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– an exploration of both sides of the interaction

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HEALTH LITERACY AND THE USE OF TELEHOMECARE TECHNOLOGY

– AN EXPLORATION OF BOTH SIDES OF THE INTERACTION

**BY
LISA KORSBAKKE EMTEKÆR HÆSUM**

DISSERTATION SUBMITTED 2015



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Lisa Korsbakke Emtekær Hæsum



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Foreword

My name is Lisa Korsbakke Emtækær Hæsum, from the department of Health Sciences and Technology at Aalborg University. I have conducted a PhD study with focus on the concept of *health literacy* and the role it has in the use of telehomecare technology. This is a brief introduction of who I am and my way to this PhD study. I have had an interest in health care for as long as I can remember - something that resulted in a Master's degree in medicine with industrial specialisation (cand.scient.med) in 2011 - an education that in my case combined medical science and healthcare economy.

My final project during the master was a health technology assessment (HTA) of a telehomecare solution developed for patients with *chronic obstructive pulmonary disease (COPD)*. The main focus of the HTA was on the technological and economic aspects of the telehomecare solution. It was during the work with the HTA that my interest in the field of telehomecare started to occur, as the field seemed to have potential with some promising results. However, the telehomecare solution did not account for the personal characteristics of the patients in terms of their socioeconomic status, knowledge of health, overall management of COPD etc.; something that can possibly be of great importance, as the effects from using telehomecare can depend largely on personal attitude and capacity (in terms of knowledge and expertise) of the participants' using it. This called for further research in the field, which led me to the development of this current PhD study that will seek to explore if personal attitude and capacity in terms of health literacy does affect the use of telehomecare...



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Abstracts

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First of all, I wish to thank the people that helped me in the development of the Danish TOFHLA; the whole PhD study would not have been possible without this important step. Huge personal thanks to Susanne Mejlsted for helping so much in the translation and adaptation process, and also with the establishment of the expert committee. The expert committee played a very important role in the process of developing the Danish TOFHLA – so thanks to all members for a constructive cooperation. After its development, I needed to test the reliability in a pilot study and in this regard I wish to thank the pulmonary outpatient clinic at Aalborg Hospital and Hjørring Health Centre for their collaboration – special personal thanks to the two healthcare professionals, Carl Nielsen and Lone Jessen, for establishing the initial contact with the COPD patients.

Then, of course, I wish to thank the TeleCare North project for their cooperation and for allowing me to conduct my PhD study in the realm of their project. Personal thanks to my colleague Pernille Lilholt for making the initial contact to the 116 COPD patients. In this regard, I also wish to extend a great thanks to the 116 COPD patients for their participation and for finding the time for two home visits.

This PhD study would never have been possible without my two supervisors: Ole Hejlesen and Lars Ehlers; it has been a pleasure to work with both of you. The two of you come from different scientific fields and traditions – and both of you are so very competent in your respective areas of research. This is something that has positively contributed to our cooperation and given rise to good and challenging discussions. Overall, then I am sitting here now with the feeling that I have gotten the best from both of your fields and working with you has been a great inspiration that helped me to develop and explore my potential as a researcher.

Finally, I wish to extend huge thanks to my family and friends for being my biggest support during the whole PhD study. Thank you for always being there ☺

Abstract

Introduction: Health literacy is in its core concerned with the individual ability to access and use health information in a way that maintain and promote good health. Over the past decades, alongside an increasing interest, health literacy has evolved into a rather broad and complex concept that makes it difficult to develop a universal definition of this concept. The concept of health literacy has only recently been introduced in the Scandinavian context and as a result the amount of literature regarding health literacy in the Danish context is very limited and there has been a total lack of screening instruments until very recently. This PhD study will seek to identify a definition of health literacy suitable for working with this concept in the Danish context and develop a screening instrument accordingly. There has been a rapid development of technology over the past years – something that is also reflected in modern healthcare systems with the occurrence of new channels for delivering health information and health care. Telehomecare is a branch of technology that allows obtainment and transmission of vital signs from the patients' residence to healthcare professionals. Telehomecare often comprises educational components that contain information on the current health status of patients and disease management – thus health literacy can be considered a prerequisite for exploiting its true potential. This PhD study uses a telehomecare intervention that includes educational components, and, in the realm of the above, the overall objective is to explore if a certain level of health literacy is needed to truly benefit from using the telehomecare technology and if the use of the telehomecare technology influences the level of health literacy.

Objectives

- To identify a definition and conceptualisation of health literacy suitable to the Danish context.
- To develop a screening instrument for assessing health literacy in the Danish context.
- To explore if a certain level of health literacy is needed to use telehomecare technology (short-term effects).
- To explore if the use of telehomecare technology influences the level of health literacy (long-term effects).

Paper 2 and 3 - Validation and pilot study of the TOFHLA in a Danish Population: A Danish version of the full length American *Test of Functional Health Literacy in Adults* (TOFHLA) was developed, as it is easier to create a reliable Danish version of a screening instrument that is already acknowledged in existing literature

on the assumption that it enjoys sufficient reliability and validity. The Danish TOFHLA was pretested in a pilot study where the face validity, reliability (Cronbach's alpha), and item to scale correlations (Pearson's correlation) were assessed on the basis of the data collected. The Danish TOFHLA demonstrated strong reliability with the original American TOFHLA and was found to be reliable for use in research projects, which test levels of functional health literacy in an elderly Danish population at risk of chronic diseases. Thereby, it was considered ready for use in the actual study.

Paper 4, 5 and 6 – The short - and long-term effects on health literacy from using telehomecare technology: The baseline study aimed to assess if the mere introduction of telehomecare has an effect on functional health literacy and if a certain level of functional health literacy is needed to use telehomecare technology (the short-term effects). No statistical significant associations between functional health literacy and the use of the telehomecare intervention (the Telekit offered by the TeleCare North project) were found in either case - suggesting that the mere introduction of telehomecare does not affect the functional level of health literacy and neither is functional health literacy a prerequisite for using the telehomecare intervention. The findings of the baseline study indicate that the telehomecare intervention (the Telekit) applied in this PhD is very easy to use and can be considered user-friendly.

The long-term effects on functional health literacy from using the telehomecare intervention were assessed in the follow-up study; a rather marked similar increase was observed in both the intervention group and the control group, suggesting that it is probably not due to the use of the telehomecare intervention. One explanation can be the enrolment in a scientific project like the TeleCare North, as this might contribute to a greater interest and more engagement in their disease and treatment –something that might make patients seek out more health information. Another explanation can simply be that the Danish TOFHLA is subject to retest bias.

Conclusion: A marked increase in the level of functional health literacy was observed in both the intervention and the control group, and is therefore probably not due to the use of the telehomecare intervention – leaving enrolment in the TeleCare North project and retest bias as possible explanations. However, it cannot be determined which of the explanations that causes the increase in functional health literacy - calling for further research that specifically addresses if the Danish TOFHLA is subject to retest bias.

Danish Abstract

Introduktion: Health literacy er helt essentielt centreret omkring individets evne til at tilegne sig og anvende sundhedrelateret information. I de sidste årtier er der kommet øget fokus på dette begreb, og som følge har health literacy udviklet sig til et meget bredt og komplekst begreb, hvilket bevirker, at der endnu ikke findes en universel definition af begrebet. Det betyder selvfølgelig også, at der endnu ikke findes en dansk definition eller conceptualisering af begrebet. Det er først indenfor de senere år, at health literacy er blevet introduceret i den Skandinaviske kontekst, og derfor er mængden af litteratur på området også meget begrænset. Ydermere, har der været total mangel på screeningsværktøjer til at "måle" health literacy i Skandinaviske lande indtil for ganske nylig. Dette PhD studie vil forsøge at definere og placere begrebet health literacy i en dansk kontekst, og på denne baggrund efterfølgende udvikle et komplementært dansk screeningsværktøj. De senere år har der været en rivende udvikling indenfor det teknologiske område – noget der også afspejles indenfor sundhedssektoren, hvor det er muligt at levere sundhedsinformation og behandling via nye moderne teknologiske hjælpemidler. Telehomecare er et område indenfor disse nye teknologiske hjælpemidler, som muliggør målinger af patientens vitale værdier i hjemmet og efterfølgende transmitteres disse til sundhedsprofessionelle. Telehomecare indeholder ofte en uddannelseskomponent i form af information omkring patientens aktuelle sundhedstilstand og håndteringen af sygdommen, og i denne henseende kan health literacy betragtes som en forudsætning for at drage maximal nytte af denne løsning. Dette PhD studie benytter en telehomecare intervention, der netop indeholder en uddannelseskomponent, hvilket har givet anledning til det overordnede formål: at undersøge om et bestemt niveau af health literacy er nødvendigt for at få mest gavn af at bruge telehomecare teknologi og ligeledes om brugen af telehomecare teknologi påvirker niveauet af health literacy.

Formål

- At finde en definition og conceptualisering af health literacy passende til en dansk kontekst.
- At udvikle et screeningsværktøj til at "måle" health literacy i en dansk kontekst.
- At undersøge om et bestemt niveau af health literacy er nødvendigt for at få mest gavn af at bruge telehomecare teknologi (kortsigtet effekt).
- At undersøge om brugen af telehomecare teknologi påvirker niveauet af health literacy (langsigtet effekt).

Artikel 2 og 3 – Validering og pilotstudie af TOFHLA i en dansk kontekst: Det er lettere at udvikle en dansk version af et screeningsværktøj, som allerede er anerkendt i litteraturen, så derfor udviklede vi en dansk version af det meget anerkendte amerikanske screeningsværktøj: TOFHLA. Den danske TOFHLA blev testet i et pilotstudie, med henblik på at undersøge "face validity", reliabilitet (Cronbach's alpha) og "item to scale" korrelationer (Pearson's correlation), for overordnet at kunne adressere applicerbarheden i en dansk kontekst. Resultaterne viste, at den danske TOFHLA har en stærk reliabilitet, og blev på dette grundlag vurderet klar til brug i forskningsprojekter, der har til formål at "måle" det funktionelle niveau af health literacy i den ældre del af den danske befolkning med risiko for kroniske sygdomme. Dermed var den klar til anvendelse i det egentlige studie.

Artikel 4, 5 og 6 – De kort- og langsigtede effekter på niveauet af health literacy ved brug af telehomecare teknologi: Baseline studiet havde til formål at undersøge om introduktion af telehomecare har en effekt på det funktionelle niveau af health literacy, samt om et bestemt niveau er nødvendigt for at få mest gavn af at bruge telehomecare teknologi (kortsigtet effekter). Der blev ikke fundet statistisk signifikante associationer mellem det funktionelle niveau af health literacy og brugen af telehomecare interventionen (Telekit –stillet til rådighed af TeleCare Nord projektet) i nogle af tilfældene. Dermed virker det til, at introduktionen af telehomecare interventionen ikke påvirker det funktionelle niveau af health literacy, og et bestemt niveau er heller ikke er en forudsætning for at anvende telehomecare interventionen. Baseline studiet tyder overordnet på, at telehomecare interventionen er meget brugervenlig. De langsigtede effekter på det funktionelle niveau af health literacy ved brugen af telehomecare interventionen blev adresseret i et opfølgende studie; en markant og meget ens stigning i det funktionelle niveau af health literacy blev fundet i både intervention – og kontrolgruppen, hvorfor den højest sandsynligt ikke kan tilskrives brugen af telehomecare interventionen. En forklaring på stigningen kan være, at inklusionen i et forskningsprojekt som TeleCare Nord måske øger patienternes interesse og engagementet i egen sygdom og behandling – og de dermed opsøger mere sundhedsinformation. En anden simpel forklaring kan være, at den danske TOFHLA giver anledning til retest bias.

