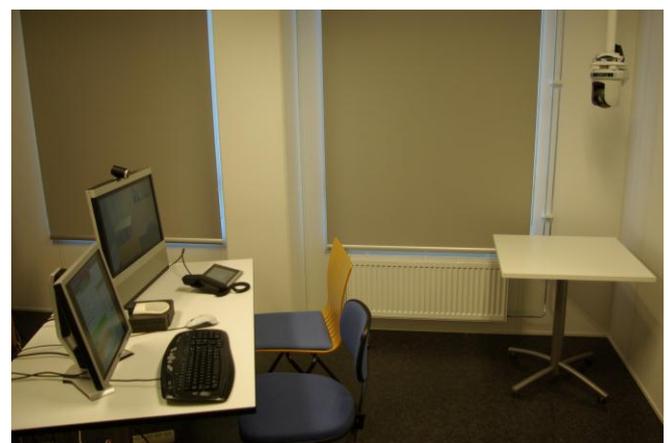
#### **Health- and Care Service Provider Test Room**

The Health and Care Service Provider Test Room is equipped for the usability tests with the user group representing the “health care specialists”.

The health care personnel test equipment runs the test applications which are subject to the usability tests with health care professionals. The test applications communicate with the collaborative services in the HIS infrastructure via LAN, and provide the user interfaces that shall be assessed regarding usability. In order to support the observation and evaluation of the operation and usage of the test application by the test persons, the user interfaces are captured and streamed to the Observation- and Control Room via LAN, using a screen capturing and streaming software.

Besides the test equipment, the Health- and Care Service Provider Test Room also contains a dedicated video conference station, which is also subject to the usability tests of collaborative services with the point-of-care user group.

Similar to the Point-of-Care Test Room setup, a set of video cameras with microphones allow observing the whole test session. The video cameras can also be remotely controlled, and their audio and video signals are digitized and streamed over the LAN to the Observation- and Control Room.



**Figure 4: Health- and Care Service Provider Test Setup**

Furthermore, a separate microphone and loudspeaker allow communication of the test persons with the test staff in the Control- and Observation Room independently from a test session.

In Figure 4 the Health- and Care Service Provider Test Room at the University of Agder can be seen as an example setup.

### **Observation and Control Room**

The Observation- and Control Room contains the installations for the observation, control and recording of the usability test sessions.

Separate loudspeaker(s) and microphones allow communicating with the user groups in both the Point-of-Care Test Room and in the Health- and Care Service Provider Test Room. The devices are connected to embedded digitizing devices, which transmit and receive the digitized audio data over IP protocol. All data is sent through the common LAN infrastructure interconnecting all rooms of the test infrastructure.

The central component of the Observation- and Control Room is a dedicated PC running the observation- and video recording software. The PC receives the IP data from all digitized audio-video sources in the two test rooms, i.e. from the video cameras with microphones, as well as from the streamed screen output from both the patient test equipment and the health care personnel test equipment. The observation and video recording software allows to observe selected sources (see left screen in Figure 5), and to record all sources simultaneously and synchronized in time on a data storage. Independently from that, selected (or even all) sources can be observed on separate screens. For that, embedded rendering devices, corresponding to the embedded digitizing devices in the test rooms, are connected to the screens, and are configured to receive a specific IP stream from the LAN.



**Figure 5: Observation and Control Setup**

During the whole usability test session, the video cameras in the test rooms can be remotely controlled by the test staff regarding camera direction and zoom. Also the control signals are transmitted from the control device to the cameras via the LAN infrastructure.

### **Realization of end-to-end test infrastructure**

The end-to-end infrastructure as presented above has been realized in the usability test laboratory at the University of Agder, and has been used for user tests in the Norwegian part of the United4Health project [2].

### **The United4Health project**

The European project United4Health involves more than 20 countries and includes 20.000 patients with chronic diseases. The idea of using eHealth technology in United4Health is to support the collaboration across organizational borders, and to

support the management of the health care information related to home-monitoring.

The Norwegian project focusses on collaborative eHealth technologies to support COPD-patients after hospital discharge. In the South-Norwegian region of Agder 200 patients are planned to be involved in a field trial.

The University of Agder was responsible for the development of the eHealth technology for home-monitoring of the COPD-patients. The development included the design of a tablet application to be used by the patients for home measurements of blood oxygen saturation (SpO<sub>2</sub>), pulse and a questionnaire to be filled out daily. Already early in the design and development process, the user groups were invited to participate in workshops about the interface design and functionality.

The hospital partner is responsible for the selection of patients for the field trial, and introduces home-monitoring to the included COPD-patients. The municipality partner has established a pilot telemedical central run by specially trained nurses that use a dedicated health care information system for management of home measurements and daily follow-up of the COPD-patients. Video conversation with the patient is supported by a video conferencing system.

### **Usability evaluation in United4Health project**

User-centered methods were applied in the development of the eHealth technology. The user groups participated in two usability evaluation sessions within two weeks. The tested eHealth applications were iteratively developed between the test sessions.

The infrastructure for the point-of-care and the health- and care service provider was used and tested in the usability evaluation.



**Figure 6: Introduction to eHealth technology**

In the first test scenario, the health and care service provider test room represented the hospital, where the nurse and the COPD-patient prepared for home measurements (see Figure 6).

In the next test scenario, the point-of-care test room represented the home of a COPD-patient. The test participant took the role of a recently discharged patient (from hospital) and interacted with the eHealth tablet technology to make home measurements and fill in a questionnaire (see Figure 7).



**Figure 7: eHealth Technology at the Point-of-Care**

In the third test scenario, the nurse from the telemedical central interacted with the dedicated health information system to evaluate the home measurements and questionnaires from the COPD-patient (see Figure 8). A videoconference system was used for face-to-face communication between the COPD-patient in the point-of-care and the nurse in the health and care service provider test room.



**Figure 8: Health- and Care Service Provider Test Setup**

During the three presented scenarios, all sources of the test infrastructure were shown simultaneously on one master screen (see Figure 5) in the observation and control room. Each source could also be followed on a separate big screen.

In parallel the audio- and video sources were recorded for later evaluation of various usability aspects.

In this usability evaluation of eHealth technology, the end to end test infrastructure simulated a scenario which was difficult to test in a real health care environment, and the outcome was relevant feed-back on functionality and usability for further system refinements.

## Discussion

In this paper we have presented an end-to-end test infrastructure to carry out usability evaluations of eHealth technology.

Collaborative eHealth services involving multiple user-groups have to be tested and validated before being released and taken into regular operation. Due to ethical reasons, usability testing can usually not be done in real clinical environments [9, 10]. Therefore a simulated test environment with an end-to-

end infrastructure contributes to a realistic scenario for the test users.

In user-centered design projects, there is a need to perform usability evaluation iteratively in each step of the development process. The iterative evaluation is enabled by a controlled environment, where the test team has full control over all steps of the test scenario, including tasks and actions of the test participants.

The trial project for the verification of the test infrastructure has limitations such as a limited number of tests and user groups. However, the test scenarios and the end-to-end test infrastructure provided a highly realistic simulation of real point-of-care (i.e. patient at home and patient in hospital) and health and care service provider (i.e. nurses at telemedical central) environments.

## Conclusion

eHealth technology is widely used by multiple user groups both at the point-of-care and at health and care service providers. Usability evaluation is essential in order to improve not only the interface design of the eHealth technology, but also the interactions between the devices and applications and the different user groups.

Our proposed end-to-end test infrastructure was validated through user tests within the trial project United4Health to carry out usability evaluations of collaborative eHealth technologies involving multiple user groups. We found that the end-to-end test infrastructure provided the flexibility to simulate highly realistic environments.

As further research of the utilization of the end-to-end test infrastructure we suggest usability evaluation of mHealth solutions, and of security management technologies in eHealth services and applications. In those areas, there's a particular need to balance technical design and functionality against the usability.

## Acknowledgments

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# Need for Telecare for Home Residents with Dementia: Potential Solutions - Based on the Experiences of Close Relatives and Healthcare Professionals

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## Abstract

*Elderly people would ideally live in their home as long as possible, even in situations with cognitive deficits, such as with an early stage of dementia. Their close relatives will often try to assist and support with problems in daily care and normal living situations, which can last for a long period of time before the home health care services get involved.*

*In a qualitative study carried out in a Norwegian municipality, we have focused on how close relatives of elderly home-living people with dementia experience their situation, and how they would like to collaborate with the municipality home health care services. During a series of group interviews with representatives from home nurse services, we highlighted the experience of a collaborative dementia care.*

*In order to evaluate potential technology solutions that might be favorable for both the elderly person and their close relatives, we investigated relationships between the experienced daily problems and how technology could be used to compensate the lack of cognitive functions, presenting some examples of current Telecare solutions.*

## Keywords:

Dementia care, family caregivers, welfare technology, eHealth, safety, confidence, coping

## Introduction

Many national care plans and research projects have promoted active involvement of informal networks in elderly care. This strategy has been presented as a crucial step for future home care services because of tremendous growth in elderly populations as a consequence of the global trend in demographic changes. The importance of technology tools in home health care in order to deliver more cost-efficient services have been highlighted [1]; however, little is known of possibilities and effects for close relatives to introduce technology tools in an early stage of dementia. Often, close relatives will lack of enough time for an optimal care, having to take care of both young children and elderly parents, combined with a full-time professional job and the travelled distances related. The burden for family caregivers can be perceived as high [2], and the use of technology to support people with dementia seems to be underestimated because of the assumption that they are no longer able to benefit from technology [3]. Few studies are reporting on the family caregivers about people with dementia and the benefits from Information and Com-

munication Technologies (ICT) use. These studies revealed the gap in literature between technology-driven interventions and the reported outcome [4]. However, interventions for care givers to people with dementia that were delivered through the Internet can have positive effects, especially if the services provided include guidance by a coach and contact with other caregivers [5].

Carers of frail elderly and disabled children living at home reported benefits from using web-based discussion forums, which resulted in better services and had a positive impact in facilitating sharing emotions and reflections with fellow carers [6]. Even if technology that can improve the lives of people with dementia and their careers are available, carers want the solutions to be complementary and not a substitute for existing provisions, and research should be focused on how ICT can meet the carer's needs, attitudes and beliefs [7].

Pilotto et al. reported that relatives/informal caregivers found ICT to be useful for patients with Alzheimer's disease, to improve quality of life and achieve a more independent lifestyle [8]. Results from a two-year case study indicates ICT systems can have a positive impact for family caregivers, but it needs to be constantly supported from formal caregiving services in the municipality [9].

In a review paper of ICT-based services for people with dementia, Lauriks et al. found that they can benefit from such technologies and thus indirectly reduce the burden for the family caregiver [10]. Currently different technologies exist on the market, but despite their proven positive impact, they are not widely used [11]. Based on a selected literature review, Vogt et al. proposed a framework for technology design and development of context-aware assistive applications for patients with dementia and their caregivers, and gave some recommendations for the design process [12]. The solutions would require a user-friendly design [13]. ICT solutions can be useful in topics such as safety and security for patients with dementia, when they provide the needed functionality and are introduced at the right time, but there should be a reciprocity between the relatives and the dementia patient in the decisions of ICT use [14]. Use of technology can also have a potential to significantly support other people, but they will need information of actual solutions and be able to incorporate that use into the existing habit of the dementia patient [15]. Technology for home healthcare can be defined by different terms. In this study, we will use *Telecare* as the solution for remote monitoring to manage risks, thereby assisting the individual to live independently [16].

The purpose of this study was to investigate the experiences

by close relatives and home healthcare services to identify the main obstacles for the user to stay longer in his/her own home. We have highlighted possible challenges of Telecare solutions for elderly people with dementia and their close relatives. In addition, we will combine their expressed challenges with an overview of technical solutions and comparison of available products on the Norwegian market

## Materials and Methods

To carry out an open study, we used a descriptive and explorative design with a qualitative approach based on focus group interviews, according to recommendations given by Graneheim & Lundman [17]. The study was carried out in the period from May to June 2011, in a typical medium size municipality in Southern Norway (ca. 21.000 inhabitants). Evaluation of actual technology solutions was conducted in the period from August 2013 to January 2014.

### Participants

The criteria for participation in the study were close relatives of a person with dementia living at home, and personnel in the home nurse services at the local municipality level. In total eight relatives and nine health care professionals were interviewed. The relatives were daughters or sons who had taken care of their mother or father for the last years, combined with regular visits from the caregiving services in the municipality. Four semi-structured focus group interviews were conducted, two with family members and two with health care professionals.

### Procedure

Local government professionals responsible for the caregiving services identified relatives of people with dementia, and health care professionals, who showed interest to participate in the study. Department nurse with a special responsibility for dementia care services contacted the participants and gave them written and oral information about the study's aim and procedure, as well as the written consent form. Subsequently she scheduled an interview appointment at a place and time preferable to the relatives. The nurse also contacted her colleagues for arranging time and place for the interviews.

The interviews were conducted separately between the two groups. Between four and five informants participated in each focus group, and the two of the authors (MMF and ET) carried out the interviews. A small focus group was easier to recruit, and was more manageable and more comfortable for the participants (18).

The interviews took place at the local health center in the municipality. It was used a semi-structured interview guide based on the research questions. One of the authors behaved as a moderator and was responsible for leading the interviews. The other one behaved as assistant moderator responsible for observation of the group dynamics, and to summarize the contents regularly, trying to focus the discussion around the significant issues in questions according to the interview guide. She was also responsible for the final group summary.

### Data collection

The interviews started with a short presentation of the reason for carrying out the study and the focus on their experiences Scandinavian Conference on Health Informatics, August 21-22, 2014, Grimstad, Norway

of the elderly dementia person's ability to carry out the normal daily activities. Questions were about concentrating on what is functioning satisfactorily, what seems to be problematic and which factors can be of importance to be able for them to continue living in their own home.

Each interview began with open questions about: *"How have the current situation for resident individuals with dementia and their family been perceived"*, *"What are the main obstacles for the user to stay longer in his/her own home"*, and *"How can it be possible to improve the elderly's ability to manage living alone at home?"* Follow up questions were used for clarification and elaboration, such as: *"Can you tell us more about this?"*, *"What did you mean?"*, *"What did that means to you?"*, *"How can use of technology contribute to improve the ability of independent living?"* The interviews lasted about 90 minutes, and were digitally recorded. Two of the authors (MMF and ET) were responsible for transcribing two interviews each, and they collaborated on the data analysis in order to obtain a broad understanding and defining meaning units.

### Data analysis

Data were analyzed by using qualitative content analysis as specified by Graneheim and Lundman [17]. Firstly, the entire text was read several times to obtain a general understanding of the content. Then, the text was demarked into meaning units corresponding to the focus in this study. The meaning units were condensed in a way that the text became compressed and abstracted. By defining groups by condensed meaning units, sub-categories were extracted as invariant themes. The last step in the analyses was to create common overarching themes by an interpretation of the content in the invariants themes.

### Literature review/state of the art of technology solutions

Based on the user inputs of ideas for actual technology solutions that could be helpful both to the close relatives and to the home health care services, we clarified actual challenges to technology use during the data analysis.

Different technology solutions were investigated by search in scientific literature, and in EU-project reports, as well as search for actual products available on the Norwegian market, in order to compare different technology solutions and evaluate possible use.

### Ethical considerations

The study was conducted according to ethical guidelines used validated and used in other studies [18, 19]. Participation in the focus group interviews was based on written, informed and voluntary consent. It was assured that the collected data were confidently treated and that the informants had an opportunity to withdraw without declaring their reasons. Consent forms were securely stored in locked rooms and lockers. Since no questions were asked about informants own health, there was no obligation in Norway to get approval from an ethical committee. The study was reported to the Norwegian Social Science Data Services (NSD) (Ref 26918).

## Results

The findings will be presented by describing the three categories "Obstacles for people with dementia living in their own

home”, “Relatives’ experience of having responsibility for the elderly with dementia living at home” and “Challenges related to living in own homes”, and then the overall theme “Use of technology to promote the sense of safety, confidence and coping”.

### **Obstacles for people with dementia living in their own home**

Both relatives and health professionals were asked to describe the typical characteristics of a person becoming demented. They talked about gradual changes in behavior, changes that may be difficult to detect because they can be mixed with normal age-related changes and personality traits of the person. They also told how they, in the beginning, rationalized the signs and symptoms of early cognitive decline.

Development of cognitive decline makes the person gradually becoming more passive and indifferent/apathetic. The person often stops with activities and hobbies and is unconcerned with their appearance and cleaning their house. The home is becoming dirty and messy. Many people are suspicious, show a lack of insight, and have periods of confusion. Gradually, the person develops disabilities, and will become further pacified. At the beginning, the person often manages to hide his failure by withdrawing from difficult situations. As the disease progresses, many develop apraxia and sensory impairments. Consequences of sensory impairment may be that they throw diapers in the toilet, they may use the trash-bin as a toilet, or the person falls because they do not see stairs or doorsteps. Both the relatives and the health care professionals explained that the person gradually developed increased resistance to interference and help from others, which makes it problematic to implement actions to improve the situation. In spite of these entire symptoms, the relatives expressed that it was important for their mother or father to be able to live in their own residents: *“I would like to say that for my mother at this time, it is important to continue to live at home. It is what keeps her in a good mood and makes sure that she would like to continue to do the things that she is looking forward to doing”*.

### **Relatives’ experience of having responsibility for the elderly living at home with dementia**

Relatives described their situation as very difficult, characterized by uncertainty, insecurity, unpredictability, suspiciousness, and they used a lot of time following up their mother or father. They also spent a lot of time to be available, or to check the daily conditions in the elderly’s home.

Relatives find that personality changes generate uncertainty and insecurity. They are insecure because they feel that a person that they think they know well, gradually change personality. The changes also make it difficult to approach the person in the normal way, which contributes to uncertainty. Many close relatives have little knowledge about dementia and is therefore uncertain how to deal with their relatives, and they have little knowledge about what kind of services the municipality can offer.

### **Consequences related to living in own homes**

During the data analysis, areas where it might be problematic for the elderly to continue living in own homes where identified and summarized in Table 1 into six characteristics.

The obstacles are reflecting the relatives and home care services experiences related to what they found to be challenging

for the elderly.

### **Use of technology to promote the sense of safety, confidence and coping**

Technology solutions were evaluated to reflect what the patients could currently need and in the future. The faithful support from close relatives has been very beneficial for the elderly in the phase of initial dementia, which makes it very necessary to be continued even when the public health care services gradually undertake the daily support for the elderly person. In Fig. 1, this collaborative approach is visualized where arrows indicate types of necessary support, showing the gap between the actual cognitive impairment and the ideal level of independence. In the early phase of a dementia situation, support from close relatives will normally be the important effort. The close relatives and home health care nurses anticipated that use of technology could have important impact. Gradually, the public health care service will increase their influence. However, both informants groups expressed difficulties in the ability of being able to exchange necessary information to be able to act as a coordinated supportive team.

Both health care providers and relatives were interested in using technology solutions for communication with each other to achieve improved cooperation and coordination of actions to the elderly. It was suggested a system where nurses and caregivers could give each other messages when they had been visiting the old, or use a *Facebook* feature that allowed for communication between patients, their families and the health care personnel and possibly volunteers. Son (1): *“I do not know if they have been with my mom now or if they come later in the day, so it would be very nice to have had control that seems to work today”*. Daughter (1): *“... one of those “beeps” that they might touch, something and that on my phone, that “now we have been there”*.

It was expressed a need for e-mail contact between health care personnel and relatives. This could make it easier to communicate and to give information about changes in the situation from both sides. Home nurse (7): *“... we have no opportunity to communicate by mail, but if we only could receive short messages, it would be a great way to communicate”*.

Both relatives and health care personnel went through a high degree of uncertainty and unpredictability in how people with cognitive impairments managed their daily living at home. A need for good technological solutions that could provide security and predictability in the home setting was expressed. Door alarms, fall alarms, fire and flood alarms, web camera, use of GPS for outdoor activities, and social security alarms were some of the solutions specifically mentioned as appropriate in order to create a safe situation.

