LUND UNIVERSITY

Paving the way for transparency

How eHealth technology can change boundaries in healthcare

Petersson, Lena

2020

Document Version:
Publisher's PDF, also known as Version of record

Link to publication

Citation for published version (APA):
Petersson, L. (2020). *Paving the way for transparency: How eHealth technology can change boundaries in healthcare* (1 ed.). Department of Design Sciences, Faculty of Engineering, Lund University.

Total number of authors:
1

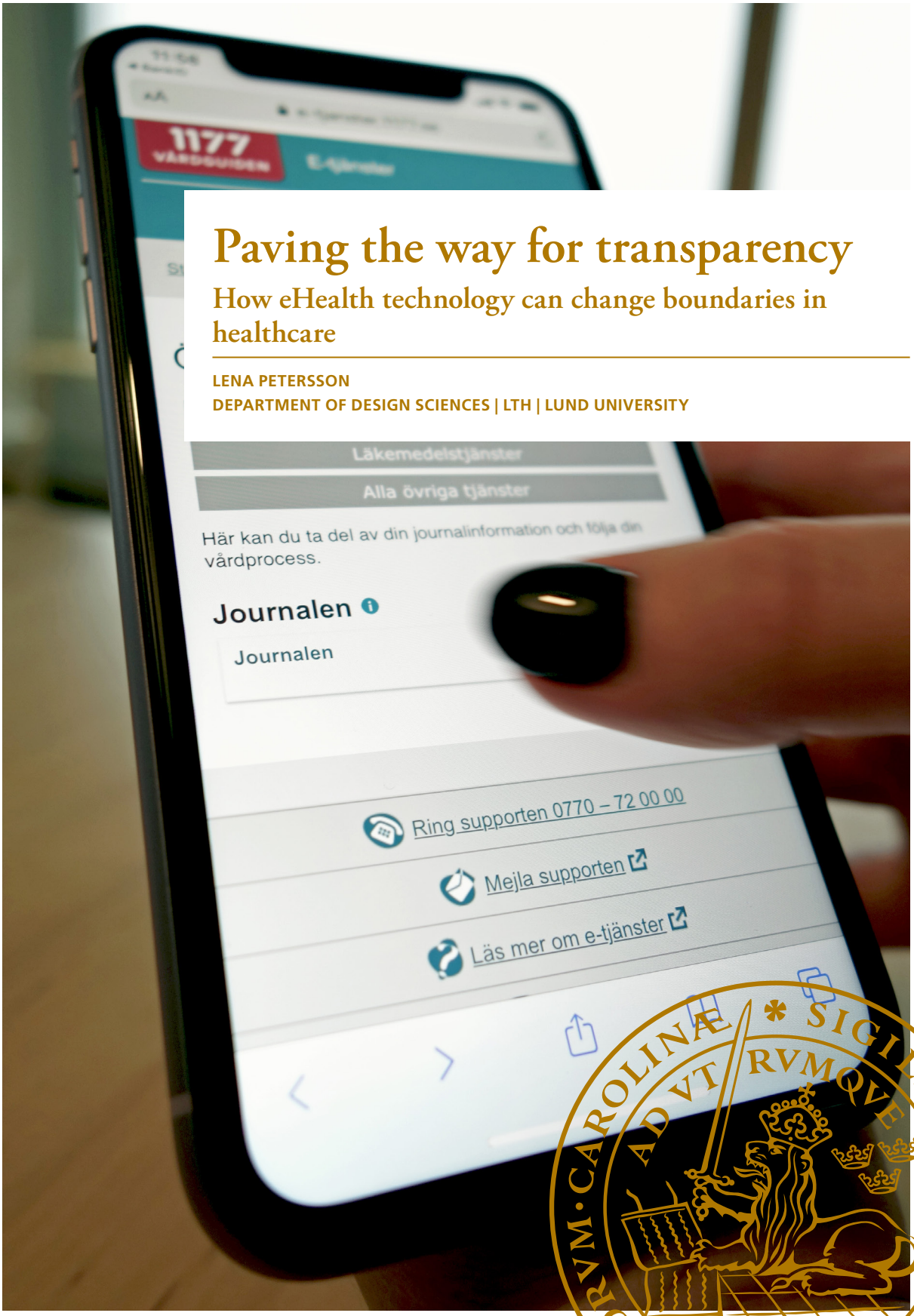
General rights
Unless other specific re-use rights are stated the following general rights apply:
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.
• Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
• You may not further distribute the material or use it for any profit-making activity or commercial gain
• You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: https://creativecommons.org/licenses/

Take down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

LUND UNIVERSITY

PO Box 117
221 00 Lund
+46 46-222 00 00



Paving the way for transparency

How eHealth technology can change boundaries in healthcare

LENA PETERSSON
DEPARTMENT OF DESIGN SCIENCES | LTH | LUND UNIVERSITY

Paving the way for transparency

Paving the way for transparency

How eHealth technology can change boundaries in healthcare

Lena Petersson

LUND UNIVERSITY

DOCTORAL DISSERTATION
by due permission of the Faculty of Engineering, Lund University, Sweden.
To be defended at Stora Hörsalen, IKDC, Lund. 7 February 2020 at 13.15.

Faculty opponent
Associate Professor Henriette Langstrup

Organization	Document name
LUND UNIVERSITY	DOCTORAL DISSERTATION
Department of Design Sciences Division of Ergonomics and Aerosol Technology	Date of issue:18 December 2019
Author: Lena Petersson	Sponsoring organization: AFA Insurance

Title and subtitle: Paving the way for transparency - How eHealth technology can change boundaries in healthcare

Abstract: The digitalization that currently is taking place in healthcare raises questions about how this development, with visions of more patient participation and patient empowerment, changes this sector and what role eHealth can play in these changes. The term civic health technologies (Invånartjänster) is used in Sweden to describe eHealth in the healthcare sector that is developed and deployed by the authorities for the citizens. Open Notes (Journalen) is a civic health technology that enables patients to access their electronic health records online. The system is an innovation in healthcare that changes when and where patients can read the content of their health records. Psychiatric care was initially exempt from the service because the content of the records was considered too sensitive and the psychiatric patients too vulnerable. In October 2015, Region Skåne became the first region in Sweden to include adult psychiatry in the service. It is thus of interest to gain more knowledge about how the healthcare professionals in this setting describe how their work changed when the eHealth solution, aimed to support and empower patients, was implemented in their practice.

The overall aim of the thesis is to explore and analyze how the transparency that is afforded to patients by eHealth technology changes the boundaries in healthcare. By analyzing these issues with the support of a theoretical framework, we can increase our knowledge of how the transparency afforded by the materiality of technologies changes the boundaries around the work of healthcare professionals. The thesis presents three studies that have a mixed methods approach.

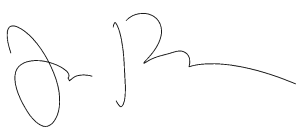
The results show that although civic health technologies, such as the Open Notes service, are aimed at the patients, they also change healthcare practice and the relations between professionals and patients. These changes are reported regardless of whether the patient uses the service or not. The idea of Open Notes is to create a transparent healthcare practice that empowers patients and enables them to be more involved in their care. The results show that the professionals do not experience that all of their patients in adult psychiatry meet these expectations. This indicates that governed individual real-time transparency may not always be the best choice either for the patients or for the healthcare professionals' work. The work of healthcare professions, by tradition, is surrounded by boundaries. The results show that key actors behind the Open Notes service, through what is referred to as configurational boundary work, have the power to transform these boundaries. Such a development could result in actions from the professions to regain control over the boundaries, referred to as competitive boundary work. The professionals reported that they had changed their behavior and conducted competitive boundary work in order to deal with the transparency in the Open Notes service because it makes their professional work visible. The professionals did this primarily to protect the patients and their relatives, and secondly to protect themselves. The results from adult psychiatry show that doctors and psychologists in many cases seem more negative to the visibility than other groups of healthcare professionals. The materiality of Open Notes thus seems to challenge professional values, and the reactions are strongest from these two professions. Their primary reason for being sceptical to the transparency that is afforded by Open Notes is that they believe that it may not always be the best and safest solution for all of their patients.

Key words: Healthcare, eHealth, Open Notes, PAEHRs, psychiatry, healthcare professionals, transparency, boundaries, boundary work, materiality, patient empowerment

Classification system and/or index terms (if any)

Supplementary bibliographical information		Language English
ISSN 1650-9773 Publication 65		ISBN 978-91-7895-410-0 (print) ISBN 978-91-7895-411-7 (pdf)
Recipient's notes	Number of pages 112	Price
	Security classification	

I, the undersigned, being the copyright owner of the abstract of the above-mentioned dissertation, hereby grant to all reference sources permission to publish and disseminate the abstract of the above-mentioned dissertation.

Signature  Date 2019-12-18

Paving the way for transparency

How eHealth technology can change boundaries in healthcare

Lena Petersson

LUND
UNIVERSITY

Coverphoto and design by Erik Andersson and Jessika Sellergren

Copyright pp 1-112 by Lena Petersson

Paper 1 © by Petersson, L., Erlingsdóttir, G. and Jonnergård, K. (Manuscript unpublished)

Paper 2 © by Jonnergård, K., Petersson, L. and Erlingsdóttir, G. (Manuscript unpublished)

Paper 3 © by JMIR Publications

Paper 4 © by JMIR Publications

Paper 5 © by JMIR Publications

Paper 6 © by Petersson, L. (Manuscript unpublished)

Faculty of Engineering
Department of Design Sciences

ISBN 978-91-7895-410-0 (print),
978-91-7895-411-7 (pdf)
ISSN 1650-9773 Publication 65

Printed in Sweden by Media-Tryck, Lund University
Lund 2020

Media-Tryck is an environmentally certified and ISO 14001:2015 certified provider of printed material. Read more about our environmental work at www.mediatryck.lu.se

MADE IN SWEDEN

Table of Contents

Abstract 9
Sammanfattning 11
Acknowledgements 13
Appended papers 15
Other publications by the author 16

Introduction 17
eHealth 18
eHealth in the form of civic health technologies 20
The implementation of the Open Notes service in Sweden 21
Changes for the healthcare professionals 24
A study that crosses the implementation line 25
Aim and Research Questions 26
The project 27
Overview of the thesis 27

Open Notes 29
The deployment of Open Notes 29
Research on Open Notes in non-psychiatric settings 30
Research on Open Notes in psychiatric settings 33
Open Notes in adult psychiatry in Region Skåne 36

Theoretical framework 43
Healthcare professionals and healthcare professions 43
Healthcare professions and boundaries 45
Different types of boundary work 47
Materiality matters 49
Transparency and visibility 50
Civic health technology and the empowered patient 52
Theoretical framework and analytical model 53

Research approach and methodology **55**
Research approach 56
Methods used in the three studies 58
Data analyses in the three studies 66
Ethical considerations 70
Summary of appended papers **73**
Paper I 73
Paper II 74
Paper III 76
Paper IV 78
Paper V 80
Paper VI 82
Discussion and conclusions **85**
Returning to the research questions 85
Summary of the results discussion 94
Methodological considerations 95
Knowledge contribution 98
Conclusions 99
Implications for practice and future research 101
References **103**

Abstract

The digitalization that currently is taking place in the healthcare sector reveals both new requirements and new opportunities for patients, healthcare professionals, healthcare providers and other actors in society. This raises questions about how this development, with visions of more patient participation and patient empowerment, changes the healthcare sector and what role eHealth can play in these changes.

The term civic health technologies (Invånartjänster) is used in Sweden to describe eHealth in the healthcare sector that is developed and deployed by the authorities for the citizens. The reasoning behind civic health technologies is to increase patient empowerment and participation in their own health by making information from healthcare visible to them. Open Notes (Journalen) is a civic health technology that enables patients to access their electronic health records online. The system is an innovation in healthcare that changes when and where patients can read the content of their health records. By the end of October 2019, more than 3 million Swedish citizens had used the service. Psychiatric care was initially exempt from the service because the content of the records was considered too sensitive and the psychiatric patients too vulnerable. However, in October 2015 Region Skåne became the first county in Sweden to include adult psychiatry in the service. It was of interest to gain more knowledge about how these healthcare professionals describe how their work changed when the eHealth solution, aimed to support and empower patients, was implemented in their practice.

The overall aim of the thesis is to explore and analyze how the transparency that is afforded to patients by eHealth technology changes the boundaries in healthcare. By analyzing these issues with the support of a theoretical framework, we can increase our understanding of how the transparency afforded by the materiality of technologies changes the boundaries around the work of healthcare professionals. The thesis presents three studies that have a mixed methods approach. The first study focuses on what kind of boundary work the key actors behind the Open Notes service conduct in order to make space for the empowered patient in healthcare. The second study compares how healthcare professionals in adult psychiatry in Region Skåne perceived Open Notes before and after the implementation in their practice. The third conceptual study compares the materiality of Open Notes with that of two other technologies.

Although civic health technologies, such as Open Notes, are aimed at the patients, the results show that they also change healthcare practice and the relations between professionals and patients. These changes are reported regardless of whether the patient uses the service or not.

The work of healthcare professions is by tradition surrounded by boundaries. The results show that key actors behind the Open Notes service, through what is referred

to as configurational boundary work, have the power to transform these boundaries. This changes the balance of power between the profession and the patient. Changes in boundaries around professions that are initiated by other groups imply that the control professions have over the boundaries decreases. Such a development could result in actions to regain control over the boundaries, referred to as competitive boundary work. The professionals reported that they had changed their behavior in order to deal with the transparency in the Open Notes service because it makes their professional work visible. This is an example of competitive boundary work. The professionals did this primarily to protect the patients and their relatives, and secondly to protect themselves.

Through the implementation of the Open Notes service (an important work tool of healthcare professionals), health records have become visibly available to patients online. The results from adult psychiatry show that doctors and psychologists in many cases seem more negative to this visibility than other groups of healthcare professionals. The materiality of Open Notes thus seems to challenge professional values, and the reactions are strongest from these two professions. The idea of the Open Notes service is to create a transparent healthcare practice that empowers patients and enables them to be more involved in their care. Thus, Open Notes can be described as an artifact that is primarily designed for a rational patient who can meet these requirements and expectations. The results show that the professionals do not experience that all of their patients in adult psychiatry meet these expectations. The results thus indicate that full transparency may not always be the best choice.

Sammanfattning

Den digitalisering som för närvarande äger rum inom hälso- och sjukvårdssektorn ställer både nya krav och öppnar för nya möjligheter för enskilda medborgare, vårdpersonal samt olika aktörer i samhället. I många av de e-hälsolösningar som utvecklas finns bakomliggande tankar om ökad egenmakt (empowerment) för patienten genom att denne skall få ökad kontroll över sin egen hälsa och den information som är kopplad till den egna hälsan. En intressant fråga blir då hur denna utveckling förändrar hälso- och sjukvården och vilken roll e-hälsolösningar kan spela i dessa förändringar.

Begreppet Invånartjänster används i Sverige för att beskriva e-hälsolösningar inom hälso- och sjukvårdssektorn som är utvecklade och tillgängliggjorda av myndigheterna för medborgarna. Tanken bakom Invånartjänster, är att öka patientens egenmakt och deltagande i sin egen hälsa genom att synliggöra information från hälso- och sjukvården för dem. Journalen (Open Notes) är en invånartjänst som gör det möjligt för patienten att få tillgång till sin elektroniska patientjournal via nätet. E-hälsolösningen är en innovation inom hälso- och sjukvården som förändrar när och var patienten kan läsa innehållet i sin patientjournal. I slutet av oktober 2019 hade mer än 3 miljoner svenska medborgare använt tjänsten. Hösten 2015 var Region Skåne först i Sverige med att tillgängliggöra patientjournaler från psykiatrin via tjänsten. Genom Journalen, har patienter i den vuxenpsykiatriska vården i Region Skåne tillgång till sin patientjournal via nätet. Journalen är ett exempel på en e-hälsolösning som syftar till att stödja patienter till att bli mer delaktiga i sin vård och den här avhandlingen bidrar med kunskap om hur vårdpersonal på vuxenpsykiatrin i Region Skåne beskriver att deras arbete förändrades när en e-hälsolösning, som syftar till att stödja och stärka patienter, implementeras i deras praktik.