Konklusion: Eftersom en markant stigning i det funktionelle niveau af health literacy blev observeret i både intervention-og kontrolgruppen, kan den sikkert ikke tilskrives brugen af telehomecare interventionen, men det skyldes nok mere sandsynligt inklusionen i TeleCare Nord projektet eller effekten af retest bias – noget som ikke kan afklares med resultaterne af dette PhD studie.

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Section 1: Background (Health Literacy)

This section will be an exploration of the concept of health literacy. It is a concept that first entered the literature in 1974 and currently there is still no consensus about the definition and conceptualisation of this concept. Over the past decades, alongside an increasing interest, health literacy has evolved into a rather broad and complex concept, which can partly explain the current lack of a universally agreed on definition of this concept. The concept of health literacy has only recently been introduced in the Scandinavian context and as a result the amount of literature regarding health literacy in the Danish context is very limited. This section, however, will try to explore the framework for working with health literacy in the Danish context and concurrently try to identify a definition of this concept suitable for this PhD study. The only recent introduction of health literacy in the Danish and overall Scandinavian context, and the very scarce amount of literature describing health literacy in this context, meant a total lack of screening instruments for assessing health literacy in Scandinavia - including Denmark - until very recently. On this basis, this section will also explore the screening instruments available in existing literature to find inspiration for the development of an appropriate screening instrument for assessing health literacy in the Danish population and context. Over the past decades there has been a rapid development in technology and science – something that is reflected in modern societies and healthcare systems with the development of various information and communication technologies that make health information more and more available to patients. Telehomecare is a branch of information and communication technologies that include the use of sensor based technology to obtain different vital signs (oxygen saturation, weight, pulse etc.) in patients and afterwards transmit these to healthcare providers. The telehomecare intervention, applied in this PhD study, includes an educational component that provides information on disease management and disease-specific data providing information on the current state of health of the patient; a component that requires the ability to understand and apply this educational information to truly benefit from the use of the telehomecare intervention, hence, health literacy can be a prerequisite for exploiting its full potential. This has given rise to the overall objective of this PhD study: to take a closer look at the interaction between health literacy and use of telehomecare technology with an exploration of both sides of the interaction; it will be both

explored if a certain level of health literacy is needed to truly benefit from using the telehomecare technology and if the use of the telehomecare technology influences the level of health literacy.

1.1 The definition of health literacy

Health literacy emerged for the first time in the literature in 1974 (1), but currently there is no consensus on its definition or conceptualisation in existing literature (2). The concept of health literacy has evolved quite a lot over the past decades with increasing attention and a changing society; a development that has turned health literacy into a broad and very complex concept – thus making it difficult to define it in a way that can be universally agreed on or at least to identify a definition that everyone, who works with this concept can agree on (3). However, as health literacy plays the lead in this PhD study, the following will seek to provide an overview of the definitions most widely used in the attempt to set the framework for working with this concept in the Danish context.

Overall, health literacy is concerned with the individual ability to access, evaluate, and use health-related information in a desirable way that maintain and promote good health, and supporting the ability to make sensible health decisions (2). One of the definitions most widely used and cited is developed by Don Nutbeam¹ for the World Health Organisation (WHO) in 1998 (4). Don Nutbeam defines health literacy as: *“the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.”* (4). The definitions of health literacy from the American Medical Association (AMA) (5) and the Institute of Medicine (IOM) (6) are also among the most acknowledged and mostly cited ones, and they define health literacy in a way very similar to the above definition developed by Don Nutbeam (WHO). From the above definition of health literacy, it can be seen that this concept comprises numerous different skills (both cognitive and social) practiced at multiple levels (access, understand, and use). Further, health literacy is influenced by personal qualities such as motivation, age, cultural background etc. After looking at the factors that comprise health literacy in one of the definitions most widely used in the literature, it is safe to state that health literacy is indeed a very broad and complex concept that

¹ Professor Don Nutbeam is a world-renowned expert in the area of public health with *health literacy* as one of his main research interests.

includes a great variety of personal skills and qualities practiced at multiple levels. As an attempt to make health literacy more manageable, and also to frame the different levels and their inclusion of different personal skills, Don Nutbeam has divided the concept into the following levels (7):

The functional level of health literacy comprises basic writing, reading, and numeracy skills – referred to as basic literacy skills – that make an individual capable of functioning effectively in relation to their health e.g. being able to read health-related materials, being able to use and navigate the healthcare system, to provide a presentation of symptoms, taking the correct dosage of medication etc.

The interactive level of health literacy refers to more advanced literacy, cognitive and social skills needed to actively participate in both everyday – and health activities. An individual with an interactive level of health literacy is capable of finding health information (for example on the Internet) and apply this information to changing circumstances, to drive meaning from different types of communication, and actively engage in a dialogue/discussion with a healthcare professional about course of treatment etc.

The critical level of health literacy comprises an advanced set of social and cognitive skills that include critical analysis of health information retrieved independently or from the healthcare system and the ability to actively act on this information. It also includes the ability to understand the economic and political dimensions of health.

Common to all three levels of health literacy is that basic literacy skills constitute the foundation in this concept; it is not possible to retrieve and critically analyse health information without the ability to read and write (7). The higher levels of health literacy seem to incorporate some of the theoretical framework from the concept of patient empowerment – something that has been criticised previously in the literature (8). Don Nutbeam finds health literacy to be critical to patient empowerment (4). The interaction between the concept of health literacy and patient empowerment will be illuminated in the paragraph following this one: *1.2 Health literacy and patient empowerment – two deeply intertwined concepts that is important to distinguish between*, to ensure a proper distinction between these two concepts in the Danish context.

The above broad definition of health literacy and the following division of this concept into the three levels provides the opportunity to view health literacy

from two angles: the simple angle and the complex angle. The simple angle includes the basic individual (literacy) skills necessary to navigate the healthcare system and to understand health information – a very tangible approach to health literacy. The complex angle includes the broader spectrum of skills and views practiced at multiple levels and can also include other types of literacies – an approach that is difficult to frame and obtain a concrete and reliable measure of (9). Don Nutbeam also views health literacy in a way similar to the simple vs. complex approach; he has stated that health literacy can either be approached as a “clinical risk” factor or a “personal asset”. In this regard, health literacy as a clinical risk factor is the more simple approach that includes proper identification and management of it. Health literacy as a personal asset includes more complex aspects, as it comprises the ability of individuals to have more control of their general health – again an approach that seems to resemble some of the theoretical framework seen in the concept of patient empowerment (10).

Current healthcare systems and societies experience a rapid development in science and technology; a development that requires more than basic literacy skills applied in a healthcare setting (*functional health literacy*) and calls for the higher levels of health literacy. First of all, it is important to recognise that health care is a very content specific area in terms of nomenclature, knowledge of the healthcare system – and this alone calls for more than basic literacy skills, as familiarity with the medical nomenclature is a prerequisite for reading and understanding health-related documents and information in sufficient manner (6). Further, the development in science and technology has changed the role of patients in the modern healthcare systems in terms of compelling them to become active players in the management and course of their own disease, and thus setting higher requirements to their level of self-management and patient empowerment (11). Modern healthcare systems sets high requirements to the level of self-management and patient empowerment, and this makes health literacy essential in the ability of chronic patients to take care of themselves and manage their own disease, as self-management and patient empowerment preferably should be based on knowledge about the disease and course of treatment (12). It is not only the level of patients’ involvement in the management and course of their diseases that has changed since health literacy originated in 1974, but also the availability of health information. The development of information and communication technologies has resulted in modern health channels and thereby made health information accessible on a variety of different technological platforms, such as the Internet. The ability to access health information from electronic sources requires skills

that are not incorporated in the “standard” definitions of health literacy, but the concept of *e-health literacy*, however, seem to capture this. E-health literacy is defined as: “*the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem*” (13). E-health literacy requires the capability to operate a computer and other similar technologies (smartphones, tablets etc.) with Internet access – a skill that is referred to as computer literacy (13). E-health literacy, further, requires information literacy that comprises the ability to critically distinguish between what resources to consult on the Internet, and also to evaluate these, to extract relevant and valid health information.(13). The concept of e-health literacy adds a new dimension to the concept of health literacy in modern societies and healthcare systems, and it is quite fascinating how this concept has changed in line with changing societies and the technological development. The still ongoing technological development creates an expectation that the concept of health literacy will continue to evolve in line with the rapid advancement in technology and science that will continue to shape future societies and healthcare systems (14).

In summary, the definition and conceptualisation of health literacy can be considered very broad and complex with basic literacy skills as the foundation. The complexity and inclusion of different skills practiced at multiple levels in health literacy can partly explain why it is difficult to define this concept in a universal manner. Further, societies are different around the world in terms of general culture, educational systems, health systems etc. – something that also makes it difficult to develop a definition of health literacy suitable to all countries in the world, as it is difficult to account for all the different prerequisites that exist in each country in the development of a “one fits all” definition. To complicate things even more, the technological development in modern societies and healthcare systems have added some new dimensions to the concept of health literacy that sets higher requirements to patients’ level of self-management and patient empowerment; something that is reflected in the definition of the higher levels of health literacy (the interactive and critical level). At first glance the higher levels of health literacy seem overlap the definition of patient empowerment, thus making it really difficult to differentiate between these two concepts. It is, however, important to distinguish between them, because one does not automatically assume the other e.g. just because you access one of these components does not necessarily mean that you access the other. This PhD study uses a telehomecare intervention, and in this area there is a high risk of confusing the concept of health literacy and

patient empowerment, because the users are required to perform certain actions that should be based on expertise, therefore, an exploration of the association and differences between these two concepts is considered necessary to ensure a clear distinction in this PhD study.

1.1.1 Health literacy and patient empowerment – the importance of distinguish between these two deeply intertwined concepts

The following discussion of health literacy and patient empowerment only includes that of patient empowerment and no other traditions of empowerment such as community empowerment (4). The concept of health literacy has previously been criticised for overlapping and incorporating theoretical framework from patient empowerment and at first glance these two constructs can seem like conjoined twins, as the higher levels of health literacy indirectly encompasses the ability to act and interact in relation to health care. The ability to take action is the core element of patient empowerment that generally views the patient as an autonomous actor that takes more responsibility in relation to own health and overall takes on a more active role in the decision making that can affect their health (10,15). In this sense, patient empowerment can refer to subjective feelings of control, power, and self-esteem that can make the patient appreciate autonomy and thereby enhance the desire and interest to participate in health-related decisions with regards to their health (16). In this regard, an increase in patient empowerment means an increase in the patient's willingness to embrace this autonomy and to become more involved in health-related decisions of concern to their own health – but this line of thought does not assume a similar increase in expertise to support the increased autonomy (16). The knowledge and expertise constitute the core element in the concept of health literacy; in the higher levels of health literacy that includes the ability to influence health-related decisions and activity interact with the healthcare system it is assumed that the patients have the needed knowledge and expertise to support their actions. Knowledge and expertise are considered prerequisites and are assumed in the concept of health literacy, which is not the case in the concept of patient empowerment - a very important point on which these two concepts are very different. These two concepts cannot be equated, as an increase in one not necessarily leads to an increase in the other, so a distinction between the concept of health literacy and the concept of patient empowerment is important (16).