Several relatives told about episodes with fall accidents because of physical impairment and subsequent cognitive decline. They had experienced that their mother or father had fallen several times because of many elderlies are shaky and that the risk of fall accidents is an imminent danger. Some believed that a fall alarm could contribute to improve security if one could be sure that it was triggered by a fall accident. Other types of alarm that relatives and health personnel mentioned were door-alarm. Daughter (2): *“So he is confused at night, he wakes up and thinks he is going to work. Then he goes out and he falls often and .. We will try a door alarm.”*

Table 1 Operationalization of the findings from the content analyzes

Obstacles	Experiences	Consequences
Orientation	Loss of orientation related to time, place and space/room - Problems in maintaining the circadian rhythm - Use a lot of energy to organize appointments	Confusion/delirium Get lost Risk of fall Forget appointments Risk of medication error Risk of disturbances in eating times
Personal hygiene	Loss of ability and initiative to perform personal hygiene - Loss of dignity - Loss of well-being	Social isolation "dirt and spills" Personal decay
Medication	Medication errors - Incorrect treatment of disease(s) - Forget or taking medication at wrong time - Obliviousness related to changes in the circadian rhythm	Risk of fall Risk of delirium Mess Difficult to detect errors in medication because of memory loss
Nutrition	Loss of ability and initiative to make food Routines gradually slipping Forget to eat and make purchases Forget meals	Malnutrition Confusion Stale food Clutter and mess Poor hygiene
Communication	Loss of language (aphasia) - Loss of insight - Reduced interaction - Reduced collaboration	Lack of confidence Suspiciousness /paranoia Loss of interests
Social isolation	Reduced social contact - Loneliness - Lack of stimulation	Withdrawal Reduced activity

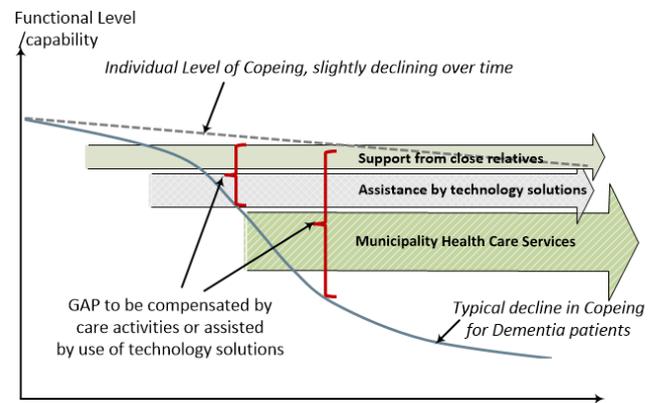


Figure 1 Gap in cognitive impairment and supportive influence from close relatives in addition to assistance by technology solutions and public health care services.

Home nurse (5): "Some of the patients are going out walking in the middle of the night, and some of them have a door-alarm which alerts us, but in other cases the personnel have put on tape at the patients front door and check it out whether the door has been opened during the night".

The needs of GPS alarm were also mentioned. Home nurse (4): "...when they go out and not find their way back home, then it is difficult to be taken care of in their own homes".

Table 2. Technology to promote the sense of safety, confidence and coping. By defining problems related to being demented, general needs related to technical aids and some technology solutions, focusing on challengers related to technical solutions are summarized.

Problems related to being demented	General needs related to technical aids	General solutions	Technical solutions	Challenges related to technical solutions
Circadian rhythm	Memorial/functional	Electronic/Digital calendar/PC with reminder functions	Web-access to the patient's calendar to fill in reminders and remote programming of electronic pill boxes	Ethical- and legal restrictions Computer security, data storage, authentication and access control issues
Medication		Electronic pill box		
Personal hygiene		Visual Communication program/ solutions		
Meals and nutrition		Reminders and instructions		
Fall accident	Safety and security	Fall alarm/ Safety- alarm	Home health-care alarm systems with internet gateway and Cellphone with integrated GPS	Interoperability issues, standardization in technology solutions based on international recommendations
Not finding their way home		GPS systems		
Going out in the middle of the night		Door alarm		
Not understanding what may be flammable		Fire alarm		
Throwing objects into the toilette		Water-flooding-alarm		
Loneliness	Social isolation	Skype Telephone/cellphone Games- or training program	Use of social media and gaming technologies, /web camera/ Skype/ video-phone	Ethical- and legal restrictions Usability Consent form
Isolation				
Lack of stimuli				
Difficult to get in touch and give and receive information	Collaboration Coordination Interaction		New collaborative web-based portals	Data security Legal restrictions Confidentiality

**Table 3** Comparison of some current products available in the Norwegian market, according to the defined user needs and functions.

Defined functions	Technological solutions/actual products								
	Memoplanner *	FlexiBlink *	Cognitass *	Numa trygghetsalarm *	Dignio trygghetspakke	Altibox alarm	Common social alarms	Common building alarms	Building automation *
Medicine reminder	X	X	X		X				
Fire alarm					X	X		X	X
Manual alarm button	X	X		X	X		X		
Stove alarm	X	X							X
Voice messages	X	X	X						
External alarm call	O	X		X	X		X	X	
Automatic speech conversation				X			X		
Calendar reminders	X		X						
Remote control function	X		X						
Controlling light & heat						X			X
Surveillance camera								X	
SMS alarm messages	O	X		X	X			X	
Skype- video functions	X								
Mail functions			X						
APP-based functions						X			X

\* Actual products tested in a lab environment

Some of the relatives had experienced that their mother or father could not find their way back home. One of them had perceived use of GPS. Son (1): " ... I feel quite more secure now and I don't need to contact my mother quite so often, and in addition to health personnel, they have to visit her two times a week to charge the GPS alarm".

Based on the content analysis findings, we have summarized in Table 2 some of the current problems related to being demented. Those problems have been expressed as important factors affecting the situation for home living elderly patients, and it has been evaluated technology aids, which can help in compensating the functional impairment. Several technical solutions might be relevant for the actual elderly person to address those problems.

There will be several general solutions available and ready to be used by elderly at an early stage of dementia. In order to evaluate actual solutions targeting user's needs, we have compared some of the products available in the Norwegian market, summarized in Table 3. Functions marked with an X indicate what the actual products support, while O indicates Scandinavian Conference on Health Informatics, August 21-22, 2014, Grimstad, Norway

optional functions. The products investigated are Memoplanner<sup>1</sup>, Flexiblink<sup>2</sup>, Cognitass<sup>3</sup>, Numa<sup>4</sup>, Dignio<sup>5</sup>, Altibox<sup>6</sup>, as well as a general overview of common social alarm systems, building control with home alarm systems and systems for building automation as for instance KNX-systems.

Of those nine different systems/solutions, we have evaluated five in a lab environment at University of Agder, those products are marked with an \* in the table.

Several different types of technologies can be implemented with important functions; however, it might be challenging to find an actual product containing all functions needed, as the extent of functions shows a plurality of combinations. Being able to use the technologies within the legal and security regulations for health care solutions, there are several important challenges to be taken into consideration upon implementation. Especially, legal requirements for privacy and secure access to medical information can be challenging for providers of new technology solutions. In addition, the need of standardization may in the future give recommendations for interoperability between different products, which can give new possibilities of plug-and-play functions for different types of sensors and alarm functions.

## Discussion

In this study, we have investigated the experiences by close relatives and home healthcare services, to identify the main obstacles for the user to stay longer in their own home. We have highlighted possible challenges of Telecare solutions for elderly people with dementia and their close relatives. In addition, we combined their expressed challenges with an overview of technical solutions and comparison of available products on the Norwegian market.

Close relatives expressed that their situation were characterized by uncertainty and insecurity for their mother or father. They stressed that it was important to find good solutions to minimize the obstacles. Both close relatives and health care providers showed a positive attitude to use Telecare if this could maintain the activity of daily life, safety and security, in a way that the dementia patient could still be able to live in their own residence. It is important to involve patients with dementia in discussion of technology, being also an ethical issue. These findings are according to what has been described by Olsson et al. [14]

Both family caregivers and health care services mentioned the need of early implementation of ICT devices in the dementia disease, while the person is still competent to make use of the device and take advantage of ICT devices. In addition, the actual solutions need to be user-friendly, as pinpointed by Vogt et al. [12] and Hanson et al. [13].

<sup>1</sup><http://www.abilia.no/produkter/produkt.aspx?productgroup=313780&product=343546>

<sup>2</sup> <http://www.vestfoldaudio.no/produkter/flexiblink>

<sup>3</sup> <http://www.cognita.no/produkt/580>

<sup>4</sup><http://www.numa.no/produkt/trygghetsalarm/numa-ta10-trygghetsalarm>

<sup>5</sup> <http://www.dignio.no/trygghetspakken/>

<sup>6</sup> <http://www.altibox.no/privat/alarm/sikkert-hjem>

Another challenge is to motivate the patient with dementia to make use of ICT devices. It is important to adapt the ICT device to the person's needs, so the device does not remain unused. On the contrary, it could be a false sense of security for both family caregivers and the health providers. As described by Hanson et al. [13], this will require sufficient support in the implementation phase.

It is also important that the professionals have knowledge and awareness about different ICT devices so they could give advice and support in training both the patient with dementia and the family caregivers. It has to be a close collaboration between family caregivers and the health providers. Use of ICT devices could also release family caregivers from daily tasks, and give them more time to social meetings, activity outside, etc.

Statements from close relatives showed that there also was a need of systems for daily communication, such as e-mail for feedback from the municipality health care services. It was relevant for relatives to know the visit agenda of careers regarding their mother or father to not to be worried or afraid about anything that could have happened. Health care personnel supported this view, and they wished to find good solutions for these challenges. Close communication and easy access with each other could provide security and predictability in home setting, but because of a strict legislation, such routines could be difficult to implement.

For evaluation of technology according to meet the challenges described in six main categories, there will be relevant products available on the market. However, it can be difficult to find optimal solutions combining several of the challenges, as there is a lack of standardization and interoperability for Telecare solutions, as described by Gerdes et al. [20]. In addition, several challenges in technology use that should be taken into consideration before implementing desired solutions have been listed in Table 2. For close relatives, it can be difficult to gain knowledge of alternative solutions, as stated by Rosenberg et al. [15], and information of useful technologies should be easily available. This can be an important issue for home healthcare services.

## Recommendations for future research

Future research should initiate development of a web-based system for sharing information between the dementia patient's informal care team consisting of close relatives, and the formal home healthcare services. Such solutions need to be user-friendly and as simple to use as *Facebook*, but with necessary data security in order to share medical information of care. Our project indicates that there is a need of supportive teamwork accordingly to the importance of close support from health care services as described by Torp et al. [6], where the importance of a secured virtual private network was highlighted.

Increased research efforts should be concentrated on investigating dementia patients, and close relatives outcome from use of Telecare and smart home solutions with sensor technology, including alarm systems. Interoperability and standardization of system design is challenging, but there might be opportunities for better follow-up in the near future, and with fewer burdens to the family members. Especially smooth transitions from support by close relatives to gradually compensate from deficits by introducing technology, and to pro-

gressively influence home healthcare services should be in the agenda. Nevertheless, those types of integrated care can be of importance for managing the expected growth in elderly populations with increased number of people suffering from dementia.

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# Future Hospital Structure in Vest-Agder?

## Analyzing a Newspaper Debate

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### Abstract

*The hospital sector in Aust-Agder and Vest-Agder counties in southern Norway is suggested reshaped in a strategic development plan focusing on the hospital structure and supply of health services in year 2030. The proposed strategic development plan has been presented for inhabitants in the counties and much activity has emerged especially in the two communities where today's hospitals are suggested degraded to lower levels of service. This research analyses the arguments presented in two newspapers through a New Public Management lens using a case study approach. Analysis shows that participants in the debate do not understand or consciously exceeds the limits of what is prescribed in the New Public Management theory. Some politicians suggest scrapping the present form of governing structure for the health sector and making the hospital sector more political. This research therefore questions the debate and the planning process for the hospital structure in Vest-Agder County in 2030 especially why the planning process does not include future development in the e-health domain and the consequences for future location of hospitals in the counties.*

**Keywords:** *e-Health, New Public Management, Technology*

### Introduction

In the last decades of last century public sector had been reformed in different ways. One of the reforms has been labelled New Public Management (NPM) [1]. The NPM concept received much interest in public sector research communities. According to [2] the concept came about as a reaction against some of the more traditional models of public administration and the traditional bureaucracy. There are 7 key doctrinal components in NPM [2 p. 4-5 referred in 1]:

1. Hands-on professional management
2. Explicit standards and measurements of performance
3. Greater emphasis on output controls
4. Disaggregation of units in the public sector
5. Greater competition in the public sector
6. Private sector styles of management practice, and
7. Greater discipline and parsimony in the resource use

Fifteen years after [2]'s publication [3] discussed NPM and characterized the concept along four axis [3]: "management (i.e. results and managerial responsibility) is a higher order function than administration (i.e. following instructions); eco-

nomic principles (i.e. drawn from public choice theory, principal-agent theory, competition, and the theory of the firm) can assist public management; modern management theory and practices (i.e. flexibility in staffing and organization) can improve public management; and service is important to citizens." [3, referred in 2, p. 354].

Ideas from NPM, especially the management ideas has been heeded in the Norwegian health and care sector [4]. The management ideas have influenced areas like finances, cost, decentralizing of responsibilities, flexibility and how leaders are viewed both for their personal behavior, how they perform their duties and responsibilities, and the result of their work [5]. One consequence of implementing the NPM ideas is that the Health Enterprises (Helseforetak) have got a role that is in a way disconnected from the political influence at least on the local level [4]. The disconnection is labelled "Distansestrategi" (strategy for making a distance) by [6].

Such 'distance strategy' may not necessarily be accepted by inhabitants [7] especially in areas where the inhabitants feel threatened by changes such distance strategy may lead to. Fighting for local hospitals in Norway has therefore been going on for a long time. A blog (lokalsykehus.blogspot.com) was established several years ago and publishes entries from different sources describing how people are fighting for their local hospitals many places in Norway. Norway is a scarcely populated country sometimes with long distances between towns and villages. The inhabitants therefore want hospitals to be located close to where they live.

[6] studied and categorized findings in the discourse about the local hospitals. Two of the findings were commonly labelled 'life and death' (liv og død) but from two different perspectives, the individual health perspective and the local community perspective. In the individual health perspective the inhabitants were occupied with the existence of maternity ward and the emergency ward in the local hospitals, meaning that giving birth and treating for accidents and other life threatening situations could be given locally. As for the local community perspective the inhabitants were occupied with the life and death of a local society, if people wanted to live there without a hospital or if people would move to places far from a local hospital. Another perspective was that local hospitals provided safety, identity and bonding to the local community where it is situated.

NPM ideas also seem to have influences the doctors' position in the hospitals in Norway. One area concerns how the management of the different wards is organized where a HF has

several hospitals. The management of the same type wards in the different hospitals is organized after a ‘klinikkjefsmodell’ [6] meaning that the same type wards in the different hospitals have a common management. This management model may be a vehicle for moving functions to larger hospitals with more specialized treatment preferably is performed [4]. Another consequence of introducing NPM ideas to the hospital sector is that the management role of doctors has changed and fewer doctors are working as leaders.

This paper wants further to reflect on the space given to present and future influences that e-health technology may have on a hospital location debate. The NPM concept does provide doctrinal components and principles as shown [2, 3] but does not provide any leads to use of technology when applying NPM in actual management situations.

Developing and deploying information systems like e-health systems is associated with change both for the organization using the systems, for the work processes and for the people performing treatment in the health and care sector. [8] discusses the role of human actors and the relationships between the human actors and the technical factors in information systems like e-health systems. [8]’s main point is that human actors have to take leadership and use the technology in a way that supports and strengthens the human actors’ objectives.

Developing information systems is an uncertain business where failures are prevalent [9, 10, 11]. It is therefore important to consider the context where the systems are to be used when the systems are developed. It is also important to consider what changes are wanted in the organization that will use the systems since failure rate is extremely high in information systems change initiatives [12]. The future operations and treatments to be given in hospitals may be even more challenging since the technical development of medicines and medical and e-health related equipment seems to accelerate at an unprecedented rate. Hospitals are already using endoscopic surgery, and keyhole technology for inspecting of patients.

A recent conference The South by South West conference held in March 2014 included presentation of body near technology both for present and for future use. Discussions were proposing medicine that will be able to report its own function when taken by the patients. Participants in the discussion at the conference predicted a revolution in the health and care sector where information about the individual patient will be collected, stores and used from cradle to grave. The information may be used both by medical personnel, and by the individual person/patient. One slogan at the conference was: Meet your new RGP: Yourself! Such possible development will challenge the role of hospitals and the relationships between the patients and the hospitals.

This paper proposes to apply NPM as a lens for analysis a case in the health sector and therefore seeks to answer the following research question: How can a newspaper debate about a strategic planning project for future location of hospitals be understood from New Public Management doctrinal components and principles?

In the next chapter the research method is described followed by a case description. The following chapter contains the analysis of the case description and discussion of the findings. The paper ends with a conclusion.

## Research Method

A case study approach was chosen to answer the research question in this paper.

Questions related to the phenomenon studied can be asked to judge the appropriateness of a case research strategy [13]. The use of case studies is one of several preferred research strategies in explorative research [14]. When the phenomenon is in its natural setting with a focus on contemporary events a case research strategy is appropriate [13, 14]. In this study the phenomenon studied is in its natural setting. The focus of this study is on contemporary events of what actually happens when strategic plans for location of hospitals are commented on and discussed in two newspapers. This study does not control or manipulate events in the cases studied or participate in the newspaper discussion [13, 14].

Even if the research question in this study is a “how” question the question is actually “what” questions [14] since some “how” questions belong to the exploratory part of the “what” question [13, 14]. The research question can therefore be answered by using an exploratory research strategy for which case studies are an appropriate research method seeking to understand what happens when a strategy planning process and related document is discussed in newspapers entries and analyse the findings using NPM as a lens.

The case studied in this paper concerns how the general public, two newspapers, employees in two hospitals, managements of the regional Sørlandets Sykehus Helseforetak abbreviated SSHF (HF means health enterprise) and politicians, discuss a strategic plan and the planning process for locating future hospitals and hospital services in Aust-Agder and Vest-Agder counties. The study focuses on the two hospitals in Vest-Agder county, Kristiansand Hospital which is the largest and situated in Kristiansand (the major city in the county where about 50% of the inhabitants in the county live) and the smaller Flekkefjord Hospital located in the town of Flekkefjord. The hospital in Kristiansand provides the most specialist treatment on the county level in addition to serving as the local hospital for the Kristiansand area, while Flekkefjord hospital serves as a local hospital for the Lister area (consisting of 6 municipalities in western Vest-Agder) and for some local municipalities in the south-western part of the neighbouring county Rogaland.

Data for the paper was collected through reading and analysing all articles/entries about the strategic plan published in two newspapers in the county, the daily regional paper Fædrelandsvennen edited in Kristiansand and the local newspaper Agder Flekkefjord tidende edited in Flekkefjord (three issues a week). The data was collected in the period from March 12<sup>th</sup> 2014 through to May 9<sup>th</sup> 2014. Fædrelandsvennen published a total of 9 entries whereof 2 were editorials, 6 written by the newspapers journalists and one special entry about use of technology in the hospital sector. The special entry was not referring to the actual hospital debate but was a general comment e-health published in several Norwegian newspapers at approximately the same time. The number of entries in Agder Flekkefjord Tidende was 30 whereof 1 was Editorial, 17 entries were written by the journalists of the newspaper, 8 were written by the readers of the newspaper and 4 entries were unsigned entries giving general information.

## Case description

The two Norwegian counties Aust-Agder and Vest-Agder have together three hospitals (listed from east to west) Arendal Hospital, Kristiansand Hospital and Flekkefjord Hospital. All three hospitals form SSHF which is part of the South-East regional Health Enterprise (one of 5 in Norway). Slogan for SSHF is “Trygghet når du trenger det mest” or in English “Security when you need it the most”.

Distance between the hospitals by road from Arendal, located in Aust-Agder, to Kristiansand is 67 km and from Kristiansand to Flekkefjord is 108 km. Kristiansand Hospital is located in the easternmost part of Vest-Agder while Flekkefjord Hospital is located in the westernmost part of the county. Over the years there have been debates about the location and functions of the hospitals. This paper will focus on the discussions focusing on Flekkefjord and Kristiansand Hospitals.

The reactions and discussions studied in this paper were fueled by a planning process in SSHF focusing on the medical services to be offered to the inhabitants of Vest-Agder in the year 2030. The planning process has been led by a project leader based in the central management of SSHF located in Kristiansand. The project leader for the planning process has initially concluded that one central hospital for the whole of Agder (including Aust- and Vest-Agder) will be the best alternative for the future provisions of governmental health services for patients in these two counties.

The first newspaper entry studied was published by the newspaper Agder and contained information about reactions from the Board of SSHF on the Director of SSHF’s involvement in the planning process. Some members of the Board of SSHF argued that the documents that were to be sent for consultation concerning the new hospital structure 2030 contained many mistakes and that it was premature to send the document to different instances for comments. One of the board members named in the newspaper article was from Flekkefjord, is working in the local hospital there and has an interest in the survival of the hospital. Other members of the board also commented on what seemed to be too early conclusions on one hospital in Agder as the best alternative. The director of SSHF defended the project leader’s suggestions for one hospital in the region and expressed full confidence in the project leader and his work capability. The project leader made an excuse if the Board or members of the Board have perceived the suggested plans as more than suggestions.