Det övergripande syftet med avhandlingen är att utforska och analysera hur den transparens som erbjuds patienter via e-hälsolösningar förändrar gränserna inom hälso- och sjukvården. Genom att analysera detta med stöd av ett teoretiskt ramverk, kan vi öka vår förståelse för hur den transparens som teknologiernas materialitet erbjuder patienten förändrar gränserna för vårdpersonalens arbete. Avhandlingen består av tre studier som har en mixad metod. Den första studien fokuserar på vilken typ av gränsarbete nyckelaktörerna bakom tjänsten Journalen utförde för att ge plats för den delaktiga patienten inom hälso- och sjukvården. Den andra studien jämför hur hälso- och sjukvårdspersonal i vuxenpsykiatri i Region Skåne uppfattade Journalen före och efter implementeringen. Den tredje konceptuella studien jämför materialiteten hos Journalen med två andra e-hälsolösningar som riktar sig till patienter.

Även om invånartjänster, som Journalen, riktar sig till patienterna, visar avhandlingens resultat att de också förändrar vårdpraktiken och relationerna mellan

vårdprofessioner och patienter. Dessa förändringar äger rum oavsett om patienten använder tjänsten eller inte.

Hälso- och sjukvårdsprofessionernas arbete är av tradition omgiven av gränser. Resultaten visar att nyckelaktörer bakom tjänsten Journalen, genom att utföra gränsarbete, har makten att ändra dessa gränser. Detta förändrar maktbalansen mellan vårdprofessionen och patienten. Förändringar i de professionella gränserna kring yrket, som initieras av andra grupper, innebär att den kontroll som professionens har över gränserna minskar. En sådan utveckling kan resultera i handlingar som syftar till att återfå kontroll över de professionella gränserna. Det finns personal uppger att de har förändrat sitt arbetssätt för att hantera den transparens som erbjuds till patienter genom Journalen, eftersom den synliggör deras professionella arbete. Detta kan ses som ett exempel på professionellt gränsarbete. Personalen uppgav att de gjorde detta främst för att skydda patienterna och deras anhöriga och i andra hand för att skydda sig själva.

Genom implementeringen av Invånartjänsten Journalen har innehållet i patientjournalen blivit tillgängligt för patienter via nätet. Resultaten från vuxenpsykiatrin i Region Skåne visar att läkare och psykologer i många fall verkar mer negativa mot denna transparens än andra personalgrupper. Materialiteten hos Journalen verkar utmana professionella värderingar och reaktionerna är starkast från dessa två personalgrupper. Tanken bakom Journalen är att skapa en transparent hälso- och sjukvårdspraktik som ger patienterna möjlighet att bli mer involverade i sin vård. Journalen kan sägas vara en artefakt som främst är utformad för en rationell patient som kan uppfylla dessa krav och förväntningar. Resultaten visar att personalen i vuxenpsykiatrin inte alltid upplever att alla deras patienter uppfyller dessa förväntningar. Resultaten pekar således på att full transparens kanske inte alltid är det bästa valet.

Acknowledgements

I would like to thank everybody that in different ways contributed to this thesis. In particular, I would like to thank:

My main supervisor, Associate Professor Gudbjörg Erlingsdóttir. Guggy I am so grateful for the opportunity to work so tightly with you during these years. It has been a privilege. You have been a supervisor that has both shared your valuable experiences and let me discover things on my own.

My co-supervisor, Professor Karin Jonnergård, for always being supportive, asking relevant questions and providing additional perspectives. I have always appreciated your experience and good advice during these years.

Professor Åsa Cajander at Uppsala University for being a co-supervisor during my first time as a Ph.D. student.

All the participants in Studies 1 and 2 who have contributed their time, knowledge and experiences. A special thanks to Gunnar Moustgaard at the Division of Psychiatry in Region Skåne and the other members in the working group eJournalen.

AFA Insurance for funding of the EPSA Project, and the Center for Research on Welfare, Health and Sport (CVHI) at Halmstad University for their support during my last period as a Ph.D. student.

Professor Helena Sandberg for valuable feedback on the early versions of Paper VI. You helped by highlighting the weak spots in the text and by questioning my reasoning in the first drafts.

Dr. Cecilia Lindholm at Uppsala University for your contribution to Study 1 and for all the interesting discussions and good laughs during your time at the Department of Design Science.

Dr. Ola Stjärnhagen at Lund University for valuable support on the software package, Sunet Survey, and for support when the web surveys were distributed.

Associate Professor Carola Aili for being the external reviewer at my final doctoral seminar. Your contribution has improved this thesis.

All my colleagues at Halmstad University for your support before and during my Ph.D. education. Especially my closest colleagues that I worked with at the College of Health Education and the project management of the Digga Halland Project. Thank you for your support and understanding, especially during my most intensive writing phase in the autumn of 2019.

All my colleagues at EAT who contributed with both an inspiring work environment and interesting discussions and laughs at the lunch table. A special thanks to Erik Andersson and Jessika Sellergren for help with the cover of this thesis.

Eileen Deaner for proofreading that has improved the quality of this thesis with both language corrections and questions about the content that helped me to clarify the text. A special thanks for your work during the last weeks of the writing phase. Thank you!

Outside of work, I would like to thank family and friends for their support during these years.

Last but not least, I would like to thank my life partner and soul mate Per G; without you this wouldn't have been possible. Thank you for your love, your enthusiasm and your support that has followed me throughout this process and made it possible for me to carry out this project.

Appended papers

This thesis was based on the following six papers published or submitted for publication in international scientific journals.

I. Petersson L., Erlingsdóttir G. & Jonnergård K. Configurational Boundary Work – Narratives from the Implementation of Open Notes in Two Swedish Regions. (To be submitted to *Financial Accountability & Management*). I took part in the design of the study. I was the main data collector. I took part in the analysis and writing of the paper.

II. Jonnergård, K., Petersson, L. & Erlingsdóttir G. How to Communicate the Indirect Implementation of Open Notes. (Submitted to *BMC Health Services Research*). I took part in the design of the study. I was the main data collector. I contributed to the writing of the paper.

III. Petersson L., Erlingsdóttir G. (2018). Open Notes in Swedish Psychiatric Care (Part 1): Survey Among Psychiatric Care Professionals. *JMIR Ment Health*, 5(1):e11. The authors designed the study together. I was the main data collector. Both authors took part in the analysis. I was the main author.

IV. Petersson L., Erlingsdóttir G. (2018). Open Notes in Swedish Psychiatric Care (Part 2): Survey Among Psychiatric Care Professionals. *JMIR Ment Health*, 5(2):e10521. The authors designed the study together. I was the main data collector. Both authors took part in the analysis. I was the main author.

V. Erlingsdóttir, G., Petersson, L. & Jonnergård, K. (2019). A Theoretical Twist on the Transparency of Open Notes: Qualitative Analysis of Health Care Professionals' Free-Text Answers. *J Med Internet Res*, 21(9):e14347. I took part in the design of the study. I was the main data collector. I contributed to the analysis and the writing of the paper.

VI. Petersson, L. New Boundaries for the Physician Profession in the Digitalized Healthcare Sector – Why Materiality Matters. (Submitted to *Information & Organization*). I designed the study. I was the main data collector. I did the analysis and wrote the paper.

Other publications by the author

Petersson, L. (2019). Nya gränser i hälsolandskapet. I Erlingsdóttir, G. & Sandberg, H. (Red.). På tal om e-hälsa. Lund: Studentlitteratur.

Petersson, L. & Erlingsdottir, G. (2017). Factors to consider when implementing patient online access to their electronic health record. I: Nordic Ergonomic and Human Factor Society Conference (NES 2017) in Lund, Sweden, 2017-08-20-23.

Erlingsdottir, G. & Petersson, L. (2016). Healthcare personnel does not consider the eHealth service "patient online access to their electronic health record" to be beneficial for work environment and patient safety. I: The 10th NOVO symposium in Reykjavík, Reykjavík, Island, 2016-11-10-11.

Petersson, L. & Erlingsdottir, G. (2016). Professionernas farhågor om införandet av eJournal inom vuxenpsykiatrin i Region Skåne. I: NORDPRO-konferensen 2016, Lund, Lund, Sverige, 2016-10-27-28.

Erlingsdottir, G. & Petersson, L. (2016). Employees' work environment and patients' rights, conflicting responsibilities when implementing patient online access to their EHR. I: The 2016 Healthcare systems Ergonomics and Patient Safety Conference (HEPS 2016) i Toulouse, Frankrike, 2016-10-7-9.

Petersson, L. & Erlingsdottir, G. (2016). Communicating to Employees the Implementation of Patient Online Access to Their EHR. The Case of Adult Psychiatry in Southern Sweden. I: The 14th Scandinavian Conference on Health Informatics 2016, Göteborg, Sverige, 2016-04-6-7.

Petersson, L. & Erlingsdottir, G. (2015). Will PatientsLikeMe.com affect the doctor – patient relation and the work environment of doctors? I: The 19thTriennial Congress of the International Ergonomics Association (IEA 2015) in Melbourne, Melbourne, Australia, 2015-08-09-14.

Petersson, L. (2015). Den välinformerade patienten. Förändrar Internet relationen mellan patient och vårdpersonal? In: FALF (Forum för arbetslivsforskning)-konferens i Landskrona, Landskrona, Sverige, 2015-06-10-12.

Introduction

The digitalization of different sectors of society is one of the largest societal changes currently taking place. The healthcare sector is no expectation. It can be described as one of the foundations of a welfare state, such as Sweden, where healthcare coverage in the country is universal. This means that all residents have access to publicly financed healthcare. The healthcare sector in Sweden is characterized by its decentralization. The state has an overall responsibility, but it is the 20 self-governing county councils and the regions that have direct responsibility for providing healthcare to their citizens (Socialdepartementet, 2014). Historically there have been clear boundaries around this sector in general, and around the healthcare professionals' specific knowledge in particular. This is changing due to the ongoing digitalization in societies all around the world (Lupton, 2018). Cajander and Grünloh (2019) point out that the healthcare sector is undergoing a paradigm shift because of the implementation of new technology for patients that is entering the domain. This can result in altering the relationships between stakeholders such as patients and doctors. It is thus important to understand different stakeholders' perspectives when designing and implementing innovative technology in a complex healthcare system (Cajander & Grünloh, 2019). Thus, technology can be a contributing factor to changing healthcare in a variety of ways. There is a need for more knowledge about how the implementation of innovative technology will change both the practice and the individuals (i.e., primarily healthcare professionals and patients) who interact with each other in this context (Cucciniello, Lapsley, Nasi, & Pagliari, 2015; Ross, Stevenson, Lau, & Murray, 2016).

At the same time, this sector is facing major societal challenges: an aging population with increasing care needs resulting in higher costs in a time of resource shortages (Hollmark, Lefevre Skjoldebrand, Andersson, & Lindblad, 2015). In addition, there are demands for increased efficiency, patient safety, and quality. In many cases, the solution to the challenges in the healthcare sector are digitalization and the implementation of technology that is referred to as "eHealth" (Doolin, 2016; Hill & Powell, 2009).

eHealth

The digitalization that currently is taking place in the healthcare sector, both nationally and internationally, reveals new requirements and new opportunities for patients, healthcare professionals, healthcare providers and other actors in society. The eHealth concept is extensive and characterizes the use of digital technology to support information and communication in healthcare. Jesper Petersson (2014) points out that both the World Health Organization (WHO) and the European Union (EU) describe the development of eHealth as a new emerging landscape that will transform the healthcare sector. WHO states that it has become increasingly clear that the goal of universal health coverage in the world cannot be reached without the use of eHealth (WHO, 2016). However, the two organizations highlight different scopes of this landscape: WHO focuses on how eHealth can be used when geographical distance is a problem for access to healthcare, whereas the EU focuses on how eHealth can be used to manage the challenges of reduced resources in the healthcare sector combined with an older population and increasing patient expectations (Petersson, 2014).

Despite the confidence in the possibilities and anticipated needs of eHealth in society, the research has shown that there is a lack of consistency in the use of the term and that there are various definitions of eHealth. A systematic review in 2005 found 51 different definitions of the term (Oh, Rizo, Enkin, & Jadad, 2005). At that point, the researchers found that the most cited definition of eHealth was Gunther Eysenbach's from 2001. This is still the case.

> "e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology." (Eysenbach, 2001)

Eysenbach goes on to state that eHealth is more than just technical development and the letter "e" not only stands for *electronic*, but also implies ten other "e's" such as increased *efficiency*, improved *empowerment* for patients and *encouragement* of new relationships between healthcare professionals and patients (Eysenbach, 2001). The definition of eHealth and the accompanying thoughts on the forthcoming evolution in the healthcare sector are loaded with wishes and expectations of how technology will enable change and improvements. The conclusion is that patients are in a position that needs to be strengthened, and that it is technology that should enable this change. In other words, the technological developments in the eHealth field can be described as a driving force for a bigger and overall transformation of

the healthcare sector that will influence both patients and healthcare professionals in different ways.

We live in an age where there are expectations from society that patients should participate in their care and that every citizen, at least to some extent, should take responsibility for his or her own health. The development of healthcare technologies that enable patients to be more active and informed challenges a 150-year-old tradition in the healthcare system. More responsibility is being delegated to patients in stark contrast to the traditional healthcare system in which the professionals functioned as experts (Brodersen & Lindegaard, 2015). However, increased patient empowerment is considered to be an important part of efforts to improve patients' health. The WHO states the importance of individuals being given the opportunity to improve their health by taking increased control over it (Schulz & Nakamoto, 2013). At the same time, there is an increased interest from patients to become active and involved in issues related to their health (Wass & Vimarlund, 2018). Thus, developments in the healthcare sector can be described as a transition from the societal desire that patients should be compliant, to viewing the patient as a co-producer in healthcare. The underlying idea is that paternalism should be replaced by a partnership with the patient, and that eHealth should be a part of this.

In line with this ambition, healthcare providers and policymakers are pursuing strategies to increase patient engagement in healthcare with the support of health technology. In Sweden, key organizers in the healthcare sector describe the development and deployment of eHealth as a paradigm shift (Cehis, 2013; Socialdepartementet, 2010), aimed at enabling patients increased access to information about themselves via patient transparency and, as a result, influence over their health situation through patient empowerment. In the document, *National eHealth – The Strategy for Accessible and Secure Information in Health and Social Care*, Socialdepartementet[1] (The Swedish Ministry of Health and Social Affairs) identified three main target groups in the eHealth field: 1) the individual, 2) health and social care staff, and 3) decision-makers in all care services (Socialdepartementet, 2010). In the policy document, *Vision for eHealth 2025*, the Swedish Government together with Sveriges Kommuner och Landsting (SKL)[2] (The Swedish Association of Local Authorities and Regions) state that Sweden should be world leading by 2025 in its use of the opportunities offered by eHealth, and that special emphasis should be placed on the first two of the above-mentioned three target groups in order to achieve this vision (SKL, 2016). The policy document emphasized that there are great opportunities for future care thanks to new technologies that enable individuals to be more involved in their care. The policy

[1] The English translation is *Ministry of Health and Social Affairs*. The official Swedish term, "Socialdepartementet", is used in the references.

[2] The English translation is *The Swedish Association of Local Authorities and Regions*. In this thesis, the Swedish abbreviation SKL is used.

document also emphasized that technologies will support contact between individuals and healthcare providers.

Another change in the healthcare sector, in line with the above-described development towards increased transparency and patient influence, is the new Patientlagen (2014:821) (The Patient Act) that went into effect on January 1, 2015. According to SKL, the purpose of the law is, among other things, to strengthen and clarify the patient's position and promote patient integrity, self-determination and participation in their care. The new law states that the duty of healthcare professionals to inform patients has been expanded, and that the patient's right to another medical assessment (i.e., a second opinion by another doctor) has also been expanded (SKL, 2015). Thus, patients' legal rights have been strengthened in line with the national vision that patients should be more informed and active in their own health, and particularly in their care. To be able to do this, patients need technological support that enables them to gain access to information regarding their health.

Thus, eHealth can be described as the largest wave of change in the healthcare sector in many years. One of the characteristics of eHealth is the vison that technology connected to Internet will provide patients with information about their health, make them feel empowered and enable them to influence their health situation (Erlingsdottir & Sandberg, 2016). eHealth interventions are often devoted to encouraging patient engagement (Barello et al., 2015). This results in a redistribution of tasks and responsibilities from healthcare professionals to patients (Dedding, van Doorn, Winkler, & Reis, 2011). This also raises questions about how this ongoing development, with visions of more patient participation and patient empowerment, changes the healthcare sector and what role eHealth can play in these changes.

eHealth in the form of civic health technologies

Civic technology, also known as "civic tech", is technology that is situated between governments and citizens with the capability to blur boundaries between different actors (McNutt et al., 2016). The concept is associated with the smart cites movement and thus smart citizens who are able to have a partnership with governments because they share the same information (David, McNutt, & Justice, 2018). The purpose of civic technology is to enable civic engagement by making data from governments available through innovations that permit transparency towards citizens (David et al., 2018).