Further, patient empowerment includes four inherent constructs: self-efficacy, self-determination, meaningfulness (relevance), and impact (17,18). These four constructs are subjective and describe the experience of patient empowerment in a subjective manner and its force in the motivation for taking action; something that also distinguishes patient empowerment from health literacy that is more objective in its construct (basic literacy skills can be assessed in an objective manner) and founded on knowledge and abilities (16).

In short, the concept of health literacy is different from patient empowerment in that it is a more objective construct founded on knowledge and expertise, whereas patient empowerment includes constructs that describe the subjective experience of it. The most essential distinction between these two concepts is that knowledge and expertise to support ones actions is a prerequisite in the higher levels of health literacy, which is not the case in patient empowerment. Health literacy and patient empowerment are intertwined, but they cannot be equated, as they are two conceptually and empirically different constructs. It should, however, be noted that these two concepts originated and expanded in the same domain of research: *health promotion*. These relationships are shown in *Figure 1*.

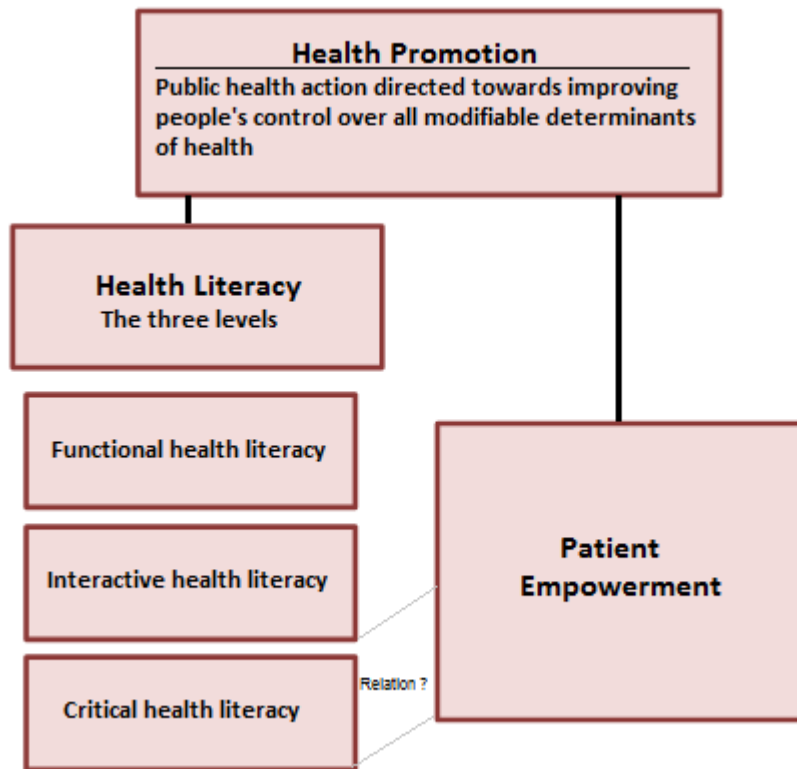


Figure 1 illustrates that both health literacy and patient empowerment are concepts that belong under the extensive domain of health promotion – a domain that has fostered a great variety of different health-related concepts: health education, health behaviours etc. Health promotion is primarily concerned with enhancing the capabilities of individuals to promote and maintain good health behaviour, but it also addresses public health and policy. It aims to change the social, environmental and economic conditions that influence health behaviour – both within the public and among individuals (4). Both health literacy and patient empowerment have their offspring as initiatives in the realm of health promotion that aims to reach equity in health. In short it can be said that focusing on enhancing both the level of health literacy and patient empowerment is essential in the strategies for promotion of health all over the world. Health literacy (knowledge and expertise) and patient empowerment (self-experienced ability to take action) has been on the agenda and subjects to discussion at a great variety of health promotion conferences; it all started with the development of the Ottawa Charter in 1986 (19) that stated if ‘health for all’

or equity in health is to be achieved there is a need to focus on health-related knowledge/education and the ability to “take action” in relation to health e.g. what is referred to as health literacy and patient empowerment today. Even though ‘health literacy’ and ‘patient empowerment’ are not the exact terms used back in 1986 ,when the Ottawa Charter was developed, they were indirectly on the agenda for promoting health already back then. Health literacy and patient empowerment are key concepts in strategies for health promotion that in its origin seek to reach equity in health.

1.2 The assessment of health literacy

The lack of consensus on the definition and conceptualisation of health literacy also causes disagreement about how it should be assessed (20), and as a result a great variety of screening instruments have been developed for this purpose over the past decades. A review of the literature in the area of screening instruments for assessing health literacy was conducted to get an overview of the area and identify the instruments most widely used. The review of the literature comprised a review of already existing reviews in the area of screening instruments for assessment of health literacy. The search resulted in an inclusion of four reviews that specifically reviewed the literature of screening instruments for assessment of health literacy (21-24). On the basis of these four reviews, the most prominent screening instruments were selected for further exploration if they met the following criteria: they had to be available, fully validated, only include objective measures, not designed to target a specific disease and have focus on health. The findings of the review in terms of the most relevant screening instruments that fulfilled the criteria are presented in *Table 1*.

Screening instrument	Description of instrument	Type of assessment	Year of development	Type of score and division	Validation
Test of Functional Health Literacy in Adults (TOFHLA) (25).	Administration time: up to 22 minutes. Also available in short form (S-TOFHLA).	Quantitative assessment to assess numeracy. Cloze method to assess reading	1995	Continuous weighted score (range 0 – 100). Categorical score:	Yes, for the American - and Spanish - speaking populations.

		comprehension.		Inadequate health literacy: 0 – 59 Marginal health literacy: 60 – 74 Adequate health literacy: 75 -100	
Rapid Estimate of Adult Literacy in Medicine (REALM) (26).	The original version contained 125 medical words. The revised version, containing 66 medical words, was developed short after the original version. Administration time: 1 to 2 minutes.	Recognition and pronunciation of medical words.	1991, but the revised version used in the existing literature was developed in 1993.	Continuous score (range 0 – 66) Grade level: 0-18: ≤ 3 rd grade 19-44: 4-6 th grade 45-60: 7 th -8 th grade 61-66: ≥ 9 th grade	Yes, for the American - and British - speaking populations.
Short Assessment of Health Literacy for Spanish Adults (SAHLSA) (27).	A list of 50 medical words – developed for the Spanish-speaking population. Based on the REALM.	Recognition and comprehension of medical words.	2006	Continuous score (range 0 – 50) Categorical score: 0-37: Inadequate health literacy 38-50: Adequate health literacy	Yes, for the Spanish-speaking population.
Demographic Assessment of Health Literacy (DAHL) (28).	The risk of low health literacy is assessed by using four demographic variables (age, gender, education and race) to predict the S-TOFHLA score.	The demographic variables: gender, age, education and race are used to predict reading ability.	2008	Continuous score (range 14 – 91) Categorical score: 0-53: Inadequate health literacy 53-100: Marginal health literacy	Yes, for the American population.
Nutritional Literacy Scale (NLS) (29).	Reading comprehension in a food/nutritional context.	Assessment of reading comprehension by modified Cloze method.	2007	Continuous score (range 0 – 28)	Yes, for the American population.
METER (30).	Includes 40 medical words and 40 non-words (words that do not actually exist but sound like medical words).	Recognition of medical words.	2009	Continuous score (range 0 – 40) Categorical score: 0-20: Low literacy 21-34: Marginal literacy 35-40: Functional literacy	Yes, for the American population.
Newest Vital	6 questions	Quantitative	2005	Continuous score	Only partial

Sign (NWS) (31).	regarding information on ice cream nutrition label. Administration time: 3 minutes.	and document health literacy skills in relation to a nutrition label, including the ability to calculate percentages.		(range 0 – 6) Categorical score: < 2: Low literacy 2-4: Possible low literacy > 4: Adequate literacy	validation – available in English and Spanish. Mentioned because it has been used quite often in the literature.
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*Table 1 is adapted and drawn with inspiration from Berkman et al (22).

Table 1 provides an overview of available validated objective screening instruments to assess health literacy, along with a description of each instrument and its type of assessment. All the screening instruments are centred on understanding medical texts and the ability to recognise and pronounce medical words – it other words they put great emphasis on document/print literacy. Some of the screening instruments also include an assessment of numeracy skills. The *Test of Functional Health Literacy in Adults (TOFHLA)* (25) and the *Rapid Estimate of Adult Literacy in Medicine (REALM)* (26) are the two screening instruments most commonly used in health literature to assess health literacy, and they have been considered “gold standards” in the literature basically since their origin back in the 90’ies (32). It is notable that none of the screening instruments in Table 1 assesses oral literacy skills applied in a healthcare context (22), which is rather problematic as the interaction between healthcare professionals and patients depends quite a lot on the spoken word; it is rather important that patients can provide a somewhat accurate presentation of their symptoms and problems.

Overall, existing screening instruments are criticised for not capturing the complexity of health literacy (6,20), as they only seem to capture the functional level of health literacy. In a modern society, with healthcare systems that seem to compel patients to play a more active part in the management and course of disease and treatment (11), then health literacy requires more than the ability to apply basic literacy skills in the healthcare setting (*functional health literacy*). For patients to become active players in the management of their own disease and course of treatment, the ability to seek out information on the desired topic and know how to critically evaluate this information (*interactive and critical health literacy*) is required. The ability to put this information to good use in both their interaction with the healthcare system and in their general everyday life as well is of course also required in the modern society. The screening instruments primarily assess functional health literacy in modern societies that comprise healthcare systems, where the higher levels

of health literacy are needed; this is rather problematic as consensus, between the definition and conceptualisation of health literacy and how it is assessed, is recommended in future research concerning the development of future screening instruments (33,34). This task becomes challenging with no unified definition or conceptualisation of health literacy to guide future work in terms of the development of screening instruments suitable for assessing health literacy. Nevertheless, there has been a proliferation in this area in the past few years, and the development of current screening instruments focus on assessing the higher levels of health literacy, which is a total shift of paradigm as previous screening instruments have their primary focus on assessing the level of functional health literacy.

1.2.1 Assessing health literacy in modern society – there has been a shift of paradigm

The shift of paradigm in the assessment of health literacy comprises a change from using previous screening instruments that mainly focus on assessing functional health literacy (by assessing basic literacy skills applied in the healthcare system) in an objective manner that produces a concrete score of the participants' abilities to the use of more current screening instruments that focus on assessing the higher levels of health literacy in a rather subjective manner (35). The objective way of assessing health literacy provide a quite accurate picture of the participants' basic literacy skills, and thereby their prerequisites for interacting with the healthcare system and make use of health information. The use of the objective screening instruments can, however, make the participants' feel rather uncomfortable, as low health literacy is often associated with shame and embarrassment, and in these types of screening instruments their basic literacy skills is exposed (6). Further, the objective screening instruments do not provide any information from the participants' point of view. In this regard, the new paradigm of subjective screening instruments can be considered more "user-friendly" with their focus on the subjective experience of the participants' interaction with the healthcare system and use of health information, which is very valuable information. It should, however, be noted that these subjective screening instruments can suffer from a high level of uncertainty – their reliability can simply be questioned – as low health literacy comes with a great deal of shame and embarrassment, and the participants' might try to hide it and therefore not answer the questions truthfully. The subjective screening instruments can probably be considered more in line with what characterises the concept of health literacy in modern

societies and healthcare systems, and also more user-friendly than the objective screening instruments, but their uncertainty needs to be assessed – a task that remains to be solved. Altogether this means that currently there is currently no golden standard for assessing health literacy – it is work in progress. Before this shift in the paradigm of assessing health literacy can be completed, there are still some major challenges that need to be considered; first of all there must be consensus about the definition and conceptualisation of health literacy to guide and refine the future work with developing screening instruments for assessing health literacy in modern societies and healthcare systems. This would in turn create a more unified way of assessing health literacy that allows comparison across borders, which is also highly recommended in existing literature (32).