In parallel with the plans for the hospital structure in 2030 a nationwide health reform (“Samhandlingsreformen”) that affects the relationships between hospitals and local communities are in its initiating phase. The reform reshuffles the responsibilities for the patients between the hospitals and the local municipalities nationwide. In principle, when a patient is ready for being discharged from the hospital the local municipality where the patient lives has to take responsibility for the further care of the patient. The Chairman of Kristiansand Municipality’s social services issues a warning to the local municipalities about the consequences of the reform where no or little central government funds is supplied in the reform. If the local municipality cannot take responsibility for the patient and the patient must overstay in the hospital the municipality is fined for every extra day the patient stays in the hospital.

An emergency exercise was performed in Flekkefjord to visualize what would happen to the injured patients in a car crash without a hospital in the vicinity (i.e. supposing Flekkefjord Hospital had no emergency ward). The leader of the ambulance Scandinavian Conference on Health Informatics, August 21-22, 2014, Grimstad, Norway

lance service in Flekkefjord said that the distance to Kristiansand Hospital was too far to save some of the injured patients even if there had been a four-line express way from Flekkefjord to Kristiansand (a possible scenario in 2030). Even calling and using a helicopter the distance itself was too far for saving some of the injured.

A new turn in the discussions about the location of future hospitals was a report (Fædrelandsvennen) in mid-March from Vest-Agder Labor Party’s annual meeting. Vest-Agder has two MPs in the Norwegian Parliament, “Stortinget”. One of the representatives is from Kristiansand; the other is from Kvinesdal a neighboring municipality to Flekkefjord. The representative from Kvinesdal wanted the planning process “frozen” for the time being and argued that Flekkefjord Hospital was important for the Lister area and some municipalities in the neighboring county Rogaland. Flekkefjord Hospital is located midway between two larger hospitals, Kristiansand Hospital and Stavanger University Hospital.

The situation might be further complicated because the Deputy Director of the SSHF Board is a Labor Party politician living in Kristiansand while the Director of the SSHF Board is a Chief officer in Kvinesdal municipality and might therefore be in a squeeze between local interests, county level interests and central government interests in the debate on locating future hospitals. A Labour Party politician in the neighboring county, Rogaland, suggests that nobody should touch Flekkefjord Hospital as it is used by people in his county even if the county has a University Hospital. The main reason for supporting Flekkefjord Hospital seems to be the shorter distance to the hospital. In case of larger emergencies or where treatment is not offered locally an ambulance helicopter may be called and will transport the patients in need to the closest larger hospitals.

One entry in the newspaper Agder, written by a commoner, problematizes the double role of one person being both the Chief Officer in Kvinesdal municipality and Chairman of the SSHF Board. The writer criticizes the local municipality for allowing the Chief Officer to hold both positions as he suggests that the Chief Officer will not give full support for keeping the local hospital in Flekkefjord. Another entry in the debate is made by a priest in the Church of Norway. He is pondering the possibility to arrange some kind of church service praying for the local hospital and the strategy process.

As a curiosity the newspaper Fædrelandsvennen published “Synspunkt” (View Point) with the title “Mail me, doctor!” in the time period of this case study. The View Point was co-written by one researcher in the Norwegian Centre of Integrated Care and Telemedicine and a Senior Advisor. The View Point discussed a possible technical revolution in e-health equipment and treatment methods in the future. Within the same time period an Oslo-based newspaper, Dagbladet (10.03.2014) is publishing news from the South by South-West conference in USA using the ingress “Meet your new RGP (fastlege): yourself”. The news article contains information on different trends within e-health and related fields like the use of DNA-profiles in future health related situations. The focus was on body close technology like cybernetic health, implanted sensors, pills that have sensors small as a grain of sand, and medicines that are reporting information about the body’s response to the medicines when the medicines are functioning inside the body. There are strong reasons to believe that the technological development within e-health and care will influence the future locations of hospitals in the two Agder counties. The newspaper Dagbladet concludes that

a gigantic health revolution has started, for the general public, for the RGP, health services, health politicians and the society at large. It is therefore strange that no mention or discussion of consequences of technological advances for future hospital services and location was found in the newspaper reports studied in this case study.

The plan for location of hospitals in Agder County in 2030 was brought to the attention of the MPs through a question raised by the Labour Party MP from Kvinesdal in the "Question Hour" in the Norwegian Parliament. The MP questioned the future hospital structure in Norway and what the present government including the Minister for health plans for the future. To give weight to the arguments an article in the newspaper Agder referred to a Torchlight parade (Fakkeltog) in Flekkefjord where 5000 people participated. The newspaper further mentions the support for Flekkefjord Hospital from many political parties opposing the SSHF strategy plan suggesting only one fully functions operated hospital in 2030.

Parallel to the process in SSHF the central government has started an assessment of the future national structure of the hospitals and treatment to be performed at the different hospitals. The assessment is based on a proposal from the political party "Senterpartiet" while the Chairman of the committee is a leader in another of the opposition parties in the Parliament Socialist Left Party (SV).

There is also a debate about the location of stroke treatment. A medical director in SSHF states that the three stroke treatment units in SSHF (one in each hospital) do not satisfy new international standards. He is therefore suggesting that all stroke treatment is centralized to Kristiansand Hospital as probably the best way to satisfy the international standards for such treatment. A group is preparing a strategy plan for a centralized stroke treatment unit. The representatives in the group that come from Kristiansand supports the suggestion while the representatives from Arendal and Flekkefjord opposes the suggestion for medical reasons. Service quality and treatment quality are often used when the newspaper Fædrelandsvennen and people living in Kristiansand were arguing for one central hospital. One Editorial in Fædrelandsvennen was even suggesting that the debate about future location of the hospital(s) was disturbing discussions concerning the medical focus on the treatments. However, no report seems to describe what quality can be handled for different treatments performed at Flekkefjord Hospital.

Other areas that are discussed are location of teams for handling traumas and for emergency teams handling accidents. Should such teams be placed in Kristiansand Hospital (centralized) or should each hospital have their own teams? An important argument for keeping local teams is the closeness to the patients where patients can get treatment locally. Complications may arise if patients are to be transferred to a centralized hospital for treatment. The argumentation from keeping the treatments in Flekkefjord Hospital includes the important of security for people living in the area. Counteracting arguments suggests that more videoconference equipment and rooms can be provided so that necessary competence can be made available to Flekkefjord Hospital "online" from Kristiansand Hospital meaning that it is not necessary to move the patient to Kristiansand for treatment.

Several entries in the newspapers, especially in the newspaper Agder, do either originate from politicians or are written by politicians. The politicians are constantly challenging political leaders in the area to give more attention to the hospital strategy plan and the promotion of Flekkefjord Hospital. Sometimes Scandinavian Conference on Health Informatics, August 21-22, 2014, Grimstad, Norway

complaints suggest that political leaders are more or less "...invisible in the hospital case".

The financial director of the SSHF is airing his concern in a rather short entry in Fædrelandsvennen stating that the funding from central government provided for SSHF will force the SSHF Board to discuss the future roles of the three hospitals. When the financial director presents the SSHF budget for 2015 he airs concern for loosing central government financial support for some treatment areas. He is also discussing possible consequences "Samhandlingsreformen" may have for the hospitals in the region. The basis for his arguments is that the number of future patients will not decrease, but the service will improve as the municipalities will, in principle, be given resources for treating the patients in their home municipality. The financial director further foresees that an explosive growth in the so-called high-cost medicine and -patients' treatment will further fuel the hospital discussion.

One turning point in the hospital location debate came when the SSHF Board decided to prolong the deadline, a second time, for comments to the strategy plan and to ask the Director of SSHF to go through the critical comments that had been given especially directed towards the strategy process. Some of the critics of the strategy planning process expressed satisfaction about the SSHF Board decision and suggested that the medical specialist and the population in the western part of Vest-Agder were in line concerning the need for a local hospital in the area.

Inhabitants in Flekkefjord and the whole Lister area were inventive in their fight for maintaining the pressure on keeping Flekkefjord Hospital in the future plans. A grass root movement combined the fight for Flekkefjord Hospital with aid to build a hospital and an orphanage in Burma. By paying NOK 100, - buying a sticker for cars the locals could contribute to two causes at the same time both giving attention to the discussion of Flekkefjord Hospital and supporting development in Burma.

The health and care committee in the Norwegian Parliament arranged an open hearing about the plans for the future hospital structure in Agder County especially regarding emergency units and maternity wards. Representatives from Flekkefjord were not allowed in the hearing. However, the chairman of the committee, a Socialist Left Party politician, invited more input from Flekkefjord area. More input was given and the chairman of the committee wanted to stop the process with the strategy plan for SSHF until central government had issued their report on the hospital structure in Norway. "He (the chairman of the committee) is pushing the pause button" was the heading of one newspaper entry. However, some days later the newspaper Agder brings another entry where a representative of the Secretary of Health and Care department state that the government has no intention of stopping the strategy planning process in SSHF.

Amongst the more odd Editorial comments is an Editorial in the newspaper Agder that admonishes the people of Arendal to wake up. The Arendal hospital is also threatened in the strategy planning process. Earlier the people of Arendal has turned out in great numbers, taken to the streets and protested against the centralization trend towards Kristiansand Hospital. The Editor comments on an information meeting arranged in Arendal where the project leader in SSHF presented the strategic plan for year 2030 hospital locations in the two Agder counties. Only 100 people turned up at the meeting in contrast to 5000 people turning up to a similar meeting two months earlier in Flekkefjord. The Editor seems to be concerned that the

voice of the people weakens in the debate and therefore seemed to want more people to turn up in Arendal to make an impression on the project leader and the SSHF management since the project leader has stated that it is important to listen to people's voice and responses to the strategy plan.

One line of argumentation by the newspaper Agder and the entities in the paper is to present the successes of Flekkefjord Hospital. Flekkefjord Hospital is presented as very good on hygiene. The employees are carefully washing their hands to prevent infection. The hospital does not allow the employees in the wards or having direct contact with the patients to wear jewelry, watches, rings and similar things as these things are difficult to disinfect or keep clean. An entry in the newspapers is describing patients' satisfaction with the services they receive in the hospital specifically mentioning the maternity ward.

Another line of arguments concentrate on arguing against the documents presented in the process like finding mistakes and wrong information in the strategy documents for the development plan 2030. Especially one health political committee reported on inconsistent information in the documents. Others argue that small hospitals are as good as larger hospitals. They refer to research stating that local hospitals are not more expensive than larger hospitals and that the small hospitals provide equal if not better quality health services than larger hospitals. The report is developed on behalf of a national interest group organization for local hospitals. The report criticized strategy processes for being too shallow, not providing reliable figures for financial advantages or advantages for quality of treatments in larger hospitals, or listening to the people that use the local hospitals. One chairman of a committee for childhood and welfare in Flekkefjord municipality suggests that the planning process was lacking democratic foundation. The writer criticizes the Minister of Health for not listening to the people's voices in the hospital location discussions. Many people voice concern that the local hospitals in Norway will be closed down and local health services be transferred to centralized larger hospitals.

Several politicians from the Socialist Left Party aired support for the local hospital in Flekkefjord. One Socialist Left Party MP visited Flekkefjord and is reported arguing that it was unwise to close down local hospitals that function well. The MP expressed her frustration of how the hospital sector was organized at present. She argued against letting HFs and other groups control the hospitals and suggested that the Norwegian parliament should again have the political control over the hospitals reverting to the former system that was phased out when NPM in many ways were implemented in the running of hospitals in Norway. The support for local hospitals from the Socialist Left Party politicians is in itself interesting as they were a part of the former government. Some of their comments may therefore be considered politically motivated. Late in the period studied in this case study a local representative for the Conservative Party assure the reader of the newspaper Agder that the Conservative Party supports the future existence of Flekkefjord Hospital. At the same time the same representative argues that a representative for the Norwegian Democrats (a small party in Norway) is misusing facts and arguing from an unfinished report when the representative argues about the hospital situation. The democrat is therefore told to spare his arguments until the final report on the strategy plans is issued and put up for discussion.

On a general level some writers are afraid that the local hospitals will be 'sneakingly' closed over time. One writer is dis-

cussing the advantages and disadvantages for patients' travel to the local versus the central hospital. Travelling a long distance to get at treatment that could have been given at the local hospital is suggested as not responding to and respecting the patients and their needs.

## Analysis and discussion

The initial analyze of the case follows the 7 key doctrinal components mentioned by [2].

### 1. Hands-on professional management

From the newspaper entries it is clear that SSHF has hands-on professional management. The project leader is professional and he is supported by the Director of SSHF. The Board of SSHF does not voice strong criticism of the management of SSHF. However one may question how the project leader and the management of SSHF are handling the planning processes. The general public criticizes how the planning processes are handled. Indirectly the Board also airs some criticism since the Board agrees to prolong the deadline for comments.

One stream in the discussion argues that even with hands-on professional management, especially one entry, argues that it is preferable to return to more political control over the hospitals. Such change will reverse the processes that are inspired by NPM.

### 2. Explicit standards and measurements of performance

In the debate the referring to standards are mainly to the quality of health services the hospitals are to provide to the citizens in the county. Still the mention does not refer to very concrete standards, but more to the types of services that is to be provided at the two hospitals especially in the emergency and the maternity units. The main argument is that too few patient treatments will not provide enough experience to the doctors and nurses; therefore it is suggesting that the service is centralized to one hospital. Cost of having an emergency ward operating at the local hospital is also an argument as these types of wards involve many and expensive resources. The opposing argument is that the patients in some cases will not survive the longer transport from Flekkefjord area to Kristiansand Hospital.

One line in the discussion tries to widen the scope to include cost that a centralized solution will infer on the patients and the families since they have to travel longer distances to accompany or visiting the patients. This extra travel may not necessarily be accepted by the inhabitants as suggested by [7] and may result in a life or death discussion as suggested by [6].

### 3. Greater emphasis on output controls

Indirectly this item is touched through better quality to the services provided. On the other side the discussion does not provide a sharp focus on output controls.

### 4. Disaggregation of units in the public sector

The political reform in the hospital sector originally promoted disaggregation of units where different health services included hospitals were brought out of political control and integrated in regional units also found by [4]. The trend in the plans in the SSHF case seems to be towards larger units as the management of SSHF does not seem to want to continue the disaggregation track. Their arguments mostly support closing or reducing services in Flekkefjord Hospital and centralize the services to Kristiansand Hospital. The aversion against dis-

aggregation is mainly built on a 'quality-in-the-services' argument and is opposing the NPM ideas.

#### 5. Greater competition in the public sector

County-wise the centralization of the hospitals or some hospital services will not lead to greater competition at the county level for hospital services. In the Norwegian system there is a nation-wide competition between hospitals. It is difficult to forecast if a county-wise centralization in Vest-Agder will lead to patients from Vest-Agder will want to use hospital services outside of the county.

#### 6. Private sector styles of management practice

This principle is in force in SSHF. The management is more private sectors styled with a Director of the SSHF that is responsible to a Board. The private sector style of management is challenged in the newspaper discussion. Some politicians are suggested more political control over the health and care sector. Ordinary people are in one way doing the same as they call on politicians to influence the strategy planning process through political channels. From the newspaper entries it seems that both politicians, reporters in the newspapers and the general public do not understand the NPM principle that the politicians have given away their power to the SSHF Board that is supposed to lead in a more private sector style. The 'distance strategy' suggested by [6] therefore does not seem to work in this case as least for some of the participants in the debate.

#### 7. Greater discipline and parsimony in the resource use

This principle may be seen as a driver for the centralization process as it presumably or at least anticipated as possible to save money for SSHF especially in the emergency ward and the maternity ward as these two wards are depending on backup personnel leading to higher cost if the two services mentioned is provided in two hospitals instead of in one hospital. At the same time this principle only considers the cost of the SSHF. In a wider societal view of hospital or health cost related to patients some of the newspaper entries argue that a local hospital has an important role in the local communities where the hospital is situated in line with the 'life and death' considerations found by [6]. Having to travel far to a hospital will lead to extra cost for the patients and their families/kinds and these costs are not calculated in the strategy planning processes. However there was a mentioning of including these costs in the planning to be able to make better decisions.

Analyzing the case presented in this paper along the four conceptual axis presented by [3] may lead to an even better understanding of the case. The first axis suggested by [3] points to management as a higher order function than administration. The idea by seeking to implement NPM ideas in the hospital sector was to give more room for maneuvering, not just administer. The Director of SSHF has power to make decision on the daily running of the hospitals in SSHF. However some of the entries in the newspapers wanted to introduce more political control with the HFs in Norway. It is reasonable to anticipate that introduction of political control will revert the hospital sector to mere administration than management. A reason for the wish may be that the inhabitants are discontent with decisions made by SSHF which is in line with [7]'s conclusions of the inhabitants disagreeing with SSHF's decisions.

The second axis, economic principles can assist public management is certainly in operation in this case. The second axis in NPM suggested by [3] may in fact be the provider or main cause of some of the challenges or problems in this case. It

seems to be challenging where to set the limits for the areas where the economy of the hospital services are to be counted. If the area is too narrow, just patients in and patients out of the hospital the community part of the health services will not be valued economically. Measuring the economic principles towards the slogan of SSHF "Safety when you need it the most" is certainly challenging and not included in the present strategy plans for 2030. Such conclusion is clearly supported by findings by [6]'s 'life and death' possibilities both for the individual patient and for the local community.

The third axis, modern management theory and practices can improve public management is certainly hoped for by many of the people that publish their views in the two newspapers. The word "can" in the third axis does not include any criteria for finding if any improvement takes place. From the newspaper entries it is therefore difficult to conclude on this axis as the evaluation criteria are differing amongst the writers. One may argue that the 'distance strategy' [6] may be used consciously to free the politicians from direct responsibilities for the difficult priorities in the health and care sector.

The fourth axis, service is important to citizens is obvious, but presents the same challenges as the third axis in this case study because the citizens certainly have different opinions of what service they want provided related to health services, especially hospital treatments in this case. An additional challenge is that citizens that participate in the newspaper debate have different roles. Some writes as "ordinary" citizens, while others carry different hats in the debate. One example is the Chairman of the SSHF Board that is also Chief Officer in a local community that wants to keep the local hospital in Flekkefjord. Some of the entries in the newspapers are written by local politicians that probably have their political agenda when arguing their case. Some of the entries even present views of politicians that are MPs. It seems obvious that these politicians that are left-wingers now want to air their views clearer than when they were part of the Government less than one year ago. The fourth axis may in a way hold the paradoxical perspectives of 'distance strategy' [6], the 'life and death' perspective and the NPM's ideas of flexibility, responsibility and so on for leaders following NPM's principles [2, 3, and 5]. Maybe the different perspectives and expectations to NPM results in a paradoxical situation of management where it is impossible to fulfill what seem to be "promised" by the NPM principles?

A surprising finding or perhaps lack of finding is that in the case description and the analysis part of this paper only one entry about e-health and use of technology was published in the two newspapers within the period of this case study. Furthermore the entries were a general discussion about future health sector technology as the race of invention in the health sector is increasing in speed. The entries mentioned and the South by South West conference report suggest that both body close technology and technology implanted in the body or taken as medicines will be developed and will be able to give feedback to the patients and the doctors and in some cases can regulate functions in the body after how the technology is programmed to respond. The lack of e-health technology and information systems in the debate is even more surprising since research in the e-health and information systems field is prone to failure [9, 10, and 11], requires preparations for change [12] and directly influences and challenges the relationship between the user of the system and the system itself [8].

A concluding remark on the discussion is to suggest that the SSHF Board could clarify their positions and base part of their

report on the eGEP Measurement Framework Analytical Model [15] developed by the European eGovernment Unit. The Framework Model suggests that the value drivers are efficiency, democracy and effectiveness. Using such drivers for analyzing strategic plans may clarify issues that are discussed in this paper. The drivers mentioned include the development of e-health technology and information systems to be deployed in the health and care sector.

## Conclusion

Reverting to the research question: How can a newspaper debate about a strategic planning project for future location of hospitals be understood from New Public Management doctrinal components and principles?

In the discussion many of the doctrinal components of NPM is partly employed in the strategic planning process for a new hospital structure in Vest-Agder. However, many of the contributors to the discussion in the newspapers act as if the hospital sector is not run according to NPM principles. It is from the data presented, impossible to find out if the people participating in the debate are conscious of the NPM ideas' consequences when implemented in practice if the participants just by acting on their own interests. It is though reasonable to assume that the MPs that are contributing in the discussion is conscious about their points of view and that they want a change in the roles of the HF Boards bringing the hospitals again under political control.

The discussion also points the some seemingly unbridgeable differences between local priorities versus the priorities of the SSHF management. This aspect may be studied in another study where the future e-health technological development and its possible influences on the future hospital structure may be included in the study.

The debate does not include the consequences of present and possible future development and deployment of technology that may pose new and unexpected challenges both to the local hospitals, a central hospital, the different treatment methods and the patients themselves.