The objective of civic technologies is thus to enable citizens' participation in government decisions. This argumentation about civic technologies is in line with the reasoning behind the concept of *invånartjänster* (*resident services*) in Sweden.

This term describes eHealth in the healthcare sector that is developed and deployed by the authorities and aimed at the citizens; in other words, the Swedish term for civic health technologies. The two main arguments behind the drive for these technologies are to increase patient empowerment and to increase patient participation in their own health. The Ministry of Health and Social Affairs states that citizen' expectations of contact with and access to healthcare has changed over the years. Today, citizens' demands from the healthcare sector are the same as their demands from other sectors in society: a greater degree of insight, participation, and self-determination. Consequently, the Ministry claims that they need to develop civic health technologies that enable citizens to communicate with healthcare services and access information about care (Socialdepartementet, 2010). The argumentation about eHealth in the form of Swedish *resident services* thus is similar to that of civic technologies: that they enable more participation by making information from healthcare visible to patients.

One of the publishers of the above-mentioned policy document, *Vision for eHealth 2025*, is SKL. SKL is both an employers' organization, and an organization that represents and advocates for local governments in Sweden. All municipalities and regions are members of SKL and the organization represents and acts on their initiative (SKL, 2019). SKL claims that civic health technologies will increase the accessibility, efficiency and quality for patients, inhabitants and families (SKL, 2014). Inera AB, a company owned by the Swedish regions and municipalities, as well as SKL, has the task to operationalize the decisions and coordinate the development and management of civic health technologies in Sweden. The company runs the patient portal *1177 Vårdguidens e-tjänster* (*1177 Healthcare Guide e-services*) that enables Swedish citizens to get information from healthcare and communicate directly with the providers via civic health technologies and book appointments. One can also renew prescriptions and get online access to one's health records through the Swedish Open Notes service *Journalen* (Inera, 2019a).

The implementation of the Open Notes service in Sweden

Healthcare coverage is universal in the Sweden, which means all citizens have access to publicly financed healthcare and thus the Open Notes service. Open Notes (*Journalen*) is one of the most important and deployed civic health technologies in Sweden. According to Inera AB, the implementation of Open Notes is an important contribution to achieving the vision that Sweden will be world leading by 2025 in using eHealth and digitalization. The purpose of the Open Notes service is to contribute to patient's empowerment and to improve quality of care and cost-effectiveness in healthcare (Inera, 2019b).

Open Notes is a civic health technology that enables patients to gain online access to their electronic health records (EHRs). The system can be described as an innovation in healthcare that changes when and where the content in the electronic health record can be read by a patient. These two circumstances (i.e., when and where) are new compared to earlier ways for patients to gain access to their healthcare information. However, neither EHRs nor the patients' legal right to read their health records is a new phenomenon in Sweden. EHRs, per se, have been standard in the Swedish healthcare sector for many years. EHR systems were used in 85% of Swedish primary care as far back as in 1994. In the hospitals, however, this kind of system is much more demanding and it was not until 2009 that 85% of hospital wards in Sweden were using EHRs (Kajbjer, Nordberg, & Klein, 2011). Swedish patients have been able to request paper copies of their health record for more than thirty years according to Patientjournallagen (1985:562) (The Patient Health Records Act), which stated that patients had the right to read the information in their health records. In 2008, this law was replaced by Patientdatalagen (2008:355) (The Patient Data Act). This law states that the information in health records must be written in the Swedish language, be clearly formulated and as easy as possible for the patient to understand. This law also made it legal for healthcare to share information with the patient through direct access to his or her health record. Thus, the regulations in this law enabled the implementation of Open Notes some years later.

In November 2012, Region Uppsala[3] was the first in Sweden (Hagglund & Scandurra, 2017a) and Europe (Mellgren, 2013) to introduce patient online access to electronic health records in non-psychiatric care. Psychiatric care was initially exempt due to the sensitive nature of the records content, and due to the risk that the patients might be specifically vulnerable (Åkerstedt, Cajander, Moll, & Ålander, 2018). However, in October 2015 Region Skåne became the first county in Sweden to include adult psychiatry in the Open Notes service (Läkartidningen, 2015).

Sweden has a decentralized healthcare system. Initially, when Open Notes was implemented, each region was responsible for its own Open Notes system and the interpretation of the regulatory frameworks differed between the counties, although they were all based on the first framework from Region Uppsala (Hagglund & Scandurra, 2017a). Today, when Open Notes has been implemented in all of Sweden's regions, Inera AB is responsible for the coordination of the Open Notes system. There is an ongoing process to create a national regulatory framework for the Open Notes service (Inera, 2019b). However, this vision is not yet implemented and the interpretation of the regulatory frameworks still differs between counties and regions (Scandurra, Lyttkens, & Eklund, 2016). Consequently, the conditions

[3] Region Uppsala was named Uppsala County Council at this time.

for both patients and healthcare professionals regarding the Open Notes system differ depending on were in Sweden the note in the health record is written.

All Swedish patients from the age of 16 can access the Open Notes service. A parent can also access his or her children's records. The EHRs of adolescences between 13 and 15, though, cannot be accessed through the Open Notes service by the patient nor by the patients' parents without permission from a healthcare professional (Inera, 2019b). Sweden has 10 million citizens and by the end of October 2019, more than 3 million had read their Open Notes online (Inera, 2019c). Statistics from Inera show that Swedish patients logged into the service nearly 17 million times in 2018, which is an average of almost 51,000 logins a day. Every day during this year, 2,300 patients used the service for the first time (Inera, 2019c).

The introduction of the Open Notes service in healthcare is a complex socio-technical challenge due to the many stakeholders that have different interests in the implementation (Hagglund & Scandurra, 2017b). Open Notes has not only become a well-used civic health technology; it was also one of the most debated implementations in Swedish healthcare. Its development and implementation in Region Uppsala was characterized by a long and infected conflict with considerable media debate (Erlingsdóttir & Lindholm, 2015). Before it was launched there in 2012, there had been fifteen years of negotiations and challenges. Erlingsdóttir and Lindholm (2015) describe a development project that challenged norms and thus had to fight against them. These included: technical norms that dictated access and use, legal norms that determined what was legally acceptable, and professional autonomy and norms that were challenged by the project's vision that patients should be empowered and given access to information from their health records through the Internet. At the time, the opinion of the team that developed and designed the Open Notes system was that the technology should only affect the patients; they did not think that the service concerned the doctors or their work, since the technology did not require any new actions or work processes from the professionals (Erlingsdóttir & Lindholm, 2015).

From the start of the development project in Uppsala until today, there has been a great deal of interest in the reform from the lay media, patient organizations and trade unions. The opinions range between "Open Notes can be dangerous" (Mellgren, 2013) to "Open Notes is a democratic tool" (Reumatikerförbundet, 2013). Six years after the initial implementation by Region Uppsala, the debate has decreased and there is less discussion in the media about the pros and cons. However, every so often, there still are articles about Open Notes published in trade media such as Läkartidningen (a doctor trade media magazine). The discussions mainly revolve around patient safety, the health record as a work tool, and the decreased safety of healthcare professionals due to the increased transparency towards the patients.

As described above, patients' access to the content in their health records is nothing new in Swedish healthcare. The new circumstances in the case of Open Notes is that the technological developments in the eHealth field have made it possible for patients to access their health record notes in real time through the Internet. This has created a transparent healthcare practice. As already mentioned, psychiatric care was initially exempt from the Swedish Open Notes service. It is thus of interest to gain more knowledge about what happened when the Open Notes service was implemented in psychiatric care for the first time in Sweden.

Changes for the healthcare professionals

The digitalization that is taking place in today's healthcare sector can be described as an important change that affects healthcare professionals in different ways. The Open Notes services are being launched all over the world in order to increase transparency in healthcare and empower patients by giving them online access to their health records (Moll & Cajander, 2019). Thus, visions and demands about increased patient empowerment with the support of eHealth (Risling, Martinez, Young, & Thorp-Froslie, 2017) coexists with the boundaries that healthcare professions set around their work (Fournier, 2000). Much uncertainty still exists about how the healthcare professionals' work changes when eHealth solutions aimed at supporting and empowering patients are implemented in healthcare.

The development of health technologies is in many cases driven by the idea of the digitally engaged citizen who is responsible and empowered (Lupton, 2018). This is in line with the ideas behind civic technologies (David et al., 2018). The same ideas can be identified behind Open Notes, and from a general point of view, this can be described as positive. However, it also raises questions as to if and then how a civic health technology such as Open Notes affects the work of the healthcare professionals. The long-term effects that patient online access to their health records has on healthcare professionals' work is highly under investigated, particularly in Europe (Moll et al., 2018). Descriptive studies from the U.S. Department of Veteran Affairs (VA) show how an Open Notes service in psychiatric care affects both the healthcare professionals and their patients (i.e., the veterans) (Denneson, Cromer, Williams, Pisciotta, & Dobscha, 2017; Dobscha et al., 2016). While these results provide some knowledge about Open Notes in psychiatric care, the VA studies have limitations because all the patients in the researched setting are veterans. Accordingly, there is a need for more knowledge about how healthcare professionals in publicly financed psychiatry expect and experience the increased transparency, and how it affects their work and patients. Given the limited research, there is a need for more empirical investigations into the effects of Open Notes on healthcare professionals' work, especially in psychiatric settings. On the whole, there is a lack

of studies, both internationally and nationally, that use a theoretical frameworks for analyzing Open Notes services.

Open Notes can be described as a new medium for information distribution in healthcare that changes when and how patients can get access to their health records. This raises questions such as: Will patients who use the service be more involved in their care according to the healthcare professionals? Will the relations between patients and healthcare professionals change when patients have immediate access to what has traditionally been seen as a work tool of the professionals? What is happening within a healthcare practice, such as adult psychiatry, when the content in the health record is made visible to patients through the Open Notes service? Will healthcare professionals change the way they write health records when patients can access them through the Open Notes service? By drawing attention to such questions and the changed roles between patients and healthcare professionals, and to how this can be understood from the theoretical perspective of the Sociology of Professions, we can understand how the transparency that is afforded by the materiality of the technologies changes the boundaries around healthcare professionals' work.

A study that crosses the implementation line

According to Paul Leonardi (2009), research on the implementation of technology uses the implementation to either begin or end a given study. This can be problematic since studies that begin at the implementation date treat the technology as a "black box", unaware of its prior history and the way this influences later assessments of the technology (Leonardi, 2015). Studies are lacking that cross what Leonardi calls "the implementation line," that is, "the space between development and use" of the technology. Studies that do so would follow the given technology "from the earliest days of conceptualization through an extended period of use" in an organization (Leonardi, 2009).

However, the study design in this thesis gave me the opportunity to open up the black box of technology to gain more knowledge about: 1) how the underlying visions of increased patient empowerment influenced the initial design of the Open Notes service, and 2) how the system has developed and changed during its use in healthcare practice. In addition, by following the implementation of the service in adult psychiatry in Region Skåne, I was able to carry out a baseline survey before the introduction of Open Notes and a post-implementation survey when the eHealth service had been in use for one-and-a-half years. This has provided knowledge about the healthcare professionals' expectations before the implementation of a civic health technology, and their experiences after the implementation. Previous surveys about Open Notes from healthcare professionals in Sweden have targeted those in

non-psychiatric care (Moll & Cajander, 2019; Scandurra, Jansson, Forsberg-Fransson, & Ålander, 2015). This study is thus unique because it examines psychiatric care, and targeted all healthcare professionals in a care practice that was in the process of introducing Open Notes. Furthermore, I compared Open Notes with two other health technologies that change boundaries around healthcare professionals in general and doctors in particular. This was done to understand how the healthcare sector, and the work of doctors in particular, can change as a result of the development and use of health technologies. What unites these three health technologies is that they were developed for patients; what distinguishes them is their materiality. By comparing them and analyzing how they differ from one another, it is possible to reveal the effect the materiality of these artifacts can have on the doctors' work boundaries, and – by extension – the organization of healthcare.

Aim and Research Questions

I have followed the implementation of Open Notes in adult psychiatric care in Region Skåne. The research project has an exploratory sequential design with a mixed methods approach that has been abductive throughout. The thesis addresses the vision of patients' involvement in their care through the Open Notes service by investigating the perspectives of the key actors behind the service, and the supposed and experienced effects of the service from the healthcare professionals' perspective.

The overall aim of this thesis is to explore and analyze how the transparency that is afforded to patients by eHealth technology changes the boundaries in healthcare.

More specifically the research questions of the thesis are:

RQ1: What kind of boundary work do key actors behind the Open Notes service conduct to make space for the empowered patient in healthcare?

RQ2: What are the supposed and experienced effects of Open Notes in adult psychiatry from the healthcare professionals' perspective?

RQ3: How do visions of the empowered patient change the boundaries in a healthcare practice and what kind of boundary work do healthcare professionals describe that they conduct to meet these changes?

RQ4: In what ways can the materiality of health technologies aimed at patients reconstruct boundaries between patients and healthcare professionals?

The project

The research presented in this thesis was conducted as a part of a larger research project (the EPSA Project, financed by AFA Insurance in Sweden) on how healthcare professionals' work and work environment are affected by eHealth services. The aim of the project was to develop knowledge to prevent work environment problems during the development and implementation of eHealth services, and to disseminate this knowledge for better understanding of future implementations. The EPSA project has focused on how the work and work environment in healthcare is affected by an eHealth service developed for patients, that is, the Open Notes service.

Overview of the thesis

This is a compilation thesis and consists of six chapters and six appended papers. Chapter 1 introduces the research area, specifies the research aim and the research questions. Chapter 2 provides an overview of the deployment of Open Notes, a summary of prior knowledge about Open Notes from both international and national perspectives, a presentation of the study's social context (adult psychiatric care in Region Skåne), and the technical prerequisites of Open Notes in this specific context. Chapter 3 presents the most relevant theoretical perspectives. Chapter 4 describes the research process, the methods used to achieve the aim of the thesis, and methodological and ethical considerations. Chapter 5 summarizes the appended papers. Chapter 6 discusses the findings by returning to the research questions in this Introduction, presents a summary of the main contributions and suggested areas where there is a need for future research.

Open Notes

Open Notes has become increasingly common in the parts of the world that have electronic health records. The technical solution that enables patients to access their health record is also known as Patient Accessible Electronic Health Records (PAEHRs) (Hagglund & Scandurra, 2017a; Jilka, Callahan, Sevdalis, Mayer, & Darzi, 2015), My Medical Record on the Internet (Erlingsdóttir & Lindholm, 2015) and OpenNotes (Delbanco et al., 2010). In Swedish, this service has been called by different names such as *Journalen*, *eJournalen*, *journal via nätet*, or just *nätjournalen* in casual conversations among patients, health care professionals, administrators in healthcare and politicians.

The deployment of Open Notes

It is difficult to get an overview of the current implementation status of Open Notes on a global level and to compare the different technical solutions with each other. However, few countries, all in the Western world, offer their citizens online access to their health data on a national level (Nøhr et al., 2017). An international comparison of the service in 10 countries by Essén et al. (2017) shows that there were differences in the type of data that were available to the patient. Some countries, such as Estonia and Denmark, have implemented mandatory, nationally enabled data sets in which all patients in the country have access to the same amount of information. Other countries, such as Australia, the Netherlands and Sweden, have a locally enabled display with differences within the country, which means that patients in different parts of the country have online access to different amounts of information from their health records (Essén et al., 2017).

The OpenNotes team at Harvard Medical School[4] in the U.S. began as a one-year demonstration and evaluation project in 2010 that included 105 volunteer primary care doctors and their 19,000 patients (Leveille et al., 2012; Walker, Meltsner, & Delbanco, 2015). Nine years later, more than 200 health systems in the United States and Canada share notes with their patients online and almost 40 of these health

[4] In this thesis, the term "Open Notes" is used as two words, except when I refer to the OpenNotes team and their project at Harvard Medical School. They write the words as one in their project name.

systems share notes with patients in psychiatric care. Thus, more than 43 million patients all over North America have access to their health records online (OpenNotes, 2019). The OpenNotes team in Boston is prominent in the field in terms of implementation support of the service and research on the clinical effects for patients and healthcare professionals in the United States. According to their homepage, they believe that providing online access to notes can empower patients, families and caregivers to feel more in control of their healthcare decisions and can improve the quality and safety of care. Altogether, the picture is that OpenNotes systems have been implemented for large groups of patients in non-psychiatric care, but also in psychiatric care in the United States and Canada, for example (OpenNotes, 2019). At the same time, researchers state that there is a need for more knowledge about Open Notes services.