1.2.2 Measuring health literacy in Europe (Scandinavia)

The *European Health Literacy* (HLS-EU) project has especially been a game changer in the development of proper screening instruments for assessing health literacy – at least in the European context. The HLS-EU project has developed a questionnaire containing 47 questions about participants' subjective experience of dealing with health information and the healthcare system (36). This project tries to set the framework for assessing health literacy in Europe; it includes eight European countries: Austria, Bulgaria, Germany, Greece, Ireland, Netherlands, Poland, and Spain. Prior to the initiation of the HLS-EU project, the research team behind this initiative had developed a conceptual framework and definition of health literacy (2), and thereby creating consensus between the concept of health literacy to be measured and the screening instrument created for this purpose; hence, the conceptualisation and definition of health literacy prior to the development of the HLS-EU questionnaire guided its development, as recommended in the literature. Further, this initiative has the potential to generate empirical data on health literacy in Europe; eight countries are already included in the project and they all assess health literacy in the same way using the same empirical referent – the HLS-EU questionnaire. It should be mentioned that a Danish research team is working on creating a Danish version of the HLS-EU questionnaire (37). Further, this Danish research team is also working on creating a Danish version of an Australian *Health Literacy Questionnaire* (HLQ) (38) that is initiative similar to that of HLS-EU project and they have also created consensus between the concept of health literacy to be measured and the questionnaire by developing a conceptualisation of health literacy to guide the development of the HLQ.

This year, 2014, the first Scandinavian screening instrument was developed – *the Swedish Functional Health Literacy scale* (39). It is a reliable instrument to assess *functional health literacy* in the Swedish population and context, as it is a translation of the Japanese Functional Health Literacy scale (35), developed in 2008. A lot is going on when it comes to assessing health literacy in the European and Scandinavian context, but there is no unified way just yet, but with the development of these new screening instruments it is very likely that a proliferation will be seen in this area in the years to come.

1.3 Health literacy in Denmark (and Scandinavia)

Health literacy is a concept that primarily was on the research agenda in America and Canada at its infant stage back in the 90'ties, but over time the interest in this concept evolved from being mainly concentrated in America and Canada to become more internationalised with its evolvement (40). In 1992, the National Adult Literacy Survey (NALS 1992) was carried out in America, and the results showed a high prevalence of low basic literacy skills (basic writing, reading, and numeracy skills) among the American population with one out of three adult Americans being functionally illiterate (6). The results of NALS 1992 increased the focus on functional health literacy, defined as basic writhing, reading and numeracy skills applied in a healthcare setting (25). It was also in the mid 90'ties that the TOFHLA and the REALM was developed. Altogether this initiated the focus on functional health literacy in the American society during the mid-90'ties. This interest continued to expand during the late 90'ties with the development of the "health promotion glossary"² that expanded the concept of health literacy and initiated the following tripartite division of health literacy developed by Don Nutbeam, see paragraph 1.1: *The definition of health literacy*. The research interest in health literacy slowly became more internationalised over time with research being conducted in Australia (41,42), Japan (35,43), Korea (44), Switzerland (45), the UK (46) and the Netherlands (47). During the 90'ties until 2005, less than one third of the global research in health literacy was carried out in Europe (48). In recent years, health literacy has

² The Health Promotion Glossary was developed for the World Health Organisation (WHO) by Don Nutbeam in 1998 with the aim of facilitating communication between countries and also within countries in their work with health promotion.

been recognised as problem also in Europe with increased attention in European legislation and politics; in this regard it should be noted that health literacy in fact was mentioned as an important area in the European Commission's Health Strategy 2008 -2011 (49). The focus on health literacy as important research has and still is becoming more widespread in Europe, and thereby also slowly making its entry in Scandinavia.

The concept of health literacy has only recently been introduced in the Scandinavian context (9), so the literature in the field is very limited as not much research of health literacy in the Scandinavian context has been conducted yet. Some of the explanation can probably be due to a complete lack of screening instruments for assessing health literacy in Scandinavian countries (39) – something that did not change before last year 2014 (39). This lack of proper research and screening instruments in Scandinavia, of course, also applies for the Danish context. Actually, to author's knowledge only one Danish report developed by the Danish Health and Medicines Authority in 2009 is concerned with a Danish translation and definition of health literacy (50). The report is concerned with health literacy in the Danish context, but is mainly based on the international literature, thus it does not manage to place health literacy in the Danish context or provide a Danish spin on the concept. In the report, health literacy is translated into Danish by "health competences", however, it also concludes that this translation might not be the answer to a Danish term of health literacy, as "health competences" is a rather broad term. So currently, there is no Danish term or definition of health literacy and with only the above-mentioned report, the Danish literature to guide the definition and placement of health literacy in the Danish context, is very scarce.

1.4 Health literacy – a prerequisite for the use of telehomecare technology?

Health care and its delivery is an important and essential part of any well-functioning welfare system. The rapid advancement in technology and science causes the life expectancy to increase around the world, which in turn leads to an ageing population with an increase in the prevalence of chronic diseases as a result (51,52). The rapid technological development in modern societies is also reflected in modern healthcare systems with the development of various health information and communication technologies

that has created many new health channels, and thus made health information available on many technological platforms. The technological development has added the dimension of navigating and mastering the world of *e-health* to what characterises being a patient – or at least a health literate patient – in modern societies and healthcare systems. E-health is defined as: “*health services and information delivered or enhanced through the Internet and related technologies.*” (13). The dimension of e-health encourages patients in modern societies to consult electronic sources for health information and use this information in the management of their own disease and treatment - also referred to as *e-health literacy* (see definition in *paragraph 1.1: The definition of health literacy*). E-health literacy requires the capability to operate a computer and other similar technologies with Internet access (*computer literacy*), and also the ability to critically evaluate and distinguish between what resources to consult on the Internet to extract relevant and valid health information (*information literacy*). E-health literacy can be considered relevant in the use of different health information and communication technologies; this is, however, not the case with the use of telehomecare technology – a branch of technology in the realm of e-health. Telehomecare technology differs from other health information and communication technologies available, because the use of it does not require the same spectrum of e-health literacy skills compared to the use of other technologies. The telehomecare intervention of this PhD study is applicable to the following overall definition of telehomecare: “*a system of care delivery based upon the acquisition and use of information obtained by a sensor based technology located in the residence and transmitted to a remote location for dispatch to care provider*” (53). This definition of telehomecare clarifies why e-health literacy does not have the same role in this area compared to the use of other technologies; the use of a sensor based technology that obtains different vital signs (oxygen saturation, pulse, weight etc.) and afterwards transmits these to healthcare professionals, simply does not require the same skills and abilities needed to search, evaluate, and extract health information from for example the Internet. The telehomecare intervention, applied in this PhD study, comprises educational information on disease management and relevant disease-specific data providing information on patients’ current state of health (see a detail description in *paragraph 2.3.1: The telehomecare intervention*), so if they are to truly benefit from it, they should not only be able to obtain the measurements of the vital signs, but they should also be able to understand and make good use of the educational information and instructions incorporated in the intervention as well. On this basis, health literacy can be

considered a prerequisite for the use of the telehomecare intervention, as a certain level could be necessary to truly exploit and benefit from all its available components.

A systematic review on the interaction between health literacy and the use of telehomecare technology was conducted to establish the “state of the art” in this area of research prior to the initiation of the actual study of this PhD study. The results of the systematic review on the interaction between the use of telehomecare and health literacy are reported in the paper: **Influence of health literacy on outcomes using telehomecare technology: a systematic review.** *Health Education Journal*, 2015 found in section 3: *Results*.

1.5 Health literacy in the PhD study

Due to the very limited amount of Danish and Scandinavian literature on health literacy in this context, it is chosen to go with the simple tangible approach of health literacy in this PhD study – referred to as *functional health literacy*. This approach ensures a distinction of health literacy from patient empowerment in the Danish context. Further, it seems like a sensible approach to start from scratch, when trying to define and place the concept of health literacy in the Danish context, as there is not enough Danish or Scandinavian literature to support a development of a Danish definition or conceptualisation of health literacy. Thus, the PhD study has to rely on the international literature in the definition and assessment of health literacy in the Danish context – something that supported the simple tangible approach that comprises the low functional level of health literacy. A foundation to guide future Danish work with health literacy might be created with the completion of this PhD study, of course depending on the results. The rationale is that a reliable and not too ambitious (trying to capture all aspects of health literacy) starting point is a necessity to create a solid foundation in the realm of this concept – a foundation on which future research can be built and the higher levels can be considered. Telehomecare technology is a branch of health information and communication technology, and it is therefore relevant to consider if e-health literacy should be incorporated in the definition of health literacy. However, this PhD study uses a telehomecare intervention that does not require the same skills, as the operation of other health information and communication technologies that normally includes skills in the realm of e-health literacy. On this basis, e-

health literacy is not considered in the development and approach to health literacy in this PhD study.

1.6 The objectives of the PhD study

With the only recent introduction of health literacy in Scandinavia – including Denmark – called for an exploration of the concept. The objective of this exploration of health literacy was to decide on a definition and conceptualisation of health literacy suitable for working with this concept in the Danish context. The overall objective of the PhD study was to explore both sides of the interaction between health literacy and the use of telehomecare technology; it was explored if a certain level of health literacy is needed to truly benefit from using the telehomecare technology and if the use of the telehomecare technology influences the level of health literacy. The interaction between health literacy and the use of telehomecare technology was explored both in the short term after two months and in the long term after ten months. However, to make this objective possible, we needed to develop a screening instrument for assessing health literacy in the Danish context – this task was performed while keeping in mind that there should be compliance between the conceptualisation of health literacy and what is assessed with the screening instrument, as recommended in the literature.

Objectives

- To identify a suitable definition and conceptualisation of health literacy in the Danish context
- To develop a screening instrument for assessing health literacy in the Danish context, while ensuring compliance between the conceptualisation of health literacy to be assessed and what is actually assessed with the screening instrument.
- To explore if a certain level of health literacy is needed to use telehomecare technology (short-term effects).
- To explore if the use of telehomecare technology influences the level of health literacy (long-term effects).

The results answering the above objectives of this PhD study will be reported in six papers in *section 3: Results/Papers*.

Section 2: Methods section

The overall objective was to explore the interaction between the level of health literacy and the use of telehomecare technology. To author's knowledge no Danish definition or translation of health literacy exists; it is only within recent years health literacy has received increased attention in Scandinavia and Denmark, which might explain the lack of a sufficient definition and placement of health literacy in the Danish context. However, even though the concept of health literacy emerged for the first time in international literature already back in 1974, there is still no universally agreed on definition or conceptualisation of health literacy in the international literature either. The lack of a definition of health literacy in the Danish context also meant a total lack of Danish (and Scandinavian) screening instruments at the initiation of this PhD study. As a result, an exploration of the concept of health literacy in the Danish context was needed to guide the development of a screening instrument suitable for application in the Danish population and context. These steps had to be completed before the exploration of the overall objective of this PhD study. Altogether, this gave rise to the three-stage model, illustrated in *Table 2*.