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# Gathering Experience with Ontology and SPARQL Based Decision Support

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## Abstract

*Use of knowledge-based decision support systems in medicine may improve the quality of medical care. We have executed several projects at UIA involving semantic web technologies like OWL, SPARQL and Jena; the application area has often been E-health; among these projects are two recent master student projects investigating the use of OWL and SPARQL to realize two different decision support systems. One project concerned monitoring vital signs of a patient estimating the state of the patient using a score system; recommendations based on score and additional rules were given. The other project defined an ontology storing medical patient information, with focus on diabetes and recommendations for diabetes patients; recommendations could be retrieved by querying the ontology. The projects used the Protégé framework when doing the development; this implied limitations that made the development cumbersome. The paper proposes another approach based on the Jena framework. The projects are analyzed in regard to technology; extensions and alternative solutions are discussed and proposed. The paper describes and recommends technology that may be used to build an advance medical knowledge-based decision support system.*

**Keywords:** *eHealth, knowledge-based decision support system, Ontology, OWL, SPARQL, Jena*

## Introduction

Decision support should be available to health care professionals (e.g. stated in report to Stortinget: St. meld.nr.9, 2012-2013, *Én innbygger – én journal*) and it may also play a role in supporting patients at home. Spring 2014 two master thesis projects [1,2] have targeted this research field. The focus of this paper has been on technological aspects and we place the students work in a wider context together with recommendations for further work.

The work of Tian Zhao was associated to a project at Sørlandet Sykehus Kristiansand, a Norwegian hospital. The project is called Tidlig Identifisering av Livstruende Tilstander (TILT) (some related work: [3]). In English this would be something like: Early Identification of Life-Threatening Conditions. By continuously monitoring vital signs of a patient, together with application of rules, a state is “calculated” and interventions proposed. The task was then to propose a software solution (or parts of a solution) to this.

The work of Angelique Mukasine was the making of ontology for supporting patients at home, with focus on diabetes.

The remainder of the paper is structured as follows: The Method section briefly outlines description logic and the use of ontologies to represent knowledge; a general overview of a knowledge-based decision support system is delineated; some ontology technologies are also presented. The Result section presents the two master projects. The section called Discussion and Some Conclusions sees the projects in light of the greater picture presented in the Method section; limitations and problems are discussed; some conclusions are drawn. Section Recommendations for Further Work advocates some technologies and solutions.

## Methods

Creation of fully envisioned systems was not within reach for the two master projects. Simplifications, focusing on only some technology and “a proof of concept approach” have been necessary. Figure 1 gives a general picture of our wider vision where the reported projects considered only a few components.

We will first describe the parts of the general picture. We apply description logic [4] where the knowledge base is composed of a terminology part defining concepts (also called classes) like *vital sign*, *blood pressure*, and *patient*. Descriptions of individual patients, etc., are found in the assertion part. Correspondingly, properties (also called roles) are described in the terminology part and applied in the assertion part, e.g., property *has blood pressure* relates *patient* with *blood pressure*; the assertion part may contain information about the blood pressure of some specific patient. This is the classical model (terminology) and model instance (assertions) separation. However, not all entities in the assertion part may have been classified and this differs from ordinary object-oriented program development.

The concepts can be categorized as *atomic* or *complex*; complex concepts are (unlike atomic concepts) built with the help of *description logic constructors* and atomic concepts. E.g., the following is the definition of a complex concept: *Potential diabetic ketoacidosis is equivalent to a patient with excessive thirst and frequent urination and confusion and*, etc. Here *Potential diabetic ketoacidosis* is the complex concept being defined; *is equivalent* and also *and* illustrate description logic constructs.

The complex concept may be used by a *reasoner* to classify individuals by inference. I.e., individuals satisfying the following belong to this complex concept: Must be of type patient, have excessive thirst, etc. Reasoners can also be used to check

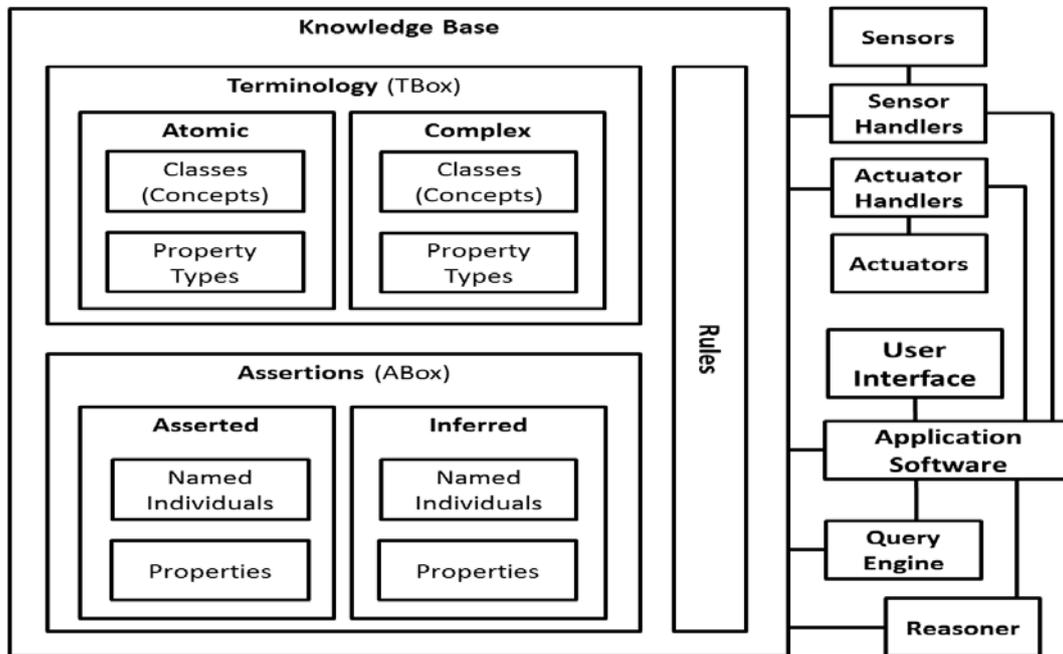


Figure 1 - Envisioned knowledge-based decision support system

the soundness of the classification hierarchies, e.g., decided if it is impossible for a concept to have individuals.

The knowledge base, often called ontology, can be described in many ontology languages. We have chosen a Semantic Web [5] approach and selected The Web Ontology Language (OWL) [6]. One argument for this is the already existing medical ontologies in this language, e.g., a version of Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT) [7] and International Classification for Nursing Practice (ICNP) [8]. The most used ontology editor and knowledge acquisition system [9], Protégé [10], also supports OWL. There is also a Java Semantic Web framework, Jena [11,12,13, 14], which supports an API for OWL (and other Semantic Web technologies).

Complex concepts (see Figure 1) can be seen as rules, but there may be additional rules specified in some other language. SPARQL Protocol and RDF Query Language (SPARQL) [15] is a part of the Semantic Web technology. The use of SPARQL has, out of interest, been a requirement for the student projects. SPARQL can be used to query and gather new information given some OWL ontology (see Rules and Query Engine in Figure 1). There are examples of OWL/SPARQL being used in medical informatics [16,17].

Protégé and Jena both support several reasoners like Pellet [18] and FaCT [19].

Sensors for measuring vital signs, etc., and actuators for medications, etc., could be applicable in a practical situation. Furthermore, application software tying the components together and a user interface is needed.

From before we had some experience with both Protégé and Jena; they could both be used separately or together as described later. Experience indicated that making a Java application utilizing Jena could be very time consuming if lacking previous experience; Protégé was consequently proposed as a tool for the projects. A shift of technology from Protégé to Jena would still allow the results to be utilized; the ontology language used in Protégé would be OWL which is also understood by Jena software; the same goes for SPARQL state-

ments. However, it turned out that the Protégé environment had some unforeseen limitations, more on this later.

## The Master Theses

To sum up the previous given information, both student projects were developed in Protégé, which supplied a user interface, application software, reasoners, OWL, SPARQL and visualization. Actuators were not involved. Sensors/sensor handlers were simulated by manually inserting sensor data in the form of OWL statements. Also input about users and their states were manually inserted with OWL statements in Protégé; a fully developed application would have a tailored user interface to handle the human machine communication instead of using the generic Protégé user interface. This gave a set up that was manageable in the limited time frame and it gave the possibility to focus on defining the OWL ontology and the SPARQL rules, i.e., the kernel of an ontology based decision system as we envisioned it.

## An Ontology-Based Decision Support System for Interventions based on Monitoring Medical Conditions on Patients in Hospital Wards

This project is a first start making the TILT system as a software system. The main intention with TILT is to give an early identification of life-threatening conditions based on parameters like measurements of respiration frequency, pulse oximetry, blood pressure, etc.. The parameters are measured regularly, how regularly should be given by the decision support system. The different parameters are given score, e.g., respiration frequency between 9 and 14 (i.e., normal frequency) is given 0, below 9 give 2, between 15 and 20 gives a score of 1. In essence 0 indicates a normal state, while a higher score indicates something that may be abnormal or a risk. The scores at one point in time are inserted into a table where they are summed. A high sum indicates a high risk and consequently: The higher sum the more frequent a new table should be assembled based on new measurements.

Suggestions when it comes to symptoms were decided with help of additional rules, e.g., respiration frequency score 3 and pulse oximetry score less than 2 and blood pressure score less than 2 gives suggestion: Hyperventilation.

An ontology modelling the following was successfully made:

- Classes *Patient*, *VitalSign*, *TILTTable*, *Suggestion*, etc.
- Relation types *hasVitalSign*, *hasSuggestion*, etc.
- Test data in the form of individuals of type *Patient*, *VitalSign*, etc.
- Test data in the form of application of the relation types (i.e., properties) *hasVitalSign*, *hasSuggestion*, etc.

SPARQL was used to define rules that gave the sum of the scores of a filled TILT table. Also suggestions were produced by applying SPAQL queries.

### Ontology-Based Personalized System to Support Patients at Home

The proposed ontology model concepts like *Patient*, *Disease*, *Examination*, *Medication*, *GlucoseLevel*; and, properties like *hasMedication*, *hasDiet*, *hasInsulinIntake*. Individuals of the concepts and application of the property types were used to model specific patients with special medical conditions. The ontology focused on diabetes patient data and the modelling of examination results concerning diabetes. Predefined recommendations were inserted into the ontology, e.g., recommendations concerning insulin intake were connected to specific glucose levels. In this way a lot of information was modelled; SPARQL queries were given to show how the stored information could be retrieved.

An existing ontology for modelling questionnaire was integrated and exploited (this ontology had been made by both the mentioned students in an earlier project).

## Discussion and Some Conclusions

OWL is a powerful language and the ontologies were expressed by utilizing only a small subset of the language. Protégé is well suited for manually defining the terminology and the assertional part of the ontology.

SPARQL can be used as a rule language as demonstrated in [17] and discussed in [20]. Protégé seems to give full support for SPARQL 1.1 which includes the *construct query*. The construct query allows a graph to be constructed based on a given query; the graph is composed of statements that can easily be inserted back into the ontology. However, the insertion is not done automatically by the construct query, implying that an insertion has to be done manually in Protégé.

SPARQL 1.1 Update [21] provides update, create, and remove operations on ontologies. In SPARQL 1.1 Update insertions can be done automatically with help of its *insert operation*. SPARQL 1.1 Update is not supported by a Protégé plugin.

And also, the SPARQL plugin found in Protégé did not allow a sequence of SPARQL statements to be run automatically (which after all is not that meaningful when insertions are not done automatically).

Using SPARQL as a rule languages were demonstrated in the project concerning TILT tables. However, using Protégé together with the SPARQL plugin, to simulate a system having rules changing the ontology, seems extremely unpractical. Such a system may run in cycles, where several rules are executed in a sequence, allowing the changes to the ontology by one rule to be used by the next. The amounts of manual work Scandinavian Conference on Health Informatics, August 21-22, 2014, Grimstad, Norway

(i.e., run a rule and copy the changes to the ontology, run next rule copy changes to ontology, etc.) would be somewhat overwhelming. In other words, Protégé does not seem like well suited for this kind of experiments.

One may consider several different types of TILT tables; the proposed solution defined only one and it did not define concepts for defining TILT tables in general. To achieve this a metamodel approach seems natural; this approach foresees 3 levels (these levels are conceptual and just meant to help understand this way of thinking); one level, defined in advance, defines concepts to be used when defining one type of TILT table; the second level “uses” the concepts of the first level defining a special type of TILT table; filled in tables reside on the last level. To implement something like this demands programming (or some tools specifically designed for doing meta-modelling) and it seems impractical to use Protégé for something like this. This approach defines two types of user roles, one defining tables and one filling tables. The same type of thinking may apply to rules, since rules also could be supplied by some user, i.e., users that were not IT personnel knowing SPARQL. However, making such a system is not trivial.

The project concerning personalized system to support patients at home supplied a rather big ontology, where different types of tables were represented, e.g., information relating glucose levels with recommendation of insulin intake. No functions or rules were supplied; all information was coded into the ontology. This kind of approach works well for small and uncomplicated cases, but will break down when the complexity grows – it will not be practical to (manually) insert all possibilities into the ontology.

We consider both the projects helpful and successful taking the limited time into account.

## Recommendations for Further Work

The high number of medical ontologies and the rather mature semantic web technologies fuel our interest in the *knowledge-based decision support system approach*. Central to this approach is an explicitly represented knowledge base, defined in some ontology language. The Ontology Users’ Survey [22] indicates that OWL is by far the most used ontology language in 2013. Adding our good experience from other projects [23] makes OWL a natural choice.

One of the purposes of using ontologies is to establish common languages and facilitate unambiguous communication in single system and among different systems; at a practical level it allows interoperability between existing applications; the ontologies are believed to be long lasting valuable assets.

We already have some experience [23] with The International Classification for Nursing Practice (ICNP®) [24]. ICNP aims at improving communication among nurses, and between nurses and other health care professionals. ICNP already contains concepts like *Diabetes*, *Blood Glucose* and *Effective Blood Glucose Level*; reusing these concepts in the aforementioned ontology would be an improvement. Another often mentioned medical ontology is SNOMED CT.

Ontologies like SNOMED CT function as standards defining medical concepts; before defining your own “new” concepts the most common medical ontologies should be checked to see if they already contain a representation of the concept. There has also been done some work on defining sensor ontologies [25].

The two projects reported in this paper did not utilize the possibility to define complex concepts. This option is very powerful; to give an example: Alarms are common in the surveillance of health conditions; the following setup may be implemented:

- The conditions identifying the triggering of alarms may be defined in advance as a complex concept, i.e., the definition of different types of alarms.
- One execution activity may continuously input sensor data into the knowledge base (in accordance with some defined sensor ontology). At some point in time the sensor data may satisfy the conditions for triggering an alarm (this could be the combination of data from multiple sensors); however, the duty of this execution activity is only to insert the sensor data.
- There are several reasoners available. One reasoner may be set to run continuously to infer individuals of complex concepts. In our case such individuals would correspond to alarms.
- One execution activity may continuously query the knowledge base for individuals of alarms, and if found then give a corresponding alarm.

Analyzing the proposed handling of alarms makes it clear that handling of time is essential when dealing with the sensory data. In general, treating of patients typically involves patient history; consequently the handling of time is important when it comes to medical informatics, and high priority should be given to doing this in an intelligent way.

There are ways to adapt Protégé and make some suitable user interface and also make plugins; however, as already mentioned the SPARQL 1.1 Update is not supported.

We have good experience with the Jena framework which also supports SPARQL 1.1 Update, reasoners, etc.; it seems to cover what we need. Using Jena means to develop a Java application and utilize the rich set of semantic web support given by existing Java libraries.

OWL ontology can be seen as a graph; the graph is broken up into triples when stored; a special database technology called triple store [26] has been developed for efficient storage and retrieval of triples. Jena gives close to transparent support for this kind of storage. The knowledge base may be distributed through different SPARQL endpoints; an SPARQL endpoint is conformant to the SPARQL protocol service (i.e., supporting queries and updates); a SPARQL endpoint may be offered at a server deploying a triple store.

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# A Belief Rule-Based (BRB) Decision Support System for Assessing Clinical Asthma Suspicion

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## Abstract

Asthma is a common chronic disease that affects millions of people around the world. The most common signs and symptoms of asthma are cough, breathlessness, wheeze, chest tightness and respiratory rate. They cannot be measured accurately since they consist of various types of uncertainty such as vagueness, imprecision, randomness, ignorance and incompleteness. Consequently, traditional disease diagnosis, which is performed by a physician, cannot deliver accurate results. Therefore, this paper presents the design, development and application of a decision support system for assessing asthma under conditions of uncertainty. The Belief Rule-Based Inference Methodology Using the Evidential Reasoning (RIMER) approach was adopted to develop this expert system, which is named the Belief Rule-Based Expert System (BRBES). The system can handle various types of uncertainty in knowledge representation and inference procedures. The knowledge base of this system was constructed by using real patient data and expert opinion. Practical case studies were used to validate the system. The system-generated results are more effective and reliable in terms of accuracy than the results generated by a manual system.

**Keywords:** Belief Rule Base; Uncertainty; RIMER; Asthma Diagnosis; Asthma Suspicion; Decision Support System; Inference

## Introduction

Asthma is a condition that affects the smaller airways of the lungs [1]. It is caused by inflammation of the airways. The inflammation irritates the muscles around the airways and causes them to constrict. This causes narrowing of the airways. It is more difficult for air to get in and out of the lungs. This leads to wheezing and breathlessness. When airways become inflamed and fill with mucus and the smooth muscles around the airways constrict, then chest tightness may be experienced. Asthma patients may cough because of the irritation inside the airways and the body's attempt to clean out the thick mucus. The respiratory rate is defined as the number of breaths a person takes in one minute. During an asthma attack, the respiratory rate often increases. The normal respiratory rate varies for different age groups, such as 30-60 breaths per minute for newborns and 12-18 breaths per minute for adults. Figure 1 illustrates airway inflammation and a cross-section of the airways during an asthma attack in the lungs and airways. Figure 1(A) shows the location of the lungs and airways in the

body, Figure 1(B) illustrates the cross-section of a normal airway, and Figure 1(C) depicts a cross-section of an airway during an asthma attack.

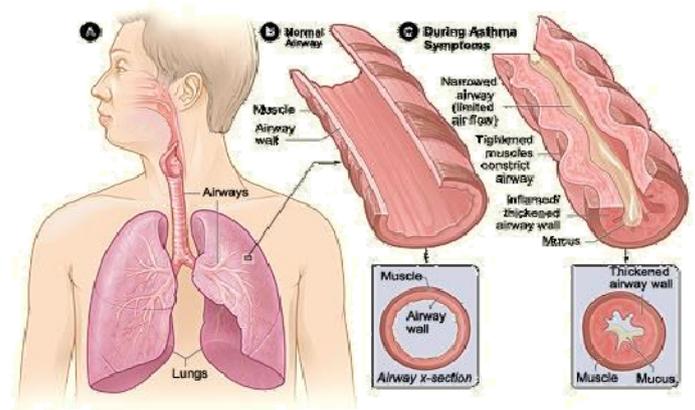


Figure 1- Mechanism of asthma<sup>1</sup>

Asthma may occur at any age but is most common in children [1]. It may also be due to hereditary factors [2]. The process for 'asthma suspicion' or diagnosis consists of observing a patient's signs and symptoms [3]. However, this asthma suspicion process contains errors because the signs and symptoms cannot be measured with 100% certainty. There are causal relationships among the signs and symptoms of asthma. These causal relationships can be represented by the If-Then rule.

An If-Then rule has an antecedent and a consequent part. The antecedent part takes input data while the consequent part shows the action to be taken. For example, signs and symptoms data are input data that is the antecedent part of various rules. Input data in a rule can differ in type and scale such as qualitative, quantitative etc. For example, a patient's breathlessness may be severe, moderate, mild or normal. This degree of illness is presented by qualitative data. These data are expressed as a linguistic term by patients and contains uncertainty due to vagueness and imprecision. However, a patient can have a respiration problem that can be within the range or out of the range. This can be measured with an optical breath rate sensor [4] that produces numeric or quantitative data. The result may be incorrect due to mishandling of the instrument, ignorance and randomness. Sometimes, a symptom such as

<sup>1</sup> Source: <http://www.nhlbi.nih.gov/health/health-topics/topics/asthma/>

cough may be hidden by patients, which arises out of ignorance and incompleteness. Therefore, various types of uncertainty can be associated with input data such as ambiguity, vagueness, imprecision, ignorance etc. Thus, the consequent part of the If-Then rule may contain uncertainty. For example, the initial belief degree can be imperfect since it contains incompleteness and ignorance.

Some expert systems for diagnosing asthma have been reported in the literature. A fuzzy rule-based expert system for assessing the severity of asthma was presented by [5]. The assessment of the severity of asthma by an expert system is illustrated by [6]. A clinical support system [7] was also developed to assess asthma. However, these systems cannot handle different types of uncertainty.