A systematic review of previous reviews indicates that there are positive signs for the adoption of Open Notes, but there is not enough evidence about the effects of the service on patients or healthcare professionals (Jilka et al., 2015). Another systematic review by de Lusignan et al. (2014) included 143 studies from primary care settings. Most of the studies were undertaken in the U.S. and Europe, but a majority originated from settings in the U.S. The results show that Open Notes services offer increased convenience and satisfaction, primarily for patients with a higher socioeconomic status. Healthcare professionals, though, were worried about increased workloads and risks to privacy. There was no evidence base in the review that Open Notes services improved health outcomes (de Lusignan et al., 2014). Thus, while Open Notes may contribute to more informed patients, the service may also do other things. For example, studies have indicated that having access to their medical records online creates new expectations (Shah et al., 2015) and increases the use of clinical services (Palen, Ross, Powers, & Xu, 2012). Consequently, it is impossible to foresee how practices that are made transparent by the Open Notes services evolve over time and how patients may change their behavior after reading their notes (Walker, Darer, Elmore, & Delbanco, 2014).

Research on Open Notes in non-psychiatric settings

The idea that patients should have access to their records is not new in healthcare as a whole (Shenkin & Warner, 1973) or in psychiatric care (Roth, Wolford, & Meisel, 1980). Over forty years ago, the revolutionary idea of patient access to their health records on a regular basis was presented and the vision was that this would enhance the quality of care (Shenkin & Warner, 1973). In 2010, Delbanco et al. from the OpenNotes project stated that thanks to the digitalization in healthcare in the last decade, it is now technically possible to give patients online access to their health records, and that society calls for more transparency. The researchers also state that there may be negative consequences such as worrying patients, unwelcomed

changes in documentation, and complications in the relationships between patients and doctors (Delbanco et al., 2010). The researchers at the OpenNotes project anticipated that there could be both benefits and problems associated with opening health records to patients online.

Several studies from the OpenNotes project in United States have reported results on the development, implementation and use of the service in non-psychiatric settings. A baseline study that included two surveys shows that the expectations among doctors (68.11%, 173/254) in primary care about Open Notes varied before the implementation of the service in 2010, at the same time as patients (41.67%, 37,856/90,826) were positive about the new possibilities of reading their health records online (Walker et al., 2011). The evaluation of the initial implementation of the service in three primary care settings was described as a real-world experiment tested by the authors. It showed that patients who participated in the project (70.02%, 13,564/19,371) were satisfied with the service and that the doctors (92.92%, 105/113) who volunteered to participate in the project experienced modest effects on their work (Delbanco et al., 2012) (Bell et al., 2017). Thus, it was decided that the project should expand and include more healthcare settings (Walker & Delbanco, 2013).

In 2015, The OpenNotes team indicated that their earlier concerns about alarmed and worried patients, records being watered down, changing relationships between patients and healthcare professionals, still existed among clinicians in primary care. However, the OpenNotes team believed that the benefits outweighed the risks. They also indicated that there was a need for more research about the effects of Open Notes on clinical outcomes (Walker et al., 2015). Klein et al. stated that a transparent health record raises many questions to be answered such as: Which patients will benefit from reading their notes and which will not? Should the content and format of the notes be changed? Should some notes be hidden and how would you explain this to the patients (Klein et al., 2016)? A follow-up survey of patients (21.68%, 29,656/136,815) at the primary care institutions in the original OpenNotes pilot showed that they found note reading to be important for their health management and that they were seldom worried about something they read. The results also showed that only a third of the respondents answered that they discussed their notes during visits or that their clinicians had recommended that they read their notes. The authors concluded that although the results suggested that the benefits of Open Notes outweighed the risks, there is still a need for more knowledge about how the service can be used as a tool for communication and interaction between clinicians and patients in different health care settings (Walker et al., 2019). A brief research report from the same study suggests that Open Notes could enhance patients' medication adherence and improve their understanding of their medications (DesRoches et al., 2019). However, an editorial comment on the results in DesRoches et al.'s (2019) study stated that although transparency is a fact of today's clinical life, it will be important in the future to investigate whether the

transparency of clinical documentation and health information has measurable effects on costs, quality of care and patient outcomes (Blumenthal & Abrams, 2019).

There are also Swedish studies on healthcare professionals and patients in non-psychiatric settings. An interview study was carried out with 12 doctors 6 months after the implementation of Open Notes in non-psychiatric care in Region Uppsala in Sweden. The results revealed that the doctors perceived the health record as their work tool and not a tool for the patients. They expected that there would be negative changes in their work environment due to the Open Notes service (Grunloh, Cajander, & Myreteg, 2016). In another study, the 12 interviews were further analyzed with a focus on patient participation and empowerment. The results showed that and there were still paternalistic practices regardless of the vision of increased patient empowerment through Open Notes (Grunloh, Myreteg, Cajander, & Rexhepi, 2018). Another survey study from Örebro County indicated that healthcare professionals (45%, 45/100) needed to increase their knowledge about eHealth services, such as Open Notes, since the services will affect their work processes (Scandurra, Jansson, Forsberg-Fransson, & Ålander, 2017). An interview study with seven nurses in Uppsala showed that their experiences were similar to physicians; the nurses stated that patient online access to their records could improve the contact between patients and professionals and that patients could play a more active role in their care (Cajander, Moll, Englund, & Hansman, 2018). However, the study also showed that the nurses mentioned insecurities for both patients and professionals, increased workload, patients having difficulties understanding the content of the health record and patients being anxious when reading new and unsigned notes in the record.

The results from a survey with oncology healthcare professionals (72%, 176/244) at Uppsala University Hospital six years after the implementation of the service, showed that Open Notes affected the work of oncology health professionals. The area most affected at the clinic was the documentation practices. Approximately 70% of both the doctors and nurses that answered the survey were more restrictive with what they wrote in their notes and doctors particularly experienced that it took longer to write and edit notes. Some of the doctors and nurses had changed the ways they wrote about mental issues, in particular, and addiction, but also about cancer and obesity (Moll & Cajander, 2019). The results further showed that a clear majority of the respondents did not believe that care could be given more effectively or that it had become safer as a result of the patients having online access to their records. A majority of both doctors and nurses did not believe that their patients felt that they could take better care of themselves. They believed that their patients felt that they had more control over their care and were better prepared for visits, but that the notes were confusing for a majority of the patients, and that most patients worried after being able to read their notes online. A case study was carried out with 146 healthcare professionals in primary care and outpatient clinics in the Region of Jönköping County. The results showed that professionals working in the primary

care unit were more positive to the service than professionals in the outpatient clinic. Approximately one third of the healthcare professionals agreed to some extent that they could not document everything they wanted in the records due to the Open Notes service. The professionals reported that they had made changes in how they wrote about specific symptoms related to mental illness, cancer, obesity and drug abuse (Wass, 2017).

On the other hand, results from a survey with Swedish patients (0.61%, 2587/423,141) who logged into the Open Notes service at least once from June to October 2016 showed that the respondents stated that it is important for them to access information through the service. Their arguments were related to patient empowerment, for instance (Moll et al., 2018). An interview study with 30 cancer patients that were under treatment showed that online access to their records helped them prepare for doctor visits and improved their communication with practitioners (Rexhepi, Åhlfeldt, Cajander, & Huvila, 2016). The results from an exploratory case study where nine Swedish patients were interviewed showed that the patients considered online access to their records to be timesaving, that it increased their involvement in care and improved the relationship with healthcare professionals (Wass & Vimarlund, 2018). In her thesis, Grünloh (2018) concludes that patient online access to electronic health records is an important step towards patient participation, and that policymakers and government agencies thus promote patient empowerment. According to the author, though, there were still paternalistic tendencies among doctors and this visualizes the conflicting interests among different stakeholders regarding values connected to eHealth technologies (Grünloh, 2018).

In summary, there is both international and national research on Open Notes in non-psychiatric settings with studies that present qualitative and quantitative data. An important factor to bear in mind is that the prerequisites of the service differ between settings regarding such factors as technological solutions, legal rights and the possibilities for both patients and health care professionals. However, the general tendency in the studies is that patients are more positive than health care professionals about the service. Studies are lacking that analyze Open Notes from theoretical perspectives, and basically all of the studies present empirical data without any theorization about the results at all.

Research on Open Notes in psychiatric settings

Open Notes in psychiatric settings has not been deployed to the same extent as in non-psychiatric settings. A comparison of 10 countries by Essén et al. (2017) showed that psychiatric notes could be displayed in six of them: Finland, Estonia, Denmark, Norway, the Netherlands and Sweden. It was not mandatory to show

psychiatric notes online in any of the 10 countries in the comparison. The information from the OpenNotes project, however, indicates that there are millions of patients in United States and Canada who have access to their psychiatry health records online (OpenNotes, 2019). In Sweden, 14 of 21 county councils and regions have added some part of psychiatric care to the service as of July 2019.

In the early 1980s, Roth et al. (1980) conducted a study were psychiatric patients in the U.S. were able to read parts of their record with a staff member present to explain the information. The authors asked themselves if patient access to records was tonic or toxin. The conclusion was that patient access to their records in psychiatry was a complex area with both benefits and challenges. Most of the small group of patients in the study appreciated the opportunity to read their records, but it was not recommended that psychiatric patients should have their own paper copy. One of the most difficult issues for the healthcare professionals to handle was related to the confidentiality of information provided by people other than the patient, and the risk that they would be harmed if such information became known to the patient (Roth et al., 1980).

Thirty-five years later, researchers from the OpenNotes project stated in a discussion paper that the development of transparency in psychiatric care could be problematic due to the content in psychiatric records. For some patients in psychiatry, reading notes may carry more risks than benefits. The authors also indicated that there could be benefits with Open Notes in psychiatric care in the form of less stigmatization and increased understanding by patients about their diagnosis (Kahn, Bell, Walker, & Delbanco, 2014). The content in psychiatric records has the potential to worry patients and negatively affect the patient-doctor relationship; the decision of what information to share with a patient depends on the patient's diagnosis (Farrell, 2012).

A survey study was carried out with healthcare professionals from different hospital departments in Uppsala, Sweden. Open Notes had not yet been implemented in psychiatric care. The psychiatric care professionals (32.85%, 91/277) who answered the survey strongly believed that there would be an increased risk if patients were given access to their health records online (Åkerstedt et al., 2018). However, an exploratory pilot study that implemented Open Notes in an outpatient psychiatry clinic in Boston showed that there could be benefits for the psychiatric outpatients who were selected by their clinicians to be included in the study. Eleven of the 12 clinicians that participated and completed the post-intervention survey after 20 months believed that patient inclusion in the Open Notes system should be done with careful consideration and that patients should be selected case by case by the clinicians (Peck, Torous, Shanahan, Fossa, & Greenberg, 2017). The clinicians in the study reported that it was important that they were able to select which patients to include, and they reported high levels of concern about including patients with psychotic disorders and personality disorders. The authors further stated that some clinicians reported that they changed the way they wrote notes and that this result

raised important questions about the differences between notes in psychiatric care and non-psychiatric care.

In another study, a comparison between patients with or without mental health diagnoses who read their notes from primary care showed no difference between the groups regarding perception of the notes. However, the authors concluded that there was still a need for more knowledge about the benefits and risks of Open Notes in mental health settings to mitigate the unwanted effects of this new tool (Klein et al., 2018).

Among the patients in North America who can access their health records online, millions are veterans from the U.S. military forces. One of the first health systems in the United States to share notes, the U.S. Department of Veteran Affairs expanded patient online access in 2013 by offering VA OpenNotes that included psychiatric care. All notes written since January 1, 2013 can be accessed through the Open Notes service three days after the notes are completed (Dobscha et al., 2019). However, in a survey study carried out by Dobscha et al. in 2016, they showed that clinicians and nurses (79.08%, 208/263) from psychiatric care in the VA system were ambivalent about the service, and reported that they were writing fewer details and less about diagnoses because of the Open Notes implementation. The results indicates that Open Notes is empowering to patients, that the therapeutic relationship between patients and clinicians changes, and that clinicians are adjusting their practice to protect both the patients and themselves from adverse consequences of the service. A qualitative study by Denneson et al. (2017) with interviews from 28 VA clinicians and nurses showed that they wanted guidance about how to document.

And yet another interview study with 28 VA patients carried out in 2017 showed that they were positive about the service, even though few of them had read their notes online (Cromer et al., 2017). Another survey by Dobscha et al. in 2018 of VA patients (83.04%, 338/407) showed that it could be helpful for the veterans if the clinicians openly discussed the availability of the notes with them to help them understand the purposes of the service. Interviews with 28 mental health clinicians and 28 patients in mental health care showed that there were three areas where the clinicians needed support: how to write notes that maintain the therapeutic relationship, how to communicate with patients about their notes, and how to utilize notes as a patient resource (Pisciotta et al., 2019). Consequently, the VA system has developed a web-based course for the clinicians to reduce the potential for unintended consequences and enhance the possibilities of positive outcomes of Open Notes. The course content consists of: basic information about using Open Notes; how to write notes to prevent unintended consequences; conversations with patients about the notes; and using Open Notes to enhance care. The 141 of 251 clinicians (56.17%) that attended the course reported improvements in communication behaviors and a reduction in worries about potential negative effects of Open Notes (Dobscha et al., 2019).

In summary, it is still unusual that patients in psychiatric care can read their notes, but the tendency both internationally and nationally is that Open Notes services are becoming more common in psychiatric care. The international research on Open Notes in psychiatric settings mainly derives from the U.S. Department of Veteran Affairs service and their VA System that enables veterans to access their health records online. It is thus important to remember that neither the psychiatric setting nor the patients in the care setting in these studies are representative on a societal level. A general tendency, however, in the studies of Open Notes in psychiatric settings is that the implementations and use of the service are described as complex and challenging with risks of unintended consequences. Results from the implementation in the VA System indicate that there is a need for education regarding how to handle a transparent practice in psychiatric care. Thus, there appears to be more challenges with the implementations and use of Open Notes in psychiatric settings than in non-psychiatric settings.

Open Notes in adult psychiatry in Region Skåne

Region Skåne is one of the three largest regions in Sweden and the population in the county is approximately 1,350,000 people. Psychiatric care in the country consists of three subdivisions: adult psychiatry, children and adolescent psychiatry, and forensic psychiatry. To begin with, it was decided that only patients in adult psychiatry should have access to the Open Notes system. Adult psychiatry has emergency services, outpatient and inpatient departments, and provides specialized psychiatric care for patients with major depression, personality disorder, severe anxiety, attention deficit disorder with hyperactivity, bipolar disorder, obsessive thoughts and problems with eating disorders, for instance. Patients with psychiatric symptoms associated with dementia, questions about gender identity or self-injurious behavior can also seek care at adult psychiatry. In other words, employees in adult psychiatry meet patients with many different diagnoses and varying care needs. Adult psychiatry employs roughly 3,000 people that work as administrators, assistant nurses, doctors, managers, medical secretaries, nurses, occupational therapists, physical therapists, psychologists and social workers. Almost of these employees meet patients in their daily work. In 2017, there were over 575,000 appointments, of which almost one-fifth were with a doctor and the number of unique patients was over 56,000.

Region Skåne was the first county in Sweden to add psychiatric care to the Open Notes service and patients in adult psychiatry were offered online access to their Open Notes in October 2015. Patients in forensic psychiatry, parents to patients in children and youth psychiatry and adolescences older than 16 years in Region Skåne were offered the service from February 2019. In this thesis, the empirical material presented derives from studies in adult psychiatric care in Region Skåne.

The regulatory framework for Open Notes in psychiatric care in Region Skåne

Sweden has a decentralized healthcare system allowing for regional decisions about the technical prerequisites for the Open Notes system. Consequently, patients in different parts of the country have access to different amounts of information from Open Notes, and the timing when they can access the information also differs (Hagglund & Scandurra, 2017a). These differences also indicate that healthcare professionals work under dissimilar conditions depending on the county council or region in which they work. As mentioned in chapter 1, Region Uppsala was the first to implement the Open Notes service, and their technical prerequisites can be described as the original regulatory framework for Open Notes in Sweden. However, when the second caregiver in the country, Region Skåne, implemented Open Notes in non-psychiatric care, they adjusted this regulatory framework and changed the technical prerequisites for the Open Notes system in their part of the country. Before Open Notes was implemented in the psychiatric division in Region Skåne, the regulatory framework was changed once again.