The three-stage model		
Stage one	Stage two	Stage three
<p>Aims</p> <p>To explore the concept of health literacy in a "mini" concept analysis.</p> <p>To decide on a definition suitable for the present PhD study.</p> <p>"State of the art" on the interaction between health literacy and the use of telehomecare technology.</p>	<p>Aims</p> <p>To develop a screening tool for measuring health literacy in the Danish population and setting.</p> <p>To conduct a pilot study of the Danish screening tool to assess the face validity and reliability.</p>	<p>Aims</p> <p>To explore both sides of the interaction between the health literacy and the use of telehomecare technology – if a certain level of health literacy is needed to use telehomecare technology and if the use of telehomecare technology influences the level of health literacy.</p> <p>The short-term effects (baseline)</p> <p>The long-term effects (follow-up)</p>

Methods Review of the literature.	Methods Interviews Various statistics	Methods Interviews Various statistics
When 1 st of August 2012 to 1 st of January 2013	When 1 st of January 2013 to 1 st of August 2013.	When 1 st of February 2014 to 1 st of December 2014.

Table 2 provides an overview of the three-stage model and the characteristics of each stage.

Stage one: The exploration and definition of health literacy in a “mini” concept analysis

Stage two: The development and pilot study of a screening instrument for measuring health literacy in a Danish context

Stage three: The actual study that comprises a baseline study and a follow-up study with focus on assessment of the interaction between health literacy and the use of telehomecare both short term and long term. The baseline study explored the short-term effects on health literacy from using telehomecare technology and also if a certain level of health literacy is needed to use telehomecare technology. The follow-up study explored if the use of telehomecare technology influences the level of health literacy in the long term.

Each of the three stages will be described separate paragraphs in the following.

2.1 Stage one: Exploration and definition of health literacy in a “mini” concept analysis

The lack of a Danish definition and conceptualisation of health literacy gave rise to the first stage in the three-stage model; an understanding of health literacy and the components that make up this multiple-level complex concept was needed to set the framework for working with health literacy in the Danish context. Therefore, the concept health literacy and all available definitions of this concept was explored – a process that resulted in a “mini” concept analysis of the concept of health literacy. A concept analysis aims to capture all aspects of the concept of interest: all used definitions and

comparing them (attributes and antecedents), the “consequences“ of occurrence of the concept (consequences) and how to measure the concept (empirical referents).

Concept analyses of health literacy had been conducted prior to this PhD study. There is no reason to repeat the work that others have already done in a sufficient and satisfactory manner, so it was chosen to conduct a “mini” concept analysis on the basis of all identified concept analyses in the literature. Two concept analyses qualified for inclusion in the mini concept analysis of health literacy in this PhD study. One of the concept analyses was conducted in 2005 and uses the method of Walker and Avant (54) and the other concept analysis from 2012 is carried out in combination with a systematic review of definitions and models of health literacy (2). The mini concept analysis is based on a comparison of these two included concept analyses instead of being based on a complete exploration of existing literature – like a complete concept analysis requires – of course supported by other relevant literature in the field. The purpose of the mini concept analysis was to help set the stage for working with health literacy in the Danish population and context; therefore, it also includes an exploration of the limited amount of Danish literature to identify knowledge and contributions to the concept of health literacy in the Danish context. Another important task, in stage one, was to get an overview of the most acknowledged and widely used empirical referents, and on this basis develop a screening instrument for assessing health literacy in the Danish population and context, while ensuring compliance with the definition and conceptualisation of health literacy suitable to the Danish context. As the main objective of this PhD study was to explore the interaction between the level of health literacy and the use of telehomecare technology, a systematic literature search was carried out in this area to identify all studies that have investigated this interaction and establish the “state of the art” in this field of research.

2.2 Stage two: The development and the pilot study of the Danish TOFHLA

A Danish version of the original American TOFHLA was developed and evaluated for cultural equivalence for the Danish population and context. This cross-cultural adaptation process was conducted according to the guidelines for cross-cultural adaptation as defined by Beaton et al (55).

2.2.1 The development of the Danish TOFHLA

The review of the literature and the mini concept analysis conducted in stage one, also provided an overview of the methods (empirical referents) for assessing health literacy around the world. It is easier to create a reliable Danish version of an already acknowledged screening instrument on the assumption that it enjoys sufficient validity and reliability. As mentioned in the background section, numerous screening instruments exist in the literature, but the two most widely used is the TOFHLA and the REALM, see *Table 1*. The REALM does not include an assessment of numeracy skills and therefore it does not provide a picture of participants' health literacy that is as detailed as the TOFHLA. Further, the REALM is based on average reading skills of a norm sample and not placed in an exact grade e.g. the scoring system is not quite as reliable as the one used in the TOFHLA. On this basis, the original American full-length version of the TOFHLA was translated and adapted for use in the Danish population and context. The main argument for developing a Danish version of the American TOFHLA instead of developing a completely new screening instrument specifically designed for the Danish healthcare system is that it is less time-consuming, and a new screening instrument would have problems reaching the same levels of reliability and validity. Further, it will be easier to make more accurate comparisons of the results obtained with the Danish TOFHLA with results in existing literature. The original American TOFHLA cannot just be directly translated into a Danish version, as the American healthcare system is very different from the Danish healthcare system. Therefore, to make the Danish version of the American TOFHLA applicable for the Danish context, some of the questions in the original American TOFHLA were modified in the translation and adaptation process. The translation and adaptation process was conducted by following international guidelines for this cross-cultural adaptation process developed by Beaton et al. (55), to ensure that these modifications were made without altering the intention of the content in the translation and adaptation process. A Puerto Rican study from 2010 (56) translated and adapted the original Spanish version of TOFHLA using these guidelines developed by Beaton et al. (55), therefore it was chosen to create a Danish version of the original American in a similar manner. The cross-cultural adaptation process and evaluation of cultural equivalence defined by Beaton et al. (55) should be conducted in the following six stages:

Stage I: Two forward translations of the original full-length American TOFHLA from the original language (American) into the target language

(Danish).

Stage II: Synthesis of the two translations produced in stage I into one joint Danish translation: T12.

Stage III: Two back-translations of T12 from target language (Danish) back to original language (American).

Stage IV: Expert committee and production of pre-final version of the Danish TOFHLA.

Stage V: Pre-test of pre-final version of the Danish TOFHLA.

Stage VI: Consistency and reliability.

In accordance with Beaton et al. (55), the Danish TOFHLA was pretested as a part of a pilot study, to ensure consistency and reliability of the instrument. In the pilot study, 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.

2.2.2 The pre-test of the Danish TOFHLA in a pilot study

The aim of the pilot study was to test the reliability of the Danish TOFHLA and to explore if the intention and structure of the original American TOFHLA have been preserved in the Danish version. The face validity, internal consistency, and item to scale correlations were assessed based on the results from the pilot study.

The pilot study included 42 patients diagnosed with *Chronic Obstructive pulmonary Disease (COPD)*. The 42 COPD patients were recruited for the pilot study using the method of consecutive sampling, which seeks to include every accessible subject at multiple data collection sites. In this case, the data collection sites included the outpatient clinic at Aalborg Hospital and Hjørring Health Centre. A healthcare professional at each site initiated contact with all accessible subjects and further gave them a short written description (developed by the researcher) explaining the requirements of participants and the overall process should they agree to participate in the pilot study of the Danish TOFHLA.

The overall face validity of the Danish TOFHLA was assessed subjectively by the researcher during the pilot study. The internal consistency of the Danish TOFHLA was determined by using the Cronbach's alpha coefficient; it was determined for the entire Danish TOFHLA, but also for the two subcategories: the numeracy part and the reading comprehension part. The criterion for reliability of an instrument is set to > 0.7 as set by Houser (57).

The item to scale correlations for each of the 67 items in the Danish TOFHLA was also explored by Pearson's (Point-biserial) correlation coefficient, high correlation > 0.2 and weak correlation < 0.2 (58). Pearson's Point-biserial correlation was determined for the entire Danish TOFHLA, but also separately for each of the above-mentioned subcategories.

Besides the health literacy score, following data were collected: *age, gender, site of recruitment, civil status, level of education and mean response time to the Danish TOFHLA*. Descriptive statistics were conducted to explore the health literacy score by the basic demographic characteristics, mean response time to the Danish TOFHLA, and level of education. Independent t-tests and ANOVA tests were applied to assess statistical significant differences between groups; division in groups by health literacy category, civil status, gender, and educational level. For comparison with existing literature, the association between health literacy and educational level – adjusted for age and sex – was explored in a multiple linear regression analysis. The statistics in the pilot study were conducted to strengthen our findings and argumentation for stating that the Danish TOFHLA is ready for application in future research projects that seeks to explore levels of functional health literacy in an elderly Danish population at risk of chronic diseases.

2.2.3 The final Danish TOFHLA

The Danish TOFHLA (59) assesses *functional health literacy* and it includes a section with 17 items that focuses on numeracy skills and a section with 50 items accessing reading comprehension skills – just like the original American TOFHLA (25). The numeracy section focuses on the ability of the participant to understand financial assistance, keep a clinical appointment, understand instructions for taking medication etc. As an example, a participant could be asked to read a card with information on blood glucose or prescription medication instructions, and subsequently, the participant is asked about what had been read. The reading comprehension part is conducted as a modified Cloze procedure in which words are randomly removed from a reading passage. (60). In the Danish TOFHLA, every fifth to seventh word is randomly deleted in various health-related reading passages, and the participant then selects the most fitting word from a list of four possible words. The total score of the Danish TOFHLA is divided into the three following categories: **inadequate (0-59)**, **marginal (60-74)** and **adequate (75-100)** –

just like the American TOFHLA (25).

2.3 Stage three: The actual study

This PhD study is centred on the influence of health literacy in telehomecare, and it is conducted as a part of a large scale telehomecare project, TeleCare North. The TeleCare North project is conducted as a randomised controlled trial (RCT), and the participants in the present PhD study were recruited from the TeleCare North project (61) in a consecutive manner following the randomisation. Overall, the method of consecutive sampling provided a total of 116 COPD patients with residence in the area of Northern Jutland. The sample comprised 60 patients in the intervention group and 56 in the control group. The actual study was carried out in two phases: **the baseline study** (the short-term effects) where the 60 COPD patients have had the intervention described below for approximately two months and **the follow-up study** (long-term effects) where they have had it for approximately ten months.