Diagnosing asthma is an example of a complex problem that can be handled by an expert system. An expert system has two components: the knowledge base and the inference engine. The knowledge base can be constructed with propositional logic (PL), first-order logic (FOL) or fuzzy logic (FL) [8,9]. Reasoning mechanisms such as forward chaining and backward chaining are used to develop the inference engine [10]. PL and FOL are not equipped to capture uncertainty. However, FL can handle uncertainty due to vagueness and ambiguity. However, FL cannot handle other types of uncertainty such as ignorance and incompleteness that may exist in signs and symptoms of asthma. Therefore, a knowledge base that can handle all types of uncertainty that exist with diagnosing asthma must be developed. A relevant inference mechanism must also be adopted. Uncertain knowledge in diagnosing asthma must be processed by using a refined knowledge base and an inference mechanism.

A recently developed Belief Rule-Based Inference Methodology Using the Evidential Reasoning (RIMER) approach [11,12] was used to design and develop the proposed decision support system. Uncertainty can be addressed by this methodology. This methodology consists of the Belief Rule Base (BRB) and the Evidential Reasoning (ER) algorithm. In RIMER, a rule base is designed with belief degrees embedded in all possible consequents of a rule. Inference in such a rule base is implemented using the evidential reasoning approach that can handle different types and degrees of uncertainty in signs and symptoms.

The rest of the paper is organized as follows. The next section provides an overview of the RIMER methodology. Then the stem architecture, design and implementation of the proposed BRBES are discussed. Experimental results and discussions are then presented. A conclusion is included to summarize the contribution.

## Overview of RIMER Methodology

The RIMER approach consists of two components [10]. They are BRB to act as the knowledge base and ER to act as an inference engine.

### Domain Knowledge Representation using BRB

Belief rules are the key elements of a BRB, which include belief degree. It is an extended form of traditional If-Then rules. A belief rule consists of an antecedent part and a consequent part. The antecedent attribute takes referential values, and each consequent is associated with belief degrees [12].

The knowledge representation parameters are rule weights, antecedent attribute weights and belief degrees in consequents, which can handle uncertainty. A belief rule can be defined as follows:

$$R_k : \left\{ \begin{array}{l} IF(P_1 \text{ is } A_1^k) \wedge (P_2 \text{ is } A_2^k) \wedge \dots \wedge (P_{T_k} \text{ is } A_{T_k}^k) \\ THEN \{(C_1, B_{1k}), (C_2, B_{2k}), \dots, (C_N, B_{Nk})\} \end{array} \right. \quad (1)$$

$$R_k : \left( \beta_{jk} \geq 0, \sum_{j=1}^N \beta_{jk} \leq 1 \right)$$

With a rule weight  $\theta_k$  and attributes weight  $\delta_{k1}, \delta_{k2}, \delta_{k3}, \dots, \delta_{kT_k}$  where  $k \in \{1, \dots, L\}$ , where  $P_1, P_2, P_3, \dots, P_{T_k}$  represent the antecedent attributes in the  $k$ -th rule.  $A_i^k$  ( $i=1, \dots, T_k$  and  $k=1, \dots, L$ ) represents one of the referential values of the  $i$ -th antecedent attribute  $P_i$  in the  $k$ -th rule.  $C_j$  is one of the consequent reference values of the belief rule.  $\beta_{jk}$  ( $j=1, \dots, N$  and  $k=1, \dots, L$ ) is the degree of belief to which the consequent reference value  $C_j$  is believed to be true. If  $\sum_{j=1}^N \beta_{jk} = 1$ , the  $k$ -th rule said to be complete;  $L$

number of all belief rules in the rule base.  $N$  is the number of all possible consequents in the rule base. An example of a belief rule in the asthma suspicion/diagnosis BRB system prototype can be written in the following way:

$$R_k : \left\{ \begin{array}{l} IF(Cough \text{ is } Yes) \text{ and } (Breathlessness \text{ is } Moderate) \text{ and} \\ (Wheeze \text{ is } High) \text{ and } (Chest \text{ tightness is } Yes) \text{ and} \\ (Respiratory \text{ rate is } Un-range) \\ THEN \\ Asthma \text{ Suspicion is} \\ \{(Severe, (0.6)), (Moderate, (0.4)), (Mild, (0.0)),\} \\ (Normal, (0.0)) \end{array} \right. \quad (2)$$

Where  $\{(Severe, (0.6)), (Moderate, (0.4)), (Mild, (0.0)), (Normal, (0.0))\}$  is a belief dis-

tribution associated with asthma consequents of the belief rule as represented in (2). The belief distribution states that the degree of belief associated with severe asthma is 60%, 40% degree of belief is associated with moderate asthma, 0% degree of belief is associated with mild asthma and 0% degree of belief is associated with normal asthma. Here, severe, moderate, mild and normal are the referential value of the consequent attribute "Asthma" of the belief rule. In this belief rule, the total degree of belief is  $(0.6+0.4+0+0) = 1$ , and thus, the assessment is complete.

### Inference Procedure in BRB

The inference procedure in the BRB inference system consists of various components such as input transformation, activation weight calculation, belief degree update mechanism and rule aggregation using ER. The input transformation of the antecedent attribute value distributes the value of a belief degree of different referential values of that antecedent. This is equivalent to transforming an input into a distribution on the referential values of an antecedent attribute by using their corresponding belief degrees [13]. At an instant point in time, the  $i$ -th value of an antecedent attribute  $P_i$  can equivalently be transformed into a distribution over the referential values of that antecedent attribute by using their belief degrees [11].

The  $i$ -th input value  $P_i$ , which is the  $i$ -th antecedent attribute along with its belief degree  $\varepsilon_i$  of a rule is shown below by (3).

The belief degree is assigned to the input value by the experts.

$$H(P_i, \varepsilon_i) = \{(A_{ij}, \alpha_{ij}), j = 1, \dots, j_i\}, i = 1, \dots, T_k \quad (3)$$

Here, H is used to show the assessment of the belief degree assigned to the input value of the antecedent attributes. In this equation,  $A_{ij}$  ( $i$ -th value) is the  $j$ -th referential value of the input  $P_i$ .  $\alpha_{ij}$  is the belief degree to the referential value,  $A_{ij}$  with  $\alpha_{ij} \geq 0 \cdot \sum_{j=1}^{j_i} \alpha_{ij} \leq 1, (i = 1, \dots, T_k)$ , and  $j_i$  is the number of the referential values.

The input value of an antecedent attribute is collected from the patient or from the physician in terms of linguistic values such as severe, moderate, mild and normal. These linguistic values are assigned a degree of belief  $\varepsilon_i$  using expert judgment. This assigned degree of belief is then distributed in terms of belief degree  $\alpha_{ij}$  of the different referential values  $A_{ij}$ . There are five input antecedents: cough ( $A_1$ ), breathlessness ( $A_2$ ), wheezing ( $A_3$ ), chest tightness ( $A_4$ ) and respiratory rate ( $A_5$ ). The referential values of these antecedent attributes consist of severe (S), moderate (Mo), mild (M) and normal (N). The devised rules are as follows:

$$\begin{aligned} & \text{IF}(S \text{ value} \geq \text{input value} \geq \text{Mo value}) \text{ THEN} \\ \text{Moderate} &= \frac{S \text{ value} - \text{input value}}{S \text{ value} - \text{Mo value}}, \text{Severe} = 1 - \text{Moderate}, \text{Mild} = 0.0, \text{Normal} = 0.0 \end{aligned} \quad (4)$$

$$\begin{aligned} & \text{IF}(\text{Mo value} \geq \text{input value} \geq \text{M value}) \text{ THEN} \\ \text{Mild} &= \frac{\text{Mo value} - \text{input value}}{\text{Mo value} - \text{M value}}, \text{Moderate} = 1 - \text{Mild}, \text{Severe} = 0.0, \text{Normal} = 0.0 \end{aligned} \quad (5)$$

$$\begin{aligned} & \text{IF}(\text{M value} \geq \text{input value} \geq \text{N value}) \text{ THEN} \\ \text{Normal} &= \frac{\text{M value} - \text{input value}}{\text{M value} - \text{N value}}, \text{Mild} = 1 - \text{Normal}, \text{Severe} = 0.0, \text{Moderate} = 0.0 \end{aligned} \quad (6)$$

In the  $k$ -th rule, it is assumed that  $\alpha_i^k$  is the belief degree of one of the referential values  $A_i^k$  (which is the element of  $A_{ij}$ ) of the  $i$ th input  $P_i$ . This is called the individual matching degree. Here,  $\alpha_{ij}$  can be calculated by using (4), (5), (6) and (7). When the  $k$ -th rule is activated, the weight of activation of the  $k$ -th rule,  $\omega_k$ , is calculated by using the following formula [10,11].

$$\omega_k = \frac{\theta_k \alpha_k}{\sum_{j=1}^L \theta_j \alpha_j} = \frac{\theta_k \prod_{i=1}^{T_k} (\alpha_i^k)^{\delta_{ki}}}{\sum_{j=1}^L \theta_j \left[ \prod_{i=1}^{T_k} (\alpha_i^j)^{\delta_{ji}} \right]}, \delta_{ki} = \frac{\delta_{ki}}{\max_{i=1, \dots, T_k} \{\delta_{ki}\}} \quad (7)$$

Here,  $\delta_{ki}$  is the relative weight of  $P_i$ , which is used in the  $k$ -th rule and is calculated by dividing the weight of  $P_i$  by the maximum weight of all antecedent attributes of the  $k$ -th rule to normalize the value of  $\delta_{ki}$  which means that its value should range between 0 and 1. The combined matching degree  $\alpha_{ki} = \prod_{i=1}^{T_k} (\alpha_i^k)^{\delta_{ki}}$ , which is calculated by using the multiplicative aggregation function. If the  $k$ -th rule as given in equation (1) is activated, the incompleteness of the consequent of the rule can also result from its antecedents due to the lack of data. The original belief degree  $\beta_{ik}$  in the  $i$ -th consequent  $C_i$  of the  $k$ -th rule is updated based on the actual input information in (8) as devised in [10].

$$\beta_{ik} = \frac{\beta_{ik} \sum_{t=1}^{T_k} (\tau(t, k) \sum_{j=1}^{j_t} \alpha_{ij})}{\sum_{t=1}^{T_k} \tau(t, k)} \quad (8)$$

Where

$$\tau(t, k) = \begin{cases} 1, & \text{if } P_i \text{ is used in defining } R_k (t = 1, \dots, T_k) \\ 0, & \text{otherwise} \end{cases}$$

Here,  $\beta_{ik}$  is the original belief degree, and  $\beta_{ik}$  is the updated belief degree. If ignorance occurs, then the belief degrees are updated. For example, if the input antecedent cough is ignored, then the initial belief degrees are updated. The updated belief degrees are shown in Table 1.

Table 1 - Belief degree update

Rule Id		Severe D1	Moderate D2	Mild D3	Normal D4	Dn
1	Initial	0.6	0	0	0.4	0
	Update	0.48	0	0	0.32	0.2
2	initial	0.8	0	0	0.2	0
	Update	0.64	0	0	0.16	0.2
3	Initial	0.4	0	0	0.6	0
	Update	0.32	0	0	0.48	0.2

All packet antecedents of the L rules are aggregated by using the ER approach to obtain the degree of belief of each referential value of the consequent attribute using the given input values  $P_i$  of the antecedent attributes. In this study, this aggregation is carried out using an analytical approach, which has been considered since it is more computationally efficient than the recursive approach [12,13]. The output  $O(Y)$ , consisting of the referential values of the consequent attributes is generated by using the analytical ER algorithm [14]. This is illustrated in equation (9):

$$O(Y) = S(P_i) = \{(C_j, \beta_j), j = 1, \dots, N\} \quad (9)$$

Here,  $\beta_j$  denotes the belief degree associated with one of the consequent reference values such as  $C_j$ .  $\beta_j$  is calculated with the analytical format of the ER algorithm [11–14] as illustrated in (10).

$$\beta_j = \frac{\mu \times \left[ \prod_{k=1}^L (\omega_k \beta_{jk} + 1 - \omega_k \sum_{j=1}^N \beta_{jk}) - \prod_{k=1}^L (1 - \omega_k \sum_{j=1}^N \beta_{jk}) \right]}{1 - \mu \times \left[ \prod_{k=1}^L (1 - \omega_k) \right]} \quad (10)$$

with

$$\mu = \left[ \sum_{j=1}^N \prod_{k=1}^L (\omega_k \beta_{jk} + 1 - \omega_k \sum_{j=1}^N \beta_{jk}) - (N-1) \times \prod_{k=1}^L (1 - \omega_k \sum_{j=1}^N \beta_{jk}) \right]^{-1}$$

The final output generated by ER is represented by  $\{(C_1, \beta_1), (C_2, \beta_2), (C_3, \beta_3), \dots, (C_N, \beta_N)\}$ , where  $\beta_j$  is the final belief degree attached to the  $j$ -th referential value  $C_j$  of the consequent attribute, which is obtained after all activated rules in the BRB are combined by using ER. This output can be converted into a crisp/numerical value by as-

signing a utility score to each referential value of the consequent attribute [7,10], as shown in (11).

$$H(A^*) = \sum_{j=1}^N u(C_j) \beta_j \quad (11)$$

Where  $H(A^*)$  is the expected score expressed as a numerical value and  $u(C_j)$  is the utility score of each referential value.

## BRBES for Assessing Asthma Suspicion

This section presents the design, implementation, knowledge-base construction and interface of the BRBES for diagnosing asthma.

### Architecture, Design and Implementation of the BRBES

The system architecture represents how its components consisting of input, process, and output are organized. The system also considers the pattern of the system organization, known as the architectural style. It consists of a user interface layer (used to get the input and produce system output), inference engine and knowledge base (consisting of the initial rule-base developed using BRB and facts including signs and symptoms of asthma).

The Relation Database Management System (RDBMS) was chosen to store data since this system has a flexible design and is portable in different system environments. PHP, which is available in Netbeans 6.9.1, was used to develop the user interface. The system architecture is shown in Figure 2.

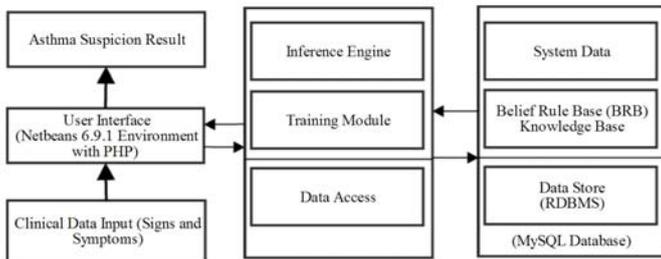


Figure 2- The BRBES system architecture

### Knowledge Base Construction in BRB

To construct the knowledge base for this BRB system prototype, a BRB framework was used by following the British Guideline on the Management of Asthma. In the framework, the input factors that determine suspicion are  $A_1 = \text{Cough}$ ,  $A_2 = \text{Breathlessness}$ ,  $A_3 = \text{Wheeze}$ ,  $A_4 = \text{Chest tightness}$ ,  $A_5 = \text{Respiratory rate}$  and  $A_6 = \text{Asthma}$ . This BRB consists of only the Asthma ( $A_6$ ) rule base and is depicted in Figure 3. The rule base has five antecedent attributes. The total number of rules,  $L$ , is usually determined with the following method:

$$L = \prod_{i=1}^T J_i \quad (12)$$

Here  $J_1 = 2$ ,  $J_2 = 4$ ,  $J_3 = 3$ ,  $J_4 = 2$ ,  $J_5 = 2$ , so  $L = (2*4*3*2*2) = 96$ . Thus, the entire BRB consists of 96 belief rules as illustrated in Table 2. It is assumed that all belief rules have equal rule weight and all antecedent attributes have equal weight. The initial belief base for the asthma suspicion BRB system is listed in Table 2.

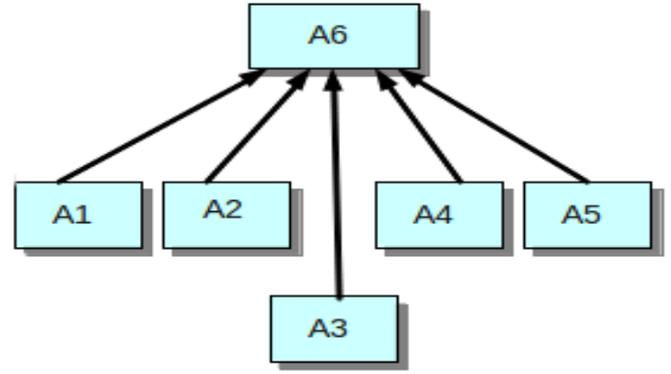


Figure 3- BRB framework for asthma suspicion

An example belief rule of this BRB system as follows:

$R_1 : IF(\text{Cough is Yes}) \text{ and } (\text{Breathlessness is Severe}) \text{ AND } (\text{Wheeze is High}) \text{ AND } (\text{Chest tightness is Yes}) \text{ AND } (\text{Respiratory rate is Out of range})$   
**THEN**  
*Asthma is*  $\{S(1.00), Mo(0.00), M(0.00), N(0.00)\}$

In this belief rule, the belief degrees are attached to the three referential values of the consequent attribute. For example, having 100 patients whose clinical information such as “Cough is Yes”, “Breathlessness is Severe”, “Wheeze is High”, “Chest tightness is Yes” and “Respiratory rate is Out of Range”. This means that if the clinical information of the antecedent parts of the rule is evaluated with a high referential value of the corresponding antecedent attribute of the rule, then all patients are judged as severe regarding a diagnosis of asthma. Consequently, the rule can assign initial belief degrees to the consequents in the rule such as “1” to “S”, “0” to “Mo”, “0” to “M” and “0” to “N” as shown in rule R1.

### BRBES Interface

A system interface can be defined as the medium that enables interaction between the users and the system. Figure 4 illustrates a simple interface of the BRBES. Here, the input antecedent for cough is yes, breathlessness is moderate, wheezing is high, chest tightness is yes and respiratory rate is within the range. The BRB/RIMER system generates the fuzzy value of the referential value. Then the system converts the fuzzy value into one numerical value by multiplying four utility factors. The four reference values are 1.0 for the *Severe* referential value, 0.66 for the *Moderate* referential value, 0.33 for the *Mild* referential value and 0.0 for the *Normal* referential value. The fuzzy output of the system is Asthma ( $A_6$ ) :{( Severe, (23.67%)), (Moderate, (39.36%)), (Mild, (3.38%)), (Normal, (33.59%))}. Severe referential value = (23.67%\*1.00) = 23.67%, Moderate referential value = (39.36%\*0.66) = 25.98%, Mild referential value = (3.38%\*0.33) = 1.11%, and Normal referential value = (33.59%\*0) = 0%. Thus, the total system output is (23.67%+25.98%+1.11%+0%) = 50.77%. The result of the system’s diagnosis is 50.77% for the asthma suspicion. This result is shown in Figure 4.

Table 2 - Belief degree update

Rule ID	Rule Weight	IF					THEN			
		Cough	Breathlessness	Wheezing	Chest tightness	Respiratory rate	Asthma			
							S	Mo	M	N
R1	1	Yes	No limitation	High	Yes	Range	0.6	0	0	0.4
R2	1	Yes	No limitation	High	Yes	Out of range	0.8	0	0	0.2
R3	1	Yes	No limitation	High	No	Range	0.4	0	0	0.6
R4	1	Yes	No limitation	High	No	Out of range	0.6	0	0	0.4
R5	1	Yes	No limitation	Medium	Yes	Range	0.4	0.2	0	0.4
R6	1	Yes	No limitation	Medium	Yes	Out of range	0.6	0.2	0	0.2
R7	1	Yes	No limitation	Medium	No	Range	0	0.4	0	0.6
.....	.....	.....	.....	.....	.....	.....	...	.....	.....	...
R93	1	No	Severe	Low	Yes	Range	0.4	0	0	0.6
R94	1	No	Severe	Low	Yes	Out of range	0.5	0	0.3	0.2
R95	1	No	Severe	Low	No	Range	0.2	0	0	0.8
R96	1	No	Severe	Low	No	Out of range	0.3	0	0	0.7

Table 3- Asthma suspicion by BRBES and expert

Patient ID	Signs and Symptoms					Expert system/BRBES output	Expert opinion/physician's opinion	Benchmark/ diagnostic result
	Cough	Breathlessness	Wheezing	Chest tightness	Respiratory rate			
P1	Yes	Moderate	Medium	No	Range	58.27%	65.0	1.0
P2	Yes	Mild	Medium	Yes	Out of range	79.48%	85.0	1.0
P3	No	No limitation	Low	Yes	Range	14.62%	24.0	0.0
P4	No	Severe	Medium	No	Out of range	68.67%	76.0	1.0
P5	Yes	Mild	High	Yes	Out of range	85.98%	90.0	1.0
P6	No	Moderate	High	Yes	Range	50.94%	57.0	1.0
P7	Yes	Mild	Low	Yes	Range	42.83%	50.0	1.0
P8	Yes	Moderate	High	Yes	Out of range	90.69%	95.0	1.0
P9	No	Moderate	Medium	Yes	Range	46.76%	56.0	0.0
P10	No	Severe	Low	Yes	Range	35.28%	45.0	0.0

## Results and Discussion

In this research, leaf nodes data of the BRB were collected from patients who suffer from asthma. Then the patient data were used in the BRBES to assess asthma suspicion. Expert opinion on the asthma suspicion was also collected as shown in Table 3. If a patient has asthma, then the benchmark datum is 1; otherwise, it is 0. The data set consists of fifty samples. For simplicity, data for only ten patients is presented in Table 3.