The discussion about a regulatory framework for Open Notes in Sweden is an ongoing process and Inera has decided that there should be a national regulatory framework (Scandurra, Pettersson, Eklund, & Lyttkens, 2017). However, this decision has not yet entered into force, as the modifications in the regional regulatory frameworks first have to be approved at regional political levels (Inera, 2019b). The remainder of this chapter describes the current regulatory framework in adult psychiatric care in Region Skåne as of May 2019 (Region Skåne, 2019) and thus, the technical prerequisites for the system, as well as the patients' and healthcare professionals' ability to adjust the default settings.

Default technical prerequisites

There are some predetermined technical prerequisites in the Open Notes system in Region Skåne that are default, and these regulations affect what a patient can access online and when the patient can access the information through the Open Notes service.

Historical notes – what information is accessible via Open Notes

Historical notes (i.e., notes written before the date that the Open Notes system was implemented) in non-psychiatric care or in psychiatric care are not shown in the Open Notes system in Region Skåne. Thus, patients in adult psychiatry can only read notes online from September 28, 2015 forward.

Timing – when is the information accessible via Open Notes

In Region Skåne, in contrast to some other counties in Sweden, patients can access their Open Notes as soon as they are entered into the system and can thus read them in many cases before the responsible healthcare professional has signed off on them. This means that the notes have not yet been approved when they become available for the patient to read online. A signed note means that the responsible healthcare professional has decided that the information is correct.

Delay in access to Open Notes for inpatients

In Region Skåne, inpatients in adult psychiatric care (approximately 5% of all patients) are exempted from immediate access to the service but can access their Open Notes four weeks after hospitalization. The rationale for this decision is the risk that inpatients will read their Open Notes at a critical stage in their treatment and that this could harm them. There is also the risk that inpatients would compare their notes with those of other inpatients, become upset, and agitate each other when they find differences in the treatment. Outpatients in psychiatric care can read their entries right away, just as patients in non-psychiatric care in Region Skåne have been able to do since the service was first introduced.

Log reports

When a healthcare professional reads information in a patient health record, it is registered. This is called "logging" and a patient in Region Skåne can demand a log report, that is, a list of who has looked at the information in his/her health record. In some county councils and regions, this is included in the Open Notes service. Thus, patients in some parts of Sweden can get access to the log reports from the EHR system in real time by logging into the Open Notes service. In Region Skåne, however, this is not the case and patients have to order a log report by sending in a paper form to Region Skåne.

Possibilities for patients to adjust the default technical prerequisites

Patients have been given some possibilities to modify the default settings in the Open Notes service. They can withhold information from the Open Notes service from themselves and they can prevent healthcare professionals from getting access to parts of the health record.

Patients can seal the health record from online access[5]

If patients do not want the electronic health record to be visible for themselves online through the Open Notes service, they can turn off this function. The patients

[5] The term for this in Swedish is *försegla journalen*.

can administer this when they are logged in to the Open Notes service or can do so by filling in a paper form and sending it to Region Skåne. The patient can choose to shut down access to all or parts of the health record. If a patient wants to have access to the health record through the Open Notes service again, he or she needs to fill in a paper form and turn it in to a healthcare professional that works in a practice were the individual is or has been a patient. For security reasons, the patient needs to identify him or herself and certify that he/she is not being forced by someone else to break the seal, and then sign the form that opens up the health record online.

Patients can block parts of the health record for healthcare professionals[6]

Patients can block parts of the health record, which means that the information from a certain part of healthcare, for example a clinic, will only be available to healthcare professionals within that part of the care. Healthcare professionals in other parts of healthcare system cannot read these entries. Thus, if the patient comes to a clinic that does not have access to blocked information in the health record, the patient has to tell them what is necessary for the healthcare professionals to know.

Possibilities for healthcare professionals to adjust the default technical prerequisites

Healthcare professionals have several factors to bear in mind that are connected to the technical prerequisites of the Open Notes system. When they write in the health record, they are responsible for deciding if there in anything in the content that for some reason should not be accessible through the Open Notes system and act on that decision. Healthcare professionals can find themselves in situations when they urgently need to shut down a patient's ability to read the health record through the Open Notes service and they then have to administer this decision.

Confidentiality check when the entry is written in the health record

The Offentlighets- och sekretesslagen (2009:400) (The Swedish Public Access to Information and Secrecy Act) states that parts of the content in the health record may be withheld from a patient if it has been determined that the patient's condition would deteriorate seriously if he or she were allowed to read the content. Content can also be withheld if another person (e.g., a relative) is mentioned in the health record, and that a person could be endangered if the patient is allowed to read this entry. Thus, the health care provider has an obligation to carry out what is referred to here as "a confidentiality check" before the patient is allowed access the information in his or her health records. Historically, this check was performed when a patient ordered a paper copy of the health record. However, the introduction of Open Notes has changed this procedure and now all healthcare professionals who

[6] The term for this in Swedish is *spärra journalen*.

enter documentation in health records need to carry out this confidentiality check each time they make an entry, since the patient has immediate access to the content.

The Specific Information template

In certain cases, the healthcare professionals can withhold information from patients that could pose risks to the patient or relatives. To ensure the ability to enter such information in the health record, there is a special template for this purpose called "Specific Information." This information is only digitally accessible to the healthcare professionals, but patients can access it by requesting a paper copy of their health record. In the original regulatory framework of Open Notes from Region Uppsala, this template was called "early hypothesis". This was not considered to be an appropriate term when Open Notes was about to be implemented in adult psychiatric care in Region Skåne and the template was thus renamed.

The Violence in Close Relationships template

Healthcare professionals use the Violence in Close Relationships template to document a patient's risk of being subjected to domestic violence. For security reasons, nothing that is written in this template is shown in the Open Notes service.

Healthcare professionals can seal a patient's health record from online access

Healthcare professionals may immediately need to seal a patient's records for direct access through the Open Notes service and they can choose to shut down a patient's online access to all health records or parts of them. When this situation occurs, healthcare professionals consult the unit manager during office hours and the doctor on call during non-office hours, who on behalf of the unit manager can decide such matters. A stop date is required when healthcare professionals seal a patient's health record, and the clinic that asked for the sealing is notified a week before the stop date expires. That clinic then needs to decide if the seal should remain or not.

In summary, the Open Notes system has some technical prerequisites that are default and thus cannot be changed by the patients or the healthcare professionals. In addition, there are possibilities for both patients and healthcare professionals to adjust these frameworks. The default technical prerequisites and patients' abilities to adjust these default settings have not changed since the implementation of the Open Notes system in October 2015. However, the healthcare professionals' abilities, and sometimes responsibilities, have changed. The Violence in Close Relationships template was introduced in 2018 and the routines for sealing a patient's health record from online access were expanded and clarified in 2018. Thus, the tendency over time is that more and more technical functions that affect the healthcare professionals' daily work are being added to the system. In the spring of 2018, the e-learning platform, eHälsospelet (eHealth Game), was launched for healthcare professionals in Region Skåne. This is an e-learning program with five-minute lessons about the services that are offered via the patient portal, *1177*

Healthcare Guide e-services (e.g., Open Notes). The idea behind eHälsospelet is that it should be an interactive tool for information, inspiration and instruction about eHealth for the healthcare professionals. Many of the short lessons are about the Open Notes system. In addition, Region Skåne is preparing for a new version of eHälsospelet aimed at patients. Thus, it seems like the Open Notes systems' design creates a need for education so that both healthcare professionals and patients can understand and use it.

Theoretical framework

This section provides the reader with an overview of the theoretical framework used to analyze and discuss the empirical results. The theoretical concepts in this thesis are profession (as applied in the sociology of professions), boundaries, boundary work, implementation, materiality, transparency and patient empowerment. In this chapter, I argue why the theoretical framework presented can be used to elaborate and further analyze the empirical results in the appended papers. This section ends with a theoretically informed analytical model that presents how I use the theoretical framework to meet the aim of the thesis and to answer the four research questions.

Healthcare professionals and healthcare professions

From a Sociology of Professions' perspective, professions can be described as the carriers of the highest knowledge in their field (Brante, 2010; Freidson, 2001). A fundamental reason behind the existence of professions in society is that professionals should know more and be able to make better assessments than their clients/patients. If they are unable to do this, laypeople would not need to consult them and the idea of professional authority in that specific field of knowledge would break down (Parsons, 1939). This line of reasoning is the central starting point for this thesis, since one of the most important functions of healthcare is to provide access to the knowledge healthcare professions have about health and medical conditions.

Talcott Parsons (1902-1979) was an American sociologist whose theories about the function of the professions in society have gained great importance in the field of professional theory. According to Parsons, the development of professions and their increased strategic significance is the most important transformation that has occurred in modern society (Parsons, 1974). The Swedish sociologist Thomas Brante's (1947-2016) early research on professions as a society's knowledge carriers is also a theoretical perspective that is important for the reasoning presented here. Professional knowledge can be constituted from different forms of knowledge: scientific knowledge, knowledge about laws and regulations, practical knowledge connected to a specific practice, and everyday knowledge (Brante, Johnsson, Olofsson, & Svensson, 2015). The authors' research shows that the professions in the healthcare sector believe that they use scientific knowledge to a high degree and

it can be difficult for a layperson to understand their expert knowledge. Professional authority is a form of power that is based on expert knowledge, where the client or patient submits to the professional's assessment and leaves the decisions to him or her in situations where there is uncertainty (Brante, 2010). Such specific professional knowledge is so hard to assimilate in terms of content and terminology that laypeople must consult professionals to gain access to it. This reasoning is in line with the following definition by Brante[7] that describes the characteristics of professions:

> Profession are (i) occupations that set out from scientifically based ontological models by which their objects can be constituted so that they are understood, explained and treatable, (ii) socially recognized, i.e., members of the professional complex, which in turn is linked to "generalized cultural values." (Brante, 2010, p. 875).

Healthcare has a long history of knowledge monopoly by the health professions. According to Brante et al. (2015), among the occupational groups in adult psychiatry, doctors, nurses, psychologist and social workers can be defined as professions. However, professions can be divided into the subcategories of classic professions and semi-professions (Brante, 2013). Doctors belong to the first category; they can be described as a "full" profession, and they are one of society's classic professions. This is because they have been a part of society for a long time, and their tasks and fields of knowledge have been clearly defined over time in relation to other healthcare professions and patients (Brante, 2010; Carlhed, 2013). The other three professions can be described as semi-professions: with the support from scientific knowledge, they have been able to get closer to the knowledge base of the doctors, but they do not fulfil the requirements of a classic profession (Brante et al., 2015).

Thus, healthcare professions gain the knowledge they use in their work through long academic education, training and practical experience. The specific knowledge legitimizes the profession and gives the members prominent positions and status. Each profession is accountable for a given set of duties within the healthcare organization, and the boundaries between the responsibilities are clear. In other word, doctors perform certain tasks and nurses perform others. Their tasks and responsibilities set them apart from other professionals and laypeople, such as patients. Their roles and accompanying expectations have been evident in the healthcare setting for many years through the boundaries that have been set in healthcare.

An important starting point for Study 2, conducted in adult psychiatric care, was to include all healthcare professionals within the practice that meet patients in their

[7] Thomas Brante used different definitions to describe the characteristics of professions during his career. I chose to use this definition from 2010.

daily work. As a result of this methodological choice, the following occupational groups were asked to answer two questionnaires and thus contribute with their expectations and experiences of working in an organizations that have the Open Notes system: assistant nurses, doctors, unit managers, medical secretaries, nurses, occupational therapists, physical therapists, psychologists and social workers. On the one hand, all of these occupational groups can be described as healthcare professionals. On the other hand, because I use the concept of profession as it is applied in the sociology of professions. This calls for a conceptual clarification since all of these occupational groups cannot be described as professions. Hence, some of my analyses and discussions are built on the sociology of professions' concept of what constitutes a profession. I then address the occupational groups that can be described as healthcare professions from this point of view. In other analyses and discussions, I build on concepts from other theoretical perspectives, such as transparency and materiality, and I then address all of the occupational groups whether or not they meet the requirement for being a profession according to the sociology of professions' perspective. The reason for this decision it that the transparency that is afforded to patients by the materiality of the Open Notes service affects all professionals in adult psychiatry, regardless of their occupation. However, the results will show if some groups of professionals are more affected than others.

Healthcare professions and boundaries

The concept of boundaries is a part of a classical conceptual tool kit of social scientists according to Lamont & Molnár (2002), and the authors believe that it is useful to distinguish between symbolic and social boundaries. The aforementioned are conceptual distinctions made by social actors in order to categorize objects or people, for example. Thus, symbolic boundaries are socially constructed; they produce distinctions and separate people into groups where some are included and others are excluded. According to Lamont, Pendergrass, & Pachucki (2015, p. 850), "These distinctions can be expressed through normative interdictions (taboos), cultural attitudes and practices, and patterns of likes and dislikes." Symbolic boundaries can be used to enforce and maintain social boundaries, and thus symbolic boundaries can become social boundaries if they are normalized and widely agreed upon (Lamont & Molnár, 2002). Lamont and Molnár go on to state that, "Social boundaries are objectified forms of social differences manifested in unequal access to and unequal distribution of resources (material and nonmaterial) and social opportunities." (p. 168). Thus, "the concept of boundaries . . . is used to understand how professions came to be distinguished from one another" and from laypeople through differing distributions of jurisdiction, for example; and also how

systems of classification develop through the drawing of social boundaries between groups (Lamont & Molnár, 2002, p. 177).

The creation and maintenance of boundaries surrounding a field of knowledge has been a fundamental part of the growth and development of professions. I focus on the boundaries between healthcare professions and laypeople/patients in the analyses by asking: How are healthcare professions' boundaries transformed through digitalization and the implementation of the civic health technology Open Notes? According to Fournier (2000), a professional field of knowledge is always dynamic, which implies that the boundaries surrounding it are not static. Various stakeholders can change the conditions for professional work. One of the most important actors is the state through its government agencies (Brante, 2014). The state decides through laws, regulations and policies the conditions for professional work. Thus, governmental agencies can play an active role in shaping professional jurisdictions by opening and closing boundaries (Liu, 2017). At the same time, is it important to the professions that boundaries around their work are maintained, with three primary types being crucial: the boundaries between professional groups, the boundaries between the profession and the market, and the boundaries between the profession and laypeople (Fournier, 2000). This thesis focuses on the last one. The authority of a professional according to Fournier (2000) is based on the existence of boundaries between themselves and the laypeople they meet professionally in matters related to their professional field of knowledge. Thus, it is important for professionals to be able to express themselves in a purely professional language that is based on scientific knowledge. If this is not possible, there is a risk for "professional regression" (Abbott, 1995). In line with this, Fournier (2000) states that there is a need for professions to maintain barriers between themselves and the lay public by making their knowledge unintelligible for those who do not belong to the profession

> The boundaries between the professions and the lay public are established by maintaining an appropriate level of "mysteriousness" and esotericism within professional systems of knowledge; such systems of knowledge are then resistant to codification and standardisation, and become inaccessible to the lay person. (Fournier, 2000, p. 75)

Thus, changes to professional boundaries can lead to professions being "transformed", with boundaries being moved, rather than disappearing (Fournier, 2000). Consequently, when the exclusive knowledge base of the healthcare professions is accessible to patients through civic health technologies, such as Open Notes, the boundaries in the healthcare sector and the balance of power between the profession and the patient may change. Accordingly, when parts of the professional field of knowledge become accessible to laypeople, the need for the professional and his/her knowledge may increase, as informed laypeople have more questions and an increased need for getting answers to them (Fournier, 2000).

From a sociology of professions' perspective, the profession's control over the boundaries of a given field of knowledge and the right to perform certain tasks in that field are referred to as "jurisdiction" (Abbott, 1988). Drawing up boundaries towards other groups has traditionally been part of a profession's claim for jurisdiction in its field of knowledge, and the work of drawing such boundaries has governed how the healthcare sector and its professions have developed and transformed over time (Carlhed, 2013). Thus, Lamont and Molnár (2002) state that the literature on professions on the one hand, has paid attention to disputes over jurisdictional boundaries between professions and how these social boundaries are redrawn, and on the other hand, on how boundaries between experts and non-professionals are developed and changed in work situations. In my analysis, I focus on the boundaries between professionals and non-professionals and analyze the ways in which the implementation of health technologies aimed at patients changes the boundaries in healthcare.