2.3.1 The telehomecare intervention

The 60 COPD patients in the intervention group received a telehomecare solution including a tablet (Samsung Galaxy Tab2 (10.1)), with software developed by Silverbullet, Aarhus, Denmark (<http://opentele.silverbullet.dk>). The tablet contains information on the management of COPD in general and software that automatically provide instructions on how to manage COPD during exacerbations. Additionally, the tablet can collect and transmit relevant disease-specific data providing information on the current state of health of the patient: weight, oxygen saturation, blood pressure and pulse. The equipment used to obtain these measurements is: a Digital Blood Pressure Monitor (Model UA-767, plus BT-C, Nonin Medical, Minnesota, USA), an attached Fingertip Pulse Oximeter (Nonin, Onyx II% SpO2, A & D Medical, Tokyo, Japan), and a scale (Precision Health Scale, UC-321PBT-C, A & D Medical, Tokyo, Japan). Overall, the tablet and the related equipment are referred to as the Telekit. Healthcare personnel (primarily community care nurses) were responsible for patient care and monitoring in the intervention group. COPD patients in the intervention group were instructed in the use of Telekit by a nurse from

their municipality. This initiating instructing session lasted approximately 45 minutes for COPD patients, who wanted to receive the Telekit at home, and 75-minutes for those, who wished to receive the Telekit at a municipality health centre (carried out in groups with three to four patients). The nurse demonstrated how to use the tablet and how to obtain physical measurements, and also guided the patients through the tablet manual before letting them try the tablet on their own. The COPD patients were asked to measure their vital signs on a daily basis during the first two weeks (both weekdays and weekends) and after the first two weeks it was reduced to one to two times a week (the specific days were agreed upon and programmed into the tablet by the nurse). The nurse also provided a description of the monitoring procedure and gave contact information to the community nurse. Finally, a 45-minute follow-up visit was scheduled three to four weeks after the first appointment to ensure appropriate use of the equipment and to check if the threshold values of the physical measurements needed adjustment (62). The intervention is of course the same in both the baseline study and the follow-up study, but the methodology used in each study will be described separately in the following two paragraphs.

2.3.2 The baseline study (the short-term effects)

The purpose of this baseline study in this PhD study was to explore if the introduction of telehomecare technology and the educational components associated with this introduction affected the functional level of health literacy in the 116 COPD patients included in the study; our study group comprised 60 patients in the intervention group and 56 in the control group.

The study design included both the control group receiving usual care and the intervention group receiving the telehomecare intervention (the Telekit) described above. The functional level of health literacy was only measured once in each group when they have had been using the Telekit for approximately two months. The functional level of health literacy was assessed with the Danish TOFHLA (*described in detail above*) (59); it was chosen to compare post intervention measurements of functional health literacy between the intervention – and the control group to avoid retest bias (63) e.g. the study design did not include a baseline measurement. A repeated application of the Danish TOFHLA can result in an increased understanding of the items, and thereby lead to an increase in functional health literacy scores the second time – and then there will be a retest effect.

A supplementary study was conducted at baseline to assess if a certain level of functional health literacy is required to use the Telekit.

2.3.2.1 Data collection in the baseline study

A face to face interview was carried out with each of the 116 COPD patients to collect data on their basic demographic characteristics and exercise habits. After the interview, each COPD patient was also asked to complete the Danish TOFHLA – providing an individual health literacy score and response time for each patient at baseline (where they have used the Telekit for approximately two months). Relevant clinical parameters were obtained at enrolment in the TeleCare North project.

2.3.2.2 Data analysis in the baseline study

The analysis was conducted in two steps: the first step was to **determine the comparability** of the intervention group and the control group in the baseline study. The second step was to **test the functional health literacy score for statistical significant difference** between the two groups. The statistical difference between groups on metric data was assessed using an independent t-test and a chi-square test was used to compare the statistical difference between groups on categorical data. The statistical difference in functional health literacy score between groups was determined using an independent t-test, and this association was also explored in a multiple regression analysis. The statistical software SPSS version 21 (64) was used to perform all statistics and testing in the baseline study.

2.3.3 The follow-up study (the long-term effects)

The purpose of the follow-up study was to explore how the use of telehomecare technology affects the level of health literacy over a ten month period of time – the long-term effects. The follow-up study was a follow-up on the baseline study that described the short-term effects of using telehomecare technology in relation to functional health literacy. The follow-up study only included 90 of the 116 COPD patients included in the baseline study, as 26 (22.41%) COPD patients were lost to follow-up; 13 in the intervention group and 13 in the control group. Hence, a total of 47 COPD patients in the intervention group and 43 in the control group were included for analysis in the follow-up study.

The study design included both the intervention group and the control group. The comparability of the two groups was assessed in the baseline study, where they were found to be comparable. The difference in functional health literacy score between groups and within groups from baseline to the follow-up study was explored and tested for statistical significance. The difference in response time between groups and within groups was also explored for statistical significance. Further, the basic characteristics of the 90 COPD patients in the follow-up study were compared with the basic characteristics of the 1225 COPD patients in the TeleCare project.

2.3.3.1 Data collection the follow-up study

The researcher asked each of the 90 COPD patients about their exercise habits again, as this parameter could have changed since the baseline study. Data about basic characteristics had been collected previously in the baseline study. Each of the 90 COPD patients was also asked to complete the Danish TOFHLA again – providing an individual functional health literacy score and response time for each patient at follow-up (where they have used the Telekit for approximately ten months).

2.3.3.2 Data analysis in the follow-up study

The basic characteristics of the 90 COPD patients at follow-up were explored using the statistical software Stata version 13 (65). The difference between the intervention group and the control group in functional health literacy score from baseline (two months) until this follow-up study (ten months) was assessed for statistical significance in SPSS (64) by conducting an independent t-test. Further, the difference between groups in mean response time to the Danish TOFHLA from baseline to follow-up was also assessed for statistical significance in SPSS (64) by conducting an independent t-test. Further, the differences within the two groups were also described e.g. it was explored if the health literacy score and response time had changed in each group since baseline.

Section 3: Results/Papers

This section will provide an overview of the primary results of this PhD study. The results from each of the stages in the three-stage model (described in *section 2: Methods*) will be reported in separate paragraphs. The results from stage one will include the results of the mini concept analysis of health literacy and also a determination of the definition most suitable to this PhD study. The results of stage two will include a description of the development of a screening instrument (the Danish TOFHLA) for assessing health literacy in the Danish population and context, and it will also include a description of the pilot study in which the Danish TOFHLA was pretested. The results of stage three that comprises a description of the results from the actual study will include a separate description of the results from the baseline study (the short-term effects after approximately two months) and of the results from the follow-up study (the long-term effects after approximately ten months). The result section will primarily be based on the following six papers: one conference paper and five papers:

1. The review of the literature that explores the interaction between the level of health literacy and the use of telehomecare technology is reported in the paper: **Influence of health literacy on outcomes using telehomecare technology: a systematic review**. Submitted and accepted for publication by the *Health Education Journal*, 2015.
2. The development of the Danish TOFHLA is reported in the paper: **Validation of the Test of Functional Health Literacy in Adults (TOFHLA) in a Danish Population**. Submitted and accepted by the *Scandinavian Journal of Caring Sciences*, 2015.
3. Results of the pilot study are reported in the conference paper: **Validation of a Health Literacy test in a Danish population - Results from a pilot study**. Scandinavian Conference on Health Informatics; August 22; 2014; Grimstad; Norway.
4. The short-term effects on the level of health literacy from using telehomecare technology are reported in the paper: **How do the use of telehomecare technology and the associated educational components affect Health Literacy short term?** Submitted, 2015.

5. The short-term effects exploring if a certain level of health literacy is needed to use telehomecare technology are reported in the paper: **Specific Technology Functionalities and Health Literacy do not Influence Benefit from Enrollment in TeleCare North Trial** Submitted, 2015.
6. The long-term effects of using telehomecare technology on the level of health literacy are reported in the paper: **An assessment of the increase in Health Literacy level from using telehomecare technology and associated educational components.** Submitted, 2015.

3.1 Stage one: Exploration and definition of health literacy using a mini concept analysis

Health literacy emerged for the first time in the literature in 1974 (1), and it is a very broad concept that has evolved a great deal over the past decades with the increased attention. In spite of the rapid evolution of health literacy during the past decades, no consensus about the definition has been reached in the existing literature (2). Multiple definitions have occurred in the literature in the attempt to frame and conceptualise this concept. A concept analysis from 2005 (54) and a concept analysis in combination with a systematic review from 2012 (2), constitute the basis for reporting the following results of the mini concept analysis. The mini analysis seeks to capture the components that constitute the concept of health literacy. Further, the mini concept analysis is supplemented with all available Danish literature in the attempt to define and place health literacy in the Danish context. Stage one will be concluded with a definition of health literacy and the results of the review that explores the interaction between health literacy and the use of telehomecare technology.

3.1.1 The mini concept analysis

Following attributes, antecedents, consequences and empirical referents in relation to the concept of health literacy were identified in the mini concept analysis:

Attributes	Antecedents	Consequences	Empirical referents
<p>Basic literacy skills (basic reading skills, basic numeracy skills, and comprehension (the ability to use context and prior knowledge in the reading process)).</p> <p>Capacity to use health information in decision-making</p> <p>Able to function successfully in the patient role</p>	<p>Demographic and social factors (Employment, income, socioeconomic status, culture and language etc.)</p> <p>Personal characteristics (gender, age, race and cultural background)</p> <p>Basic literacy skills</p> <p>Health-related experience in terms of familiarity with healthcare system and health concepts (medical nomenclature)</p>	<p>Health status</p> <p>Health behaviour</p> <p>Health outcomes/health service use (emergency care, hospitalisations etc.)</p> <p>Costs</p> <p>Self-efficacy (improvement)</p> <p>Knowledge and information of diseases, treatments, risks etc.</p> <p>Patient/provider interactions</p>	<p>Test of Functional Health Literacy in Adults (TOFHLA)</p> <p>Health literacy component of the National Assessment of Adult Literacy (NAAL 2003)</p> <p>Rapid Estimate of Adult Literacy in Medicine (REALM)</p>

The mini concept analysis of health literacy identified basic literacy skills as the foundation in the concept of health literacy, which is in accordance with eligible literature (6). The ability to use health information, when making decisions affecting your health, is also considered a part of the concept of health literacy. Further, the patient role is brought into the equation, something that also set some requirements to health knowledge and the ability to perform appropriate health decisions. The level of health literacy is said to influence health status, self-efficacy, the interaction between patient and healthcare provider etc. (2,54). The results of the mini concept analysis illustrate the complexity of health literacy, as multiple skills and levels were identified as components in this concept.

To author's knowledge only one Danish report developed by the Danish Health and Medicines Authority in 2009 is concerned with a Danish translation and definition of health literacy (50). In the report, health literacy is translated into Danish by "health competences", however, it also concludes that this translation/definition might not be the answer to a Danish term of health literacy, as "health competences" is a rather broad term; so there is currently no Danish term or definition of health literacy. No qualified Danish literature was identified for the purpose of placing health literacy in

the Danish context. The empirical referents were only included in the concept analysis from 2005 (54), in which they were identified as the TOFHLA (25) and the NAAL 2003 (66). The review of the literature also identified the REALM (26) as one of the screening instruments most widely used screening instruments for assessing health literacy.

3.1.2 The definition of health literacy

On the basis of the results of the mini concept analysis and overall literature search, it seems that health literacy can be viewed in two ways: the simple measurable form e.g. what is referred to as *functional health literacy* by Don Nutbeam (7) and Parker et al. (25) or the more complex form (*interactive and critical health literacy*) that includes elements from patient empowerment where the ability to act is the primary focus (see definitions in *section 1:Background*). However, it should be noted that even though health literacy and patient empowerment are closely intertwined then it is important to distinguish between these two concepts (16); the greatest difference between health literacy and patient empowerment is that health literacy is a more objective construct based on knowledge and expertise and it can be measured producing a concrete score, whereas patient empowerment is a more subjective construct that describes the experience of being empowered. Further, the higher levels of health literacy presuppose that patients' have the knowledge and skills to put the retrieved information to use in the most desirable way that maintain and promote good health. This is not presupposed in the concept of patient empowerment that is primarily concerned with the patient's ability to take action and does not focus much on the consequences of the action or how desirable the outcome of the action is.