The receiver operating characteristic (ROC) curve can help effectively analyze the performance of the suspicion/diagnosis tests that have ordinal or continuous results [16]. It can be

used to test the results of the BRB Expert System and the manual system/expert opinion results by using the benchmark results. The system performance can be measured by calculating the area under the curve (AUC) [16–19]. If the AUC of the BRBES is larger than the expert opinion, then the BRBES produces more accurate and reliable results. Figure 5 shows the two ROC curves. One represents the suspicion performances of the BRB system prototype, and the other is the result of the manual system/expert opinion. The ROC curve with a red line in Figure 5 illustrates the BRB system asthma diagnosis while the curve with green line illustrates the manual system asthma diagnosis. The AUC for the BRB system prototype is 0.952 (95% confidence interval = 0.960–1.012), and the AUC for the expert opinion is 0.857 (95% confidence interval = 0.939–1.014). From the AUC of the BRBES and expert opinion, the AUC for the BRBES is greater than the

AUC for the expert opinion. This implies the results generated by the BRBES are better than the results generated by expert

opinion. SPSS 16.0 was used to construct the ROC curve and to calculate the AUC of the curves.

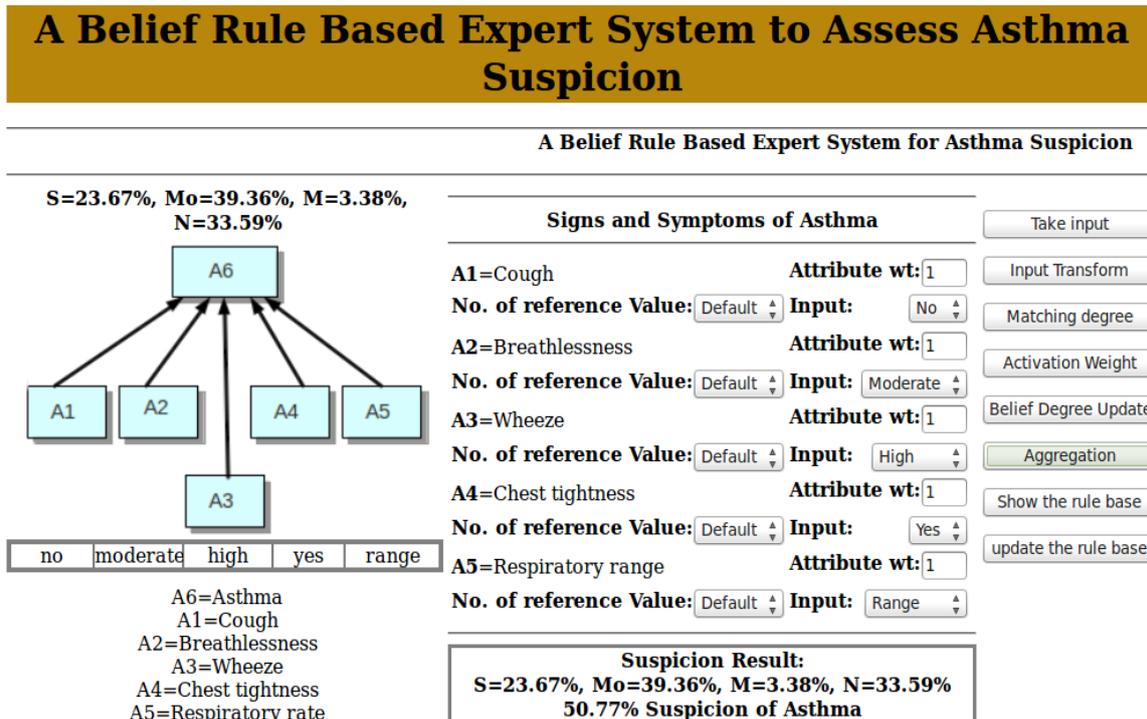


Figure 4- BRBES interface

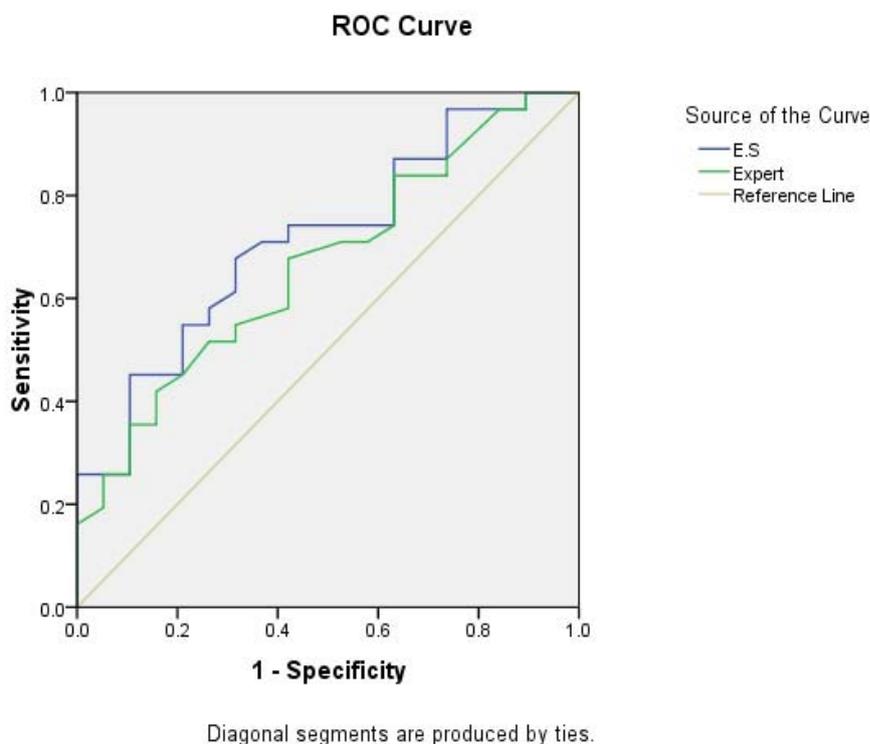


Figure 5- ROC curves of asthma suspicion between the BRBES and expert opinion (manual system)

The great achievement of our research is to overcome the uncertainty problem involved in diagnosing asthma, which cannot be overcome with the traditional rule-based system. The BRBES can handle various types of uncertainty such as ambiguity, vagueness, imprecision, ignorance etc.

## Conclusion

In this paper, we demonstrated the development and application of a BRBES to diagnose asthma based on signs and symptoms. This BRBES used a methodology known as

RIMER that handles various types of uncertainty found in domain knowledge. The BRBES is a robust tool that can aid in assessing asthma suspicion. The system will help patients assess improvement in asthma severity as well. This BRBES provides a percentage of the assessment, which is more reliable and informative than from a traditional expert's opinion that given without a degree of belief that is weighted with percentage value. Results generated by the BRBES were more reliable than the traditional expert opinion.

The system has strong potential in developing countries in Africa and Asia, in addition to other countries, where there is a lack of healthcare resources, diagnosis machinery and expert physicians.

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# Prototyping a Diet Self-management System for People with Diabetes with Cultural Adaptable User Interface Design

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## Abstract

*Diet management is a critical part of diabetes self-management. This project developed a working prototype application on Android-based mobile phone called SMART CARB that assists people with diabetes to self-manage their diet. The system particularly focused on monitoring carbohydrate intake in order to control their blood glucose levels. The project was positioned as a research extension to the development of the Few Touch mobile phone-application for diabetes self-management system that has been already in use. Food and meal are deeply embedded in local cultures. The project goal was to develop a prototype application that provides diet-self-management tools that reflect users' behavioral patterns and nature of food in their cultures. For the comparative case studies two cultural settings, Norway and Korea, were selected in order to understand differences in requirements from different food cultures that are critical for developing cultural adaptation mechanisms for the diet self-management system. Two versions of the application, one for Norwegian users and the other for Korean users, were developed with different interfaces reflecting the different natures of these two food cultures and user feedback was obtained through interviews with people with diabetes in these countries.*

## Keywords:

Cultural factors, Interaction design, Diabetes, Diet management, Mobile applications

## Introduction

Recently many mobile applications have been developed to assist people to enhance their health and healthy life behavior such as dietary monitoring and fitness assistance. People with chronic medical conditions such as diabetes require more rigorous control over their health conditions. Some mobile phone applications have been developed for monitoring glucose level and diet patterns in order to enhance self-management capability for people with diabetes. The application we have developed and implemented is one of such systems developed over the last several years on different device platforms and features for both diabetes mellitus Type 1 (T1DM or commonly called Type 1 diabetes) and diabetes mellitus Type 2 (T2DM or commonly called Type 2 diabetes) [2, 3]. It has been tested and used by several hundred people in Norway.

Feedback from users of our application suggested that some improvements were needed in the nutrition management module. With the rough categorization scheme of Few Touch (six different categories: low carbohydrate snack, high carbohydrate snack, low carbohydrate meal, high carbohydrate meal, low carbohydrate drink, and high carbohydrate drink) by low and high carbohydrate, users could not make a judgment where the food they consumed should be placed. In addition they wanted to have more detailed food information than just categories. Moreover the users wanted to know how different food types influenced on their blood glucose level.

Medical recommendations for both Type 1 and Type 2 diabetes include the areas of nutrition, physical activity, and medications. These are the main factors that affect the blood glucose level. Of these three factors, patients regard following nutrition recommendations as especially challenging due to their lack of knowledge, understanding or skills concerning diet management. Ahlgren et al. [4] said that in diabetes management, adjusting dietary lifestyle is often very hard for people with diabetes. According to the findings by Nagelkerk et al. [5], 'Lack of knowledge and understanding of a specific diet plan' was ranked top as the perceived barrier by twenty-four people with Type 2 diabetes. They need to have a good understanding of the diet regimen for their successful diet management [6].

Successful implementation of dietary management systems therefore requires consideration on factors such as user acceptance, motivation, usability, learning as well as basic functionality of the system. Dietary patterns are deeply embedded in people's lifestyle and underlying food culture. People have different ways of living, understanding their environments, managing daily activities, motivating themselves, etc. Particularly people living in different culture have different living environments, history, social settings, value systems and different ways of viewing and thinking. Such cultural difference influences every stages of human action cycle that is modeled as "the seven stages of interaction" by Norman [7]. In order to enhance people's acceptance of a new technological solution and its sustainable usage, design of interactive systems such as dietary management applications needs to adapt to and accommodate cultural differences.

The goal of the project was to develop a prototype mobile phone application that provides a platform for studying different cultural needs for dietary management as a part of the diabetes self-management. This paper presents the results of the project.

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## Materials and Methods

An android-based smart phone prototype application, SMART CARB, was developed as a potential extension of Few Touch mobile diabetes management system in order to help people

with diabetes make better choices in selecting food items and improve their nutrition management. This prototype can also be used as a platform to further explore culturally adaptable solutions for diabetes self-management systems.

For the comparative case studies two cultural settings, Norway and Korea, were selected in order to understand different requirements of the two cultural groups, particularly on food and food related activities that are critical for developing cultural adaptation mechanisms for the diet self-management system. Each version was tested with people with Type 2 diabetes in the corresponding country and the study produced important information for future research and design of a mobile diet self-management application in different cultures.

In the initial phase after setting the general goal of this project, in order to figure out the current status of the related research fields and to obtain future prospects, academic literatures about mobile terminal-based tools for diabetes diet management, food in different cultures, general cultural issue in UI design were reviewed. In parallel to the literature research, a series of interviews were conducted to elicit expert opinion about self-diet management for people with diabetes. Unstructured interviews were held with nutritionists in Norway and South Korea. Few persons with diabetes who participated the previous Few Touch development project were also interviewed. In the second phase, requirements and specifications for the system development were generated based on the findings from the first phase. Then the following phase, prototype models with different media, first paper much with sketches, then Excel prototype models with more details were developed. Informal evaluation by a person with diabetes who is familiar with diet and glucose level management applications made a final adjustment of ideas before the real system prototyping. Two versions, one for Korea and the other for Norway were developed. The two versions were then used for interview sessions with people with diabetes in respective countries for acquiring feedback regarding cultural adaptation of each version.

## Existing Research

Applications (apps) developed for use on mobile phone platforms offer potential to address the challenges that are associated with the chronic disease, diabetes – both Type 1 and Type 2 [8]. There are a growing number of research publications and applications around diabetes self-management support, and advances in information and communication technology (ICT) provide a variety of options for developing efficient hardware and software platforms. Mobile phones provide a promising foundation for developing cost-effective diabetes systems that can be incorporated into diabetes patients' routines. However, research on usability and suitability in different cultures with a focus on this domain is difficult to find.

Mobile phones have proven to be a helpful tool for the self-treatment of diabetes [9, 10]. Our research have been focused around the Few Touch Application concept, a mobile phone system that has been developed and tested as a tool for research and assistance in self-management for people with Type 1 and Type 2 diabetes (T1DM and T2DM) [2, 3]. The system emphasizes ease of use through the application Diabetes Diary, where automatic wireless transfer of blood glucose values from the blood glucose meter using Bluetooth, and physical activity-, nutrition- and medication data captured through a simple user interface. Trials have shown a high degree of user adherence, with many users expressing their wish to use the tool after the trial. Many users also reported health benefits from using the system. However, feedback has also revealed the need for general food information that is useful

for managing their health conditions as part of a mobile phone-based tool.

In their recent review of mobile-phone-based apps for diabetes management, Goyal and Cafazzo [11] concludes that “fully harnessing the capabilities of smartphones to deliver real-time feedback, diabetes education and secure data sharing remains largely underexplored” – which also is true for the nutritional functionalities part of such apps. Suggestions such as mobile systems including digital image recognition technology described by Hu et al. [12], nutritional behavior change interventions for young adults described by Hebden et al. [13], mobile phone messaging interventions where healthy nutritional reminders were part of a type 2 diabetes prevention programme described by Ramachandran et al. [14], and a PDA-based nutrition monitoring intervention using barcode scanning combined with voice recording described by Connelly et al. [15]. All these are good examples on innovative mobile nutritional systems and illustrates the variety of possibilities.

A mobile phone based system for supporting lifestyle changes among people with type 2 diabetes, the application has been designed and tested on a cohort of 12 patients [2, 3]. This application comprises a blood glucose monitor connected to a Bluetooth adapter, a tailor-made step counter, a nutrition habit registration system, and a system for practical tips. Feedback received from participants after a 6-month trial of the Application, indicated that there is a need for information related to calorie-rich food in order to enhance practicality of the system use.

## Cultural Issues in the design of mobile phone-based systems

Food is an important factor of culture. In different cultures, people attach different meanings to events and objects in their daily lives and develop their unique patterns of behavior, significance, interpretation and rituals. In Norway, cold food for breakfast and lunch and hot food for dinner is a common pattern. Some also include a cold supper if they have an early dinner. In Korea every meal usually includes some hot food although Korean meal traditionally includes many cold side dishes.

Culture may be defined as ‘Cultivation of individuals through the agency of external forms which have been objectified in the course of history’ [16]. There have been many academic arguments and definitions made around the term “culture” from different perspectives including anthropology, sociology, philosophy and psychology [17]. The term culture can be used in a simple pragmatic way to indicate ways of living, including food, customs, language, etc. An interesting exhibition ‘East Meets West – Differences of German & Chinese,’ by Yang Liu [18], illustrated some different viewpoints from people in Germany and China, with simple diagrams for example, contrasting social relations, behavioural patterns, and characteristics of meals between the two countries.

## Theoretical Frameworks of Cultures

In design, in order to better understand people's needs in different culture and create a better way to make technology accessible, acceptable and effective in the cultural context, frameworks of cultures have been often referred and used by designers. Some frameworks are more suitable for certain types of design problems and more practical implications. Examples of such frameworks are Hall's framework [19] with four dimensions, time, context, message speed and space and Hofstede's framework “five dimensions of culture” [1] that explain how the dynamics of culture influences individual and organizational behavior.

Hofstede's framework is composed of five dimensions: 1) Power Distance Index (PDI), 2) Individualism versus collectivism (IDV), 3) Masculinity versus femininity (MAS), 4) Uncertainty avoidance (UAI), 5) Long-term versus short-term orientation (LTO), 6) Indulgence versus Restraint (IVR). This framework has been applied in many areas such as marketing, organization, services and policies. With a focus on organizational culture, the framework has been further developed to a framework with eight dimensions. Table 1 shows a comparison of behavioral patterns possibly exhibited by weak and strong UAI groups.

*Table 1 - Comparison of example behavioral patterns based on the difference on uncertainty avoidance (adopted from [1])*

Weak UA	Strong UA
People feel happy	People feel less happy
There are more nurses but fewer doctors	There are more doctors but fewer nurses
Teachers may say "I don't know"	Teachers are supposed to have all the answers
In shopping, the research is for convenience	In shopping, the research is for purity and cleanliness
Risky investment	Conservative investment

Nisbett [20] revealed the difference in the pattern of viewing information between Asian and American through his eye tracking pattern experiments. He interpreted the resulting differences between the two groups as a representation of difference between holistic versus analytic ways of viewing the world.

These theoretical frameworks offer system designers conceptual foundations and tools for understanding cultural difference and for further investigating specific design issues and designing specifications for interactive systems design. For example, cultural frameworks could be effectively applied for answering design questions such as how information should be presented and how navigation should be structured. But such information should be used in combination with rigorous user studies looking into more specific use issues in the overall system operation context. There have been many studies done in UI design areas to produce general design guidelines for cultural UI design (for example, [21-23]). Marcus, for example, thoroughly interpreted Hofstede's framework for practical UI design [21].

### Cultural Background of Diet Management

In this research, the focus was on the issue of how the mobile application for diet management can make an easy access to its food database and effective assistance for entering meal data. Within this scope of the interest, types of ingredients, food items, categorization schemes of food items, and the way of assessing the amount of food in different cultures are primary elements that provide a basis for cultural differentiation of the user interface. Types of food regularly served in particular regions or countries are often available on databases provided by government agencies or private organizations. Regardless of how databases categorize food items, people develop their own categorization schemes and associations between food items based on various cultural aspects includ-

ing daily meal patterns, distribution, associated events, and preparation methods.

Norwegians eat a mix of cold and warm meals. Contemporary Norwegian breakfast typically serves cold food with possibly hot drink; lunch most commonly consists of cold sandwiches; and dinner includes at least a primary warm dish although sometime it is simplified to a cold supper. South Koreans often have three warm meals. Food categorization methods in Norway and Korean are also different. Norwegian food items are more often categorized by food type. However Korean food items were categorized both by cooking types and by food types. Measuring methods of food amount are also different in the two countries. Different reference units for displaying the amount of carbohydrates were used for Norwegian food and Korean food due to different characteristics of food items and serving.

Culture changes over time by its internal evolutionary forces and external forces from other cultures. Food types and meals have been changed fast in recent years by social changes such as urbanization, industrialization, globalization, information accessibility etc. Therefore the difference of food cultures is caused by many other factors besides regional and ethnic traditions. As a result even within a country many cultural groups can be identified with different differentiation factors such as life styles, food preference, and meanings of meals.

## Requirements and System Specifications

### Source of requirement

Previous work [2, 3] provided the main source of requirements regarding food registration. People with diabetes were recruited for this previous research and the group has been working on diabetes self-help tools. From the participants' feedbacks, it was found that they wanted to have more advanced tool for nutrition management. This project was initiated in response to this user need.

More detailed information about the food they eat, and a function that enables them to know the influence on their blood glucose level by changing their dietary habits are the main focuses for improvement.

A paper prototype was made first. Then an Excel prototype was built based on the initial idea informed by literature research. Since most of the functions of the system are based on simple calculation, Excel was used as a tool for making rapid prototypes. To get Experts' feedback and opinions about the Excel prototype, a meeting with a nutritionist was held. Requirements and points to improve were discussed at the meeting. Based on the feedbacks from the nutritionist, second version of the excel prototype was developed. A person with diabetes was also invited in testing excel prototypes to evaluate prototype concepts, then four versions of the next round excel prototype were sent to the same person for evaluation. The areas for improvement were discussed through phone and Skype. Some requirements that he indicated were adopted. Regarding other requirements such as how to categorize the food items and select food items included in the app, e-mail advices from the nutritionists both in Norway and South Korea were also adopted.