Boundaries may be taken for granted in the organizing of everyday life in healthcare. In times of change, though, they can become visible and questioned (Lindberg, Styhre, & Walter, 2012). Eriksson-Zetterquist, Lindberg and Styhre (2009) state that new technology can pose a threat to a professions' identity and established working methods, especially when that technology is part of political and ideological changes in organizations. Professional identities and boundaries are both shaped by and shape the use of new technology. The ability to adapt the new technology within the professional jurisdiction varies (Eriksson-Zetterquist, Lindberg, & Styhre, 2009). Professional boundaries can influence the implementation of eHealth that is intended to work across such boundaries (King et al., 2012). Thus, changes in the boundaries around professions that are initiated by other groups imply that the professions' control over the boundaries decreases. Such a development can result in actions to regain control over the boundaries, that is, in boundary work.

Different types of boundary work

In 1983, Gieryn coined the term "boundary work" to describe the work that scientists do in order to draw a boundary between science and non-science (Gieryn, 1983). However, it was not until the last decade that the notion of the concept began to increase, with multiple levels of analysis and descriptions of the concept of work (Langley et al., 2019). Lindberg et al. (2017) argued that boundary work is important because of its influence on work practices in organizations, for example.

From a sociology of professions perspective, Abbott (1988) suggests that professionals always are conducting boundary work since their jurisdictions and authorities constantly are being questioned. Still, professionals can conduct different types of boundary work in order to maintain the boundaries around their work.

Fournier (2000) stated that there are two processes related to boundary work in the making of a profession that need to be understood: first, the establishment of a field of knowledge as an autonomous area that can be controlled, and second, the dependency on the distribution of tasks that makes it possible to establish boundaries defining the profession. Boundary work can be described as a process wherein professions lay claim to and try to protect certain kinds of professional tasks (Liljegren, 2008). When new technology is implemented in a care practice, the professionals' "boundary work is dependent on and conditioned by the material arrangements" of the technology (Lindberg, Walter, & Raviola, 2017).

However, the definition of boundary work can be broader than the description above and can include boundary work of other groups than professions. In a recently published paper, Langley et al. (2019 p. 705) state that, ". . . we define boundary work here as purposeful individual and collective effort to influence the social, symbolic, material, and temporal boundaries, demarcations, and distinctions affecting groups, occupations, and organizations". I use this definition of boundary work in my research analyses. In the review, Langley et al. (2019) also "identify and explore the implications of three conceptually distinct but interrelated forms forms of boundary work":

- Competitive boundary work – involves people that are raising and mobilizing boundaries around themselves to establish some kind of advantage over others.
- Collaborative boundary work – involves people realigning the boundaries separating them from others to enable collaboration.
- Configurational boundary work – involves people designing boundaries to manipulate patterns of differentiation and integration among groups.

The first of the three categories – competitive boundary work – is described as *work for boundaries* and according to Langley et. al (2019), this is the largest category of boundary work in their review of academic literature. This category includes the form of boundary work that is described above and that can be conducted by professions. The competitive boundary work can be people defending boundaries; this work can be triggered by new governmental policies or new technology, for example. The review indicates that there is a need for more research on competitive boundary work, firstly in the role of technologies' materiality, and secondly in the role of powerful third parties that influence boundaries from outside.

The second category – collaborative boundary work – is described as *work at boundaries* and includes work that enables learning, negotiation and interaction between groups.

The third category – configurational boundary work – is described as *work through boundaries*. This includes work that is conducted by people from outside an

organization, such as managers, institutional entrepreneurs and leaders, in order to deliberately change and rearrange existing boundaries and thereby influence others' behaviors (Langley et al., 2019). Configurational boundary work thus has three main characteristics according to the authors: 1) it involves people acting at a distance to indirectly or directly influence the boundaries of other people; 2) it involves people using boundaries to change interactions between others; and 3) it focuses on creating space to influence the actions that are taking place around a boundary.

The three different types of boundary work are often intertwined in practice. Configurational boundary work, however, can be described as a force that drives the other two categories of boundary work since it orients the actives of others (Langley et al., 2019).

In my analyses, the forms of boundary work identified by Langley et al. (2019) were useful concepts for analyzing the empirical material. Langley et al. conclude that there is a need for both multilevel studies that establish connections between the different types of boundary work and studies that take into account the materiality of new technology on boundary work.

Materiality matters

In many papers on technology use in organizations, the term "socio-technical systems" (STS) is used as a way to describe the study object. STS can be described as a technical infrastructure that includes technologies' materiality and people's responses to it (Leonardi, 2012). Technology is an important part of the work environment of many employees. Nowadays, few healthcare professionals in the Western world can carry out their work without the use of technology. Technologies are designed in different ways and have material aspects that are intrinsic to the technology, and thus not a part of the social context where the technology is used (Leonardi, 2012). Digital artifacts have material agencies. Even though the artifact cannot be physically touched, the material agency is found in the design and programming of the software application (Leonardi, 2010); in other words, this is part of the technology that the user cannot control (Leonardi, 2011).

The design of a technology offers users various affordances, which can be described as the artifact's materiality (Leonardi, 2010). User affordances and constraints have a basis in the underlying visions and ideas, and that affects what is possible to do with the support of the digital artifact (Leonardi, 2010). The term "materiality" refers to those properties of an artifact that endure over time or across different locations and are important for users; thus, the materiality makes certain actions possible and other impossible (Leonardi, 2012). The materiality of the artifact exists independent of the individuals who encounter it, but the affordances (possible uses

and actions offered by the technology) and constraints (limitations imposed by the technology) do not. In other word, individuals are, depending on their role, introduced to an artifact whose materiality is already preconfigured for them (Leonardi, 2013). When employees find out that they are unable to fulfil the goals of their work in the current environment, they can either change the materiality of the technologies or the composition of their routines (Leonardi, 2011).

The design of the technology can mean that tasks and roles shift between different parties, and a technology governs the behavior of individuals because it is designed in a certain way. This leads to altered or entirely new ways of performing actions (Leonardi & Barley, 2008). Thus, it is people who design artifacts, and they are not passive objects in the social contexts in which the artifacts are used. Put another way, those who design artifacts are those who have the power to enable or disable future actions through the artifacts. Lupton (2018) argues that more knowledge is needed on how the design and affordances of digital health technologies govern what is possible for people to do with them.

Consequently, the design of health technologies can be seen as practical examples of how visions and ideas about patient empowerment, for instance, is realized in a digital artifact. Is the materiality of health technologies aimed at patients significant because it governs what is possible for patients and healthcare professionals to do with the support of technology? This in turn can have an impact on and transform the boundaries between healthcare professionals and patients. It is thus of interest to gain more knowledge about how the materiality of health technologies aimed at patients can be used to reconstruct boundaries between patients and healthcare professionals alike. Moreover, the Open Notes service can be described as a civic health technology that enhances transparency and through its materiality makes the work of the healthcare professionals visible to the patients. It is thus of interest to use the theoretical concepts of transparency and visibility in the analyses of the Open Notes service.

Transparency and visibility

The affordances that a technology offers is a useful perspective for analyzing how digital technologies enable transparency (Flyverbom, Leonardi, Stohl, & Stohl, 2016). Our understanding of transparency can be enhanced if we give more attention to the constraints and opportunities provided by various technologies and devices (Flyverbom, 2016). According to Flyverbom (ibid.), transparency efforts always involve selectivity (what to disclose and to whom), directionality (flows of information and direction of visibility), and interpretation (processes that involve an active audience). Transparency is often connected to desired things like efficacy; however, there is no consensus around the meaning of the concept (Levay, 2016).

Thus, a recent literature review shows that transparency can mean many different things, and it is thus necessary to have a deeper understanding of the concept (Albu & Flyverbom, 2019). The authors divide research on transparency into three dimensions: conceptualizations, conditions, and consequences. *Conceptualizations* describe whether transparency can be seen as a mode for information disclosure or as a social process. *Conditions* describe whether transparency includes only the quality and relevance of the information or also the processes connected to communication and negotiations. *Consequences* describe whether outcomes of transparency are evaluated in terms of effectiveness or as surprising complications. As a result, Albu and Flyverbom (2019) present two approaches to transparency: verifiability and performativity. The former focuses on "how information is disclosed to verify a particular state of affairs" (p. 281), and the point of departure is that the information that is made available can regulate behaviour and efficiency. The latter has a different focus since "the performativity approaches are less certain that more information generates better conduct" (p. 281). These two approaches thus place the emphasis on complications generated by transparency projects. Thus, the performativity approach to organizational transparency views it as a process that is connected to the social actions that can arise when an organization makes information visible (Albu & Flyverbom, 2019).

Visibility is a fundamental affordance in a digitalized society (Flyverbom et al., 2016) and digital technology-enabled visibility is strongly connected to transparency; however, the two different concepts need to be understood and analyzed separately (Stohl, Stohl, & Leonardi, 2016). Visibility is the combination of three attributes according to Stohl, Stohl and Leonardi (2016); availability of information, approval to disseminate information, and the accessibility of information to third parties. Transparency is achieved when there are high levels of these three attributes. Thus, visibility enables transparency and the attributes through which visibility is produced are as follows according to Stohl et al. (2016):

- Availability – the information is available. Actions and decisions that occur in an organization are written down and turned into data that is kept in a format that can be accessed by others. This is the primary attribute of visibility.
- Approval – someone has approved to share the information. It is not enough that data is inscribed and stored in a way that could make it visible, someone in the organization has to approve that it should be visible to others. This second attribute of visibility can be based on approvals such as legal obligations, norms or social consciousness.
- Accessibility – the information is accessible to third parties. Data that is available and approved for dissemination by an organization also has to be accessible to those who wish to see the information. This is the third attribute of visibility. Thus, people have to be aware that the data is to be

> seen; that the data has to be organized in a way that makes it easy to access; that people need skills to access and understand the data; and finally, that the effort to access the data should not be too burdensome.

Still, there does not have to be a direct correspondence between the two concepts of transparency and visibility. In fact, increased visibility can reduce transparency and create opacity instead (Stohl et al., 2016). In other words, the authors question the assumption that higher visibility results in more transparency and call this "the transparency paradox".

> Increasing the availability, approval, and accessibility of information, which makes it more visible, can have the paradoxical effect of making decision-making paths in organizations more opaque rather than more transparent. (Stohl et al., 2016, p. 132).

Thus, actions in an organization to manage the attributes of visibility can create opacity (Flyverbom et al., 2016). Additionally, pursuits for transparency in healthcare can be problematic due to the fact that healthcare is an activity performed by healthcare professions that have specialized knowledge, which could be difficult to understand for laypeople (Levay, 2016). This raises questions about how the transparency that is afforded to patients by the Open Notes service may change the boundaries in healthcare, according to the healthcare professionals.

Civic health technology and the empowered patient

Implementing new technology involves processes that change both the healthcare organization and the work of the healthcare professionals (Mair et al., 2012). There are social challenges when implementations of information systems meet everyday work in healthcare, and professional identities that are influenced by ingrained professional characteristics can be challenged by the implementation (Nilsson, 2014). Thus, eHealth implementations can be described as complex processes due to the many independent relationships that characterize healthcare, which can lead to unintended consequences (Cucciniello et al., 2015; Doolin, 2016).

Furthermore, an English study of the introduction of the eHealth service, *Choose and Book*, showed that the implementation was guided by visons about patients being active and information seeking. However, it is not always the case that sick patients understand their role and make the rationale choices that are expected (Greenhalgh, Stones, & Swinglehurst, 2014). Still, the technology that is implemented in a healthcare practice has been designed based on these visions, and it is important to gain more knowledge about how the implementations affect patients, healthcare professionals and the practice. This might be even more important when a civic health technology such as Open Notes is implemented, since this type of technology is meant to support patient empowerment and improve the

quality of care and cost-effectiveness. Thus, eHealth technologies can be promoted as being beneficial for both patient participation and the welfare state (Nielsen & Langstrup, 2018).

As presented above, patient empowerment is often used as an argument in policies and by different key actors as a positive outcome of eHealth. However, it is unclear what the term "patient empowerment" stands for. There is a need for a consensus definition of the term (Werbrouck et al., 2018). Different studies use different approaches to measure patient empowerment (Ammenwerth, Schnell-Inderst, & Hoerbst, 2012), or do not use specific patient empowerment measures at all (Risling et al., 2017). A systematic review and meta-analysis showed that interventions aimed to strengthen empowerment for patients with chronic non-psychiatric diseases has been successfully applied in diabetes care, but it is still uncertain if these results can be generalized to other areas of non-psychiatric care (Werbrouck et al., 2018). The review goes on to show that the most used technique for supporting patient empowerment was increased knowledge.

As described previously, the Open Notes service in Sweden is available through the patient portal *1177 Care Guide*, and one aim is that the technology will support patient empowerment. However, a systematic review that studied the impact of patient portals on patient care showed that the impact is limited and even though such portals often are presented as a way to improve quality of care and to empower patients, the evidence from the review does not support this assumption (Ammenwerth et al., 2012). This can be seen as an example of what Morley and Floridi (2019ab) call "the empowerment narrative". That means that there is a rhetoric and a narrative around the impact of technology on patients health that relies on a techno-utopia (Morley & Floridi, 2019a, 2019b). The authors also argue that it is often unclear exactly how access to data will empower patients and they stress that there is a need for a reframing of the empowerment narrative.

Theoretical framework and analytical model

This last part in the chapter sums up and describes how the theoretical framework presented will be used to explore and analyze the results from the six appended papers.

Patients are afforded transparency by the civic health technology, Open Notes. In order to explore how this transparency changes the boundaries in healthcare, I analyzed:

(i) The boundaries. How does the vision of the empowered patient change the boundaries in healthcare?

(ii) The materiality. In what ways can the materiality of healthcare technologies aimed at patients be used to reconstruct boundaries between patients and healthcare professionals?

(iii) The boundary work. What kind of boundary work is conducted by the key actors behind the Open Notes service, and by the healthcare professionals that work in a practice where the Open Notes service is implemented?

The intention is to shed light on the supposed and experienced effects of Open Notes from the healthcare professionals' perspectives for both the patients and the work of professionals in adult psychiatry.

Table 1 shows how the theoretical concepts are used for analyses in the appended papers and how they will be used to answer the research questions in the Discussion chapter.

Table 1:
Theoretical framework and its connection to the research questions and the papers

Theoretical concept	Research questions in the thesis where the theoretical concept is used for analysis	Appended papers where the theoretical concept is used for analysis
Professions	RQ 2, RQ3	Paper II and Paper VI
Boundaries	RQ1, RQ2, RQ3, RQ4	Paper VI
Boundary work	RQ1, RQ3	Paper I
Implementation	RQ2	Paper II
Materiality	RQ3, RQ4	Paper VI
Transparency	RQ1, RQ2, RQ3, RQ4	Paper V
Patient empowerment	RQ1, RQ2	Paper I

Figure 1 provides an illustration of how the concepts in the theoretical framework relate to another.

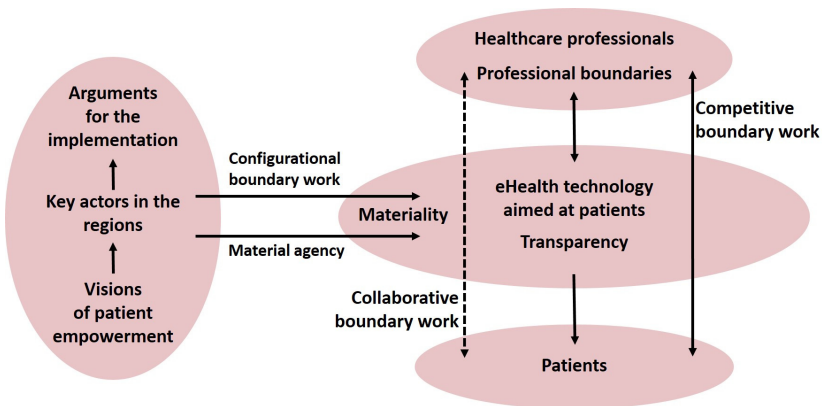


Figure 1:
Theoretically informed analytical model

Research approach and methodology

This chapter describes problematizes and discusses the strategies and choices regarding the research approach, methodological considerations, data collection, analysis of empirical material and ethical considerations. The thesis research consists of three studies that were developed and carried out during the EPSA project. The research was conducted around exploring and analyzing the four research questions presented in the Introduction chapter. The process can be described as iterative and the research questions were formulated and reformulated during the research process. The issues in the research questions guided the choice of methods in each study. Given that, there is a need for more knowledge about how eHealth, developed for patients, can change boundaries in healthcare. It was important to use different methods and data in order to generate knowledge in this relatively unexplored area. Together, the results from the three studies answer the research questions and the overall aim of the thesis. Table 2 presents an overview of the connections between the research questions, the three studies, the methods used, and the papers in which the results are presented.