Through the mini analysis and the review of the literature it became clear that *functional health literacy* is the foundation in the concept of health literacy, on which a great variety of other more advanced skills can be built (3). The lack of qualified Danish literature, to help define and place health literacy in the Danish context, compelled the author to define health literacy in this PhD study on the basis of international English literature even though it is carried out in the Danish context.

Due to this complete lack of a Danish definition of health literacy and the fact that this area in general seems to be rather unexplored in the Danish

context, it was chosen to base the approach to health literacy in this PhD study on the simple measurable definition of health literacy – being the definition of *functional health literacy*. This approach also ensures a clear distinction of health literacy from patient empowerment. The screening instruments most widely used – the REALM and the TOFHLA (The NAAL was only used once to assess the level of health literacy in America's adults) – are designed to assess the functional level of health literacy, so to ensure compliance between the definition and conceptualisation of health literacy we wanted to assess – being the functional level of health literacy – it made sense to create a Danish version of either the REALM or the TOFHLA for assessing functional health literacy in the Danish context. As mentioned previously, the TOFHLA was found to be more detailed in its assessment of functional health literacy and also to have a more reliable scoring system, so it was translated and adapted process followed by a pre-test in a pilot study prior to the actual study – results of this will be described as the results of stage two.

3.1.3 The interaction between health literacy and use of telehomecare technology

The interaction between health literacy and the use of telehomecare technology is described, on the basis of existing literature, in **paper 1** (*papers are listed on page 29*). This paper describes a systematic review of the literature on the interaction between health literacy and the use of telehomecare technology. The findings suggest that this area of research is rather unexplored.

3.2 Stage two: Development and pilot study of a screening instrument for measuring health literacy in the Danish setting and culture

3.2.1 The development of the Danish TOFHLA

A Danish version of the full length American TOFHLA was developed; this process is described in detail in **paper 2** (*papers are listed on page 29*). The Danish TOFHLA demonstrated strong reliability and was found to be reliable for use in research projects, which test levels of functional health literacy in

an elderly Danish population at risk of chronic diseases. Thereby, it was also considered ready for use in the actual study.

3.2.2 Results of the pilot study

After its development, the Danish TOFHLA was pretested in a pilot study to assess the applicability in the Danish context. The results of the pilot study are reported in **paper 3** (*papers are listed on page 29*). The Danish TOFHLA demonstrated the ability to divide the test participants into the proper categories (Inadequate, marginal and adequate) according to their level of functional health literacy.

3.3 The actual study

3.3.1 The short-term effects on functional health literacy from using telehomecare

A baseline study was conducted after two months to assess if the mere introduction of telehomecare has an effect on the functional level of health literacy in COPD patients (the short-term effects) – results are reported in **paper 4** (*papers are listed on page 29*). No statistical significant associations between functional health literacy and the use of the telehomecare intervention (the Telekit offered by the TeleCare North project) were found - suggesting that the mere introduction of telehomecare does not affect the functional level of health literacy in COPD patients.

3.3.2 The short-term effects describing if a certain level of functional health literacy is needed to use telehomecare

The baseline study (conducted after two months) also explored if a certain level of functional health literacy is needed to use telehomecare technology. The results in the realm of these short-term effects are described in **paper 5** (*listed on page 29*). The findings suggest that functional health literacy is not a prerequisite for using the telehomecare intervention.

3.3.3 The long-term effects on functional health literacy from using telehomecare technology

After ten months, the long-term effects on functional health literacy from using the telehomecare intervention were assessed in a follow-up study. Results are reported in **paper 6** (*papers are listed on page 29*). A rather marked similar increase in the level of functional health literacy was observed in both the intervention group and the control group.

Section 4: Discussion

The overall purpose of this PhD study was to explore the interaction between functional health literacy and the use of telehomecare technology in the Danish context. However, this is a very challenging task as no Danish definition or conceptualisation of the concept of health literacy exists in the Danish context. In fact, the Danish literature in the field of health literacy was and still is rather scarce, which means that the knowledge of health literacy in this context is rather limited; this actually applies to Scandinavia in general (9). The lack of a definition and placement of health literacy in the Danish context or the Scandinavian context also meant a total lack of appropriate screening instruments for assessing health literacy in Scandinavian countries until recently (39). Therefore, the first steps were to try and place health literacy in the Danish context and chose a definition suitable to this PhD study – and then develop a screening instrument accordingly. As health literacy is a very complex and broad concept it was decided to go with the simple approach that focuses on basic literacy skills applied in a healthcare setting – referred to as *functional health literacy*. The same applied when it came to the development of a screening instrument for assessing health literacy in the Danish context; instead of developing a new screening instrument specific to the Danish healthcare system without any knowledge of health literacy in the Danish context it was chosen to translate and adapt one of the empirical referents most widely used in the literature for use in the Danish population and context: the TOFHLA. The TOFHLA was developed in America in 1995 (25) and assesses the simple functional level of health literacy; thereby compliance between the definition of health literacy chosen for the Danish context and the screening instrument used to assess it is created, as recommended by the literature (34). It was chosen to develop a Danish version of the full length American TOFHLA, as it is easier to create a reliable Danish version of a screening instrument that is already acknowledged in existing literature on the assumption that it enjoys sufficient reliability and validity. The Danish TOFHLA was pretested in the pilot study prior to the actual study; the purpose of the pilot study was to assess the applicability of the Danish TOFHLA in the Danish context. In this regard, the face validity, reliability (Cronbach's alpha), and item to scale correlations (Pearson's correlation) of the Danish TOFHLA were assessed on the basis of the data collected in the pilot study. The Danish TOFHLA demonstrated strong reliability with the original American TOFHLA and is found to be reliable for use in research

projects, which test levels of functional health literacy in an elderly Danish population at risk of chronic diseases. On this basis, it can be considered ready for use in the actual study.

The first part of the actual study aimed to assess if the introduction of the telehomecare technology and the educational components associated with this introduction affected the level of functional health literacy in the COPD patients included in this PhD study – referred to as the baseline study in *section 3: Results*. The intervention group and the control group of the study were found to be very comparable as no relevant statistical significant differences are observed in basic characteristics and clinical parameters. Further, no statistical significant difference is observed in the mean functional health literacy score between groups with a sig. p – value of 0.999 – very close to 1, which equals no difference at all. This finding is supported by a multiple regression analysis that shows no association between the two groups and mean functional health literacy score. Overall, the results of the baseline study indicate that the introduction of the telehomecare intervention (the Telekit offered by the TeleCare North project as described in *section 2: Methods*) has no effect on the level of functional health literacy in the short term. A supplementary baseline study explored if the level of functional health literacy influence the use of the telehomecare intervention in terms of an increased sense of security, control, freedom, and increased attention to symptoms related to COPD; the results of this study indicate that the telehomecare intervention is easy to use and can be considered user-friendly, hence, a certain level of functional health literacy is not needed to use it. Further, the supplementary study also explored the association between the use of the telehomecare intervention and the use of general everyday technologies (computer, tablet, phone etc.), and again no significant association is found – supporting the statement of user-friendliness. Altogether, the results of these two baseline studies indicate that the telehomecare intervention is so user-friendly that a certain level of functional health literacy or experience with using everyday technologies are not a prerequisite for using it; hence all COPD patients are able to use it regardless of these two factors .

The second part of the actual study assessed how the use of the telehomecare technology affected the level of functional health literacy over a ten month period of time – referred to as the follow-up study in *section 3: Results*. A very similar increase in the average functional health literacy score is observed, in both the intervention group and the control group, over the time period of ten months. In addition, a reduction in the mean response

time for completion of the entire Danish TOFHLA is also observed in both groups. These observed differences are not statistically significant between the intervention group and the control group in either case. It is notable, however, that the increase in the average functional health literacy score in both groups is rather large with a difference of 4.98 in the intervention group and 4.37 in the control group – representing the difference from baseline to follow-up after ten months. The average functional health literacy score in both the intervention group and the control group - the average functional health literacy score of all COPD patients in each group - actually shifts from being in the marginal level range to being in the adequate level range of functional health literacy. The observed increase in functional health literacy is very similar in both groups, and can therefore probably not be ascribed the telehomecare intervention used in this PhD study. One explanation to the rather marked increase in both groups can be the enrolment in a scientific research project like the TeleCare North, as it might compel the included COPD patients to seek out information regarding their disease and course of treatment through a different variety of available sources like the Internet, newspapers, media etc., and overall just make them more active players in the management of their own situation. This might in turn increase their contact with the healthcare system, in terms of more questions and a general requirement for information about both their disease and participation in the project, because they wish to prepare for the participation in the project. Overall, the marked increase in the functional level of health literacy, observed in both the intervention group and the control group in this PhD study, can very well be ascribed the enrolment in the TeleCare North project, because it might contribute to a greater interest and engagement in their own disease and course of treatment – something that might motivate them to seek out more information about their disease and course of treatment that in turn make them more capable of actively engaging in the management of it. Another explanation can be that the Danish TOFHLA is simply subject to retest bias (63). However, in this regard, it should be noted that the TOFHLA has not previously been shown to be subject to retest bias in the literature.

26 COPD patients were lost to follow-up (13 in the intervention group and 13 in the control group) for various reasons – the most prominent being that they had withdrawn from the TeleCare North project or that they were too ill to participate. The 26 COPD patients lost to follow-up constitute approximately 22 % of the original study group of 116 COPD patients, and there is a risk that this loss could have influenced the results. Therefore, a comparison between the 26 COPD patients lost to follow-up and the original

study group of 116 COPD patients has been conducted to establish if there were any influential differences between these two groups of COPD patients. Hence, it was assessed if a participation of the 26 COPD patients lost to follow-up could have influenced the results and thereby also altered the conclusions. Overall, the 26 COPD patients lost to follow-up do not differ noticeably from the original study group on basic characteristics and clinical parameters, but a difference is observed in the average functional health literacy score at baseline. The average functional health literacy score in the original study group is almost identical between the intervention group (71.42) and the control group (71.41) at baseline, but the score is markedly lower in the control group (66.69) compared to the intervention group (75.00) in the 26 COPD patients lost to follow-up. The average functional health literacy score is also lower in the control group of the 26 COPD patients lost to follow-up in comparison to the control group of the original study group of 116 COPD patients, giving rise to the thought that participation of the 26 COPD patients might have altered the results of the study with regards to the observed difference in the average functional health literacy score between the intervention group and the control group; their participation might have resulted in a lower increase in the functional health literacy score observed in the control group, however, as it is only a matter of 13 COPD patients then this must be regarded as pure speculations.

The basic characteristics of the 116 COPD patients in this PhD study has also been compared with the basic characteristics of the 1225 COPD patients in the TeleCare project to explore the generalizability of the results produced. Overall, no notable differences are observed between the study group in this PhD study and the study group in TeleCare North project. There are two parameters where the study group in the TeleCare North project differs slightly from the study group in this PhD study; in the TeleCare North project there are slightly more women than men in the intervention group, whereas in our intervention group there are slightly more men than women and the majority in the control group of the TeleCare North project live with a partner, where the majority live alone in the control group of our study. However, these differences are so small that it is rather safe to state that the study group of this PhD study is very similar to the overall study group in the TeleCare North project. Therefore, it reasonable to assume that the findings of the PhD study, in spite of the relatively small sample size, can be generalised to all 1225 COPD patients offered the Telekit in the TeleCare North project, which is a great representative of Danish COPD patients in general.