Then a simple Android mobile application was developed with the improved design specification. This prototype includes 24 Norwegian food items based on the fifth excel prototype to check the application's usability. The design was done by the app inventor designer and tested using the android emulator.

## Information and Navigation Structure for Selecting Food Types

Different food cultures use different ingredients, combinations of use, processing methods, and serving methods. Therefore people's association patterns between even same ingredients are different. Different categorization methods of food types were used for quick search and access in the Norwegian version and the Korean version. Norwegian food items were categorized primarily by food type and Korean food items were categorized by the way to cook.

The following categories were used in the Norwegian version: Bread, Meat and fish cold cuts, Cheese, Breakfast corn and porridge, Milk and Yogurt, Drinks, Sugar, honey and jam, Fruits, Vegetables. These categories were selected and organized based on discussions with a Norwegian nutritionist. Oil, butter, margarine, mayonnaise was excluded in the categories because only small amount of oil is used compared to other types of food items. However some food items such as salami, cooked ham and white cheese, which do not have any carbohydrates, were included in categories as well. Because the SMART CARB application also addresses the need of self-learning, these foods items with no or negligible amount of carbohydrate were included. Although overall diet pattern is important for all of us particularly people with diabetes, SMART CARB as a prototype only implemented carbohydrate-monitoring functions for simplicity.

The following categories were used in the South Korean version based on Korean nutritionist's consultation: Rice/Porridge, Soup/Stew, Kimchi/Pickles, Herbs/Seasoned food, Steamed food/Boiled food, Fried food/Grilled food, Fried food, Noodles/Dumplings, Drinks, Fruits/Vegetables, Rice cake/Bread. The categorization of food item was discussed with a Korean nutritionist through e-mail.



Figure 1 - Opening screen for the Norwegian version (left) and the Korean version (right).

### Selecting food items

Due to the different food culture and dishes that normally are served in Norway and in Korea, different food items were included into each application. For the Norwegian version, the Norwegian table of food "Matvaretabellen" was used to select food items and to provide the amount of carbohydrates in the food items. Since only bread-based meal type was regarded in the Norwegian version, 118 related bread meal food items were selected. (As mentioned above, most Norwegians have a cold, mostly bread-based, 1<sup>st</sup> and 2<sup>nd</sup> meal.) The 150 most Scandinavian Conference on Health Informatics, August 21-22, 2014, Grimstad, Norway

common and popular food items were selected for the South Korean version. These items and the information about the amount of contained carbohydrates from a smart phone application 'Calorie Codi' developed by the Korean food and drug administration were used.

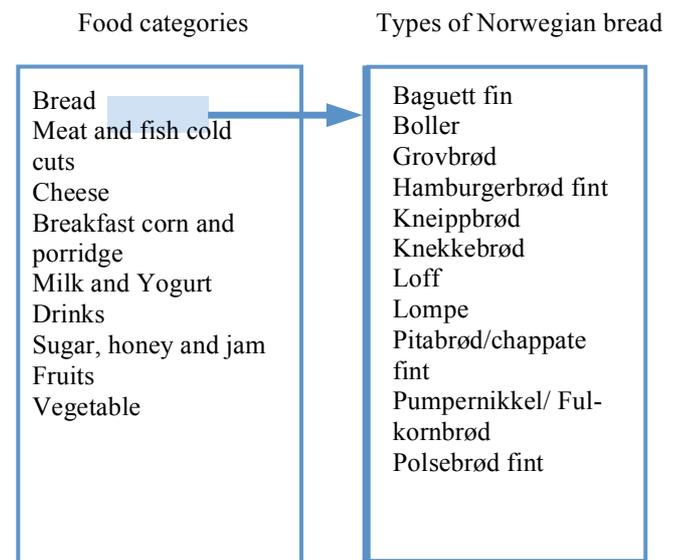


Figure 2 - Categorization of food items in the Norwegian version. When "Brød" (Eng., bread) is selected, the list with types of bread (to the right) appears.



Figure 3 - Categorizing of food items in Korean version.

### Measuring amount of food items

The SMART CARB application also had to take into account the differences in measuring methods for the food portion. In the Norwegian version estimations are based on weight. In the South Korean version the estimations are based on portions. It is easier to measure the weights of Norwegian food items with scale since the form of food items for bread meal type is easy to weigh. However it's difficult to weigh Korean food items because there are many liquid food items such as soup, stew, etc. Due to the characteristic of food items, different portion sizes were used for Korean food. Therefore standard portion sizes were used in the Korean version and 100 gram portions was used in the Norwegian version as the reference unit for displaying the amount of carbohydrates.

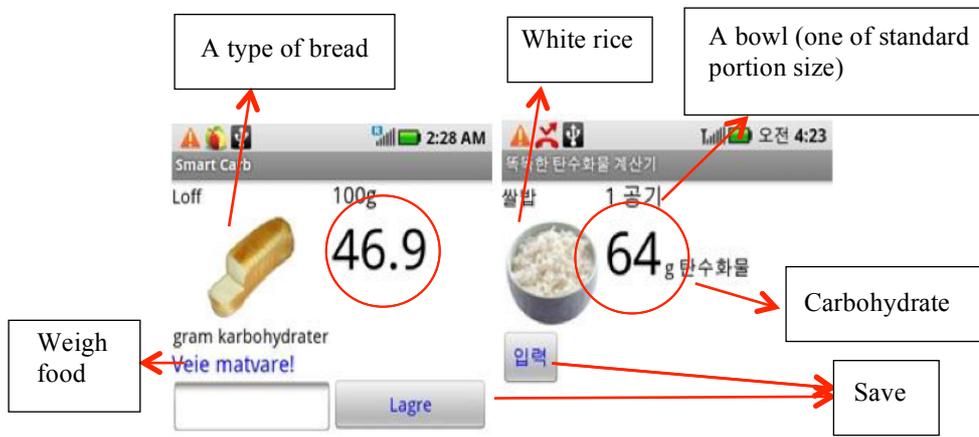


Figure 4 - The Norwegian version with weight (in 100 g) (left) and the Korean version with standard portion size (right).

## Design and Prototype Development of SMART CARB

### Basic Functions and Use case

After the information to be displayed on the graphical user interface was identified, paper prototypes and Excel prototypes were developed based on the accumulated information. A meeting with nutritionist was held to get feedback about the developed prototypes and to discuss the points that should be improved. The prototype was then further improved based on the advices from the nutritionist. A UML use case diagram was built to outline the scope of the prototype.

#### Opening screen

Different food pictures were used for the opening screens. The displayed food items represent the different characteristic of food in Norway and South Korea.

#### Categorizing Food Items

Different categorizing methods were used for easy follow-up and quick finding in the Norwegian version and the Korean version respectively. Norwegian food items were categorized

by food type and Korean food items were categorized by the way of cooking.

#### Task Flow

Figure 6, left, shows the flow chart for the use of the Norwegian version of Smart Carb. For the food items in 'Drink' and 'Milk and Yogurt' categories, empty glass should be weighed first, before the food item with glass are weighed for the first time users and occasional calibrations.

Even for Norwegian version, it is too demanding and troublesome to carry around a scale and weigh food at a table. Weight

can be still used for entering food amount but by using conversion table or some references for accurate estimates. It is ok for sandwiches but Norwegian each other types of food too.

The South Korean version of Smart Carb is presented in Figure 6, right. The difference is that there is no process of weighing food items in the South Korean version. Thus there is no process of weighing empty glass, either. Due to the characteristic of the South Korean dishes, it is difficult to weigh the food items. Instead of weight, standard portion sizes are displayed with the amount of contained carbohydrates of the selected food items.

#### Case Study and User Feedback

To compare the perception of this application from a comparative point of view, interviews and usability tests were conducted in Norway and South Korea. Interviews were held with this android mobile phone application by showing how to use the application first and then letting them try the application. Seven and 20 participants with Type 2 diabetes were involved in individual interviews in Norway and in South Korea, respectively. The age range of the subject group was between 40 and 80 years old. The participants were also requested to fill out a questionnaire at the same place before interviews to see the condition of their nutrition management and their level of satisfaction.

'Smart carb' was introduced with a PowerPoint file. This presentation included the purpose of 'Smart Carb' application, the procedure of using the application, examples of screen shots by following step by step, required amount of carbohydrate per day or per meal and practice with some typical diet. To give participants a better impression they practiced 'Smart Car' application with supervision and to enhance the reality, real food items were used. Below are the food items, which were displayed:

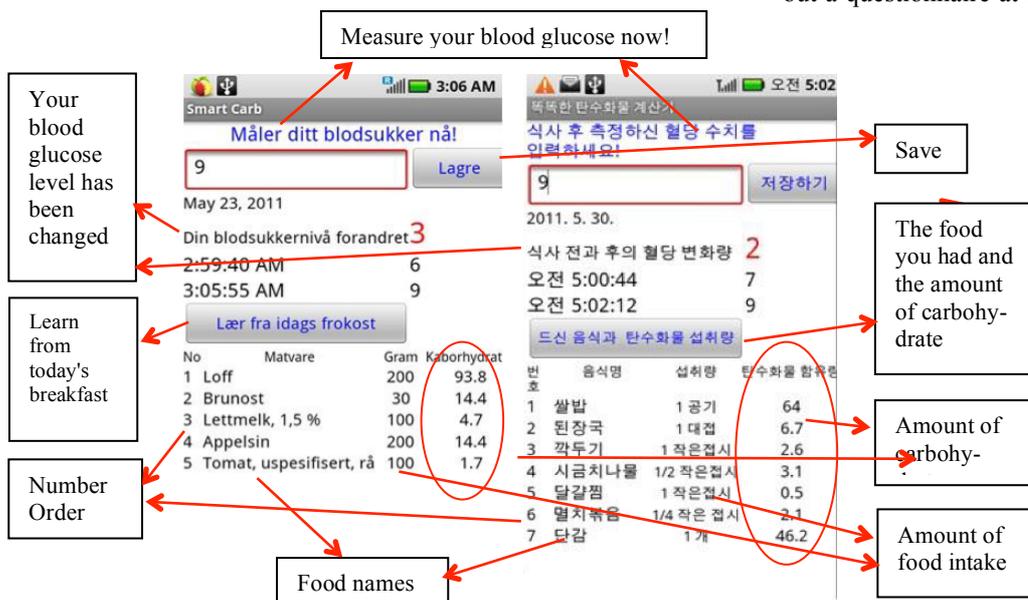


Figure 5 - The amount of food intake by gram (Norwegian, left) and the amount of food intake by portion (South Korean, right)

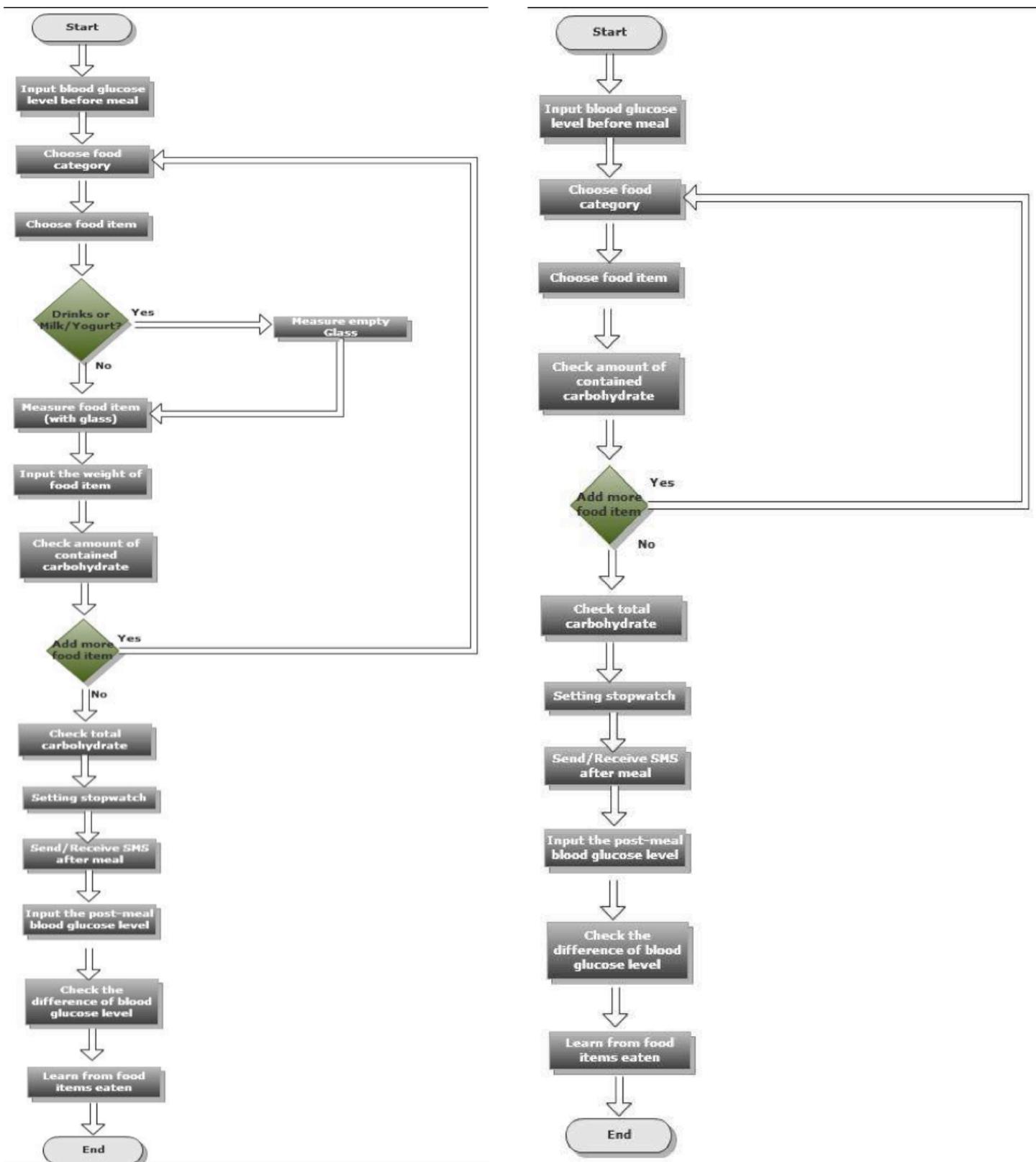


Figure 6 - Flow chart for Norwegian version (left) and. South Korean version (right)

- Bread: 2 boller, 3 slices of bread
- Topping: 3 slices of boiled eggs, 3 slices of white cheese, 2 slices of salami, 2 slice of ham (2 types)
- Vegetable: cucumber, tomatoes
- Fruits: 1 mandarin, 1 apple, 4 slices of orange, half kiwi, green grape, strawberry
- Drinks: milk, orange juice, 2 bottles of soda
- Equipment: 1 empty glass, scale

When the participants tried Smart Carb application, they were allowed choose the food items they would like to eat for their meal. They weighed each items with scale and registered the weights of the food items into the application.

However no real food item was used for the Korean participants' practice because Korean food items are difficult to weigh. Serving portion was displayed for users' reference instead of weigh the food items. The Korean participants found the food items which they wished to eat in the application and checked the carbohydrate amounts in default portion size. Then they registered the food items.

User feedback was collected through usability test sheets and verbal interviews.

The Norwegian participants who had experience with the 'Few Touch application' [2, 3] expressed a strong willing to use this application. However the Korean participants who did not have experience with such kind of application and the smart phone itself, were skeptical or afraid of using this application. Most of the participants agreed on the importance of tracking the amount of carbohydrate intake, and expressed difficulty in estimating the amount of carbohydrate in food items. Therefore they wanted to have a tool to help them to estimate carbohydrate amounts.

Lessons learned through the interviews are as follows:

- Difficulties in behavior change are reported in terms of nutrition habit
- Concerning tool features, customization or modification based on personal data or users' skills is considered important and beneficial
- Timely, automatic and personalized feedback should be incorporated in a motivating and easily interpretable manner
- A system showing nutrient and calorie content is considered powerful if it contains enough variety and numbers of food and drink items that are familiar to users
- Simple categorization for recording nutrition habits was well accepted and appreciated for routine use, but some participants consider such categorization too coarse).
- Photographs of food and drink items are considered useful, especially if they include a scale or familiar cutlery as a reference of size, for adjusting portion sizes.

## Conclusion

This paper described the process of developing a mobile application for diet self-management, SMART CARB, with a focus on users' cultural difference. The way cultural factors were incorporated in the solution to enhance accessibility to information and data entry for people from two cultures, Norway and Korea. Because of the very different food cultures, two versions of user-interface were built with the same platform with the same concept to enhance user's awareness about calorie intake and nutrition in general. Several versions of prototypes including the final working prototype application were developed and used to get feedbacks from potential users and experts. Each patient's nutrition management and the level of satisfaction with the application presented to him or her through the process were recorded.

This application enables the user to learn effects of diet patterns on blood glucose level by providing carbohydrate Smart Carb represents a self-help tool for people with diabetes which can provide rich information regarding nutrition management. The paper presents an attempt to test a nutrition self-management mobile phone based application for people with diabetes in different cultures.

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# Abstracts



# A Success Story about a Communication Reform in the County of Sogn & Fjordane

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## Introduction

The project "Meldingsløftet Sogn & Fjordane" worked to introduce electronic messaging between local health services, general practitioners (GPs) and specialist care in the county of Sogn og Fjordane. A checklist was developed and all 26 municipalities enrolled in the project in the first phase. By June 2014 all municipalities had established electronic communication between local health services and GPs, and between local health services and specialist care. The aim of this study is to evaluate the project and the introduction of electronic messaging. Only two years ago, when the first stage of electronic interaction in health services between GPs and hospitals in Sogn & Fjordane was evaluated, it was the long and winding road that dominated: years of challenges and delays (Larsen & Skogseid 2012). This time the evaluation tells about a project that fulfilled its goal in time with motivated and proud participants – in short, it is told as a "success story".

## Materials and Methods

The evaluation is based on interviews with project groups in seven municipalities involving local health care, GP, and ICT. They represent variations in population (< 2000 to > 11000), regions, as well as different ICT systems for health care services. A semi structured interview guide followed the structure of the initial checklist and its main areas, asking project groups to share their experiences regarding external cooperation, technical challenges, establishment of routines, training, incident reporting and budget, as well as their overall impression of the project. We also asked the project groups about effects of electronic communication, and finally, about drivers and barriers affecting the process.

## Results

The system for electronic messaging was new for the local health services and they had little knowledge about the system when they started: "*Here we are, amateurs, meant to accomplish something that we don't even know what is.*" But still we met an extraordinary positive attitude in the project groups, as also documented in their self-evaluation on a scale from 1: 'very poor' to 5: 'very good' on questions of satisfaction concerning project progress, technical installations, establishing routines, technical training, and professional training. Two of the project groups scored an average of 5, one scored 3, and the rest scored an average between 4.2 and 4.75. Together with claims like "*this wasn't difficult*", "*everybody wants this be-*

*cause they see it is sensible*", the overall impression of the project is that it worked very well. One of the success factors in the project was two municipalities acting like pilots both in this project and in the larger project *Vestlandsløftet*. The pilots were dealing with technical issues and contributing with knowledge, experience, user manuals and routines, as well as being motivators. Despite an average score of 4.1 among all groups on the question of technical issues, all project groups reported about initial technical challenges, problems with addresses on the Norwegian Health Network as the most severe issue. However, once the initial technical challenges were solved it was all running smoothly: "*the breaks were on the technical part*"; "*it wasn't hard getting people involved*". Despite the support from the pilots, the project groups emphasised that they had to learn and adjust as they went along. This "learning by doing" meant that local "*super users*", "*enthusiasts*" and "*people who want something*" were important. All project groups agreed that the new system increased the quality of health care, mainly by turning previous oral messages into written communication, but also by improving contact between local health care, GPs and specialist health care. The odd voice that stood out was one project group that did not see major improvements, but rather a time and resource "thief", as the small municipality already enjoyed good communication between health care units.

## Discussion: What makes this a success story?

"Meldingsløftet Sogn & Fjordane" completed its mission, making S&Fj among the first counties to complete the triangle of electronic messaging between local health services, GPs and specialist health care. Compared to the earlier project with delays and lack of motivation, this project is a success not only due to the actual achievements, but also due to the attitudes. Almost the same words are chosen by one of the pilot groups as we heard from the specialist health care: "*It has been incredibly fun to work with this project because people can see the benefits!*" The stories from the project groups are filled with examples of health care workers' will to participate, cooperation between institutional sections and ICT experts, ability to adjust, and not the least, satisfaction and pride: "*We have become proud of ourselves.*"; "*People are proud of working here.*"

## Acknowledgments

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# Information Technology Managers and Critical Success Factors in Healthcare Organizations in Nordic countries

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## Introduction

Many studies have attempted to identify the success factors for Health Information Technology (HIT) implementation. Unfortunately, such success factor lists are long and unwieldy, and it can be difficult to see which ones should have received more attention than others. Thus, there is a need to examine critical success factors (CSFs) that should be most attended to in the context of competing priorities. IT managers, through their experience, can know best which relevant factors have been crucial for successful implementation of the projects; therefore, it is imperative to understand the perceptions of IT managers regarding relative importance of success factors in HIT implementation. This research aims to reassess and synthesize CSFs influencing HIT implementation, focusing on the question: “What are the CSFs in HIT implementation from IT managers’ point of view?” We surveyed the IT managers in four Nordic countries (Denmark, Finland, Norway and Sweden) and discuss the preliminary results regarding IT manager background and the CSFs in this research-in-progress paper.