Table 2:
A summary of which studies answer the respective research questions, the methods used, and the papers in which the results are presented.

Research question	Study	Methods used to answer the research questions	Papers in which results are presented
RQ1: What kind of boundary work do key actors behind the Open Notes service conduct to make space for the empowered patient in healthcare?	Study 1	Interviews with key actors behind the Open Notes service.	Paper I
RQ2: What are the supposed and experienced effects of Open Notes in adult psychiatry from the healthcare professionals' perspective?	Study 2	Baseline survey and post-implementation survey sent to healthcare professionals.	Paper II, Paper III, Paper IV and Paper V
RQ3: How do visions of the empowered patient change the boundaries in a healthcare practice and what kind of boundary work do healthcare professionals describe that they conduct to meet these changes?	Study 2	Baseline survey and post-implementation survey sent to healthcare professionals.	Paper IV and Paper V
RQ4: In what ways can the materiality of health technologies aimed at patients reconstruct boundaries between patients and healthcare professionals?	Study 2 & Study 3	Baseline survey and post-implementation survey sent to healthcare professionals and document studies.	The results from Study 2 are presented in Paper III, Paper IV, Paper V The results from Study 3 are presented in Paper VI

Research approach

This is a thesis in Working Environment Technology, which can be described as a multidisciplinary research field that rests on different research approaches. The three studies presented in the thesis also rest on different research approaches that have an explorative research design using both qualitative and quantitative approaches. Pragmatism as a research paradigm supports the use of a mix of different methods, different modes of analysis and abductive reasoning (Creswell & Creswell, 2018; Feilzer, 2009; Morgan, 2014; Teddlie & Tashakkori, 2009). For a mixed method researcher, this can open the door to multiple methods, types of data collection and types of analysis (Creswell & Creswell, 2018). In a pragmatic paradigm, research approaches should be mixed in ways that offer the best opportunities for answering the research questions (Johnson & Onwuegbuzie, 2004). In the research presented, different methods are combined, using both qualitative and quantitative data to contribute to a broader understanding of the research field. The research approach has been abductive throughout the research process. Abduction starts from an empirical basis, but does not reject theoretical preconceptions. Thus, the research process has alternated between empirical material and theory (Alvesson & Sköldberg, 2009).

One important aspect in studies of new technology is the technology's date of implementation. Many research projects uses the moment of implementation either as the end of a study or as the beginning of a study. Studies that cross the implementation line are unusual (Leonardi, 2009). When studies begin at the time of implementation, the technology in many cases arrives at the organization to be investigated as a black box without any prior knowledge about its social history (Leonardi, 2015). An overview of how the three studies presented in the thesis are related to the implementation line of Open Notes in adult psychiatric care in Region Skåne can be found in Figure 2.

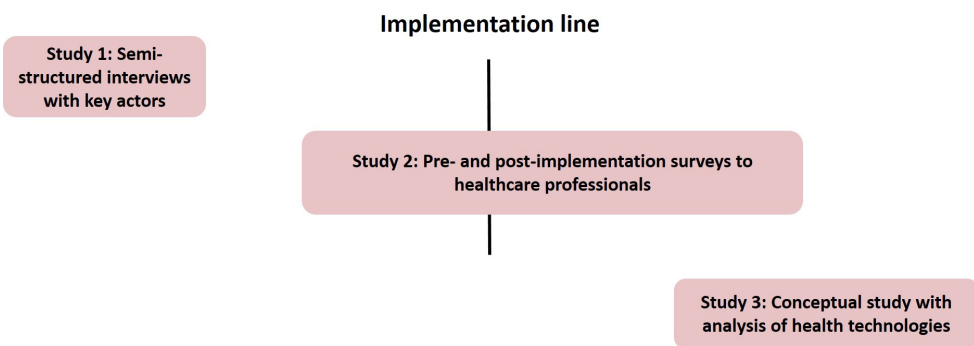


Figure 2:
The different studies in the research project

Study 1 focuses on how key actors describe the design and implementation of the Open Notes service. Study 2 is a comparison of how healthcare professionals perceive Open Notes before and after the service technology crosses the implementation line. Study 3 is conceptual and compares the materiality of Open Notes with two other technologies.

There can be linkage between qualitative and quantitative data at different chronological strands in a mixed research design (Teddlie & Tashakkori, 2009). Overall, the thesis' research has a sequential design in regard to the implementation of Open Notes in adult psychiatric care in Region Skåne. Study 2 also has a sequential mixed design. A sequential design seeks to answer exploratory questions and is a research design in which at least two strands occur chronologically. The conclusions from the first strand lead to the formulation of the next strand (Teddlie & Tashakkori, 2009).

Exploratory design is appropriate to use if researchers wants to analyze a topic that has not been examined before (Creswell & Creswell, 2018). The choice of this approach was thus based on the fact that the area of Open Notes in psychiatric care was more or less unexplored previously. There is still a need for more knowledge about the service, especially about Open Notes in psychiatric settings in universal healthcare. Therefore, it has been important to use different methods and to integrate qualitative and quantitative data in the three studies to gain more knowledge about Open Notes. The results from the three studies are presented in the six appended papers. As illustrated in Table 2, the results from Study 1 are presented in Paper I. The results from Study 2 are presented in Papers II, III, IV and V. The results from Study 3 are presented in Paper VI. An overview of the research design in the appended papers can be found in Table 3.

Table 3:
A summary of the methodologies used in the appended papers.

Title	Empirical material	Analysis
Paper I: Configurational Boundary Work – Narratives from the Implementation of Open Notes in two Swedish Regions	16 semi-structured interviews with key actors in the process of developing and deployment of Open Notes.	Qualitative content analysis
Paper II: How to Communicate the Indirect Implementation of Open Notes	Risk analysis of the implementation, observations of multi-professional working group meetings and education events, and results from two survey questions from the baseline survey of healthcare professionals: one question about the communication process and one question about the implementation process.	Analysis of qualitative material Descriptive statistics Chi-square tests
Paper III: Open Notes in Swedish Psychiatric Care (Part 1): Survey Among Psychiatric Care Professionals.	Baseline survey of healthcare professionals with a response rate of 28.86% (871/3017).	Descriptive statistics Chi-square tests
Paper IV: Open Notes in Swedish Psychiatric Care (Part 2): Survey Among Psychiatric Care Professionals.	Post-implementation survey of healthcare professionals with a response rate of 27.73% (699/2521).	Descriptive statistics Chi-square tests
Paper V: A Theoretical Twist of the Transparency of Open Notes: Qualitative Analysis of Health Care Professionals' Free-text Answers	1,554 answers from open-ended questions in the baseline survey and the post-implementation survey.	Qualitative content analysis
Paper VI: New Boundaries for the Physician Profession in the Digitalized Healthcare Sector – Why Materiality Matters	Document studies	Analysis and comparisons to reveal similarities and differences in the materiality of the different artifacts

Methods used in the three studies

This is a presentation of the three studies and the methods used in this mixed methods research approach in order to answer the four research questions.

Study 1

Region Uppsala and Region Skåne were the first two regions to implement Open Notes in non-psychiatric care in Sweden. In Study 1, interviews were conducted with key actors in the two regions to obtain data on their interpretations of how the Open Notes service would affect the work of the healthcare professionals, and how they reasoned about the implementation. This is an interesting topic since a region

is responsible for: 1) the implementation of the civic health technology with the aim to empower patients, and 2) the work environment of the healthcare professionals. How did the key actors behind the service describe the ways that they and others reasoned and acted in order to manage these two responsibilities? And did the key actors from the two regions differ in how they reasoned regarding the implementation of Open Notes in general, and the impact on the healthcare professionals' work in particular?

Interviews

Through earlier studies (Erlingsdóttir & Lindholm, 2015) and pre-knowledge, we knew that there had been different key actors such as project managers, politicians, union representatives and lawyers involved in the process in the two regions that first implemented Open Notes. An interview study was thus conducted with key actors in Region Uppsala and Region Skåne in 2014 and 2015. The interview guide was constructed based on our pre-knowledge and pivoted around the role of different key actors during the development and implementation of the service, the implementation process, the healthcare professionals' work, and the Open Notes service. The interview guide consisted of what Charmaz (2014) describes as initial open-ended questions, intermediate questions and ending questions. Bryman (2016) suggests that these three categories of questions often are intertwined; still the purpose is that they indicate different stages in an interview. An interview can be described as a site of narrative reproduction in which a researcher should try to avoid accounts and instead try to prompt narratives (Czarniawska, 2014). During the interviews, I tried to obtain narratives by asking questions that encouraged the key actors to describe their role and the roles of others during the development and deployment process of the Open Notes service. In total, 16 semi-structured in-depth interviews were conducted (eight in each region). The interviews were recorded and transcribed. In a semi-structured interview, the researcher has a list of questions (an interview guide) that should be answered, but the interviewer can also ask follow-up questions or pick up on interviewees' replies (Bryman, 2016). I conducted fifteen of the interviews. One interview in Region Uppsala was conducted by another researcher[8] for practical reasons.

We sent emails to the key actors that we wanted to interview and invited them to participate in the study. In the email, we informed them about the aim of the study, that it was optional to participate, that the interviews would be recorded and that their answers would be handled with confidentiality. The method to find these key actors in the two regions can be described as a snowball sampling. This technique can be useful when researchers are trying to discover who the important actors to talk to about an issue are, and what connections exist between significant individuals (Seale, 2012). This can also be described as within-case sampling with an iterative

[8] Cecilia Lindholm, Department of Business Studies at Uppsala University.

design (Miles, Huberman, & Saldaña, 2014). The respondents in each region were all within the same network, but they had different professional backgrounds and different roles during the Open Notes implementation. By interviewing different key actors, we got their descriptions of how they and other key actors in Region Uppsala and Region Skåne were reasoning during the implementation process, and how they interpreted that the Open Notes service would affect the work of the healthcare professionals.

Study 2

In Study 2, we were interested in the expectations the healthcare professionals in psychiatric care had about the effects of the Open Notes service pre-implementation, and how they later experienced the effects of the technology on their own work and on patient behavior post-implementation. This was especially interesting since adult psychiatry in Region Skåne was the first such setting in Sweden that afforded their patients access to the Open Notes service. The study design allowed us to compare expectations and experiences between different groups of healthcare professionals. The main method used in Study 2 consisted of the distribution of two web surveys to the healthcare professionals in adult psychiatry in Region Skåne: one baseline survey and one post-implementation survey. In addition, I participated at meetings at the Psychiatry Division, carried out observations at educational meetings, read documents, and conducted focus groups. All of these methods provided qualitative data that, together with the pre-knowledge from Study 1 was primarily used to validate the areas of interest in the questionnaire of the baseline survey in Study 2.

Participation in meetings

In the Psychiatry Division in Region Skåne, a multi-professional working group including representatives from patient organizations was established in the autumn of 2013. The working group had regular meetings to discuss and make decisions on the introduction, implementation and development of Open Notes. There had been ongoing information and discussions about experiences from the clinical practices, previous and upcoming implementation issues, and changes regarding the technical prerequisites of Open Notes. I attended to these meetings from the spring of 2015. My role in the group can be described as full membership. The other group members were aware of my status as a Ph.D. student from Lund University. Bryman (2016) states that there are different levels of participation in the social context being investigated. He calls my type of field role at the meetings as “overt full membership” and one advantage of this role is, according to Bryman, that it offers the opportunity to get a more complete understanding of the social context. I attended 20 meetings and always took field notes. These notes included summaries of important discussions and reflections on the topics discussed. The notes were used to gain knowledge about the implementation process and to define the

information and communication activities directed at professionals before the implementation of Open Notes.

Observations on educational events

I attended eight education events that were held for employees in adult psychiatry before the implementation. My role was that of a partially-participating observer. The healthcare professionals that attended were aware of my status as a Ph.D. student from Lund University. I introduced myself and informed them that the EPSA project was conducting research on the implementation. Bryman (2016) describes this kind of role as someone who does observations in order to collect data, but these observations are normally not the main data source in the research project. The educational events in the Psychiatric Division in the spring of 2015 consisted of two identical, 1.5 hour sessions (one morning and one afternoon session) in four geographic places in Skåne. The reason for me to be a partially-participating observer was to gain knowledge about the content of the education and about the questions posed by employees in the Psychiatry Division in Region Skåne about the implementation of Open Notes. I was also there to validate the areas of interest in the questionnaire of the baseline survey in Study 2. Field notes focused on important questions and discussions documented the eight observation events.

Document studies

Documents can be a source of data in the research process. What characterizes them is that they have not been produced at the request of the researcher (Bryman, 2016). Representatives from the working group in the Psychiatric Division carried out a risk analysis in the spring of 2015 to identify risks before the implementation of Open Notes in adult psychiatry. The document can be described as an official document derived from private sources. These kinds of documents are, according to Bryman (2016), official but they are not accessible through the public domain such as on websites, and the researcher thus has to gain access to them through other contacts in the organization. In my case, the aforementioned membership in the working group gave me access to these documents. In Study 2, the risk analysis was a source of information when creating the questionnaire for the baseline survey and regarding the strategies for information and communication.

Focus groups

Focus groups can be described as a group interview with at least four interviewees and a moderator who runs the session (Bryman, 2016). In the autumn of 2015, I conducted four multi-professional focus groups with employees in adult psychiatry before the implementation of Open Notes. Researchers conducting focus groups often use stratifying criteria to ensure that individuals from different groups will be included (Bryman, 2016). In this study, the stratifying criteria consisted of geographical and professional factors. Consequently, I conducted one focus group

in each of the four geographical subdivisions in Region Skåne and in each group, representatives were invited to participate from the following professionals : assistant nurses, doctors, nurses, psychologists, and social workers. Bryman (2016) states that it is preferable to audio record focus groups instead of writing notes, since it often is difficult for the interviewer to write down what interviewees say and who says it. I recorded all four group sessions, and listened to the conversions subsequently, and wrote down summaries of the most interesting parts. The purpose of the focus groups was to gain knowledge about how healthcare professionals in adult psychiatric care in Region Skåne anticipated the future effects of Open Notes before the implementation and to validate the areas of interest in the questionnaire of the baseline survey in Study 2.

Web surveys

In Study 2, two web surveys were performed. Bryman (2016) argues that web surveys have many advantages compared to other forms of surveys. They can be designed in a way that makes them easy to answer. The questionnaire can be designed with filters and the respondents' answers can be downloaded directly into a database for analysis. Another advantage is that one can invite a large number of individuals to participate in a study. Bryman (2016) states that one advantage of using web surveys is that they eliminate the risk for errors during the coding of a large number of questionnaires. Another advantage is that one can construct a survey with both fixed-choice questions and open-ended questions. Free-text answers from open-ended questions in surveys can be described as "elicited documents" in which it is the research participants who produce the data by answering these kinds of survey questions (Charmaz, 2014). Thus, the respondents can choose to write as much or as little about the subject as they wish. This method for gathering data is appropriate when the participants have a stake in the topic addressed, when they have experience in the area, and when they have the writing skills to express themselves and their views on the topic (Charmaz, 2014). The healthcare professionals met these requirements and the web surveys in Study 2 contained both fixed-choice and open-ended questions. When Study 2 was planned, there were no validated questionnaires about Open Notes for either baseline surveys or post-implementation surveys. However, there were surveys that had been developed and used by the OpenNotes project at Harvard Medical School. They were used in their studies and the same questionnaires were used by researchers at the U.S. Department of Veteran Affairs. My supervisor contacted Jan Walker of the OpenNotes project to ask permission to use the OpenNotes surveys in our research project and we received a positive response. She then sent the surveys for us to use.