Section 5: Conclusions

The concept of health literacy has only recently been introduced in Denmark and the rest of Scandinavia and as result there is no definition or conceptualisation suitable for working with this concept in the Danish context or even other Scandinavian studies to lean upon in the process of setting the framework for working with health literacy in Denmark. The only recent introduction of health literacy in Denmark and Scandinavia of course also means that the literature in the field is rather scarce. Even so, this PhD study attempted to try and set the framework for working with health literacy in the Danish context – the first step being an exploration of the concept with a following decision on a definition suitable to this PhD study. With the very limited amount of Danish or Scandinavian literature in the field, and with health literacy being a very broad and complex concept, it was chosen to go with the simplest approach to health literacy that focuses on basic literacy skills applied in a healthcare setting – referred to as *functional health literacy*.

To ensure compliance between the simple approach to the concept of health literacy (*functional health literacy*) and what it is actually assessed in this PhD study, it was chosen to translate and adapt one of the empirical referents most widely used in the literature: the TOFHLA – designed to assess functional health literacy.

The Danish TOFHLA is now validated for use in the Danish context and can be applied in future research projects that seeks to assess the level of functional health literacy in elderly patients at risk of chronic diseases. The Danish TOFHLA have shown that it can assess the basal functional level of health literacy in the Danish context and properly distinguish between the different levels of functional health literacy assessed with it. This is a rather important finding, as it allows for future subgroup analyses on the basis of the three different levels of functional health literacy: *inadequate*, *marginal* and *adequate*. The functional level of health literacy is assumingly a more precise predictor of health than other predictive socioeconomic factors like level of education and income often associated with the prediction of health in the literature. The ability to distinguish between the different levels of functional health literacy and use this as a predictor for health can be valuable in many different areas of research; in the realm of health economic analyses a distinction between the functional levels of health literacy, as assessed with the Danish TOFHLA, can allow valuable subgroup analyses

in terms of the association between functional health literacy and different health outcomes (admissions, medication, quality of life etc.).

The baseline study of this PhD study shows that the introduction of the telehomecare intervention does not affect the level of functional health literacy in the short term. The results of the supplementary baseline study indicate that the telehomecare intervention is very easy to use and can be considered so user-friendly that a certain level of functional health literacy or experience with using general everyday technologies are not a prerequisite for using it; hence all COPD patients are able to use it regardless of these two factors.

The change in the level of functional health literacy was assessed over a ten month period of time in both the intervention group and the control group, and a very similar marked increase in the average functional health literacy score is observed in both groups. As the increase is very similar in both the intervention and the control group then it is probably not the use of the telehomecare intervention that causes it – leaving enrolment in the TeleCare North project and retest bias as possible explanations. However, this PhD study provides no information on which of the explanations that causes the increase, so the conclusion must be that it cannot be determined to what this increase in functional health literacy can be ascribed. This calls for further research that specifically addresses if the Danish TOFHLA is subject to retest bias, as it is very relevant knowledge to establish whether the Danish TOFHLA is in fact subject to retest bias and therefore not so suitable for assessing changes in functional health literacy over time. Following, it will be possible to further explore if the use of telehomecare technology have played a role in the increase of functional health literacy observed in this PhD study or if an association simply does not exist.

Section 6: Perspectives

Functional health literacy constitutes the foundation in the concept of health literacy - a foundation on which more skills in relation to health can be built. It is the lowest level of health literacy and therefore it made sense to take on this approach in the Danish context with very little knowledge and literature available on this concept. In both the pilot study and the actual study, more than 50% of the COPD patients were characterised as having an adequate level of health literacy (assessed with the Danish TOFHLA), which contradict the tendency in existing literature, where people with a chronic disease tend to be at greater risk of having a low level of health literacy (7,67) . This could indicate that basic literacy skills (the foundation in *functional health literacy*), in the concept of health literacy, should not be the primary focus in the Danish context. Of course, as basic literacy skills constitute the foundation in health literacy and are needed to navigate and interact with the healthcare system and use health-related information at any level, these skills are still a necessity in the Danish context like it is in the American, but the difference lies in the importance of focusing on these skills. In America, low basic literacy skills is a problem, as more than 50% were found to have inadequate literacy skills in a national assessment from 2003 (66). Moving from the American context to the Danish, the Danish healthcare system is very different from the American; the main difference being that everyone have equal access to health care, which is not the case in the American society. This fact, combined with the free access to education, give rise to the thought that the Danish tradition of delivering health information and the overall relationship to this, is very different from the American tradition – both from a healthcare point of view, but also from a general societal point of view. A variety of patients educational and rehabilitation programmes exists when being patient in the Danish healthcare system, and these programmes contain a great deal of information about diseases and how to manage the disease in the most optimal way. These programmes are designed specifically to target different diseases e.g. patients with cardiac diseases are offered education and rehabilitation specifically designed and relevant to their disease and patients suffering from COPD are offered another type of education and rehabilitation tailored to their needs with information on for instance smoking cessation. The important notification in relation to these health-related offers specifically designed to various patient groups in Denmark is that everybody has equal access to these offers – it is the

patient's own responsibility to attend these programmes, but everybody has the opportunity - again something that is different from the American healthcare system. The point in mentioning these educational and rehabilitation programmes is not so much that they exist in Denmark, because similar initiatives probably exist in America, but the point and importance is that everybody has the opportunity to use the programmes in Denmark. This leaves the challenge of getting patients to see value of these health educational and rehabilitation programmes, and making them benefit as much as possible from them – a challenge with regards to health literacy in the Danish context that is quite different from the American challenges in this regard.

Until recently, the two objective screening instruments - the REALM and the TOFHLA – were the most acknowledged ones and most widely used, but there has been a shift of focus with the increased focus on health literacy. The TOFHLA and other similar objective screening instruments have been criticised for not capturing the complexity of health literacy (6,68), and as a result recent initiatives in the development of screening instruments have focused on capturing the higher and more complex levels of health literacy (the *interactive* and the *critical* level) in a more subjective manner (35,36). The most prominent initiative is the European Health Literacy (HLS-EU) project that seeks to set the framework for working with health literacy in Europe (36). The HLS-EU project developed a questionnaire for use in eight European countries. The questionnaire measures self-experienced and self-rated abilities to carry out tasks relevant to the management of health information. Thus, the questionnaire reflects self-evaluated health literacy skills of populations in relation to the health literacy demands of specific national situations concerned with health and health care. The HLS-EU questionnaire has been developed with the purpose of being able to collect empirical data on health literacy in Europe, as it allows comparison across populations and cultures (69). The HLS-EU questionnaire tries to capture health literacy on a deeper level that goes beyond the ability to read and write (69), which is the exact major change in the development of newer more current screening instruments: they try to assess health literacy on a level that goes beyond basic literacy skills. Literature has suggested that there should be more compliance between the theory and conceptual framework of health literacy and what the screening instruments actually assesses (34). An application of this to the Danish context means that a Danish definition of health literacy for application in the Danish context should be developed to guide the development of screening instruments for assessing health literacy in the Danish population and context. An initiative

to transfer the HLS-EU questionnaire to the Danish context was initiated in the beginning of this year, and a Danish version is expected in 2015 (37). Prior to this initiative a Danish definition of health literacy was developed on the basis of the one used in the HLS-EU project; hence, it is a direct translation of the one used in the HLS-EU project (70). It should be noted that the applicability of this Danish translation of the definition of health literacy developed for use in Europe (2) remains to be explored and assessed for applicability in the Danish context. The advantage of the subjective screening instruments is that they provide valuable information on the patient experience when they interact with the healthcare system, and they can also be considered more “user-friendly”. The objective screening instruments that assess functional health literacy by testing reading comprehension and numeracy skills can make the participants’ feel uncomfortable as a low level of health literacy often is associated with shame and embarrassment. However, the reliability of the subjective screening instruments can be questioned, as there is a risk of people will try to hide a low level of health literacy, due to shame and embarrassment. Following this line of thought, research that includes both the Danish TOFHLA and the Danish HLS-EU questionnaire used in synergy, could provide valuable information on the use of objective vs. subjective screening tools, and maybe bringing us one step closer to an optimal assessment of health literacy in the Danish context – but first of all, the risk of retest bias in the Danish TOFHLA should be addressed in future research to establish if the Danish TOFHLA is in fact subject to retest bias (63). Another important task in future research is to develop a definition of the framework and conceptualisation of health literacy in the Danish context to ensure compliance between the concept assessed and what is actually assessed with the different screening instruments, as suggested by the literature (34). This would also allow the collection of empirical data on health literacy in the Danish context.

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Appendix 1: Basic characteristics of the participants in the TeleCare North project

The basic characteristics of participants in the TeleCare North project at baseline		
Variable	Intervention group (n = 578)	Control group (n = 647)
Age (Mean, 95%CI)	69.56 (68.79;70.32)	70.33 (69.63;71.04)
Gender		
Men (n, col %)	279 (48.27)	283 (43.74)
Women (n, col %)	299 (51.73)	364 (56.26)
Civil status		
Married or living with a partner (n, col %)	323 (55.88)	351 (54.25)
Living alone (n, col %)	215 (37.2)	250 (38.64)
Missing (n, col %)	40 (6.92)	46 (7.11)
Level of education		
Elementary school (n, col %)	262 (45.33)	265 (40.96)
High school (n, col %)	10 (1.73)	10 (1.55)
Skilled worker (n, col %)	173 (29.93)	203 (31.38)
Higher education (n, col %)	74 (12.81)	94 (14.53)
Missing (n, col %)	59 (10.21)	75 (11.59)
Clinical parameters		
Systolic blood pressure	130.00 (128.57;131.43)	131.92 (130.53;133.32)
Diastolic blood pressure	76.84 (75.98;77.71)	77.48 (76.55;78.40)
Pulse	79.2 (77.99;80.41)	79.83 (78.64;81.03)
Forced expiration in 1sec (FEV ₁)	47.70 (46.06;49.33)	48.37 (46.74;50.00)
Forced vital capacity (FVC)	70.38 (68.36;72.40)	74.34 (72.13;76.56)

The numbers in this table are retrieved from the TeleCare North webpage: <http://www.m.dk/Sundhed/Til-sundhedsfaglige-og-samarbejdspartnere/TeleCare-Nord/Evaluering-og-forskning>

Appendix 2: Basic characteristics of the 26 COPD patients lost to follow-up

	Intervention group	Control group
Number of participants	13	13
Age	Mean = 69.85 (range 62-77 years, SD: 5.39)	Mean = 69.85 (range 60-77, SD: 5.08)
Sex		
Men	8 (61.5 %)	5 (38.5 %)
Women	5 (38.5 %)	8 (61.5 %)
Civil status		
Living alone	5	7
Married or living with a partner	8	6
Educational level		
Elementary school	4	6
High school	1	0
Higher education	2	1
Skilled	6	6
Years of education (unadjusted mean, SD)	11.76 (SD: 2.78)	10.42 (SD: 2.78)
Clinical parameters		
Systolic blood pressure	126.56	145
Diastolic blood pressure	75.67	84.14
Pulse	75.33	73.00
Forced expiration in 1sec (FEV ₁)	44.40	55.04
Forced vital capacity (FVC)	70.44	68.07
Health literacy level		
Inadequate HL	1	5
Marginal HL	4	3
Adequate HL	8	5
Health literacy score (unadjusted mean, SD)	75.00 (SD: 11.23)	66.69 (SD: 23.76)
Participation in rehabilitation-or exercise programmes	7 of 13	3 of 13

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