## Materials and Methods

The questionnaire was based on a literature review, which identified and extracted 15 success factors for HIT implementation. The questionnaire was pilot-tested and revised into a total of 25 factors. The questionnaire was translated into Danish, Finnish, Norwegian and Swedish and sent to IT managers in healthcare organizations in these four Nordic countries. Since no comprehensive source of information was available on IT managers in the healthcare organizations of these Nordic countries, the list of research subjects was created manually. We used two methods to find the respondents. The first focus group comprises people who were found directly by the researchers. The second focus group was composed of contact persons in the target organizations who were asked to forward the questionnaire to IT managers in their hospitals. The survey duration was two months and a total of 94 responses were received which equals to a 30.42% response rate. Uniform criteria were used to screen all the respondents and a total of 91 respondents were included.

## Results

The average age of the respondents is 50.42 years old and thus they had extensive experience in the field. The proportion of female IT managers overall was 36%; however, 92% of Norwegian IT managers were male. The most common education background of the respondents was technical and very few IT managers had the clinical background. Almost 60% of respondents had held management positions prior to becoming IT managers. Norway had the highest number of IT managers employed from inside the organization (67%) while Denmark had the highest number of external hires (64%). The survey resulted in a CSFs list which priorities the mean of the ranking made by IT managers in healthcare organizations of the four Nordic countries. The top ten CSFs were: (1) commitment and support of leaders, (2) system quality, (3) end-user participant, (4) information and service quality, (5) infrastructure, (6) department cooperation, (7) resources, (8) staff training, (9) co-development of the system and workflow, and (10) vendor cooperation.

## Discussion

This research indicates that surveyed CSFs in Nordic countries are relevant to HIT implementation projects and can therefore be used as a checklist across countries. However, it also indicates that Nordic IT managers have certain differences in perceptions (Cronbach-alpha test indicates the data is reliable). For example, “openness of the organization to the change and innovation” was judged more important in Sweden, and “the role of incentives and regulation in promoting HIT” was seen as more important in Denmark compared with the other countries. While organizational type does not appear to play a role, these differences may result from subtle variations in the healthcare system or organizational features, for instance, and therefore, future research is needed to account for these contextual issues.

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# Electronic messaging-a contribution to fulfil the Coordination reforms intentions of coherent, seamless, coordinated and safe health services?

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## Introduction

Patient information is exchanged between different levels of health care to provide new health level with adequate information in order to secure a seamless and continuous healthcare.

All municipalities are now able to communicate electronically by e-messages. Will this help nurses to produce, send and receive adequate and correct information in electronic messages – and thereby contributing to an adequate and safe patient care?

This projects objective is to assess the information quality of electronic messages and in particular if the information received meets the recipient's need of information to customize patient treatment and care.

## Materials and Methods

The project made requests to one hospital coordination manager and 5 interaction coordinators in a region in Norway, who communicated the projects request for participants to the two sub-studies, to appropriate hospitals and municipalities. Some participants were recruited one by one by e-mail.

In sub-study 1, the Delphi study, 17 nurses and other experts from community health services and hospitals were recruited. The group also included other experts on the subject e-messages. In sub-study 2, the quantitative study, 10 hospital wards, including 22 nurses participated from one hospital in the region. 8 municipalities and 23 nurses and caseworkers from the community health services were recruited to participate.

The aim of the Delphi study was to define indicators related to the content quality of e-messages.

The results from sub-study 1 were qualitatively analyzed. The identified indicators were transformed into variables in two separate assessment scales, one for each chosen message ("admission report" sent from the municipality health care when the patient is admitted in hospital, "health information" sent from the hospital when the patient is ready to be discharged). The scales had 11/12 variables, and most of them could be answered on a scale from 1 (lowest) to 9 (highest). 2 variables had a yes/no choice, and the last variable provided an opportunity to comment.

In sub-study 2 nurses and caseworkers used the scales to assess the information quality in real life received messages.

## Ethical considerations

The ethical committee at the faculty approved the study. The study was reported to the Norwegian Social Science Data Services (NSD).

## Results

After four iterations in the Delphi study, the participants were presented to three tables with the final results concerning the indicators of quality. The participants gave a verification of the lists as they appeared. The results are shown in table 1.

Table 1- results Delphi-study, question 1 and 2.

Question 1, Delphi. What do you think constitutes good quality in an e-message? Mention 5 key words.	SUM
Updated medical information and diagnosis	31
Assessment of function, level of care and further help needed	26
Correct recipient	23
Precise and understandable language	22
To define a clear issue	20
Function descriptions	19
Planned treatment	15
Medical information	16
Sequence of events	13
Relevant information	9
Patient resources and goals	7
Question 2, Mention five key terms you think should be included in the free text area, Delphi, Admission Report.	SUM
Special conditions such as ulcers, diets, allergies	9
Current situation / cause of hospitalization	8
Medicine given today	6
Scheduled date of discharge	6
Rehabilitation potential	5
The patient's self-care skills / resources	4
Further follow-up appointments after discharge	4
Risk of falls, pain, nutrition status	3
Treatment / care, including drugs	3
Mobility / limitations	3
Inpatient examinations / results.	1
Need for facilitation / aids	0
Information on new prescriptions / new medicine supplied at discharge.	0
Question 2, Mention five key terms you think should be included in the free text area, Delphi, Health Information.	SUM
Planned discharge date	21
Further follow-up appointments after discharge	20
Inpatient examinations / results	20
Treatment / care, including drugs	14
Mobility / limitations	13
The patient's self-care skills / resources	11
Current situation / cause of hospitalization	11
Special conditions such as ulcers, diets, allergies	10
Rehabilitation potential	9
Risk of falls, pain, nutrition status	7
Medicine given today	6
Further follow-up appointments after discharge	4
Need for facilitation / aids	5

An overview of the total number of sent and received messages in sub-study 2 is presented in table 2.

Table 2- the overall number of sent and received messages in the period

	The overall number of sent messages	Assessed messages in the survey	Percentage (of total messages) assessed in the project	Number of participating hospital wards / Municipalities
Admission Report	207	51	24,64 %	10 hospital wards
Health Information	609	132	21,67 %	8 Municp.

### Admission Report:

Table 3 presents the nursing variables in the Admission Report, average score in ascending order.

Table 3, Admission Report

Admission Report, Descriptive Statistics				
		N	Mean	Std. Devia-
Var. 5	To what extent does the message contain information about nutrition / diet?	46	3,37	2,855
Var. 4	To what extent does the message contain information about specific conditions such as sores and allergy / Cave?	40	3,67	3,125
Var. 6	To what extent does the message contain information about the patient's mobility, possible risk of falls?	49	5,16	3,118
Var. 8	Overall- to what extent is the message data of sufficient quality according to your need of information?	49	5,80	2,614
Var. 3	To what extent does the message contain information about the patient self-care ability and resources?	51	5,90	2,730
Var. 1	To what extent does the message have a clear problem / information about current situation?	51	6,12	3,356
Var. 2	To what extent does the message contain information about the patient's level of functioning and need of assistance?	51	6,16	2,788
Var. 7	To what extent does the message have a precise language?	50	6,92	2,346
	Valid N (list wise)	35		

### Health Information:

Table 4 presents the nursing variables in the Health Information message, average score in ascending order.

Table 4, Health Information

Health Information, Descriptive Statistics				
		N	Mean	Std. Deviation
Var. 4	The extent to which the message contains information on follow ups and appointments after discharge?	125	4,62	3,167
Var. 2	The extent to which the message contains information about the treatment, including given medication during stay?	129	5,52	2,670
Var. 1	The extent to which the message contains information about the patients level of functioning, further needs for assistance, if necessary- aids?	130	6,28	2,559
Var. 7	Overall- to what extent is the message data of sufficient quality according to your need of information?	132	6,52	2,435
Var. 3	To what extent has the message timely and adequate information on discharge date?	127	7,09	2,918
Var. 6	To what extent does the message have a precise language?	130	7,95	1,704
Var. 5	The extent to which the message contains information about admission cause / issue?	131	8,15	1,756
	Valid N (list wise)	121		

The respondents in sub-study 2 indicate that a high percentage of the assessed messages do contain faults and deviations, see table 5.

Table 5- messages containing faults or deviations, shown in %.

Do you consider that the message contain fault or deviations?	Yes	No
Admission report	47,10 %	52,90 %
Health information	45,00 %	55,00 %

Even with major deficiencies, 60-70 % of the participants indicate that deviations will not be reported.

Conducted factor analysis supports the assessment scales` reliability and validity, and indicates that the variables measure the same underlying phenomena.

## Discussion

The quality of the information in "Admission Report" and "Health Information" is varying - and sometimes even has poor quality. The overall impression is that the information in e-messages to a certain extent may be incorrect, incomplete, and inconsistent or delayed, and that there is a clear potential for improvement. The information quality in e-messages must be improved to ensure the exchange of vital patient information. The overall impression also includes the fact that faults and deficiencies in e-messages must be reported- if not a vital area of learning to improve the content will be ignored. It may be questioned whether the channel (the message templates/standards) is good enough, or if the overall methodology is well enough established. It is certainly a fact that obtaining information from multiple channels is time-consuming and ineffective, and may even threaten patient safety. With this backdrop, it may be suggested that e-messages do not always work as intended.

There is a plethora of information nurses must consider before sending a message, and checklists/guidelines based on this projects indicators could probably be of help in improving information quality in e-messages.

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# Design and Development of a Smartphone Application for Cue Exposure Treatment

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## Introduction

Individuals with alcohol dependence have high relapse rate after outpatient treatment when confronted with alcohol related cues in real life. Cue Exposure Treatment (CET) is a method focusing on confrontation with alcohol cues in order to reduce cravings as well as the likelihood of relapse. The standard aftercare treatment is delivered via regular appointment with therapists, which consume time and clinical resources. We have formulated a study to investigate whether a smartphone based CET could increase the efficiency of cognitive behavioural treatment of alcohol dependent individuals. The smartphone app of CET has been developed based on a multidisciplinary collaboration involving patients, therapists, psychologists, psychiatrists, designers and engineers. This abstract describes the design and development of the app.

## Materials and Methods

The initial structure and content of the treatment is designed by psychiatrists and psychologists according to a comprehensive literature survey on alcohol cue exposure studies. Designers start the sketches, and build the first prototype. After several user tests with psychiatrists, psychologist and therapists, a detailed structure of the program is confirmed. Then engineers and designers develop the app and test it among patients. Based on the feedbacks, a final version of the CET app is developed and will be used in future studies of testing its feasibilities and efficiency. The open-source Linux-based operating system Android was elected as the platform to develop the smartphone app. A customized version of Java in Eclipse (Oracle Corporation, Redwood City, CA) is used as the main programming language, and an online server is registered for database and monitoring of the treatment process remotely.

## Results

The CET app includes four main-sections: Introduction, Training, Exposure and My Progress. The Introduction provides the rationale of CET and guidelines of the app. The Training section comprises the following five coping-strategies: 1) Endure the urge, 2) Negative consequences of alcohol abuse, 3) Positive benefits of sobriety, 4) Alternative beverages and food, 5) Alternative behaviour. At every session a new coping-strategy

is applied when exposed to alcohol. The Training section is integrated with the Exposure section. However, it is also possible to go directly into the Exposure section, when the five strategies have been trained. The Exposure section includes ten different alcohol exposure videos, where the patient can select preferred alcohol subject. During exposure the urge level is self-assessed for three times in order to monitor the exposure process. My Progress is designed in the app that enables the check of progress and performances on each training session. The training progress is displayed in graphs that show the trend of performance. Several algorithms are available to demonstrate the results, including the average and the best results of each session, history performance in a calendar, the most efficient coping-strategies and the best performed sessions, and overall result of the five sessions. User information and training records are saved in a local database. When the smartphone is connected to internet, the database is synchronized to an online database in a server. This protects the loss of data, and it also provides the access to clinical professionals for monitoring of the individual progress, as well as data analysis.

## Conclusion

This abstract presents the process of developing a smartphone application for alcohol cue exposure treatment. It is based on a multidisciplinary collaboration, and transfer a complicated clinical therapy of alcohol dependency individuals into a smartphone application. From a comprehensive study on literatures to user centred design, it ensures the app with theory supported as well as a friendly user interface. The smartphone app is ready for clinical professionals on further studies of feasibility and efficiency test.

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# A Usability Evaluation of a Web based ICT System for Quality Management

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## Introduction

Policies and strategies to achieve welfare in the Norwegian society demand a well-developed and complex organization of public services. Statutory demands to deliver quality in public services are following the growth of the welfare state. In the purpose of learning from failure, it is required by law to report adverse events in the health services [1]. To support the increasingly complex public management that the growing welfare state requires, there is confidence in how information and communication technology (ICT) can support the processes. ICT systems are developed and implemented to facilitate processes and demands in public services, but display varying success. Implementation success depends on several factors[2]. System quality in terms of usability is one critical factor for success. The aim of this study was to evaluate the graphical user interface (GUI) of an ICT system module for reporting adverse events, developed for quality management in the municipality healthcare services in Norway.

## Materials and Methods

The cognitive walkthrough approach and a survey were used. The content analysis was used to categorize data according to classical aspect of Human Computer Interaction (HCI); information content (does the information system provide too much or too little information?), comprehensiveness, graphics and text (whether a computer display is understandable to the subject or not), navigational difficulties (does the subject have difficulty finding desired information or computer screen?) and overall system understandability (of icons, required computer operations and system messages)[3]. Six nurses and one social worker, all experienced ICT users, participated in the study. Five considered themselves experienced users of quality management systems; however, no one had experience with or previous knowledge of the system used in this study.

## Results

**Information content:** Six of the participants reported that the information displayed in the GUI were sufficient. Five of the participants reported that they found the information were it was expected to be found.

**Comprehensiveness, graphics and text:** All participants found the module at the homepage. Two of the participant had no error keystrokes during the test. The five others had one each where two were connected to the same issue in the GUI, but they all found the right option without problems in a few

seconds. According to the size of the letters, the font and the flexibility the survey showed some variation. The organization of the functions was considered logical by five participants and less logical by two participants. Five of the participants found it pleasant to use the system.

**Issues of navigation:** According to the survey six participants found it easy to navigate in the system. One participant did not find information about whom the report was sent to. Average time to accomplish the task was 7 min and 14 sec. (max 9 min 55 sec. and min. 4 min. 54 sec).

**Overall system understandability:** All participants found the system easy to use and easy to learn. None of the participants had problems entering information into the system, and all were able to perform the given task without training or knowing the system.

## Discussion

To successfully implement ICT to support learning in an organization the technology has to be used by the employees. The systems usability is a critical factor for success. Overall the ICT system shows facilities that support the user according to classical aspect of HCI. It was above all perceived as easy to use and easy to learn. The size of the letter, the font and flexibility might be area for improvement.

## Acknowledgments

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# PALANTE – an EU project that will demonstrate the user value of electronic patient solutions

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## Introduction

PALANTE (PATients Leading and mANaging their healThcare through EHealth) is an EU project where 9 different countries/regions in Europe and 21 partners participate to establish new services for existing patient related communication solutions. The partners also work to ensure that the solutions are taken into use in a large scale and will perform a common evaluation. The evaluation will be carried out in cooperation with Sustains, a twin project that covers further 12 regions/countries in Europe. The evaluation will therefore in total be the largest evaluation of patient activation that has ever been performed. The aim of the evaluation is to assess and deliver significant results regarding how electronic health care services are accepted by patient users and how these services effect and have impact on patient empowerment.

Oslo University Hospital and CSAM Health AS are partners in the Norwegian pilot of PALANTE and participate with the electronic communication tool MinJournal. Discharge notes will be available online for a large number of patients through MinJournal. A chronic care module is developed specifically aimed for patients with diabetes. The use of this module will also be evaluated as a part of the PALANTE project. The chronic care module contains different self help tools and tools to improve the communication with health care personnel.

## Method

In PALANTE there are commonalities and differences in the eHealth solutions provided by the partners. Based on a literature review, an evaluation framework has been identified incorporating measures of patient empowerment, health care professionals and patient satisfaction, as well as assessment of access, cost, utilization and control variables. As there is not a clear and authoritative definition of patient empowerment present, a systematic literature review has been carried out, with findings utilised in PALANTE evaluation framework.

User evaluation is carried out by utilising electronic questionnaires. The questionnaires cover common measures throughout all pilot sites involved. The evaluation will be carried out in two waves for most of the pilot sites, and current activities within all pilot sites are focused around enrolment of users in the evaluation phase of this project.

## Results

As per April 2014 approximately 2900 respondents are involved throughout the PALANTE project. Although not finalized, the

project has great potential in providing significant results in three aspects:

- Acceptability of technology and the effects of eHealth services on citizens.
- On evaluation methodologies on how to collect feedback from citizens and the analysis of the results.
- Evaluation of the different functionalities provided in PALANTE by all pilot sites, indicating what services that are needed and perceived as beneficial by citizen users.

The results mentioned above will in turn have a high potential of creating impact on the implementation of European eHealth policies and electronic services.

PALANTE project started in February 2012 and has 36 months duration.

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# Piloting the Norwegian version of the “The Measuring Instrument for Determinants of Innovations” (MIDI) - a new instrument for implementation of innovations in health care

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## Introduction

Some of the future challenges of the municipal health care services can be met through increased use of welfare technology and service innovation. There is little research about the implementation of welfare technology and Health Information Technology, regarding aspects as organisational change, incentives, liability issues, user's competences and skills, structure and work process issues. Fleuren, Wiefferink and Paulussen (2004) introduced an overview of 50 determinants that may facilitate or impede innovations in health care. The list has since been used in 8 studies which were combined into a meta-analysis that has been discussed with 22 implementation experts, resulting in “The Measuring Instrument for Determinants of Innovations” (MIDI). The MIDI consists of 29 determinants that 'predict' successful implementation separately and in combination (Fleuren, Paulussen, Dommelen and Buuren, 2014). The Science Centre Health and Technology's research group at Buskerud and Vestfold University College has identified the MIDI as a possible useful tool in our implementation research. The purpose of this study was 1) to contribute to the further development of the MIDI and in order to do so, 2) to develop a Norwegian version of the MIDI.

## Materials and Methods

We got permission from Dr Fleuren to use the MIDI and contribute to the further development of the instrument, which is formed as a questionnaire. The MIDI was translated from English (JD) and Dutch (HE) into Norwegian. The two translations were compared and modified into a single questionnaire. The Norwegian MIDI was piloted in *the Digital Night Surveillance project* in January 2014. The innovation which the MIDI referred to was in this case digital night surveillance technology implemented in 5 municipalities. The respondents were instructed to write down comments as they worked their way through the questionnaire, and were then invited to comment and discuss each question (item) and the alternatives per question in a group discussion. This resulted in an adjusted version which was piloted in the evaluation of the *LEAN education program* in the Health-, social- and care sector in Drammen, during spring 2014. The innovation which the MIDI referred to was in this case the new, LEAN way of working (i.e., service innovation). The respondents were invited to write down comments. The adjusted MIDI is currently being sent to all the employees involved in the Digital Night Surveillance project. The instrument will be translated back into the original languages by July 2014, in order to ensure that the Norwegian version is compatible with the original versions.

## Results

The initial feedback from the night shift nurses and health care workers in the Digital night surveillance project (n=19) resulted in rephrasing of some of the questions (items) and the alternative responses. The group also identified parts of the innovation that should be included when the questionnaire is used in their project, but was overall satisfied with the perceived relevance of the MIDI. The feedback from the LEAN group consisting of coordinating nurses and managers of nursing homes and home care services (n=25) did not result in changes to the questionnaire, but made it clear that additional information/material was needed. The remaining results will be available in August.

## Discussion

The MIDI questionnaire is intended for research on intermediary users of an innovation and their perceptions based on expectations or on experience with the innovation or components of the innovation. Preliminary results show that the MIDI covers determinants within 4 categories (the innovation, the user, the organisation and the related governance) that are relevant to the employees of the municipal health and care service when implementing welfare technology and service innovation, which is a new setting for the use of the MIDI. Furthermore, we have piloted, made adjustments and finally suggested a Norwegian version of the MIDI that will be used in ongoing research projects and made available to other researchers. The data will contribute to a larger dataset that can form the basis for cut-off values in the further development of the instrument.

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