Baseline survey

Survey Design

The baseline survey used in Study 2 is based on the one developed and used by the OpenNotes Project at Harvard Medical School (Delbanco et al., 2010; Walker & Delbanco, 2013; Walker et al., 2011). In line with the original survey (Leveille et al., 2012; Walker et al., 2011), our baseline survey covers three themes: *the impact on the patients*, *the impact on the practice*, and *about me*. We first translated the original OpenNotes baseline survey and adjusted it to fit the Swedish context. In addition, as mentioned above, I attended the educational events, read the risk analysis, and conducted the focus groups in order to gather supplementary information and validate the areas of interest in the questionnaire. As a result, we added questions about the information process, the implementation process, and changed relationships, for example. A trial test of the questionnaire was carried out involving two members of the working group and some adjustments were made. Thereafter a web survey was designed and programmed in the software package *Sunet Survey* (Artisan Global Media). The survey consisted of 34 fixed-choice questions (mostly 4-point scale answers) and three open-ended questions. There can be different kinds of open-ended questions in surveys. The most common is the general question where respondents are asked to elaborate on the overall topic of the survey, another is an expansion question that follows a fixed-choice question (O'Cathain & Thomas, 2004). There were three open-ended questions in the baseline survey. They were all general in nature and did not relate to any specific fixed-choice question. The survey was designed so that the respondents could choose not to answer all the questions. The questions with the fixed response alternatives for each question in the baseline survey are presented in Paper III.

Population

The entire population of health care professionals (n=3017) in adult psychiatry in Region Skåne who meet patients were invited to participate. This included assistant nurses, doctors, medical secretaries, nurses, occupational therapists, physical therapists, psychologists, and social workers. The rationale for not taking a sample was that it is a heterogeneous population where some of the professional groups are large and others are small. In addition, the employees in Region Skåne were the first in psychiatric care in Sweden whose patients would be able to read their notes online, and thus, it was important that everyone in the population had the opportunity to answer the survey and that all opinions were welcomed and important – no matter which healthcare professional group the employee belonged to.

Survey Administration

A prenotification email was sent from Lund University to the study population. A day afterwards, the survey was sent electronically to the institutional email addresses of the professionals with a cover letter and a link to the survey. We

received these email addresses from Region Skåne. Both the prenotification email and cover letter informed the recipients that participation was voluntary, that the computer files with the results were confidential, that respondents could terminate their participation at any time, and that tracking of individual responses was not possible. We did not offer any survey incentives. We sent four reminders, and the survey closed three days before patients were given access to the Open Notes service. Thus, all the material in the baseline study was collected before the implementation. The employees in adult psychiatry were not presented the results from the baseline survey until after the post-implementation survey was closed in order to avoid biasing the respondents' opinions.

Post-implementation survey

Survey Design

The post-implementation survey was distributed one-and-a-half years after the implementation of Open Notes in adult psychiatric care in Region Skåne. The was because we wanted both the staff and patients to have had experience from using the service before the follow-up survey. The post-implementation survey was based on the survey developed by the OpenNotes Project in the United States (Delbanco et al., 2012; Delbanco et al., 2010; Walker & Delbanco, 2013; Walker et al., 2011). The original survey was translated and adjusted to fit the Swedish context. The post implementation survey covers the following themes: *benefits and risks for patients*, *changes in practice*, *changes in clinical documentation and work conditions*, *about me*, and *future development of Open Notes*. Most of the questions from the baseline survey remained the same, but we changed the verb tense in many of them. We also changed the response options in some questions because some professional groups would otherwise not have been able to answer the specific question, or because we were interested in a more detailed answer than the response options the baseline survey offered.

The web survey was designed and programmed in the software package *Sunet Survey* (Artisan Global Media). The survey consisted of 44 fixed-choice questions and 20 open-ended questions. Twelve of these were expansions of specific fixed-choice questions in which the respondents were asked to elaborate on the answer given. The remaining eight open-ended questions were general and did not relate to any specific fixed-choice questions. We designed the post-implementation survey so that the respondents could choose not to answer all the questions. The questions with the fixed response alternatives for each question in the post-implementation survey are presented in Paper IV.

Population

The entire population of HCPs (n=2521) in adult psychiatry in Region Skåne who meet patients were invited to participate. This included assistant nurses, doctors, medical secretaries, nurses, occupational therapists, physical therapists,

psychologists, social workers, and unit managers. Approximately two-thirds of the doctors were psychiatrists, and nearly half of the nurses were specialists in psychiatric care. These two professions are referred to as doctors and nurses in both questionnaires. The rationale for not taking a sample was the same as in the first survey: the employees are a heterogeneous population where some of the professional groups are large and others are small. In addition, the study design required that it would be possible to compare the results from this survey with those from the previous full population baseline survey. The population of healthcare professionals in this post-implementation study was smaller than in the baseline study: approximately 500 fewer individuals. The main reason for this is that the list of institutional email addresses that we received from Region Skåne had been revised and updated in the meantime; the list no longer included summer employees, for instance.

Survey Administration

A prenotification email was sent to the study population and two days afterwards, we sent a cover letter with a link to the online survey to the institutional email addresses of the professionals. Both the prenotification email and cover letter informed the recipients that participation was voluntary, that the computer files with the results were confidential, that respondents could terminate their participation at any time, and that tracking of individual responses was not possible. We did not offer any survey incentives. We sent four reminders and the survey closed on April 22, 2017.

Study 3

The results in Study 2 revealed that the doctors were the group of health care professionals that were the most affected by the Open Notes service. The focus in Study 3 was thus solely on this profession and how the materiality of digital health technologies can transform the boundaries of their work. By comparing the Open Notes service with two other health technologies, the aim of this conceptual study was to describe and theoretically analyze how the work of doctors may change due to the development of health technologies.

Virtual documents

In Study 3, content on websites were used as the main source of data. The Internet is the most comprehensive place for information storage in today's society and the amount of information available is limitless (Hewson, Vogel, & Laurent, 2016). Websites are potential sources of empirical material and an organization's website can be used as a source of information about an organization and its activities (Bryman, 2016). When doing research on the Internet, it is important to judge if the webpage is a reliable source of information (Hewson et al., 2016). My interest was

in if the materiality (i.e., the design of health technologies aimed at patients) may have an impact on the work of doctors, and if so, in what way? In order to gain more knowledge about this, I compared the materiality of Open Notes with two other health technologies. The three health technologies were selected because they constitute deviant examples (Silverman, 2011), not because they are representative for health technologies in general. Their value as deviant examples lies in that they differ from one another and thus reveal the effects the materiality of digital artifacts can have on doctors' work.

Two of the artifacts consist of civic health technology, promoted and developed by the Swedish authorities and aimed at Swedish citizens (Open Notes and HealthForMe). The third artifact consists of a digital patient support platform initiated and developed by an American company and aimed at patients all over the world (PatientsLikeMe). Thus, I wanted to analyze and compare the materiality, that is, the affordances and constraints of Open Notes with the two other technologies. To be able to do this, I collected information about HealthForMe and PatientsLikeMe, This information was gathered from the public portions at their respective websites. This information included descriptions of the artifacts that can be used for analyzing their materiality. The PatientLikeMe.com content was mainly found under the heading "About Us" and "FAQ", which contained descriptions of the site and its content. The information about HealthForMe was found on the Swedish eHealth Agency's website ehalsomyndigheten.se under the heading "HealthForMe". The two websites were accessed in August 2018. Documents from web pages can consist of existing documents or solicited documents (Hewson et al., 2016). In this study, only documents that already existed were used. Previously published information on the health technologies was also used as supplementary material.

Data analyses in the three studies

Study 1

Analysis of the interviews

The empirical material from the interviews was analyzed by means of qualitative content analysis (Graneheim, Lindgren & Lundman, 2017) and the theoretical concept of boundary work (Langley et al, 2019). Following Graneheim, Lindgren & Lundman (2017), the transcriptions were interpreted and deconstructed by asking questions such as: Who initiated the service and pushed it forward? Who was involved in the processes? Who was seen as user of the service and why is the service needed? Who creates and moves boundaries and for whom? What is

important according to the key actors? What are the arguments and rhetoric around the idea behind the Open Notes service? During the analyses, we were looking for actions and events that described boundary work. The process can be described as a focused or selective coding (Rennstam & Wästerfors, 2015). Paper I presents a description, analysis and comparison of what kind of boundary work key actors in Region Uppsala and Region Skåne reported that they conducted during the development and implementation of the Open Notes service.

Study 2

Analysis of qualitative data from documents and observations

I attended meetings, studied documents, and conducted observations to investigate the strategies behind decisions on what information and communication professionals were thought to need before implementation, and from which media they could access it. This empirical material was analyzed and presented as narratives in the results section of Paper II to shed a light on the strategies behind the information and communication activities before the implementation of Open Notes. A narrative requires an original state of affairs, an action or an event and the results of the action or event (Czarniawska, 1998).

Analysis of quantitative data from the web surveys

One of the advantages with web surveys is, according to Bryman (2016), that the answers can be downloaded directly from the web survey tool into a database for analysis and this eliminates the risk for errors during the coding of a large number of questionnaire results. The web survey tool used in Study 2, *Sunet Survey*, is compatible with the Statistical Package for the Social Sciences (SPSS). Thus, the web survey tool is designed so that the results can be exported into an Excel document and thereafter, it is possible to import the results to IBM SPSS (IBM Corporation) for analysis. The quantitative data from both the baseline survey and the post-implementation survey were imported into IBM SPSS, version 23 (IBM Corporation) for analysis.

In statistics, there are four data measurement scales: nominal, ordinal, interval, and ratio. The quantitative data from both surveys are on a nominal or ordinal level and this determines what kind of analysis can be done. A nominal scale consists of a set of named categories without a specific order between them, for example, gender or profession. An ordinal scale consists of categories that are organized in a specific order where the measurements are ranked, for example, from a low level to a high level (Gravetter & Wallnau, 2013). Most of the fixed-choice questions in both surveys were on the ordinal scale and the questions that asked for personal information in the theme *About me* were on a nominal scale. In Study 2 the question was about the importance of professional belonging, since I wanted to examine the

relationship between this variable and attitudes to the Open Notes service. Thus, the variables about professional belonging were on a nominal scale and the variables about attitudes were on an ordinal scale. Both nominal and ordinal data can be presented with descriptive statistics to describe the proportions across categories, and chi-square tests can be used to evaluating the relationship between two variables from different measurement scales (Gravetter & Wallnau, 2013).

Thus, Paper II presents descriptive statistics and chi-square tests for two fixed-choice questions from the baseline survey: one about the communication process, and one about the implementation process. Paper III presents descriptive statistics for each fixed-choice question in the baseline survey, and Paper IV presents descriptive statistics for each fixed-choice question in the post-implementation survey. Additionally, Papers II and III present chi-square tests to examine the relationships between professionals and their attitudes to the Open Notes Service in the baseline survey. Paper IV presents chi-square tests to examine the relationships between professionals and their attitudes to the Open Notes Service in the post-implementation survey. Paper IV also presents the frequency results of two of the independent open-ended questions in the post-implementation survey on how the service influenced patient groups with different diagnoses. Finally, Study 2 consisted of a baseline survey and a post-implementation survey, the aim of which was to compare the answers between the two surveys. Thus, the results from the 28 questions that were similar in both surveys were compared on a group level. Paper IV presents an overview with descriptive data of the comparison between the expectations before the implementation and the experiences after.

Analysis of qualitative data from the web surveys

Open-ended questions in web surveys make it easy to offer respondents an opportunity to tell the researchers what is on their minds with respect to the survey subject; however, it is uncommon that free-text answers are systematically coded and analyzed (Singer & Couper, 2017). Still, free-text answers are a valuable data source, suitable for example for content analysis, particularly when collected over time (Rich, Chojenta, & Loxton, 2013). The quantitative results from the two web surveys are presented in Papers III and IV. In addition, we analyzed the open-end answers to the questions in the baseline survey and the post-implementation survey in order to capture the perceptions of the healthcare professionals and to deepen the understanding of the transparency that Open Notes implies.

The qualitative data from the web surveys were analyzed by means of qualitative content analysis. Altogether, there were 1,554 free-text answers from the two surveys. The research process can be described as abductive with an initial inductive approach during the coding and categorization of the free-text answers from the baseline survey. In the next step, these inductively created categories were used in the analysis of the free-text answers from the post-implementation survey. A content analysis of an inductive data analysis goes from the specific to the general; smaller

units are combined into a larger whole (Elo & Kyngas, 2008). Finally, a deductive approach was applied during the creation of the final categories that are presented in Paper V. The deductive analysis and thus the organization of the results are structured according to the seven factors of trade-offs and synergies with transparency described by Heald (2006). An abductive approach is used in a qualitative content analysis when the analysis moves between inductive and deductive approaches during different stages of the research process (Graneheim, Lindgren, & Lundman, 2017).

Study 3

Analysis of the materiality of three health technologies

Study 3 is based on the descriptions of three digital health technologies that in different ways have a digital materiality that offers patients information, and in some instances, knowledge about their health and how this can result in changes of the existing boundaries between doctors and patients. From a sociology of professions perspective, doctors are a classic profession with boundaries surrounding their knowledge base. However, digitalization has transformed the conditions for laypeople's knowledge development and the analysis in Study 3 highlights what may be the consequences of these changes for the doctors.

According to Leonardi (2017), the role of technical artifacts in organizations can be analyzed according to these three steps: accounting for the materials out of which a technological object is produced, accounting for the materiality, and accounting for the way in which technological artifacts materialize in the organizing process and come to shape (e.g., actions and interactions in an organization). Each artifact was analyzed based on these three cumulative steps that examine the role of technical artifacts in organizations. However, this study does not focus on the organization of healthcare per se. Each of the artifact was thus analyzed with a focus on the materials that produce the technological artifact, the materiality of the artifact, and how these factors can change the boundaries of doctors' work.

I gathered information about the three health technologies from their respective websites and used previously published information in order to carry out these steps in the analysis. I compared the three analyses to reveal similarities and differences in the materiality of the different artifacts. Paper VI is a conceptual paper and presents the analyses of the three health technologies focusing on the materials out of which the three artifacts are created, the materiality of the artifacts, and the processes in healthcare where the affordances materialize into practice. A conceptual paper focuses on integration and the proposal of new relationships that can connect existing theories in interesting ways (Gilson & Goldberg, 2015).

Ethical considerations

All three studies followed the guidelines on research ethics issued by the Swedish Research Council. It is the content of a research project that determines whether it falls under the Ethical Review Act (Council, 2017). None of the studies in this thesis covered any sensitive information and thus did not require ethical approval according to the Swedish regulations on research ethics. However, there are still ethical considerations to reflect upon and handle since the studies involve people and the Swedish Research Council (2017) states that there are ethical aspects regarding the choice of method, both in studies with quantitative and qualitative data.

In Study 1, it was important to inform the interviewees about the ethical aspects of the research in the study. In the email where we asked the respondents to participate, we informed them that we would take into account the Swedish Research Council's research ethics principles during the interviews. We elaborated on this and informed the respondents that participation was voluntary and that they could terminate their participation at any time. In addition, we informed them that their participation and answers would be treated confidentially and that the result would only be used for research purposes.

Study 2 is about the supposed and experienced effects of Open Notes in adult psychiatry from the healthcare professionals' perspective and the assessment was that there were no risks of injury and discomfort to the employees when they answer questions on this subject. The focus groups in Study 2 were audio recorded on tapes, but they were not video recorded. Individuals can be identified in video recordings and this could be a research ethical problem. The Swedish Research Council (2017) argues that the researcher should be restrictive with the use of video recording and the method should only be used if one considers that the individual's gestures and mimicry are important for the analysis. Informed consent was obtained from all of the participants in the focus groups.

The assessment was that the content of the questions in the two web surveys did not entail any risk of injury, but there still was reason to reflect on the choice of method. Thus, an important factor to consider in Study 2 is the programming of the two web surveys and the design of the technical systems used to distribute the web surveys. Consequently, during the summer of 2015 we had a dialogue with the system administrator at Lund University and the company that provided the web survey tool that we intended to use for the baseline survey to answers to the following questions:

- What does an anonymous respondent survey mean? Is it possible for someone (researcher in the research project, other employees at Lund University or employees at Artisan Global Media) to track a response to a question to a respondent?

- What are the agreements between Lund University and the Artisan Global Media regarding personal data?
- What is the security of the cloud service like and where are the servers located? How is data encrypted?

These questions are important from an ethical research perspective, as they concern the ability to identify individual respondents and their answers and the level of security in handling the answers. The answers to our questions were satisfying from an ethical research point of view, and we decided to use the software package *Sunet Survey* from Artisan Global Media for the distribution of the web surveys. *Sunet Survey* is a commercial IT system that has been procured in accordance with the Swedish Public Procurement Act.

In both surveys, the prenotification email and cover letter informed the recipients that participation was voluntary, that the computer files with the results were confidential, that they could terminate their participation at any time, and that tracking of individual responses was not possible. Both surveys were programmed so that it was not possible to track specific respondents' answers, since the connection between the email address and the answers are deleted when the respondent sends the answers to the server.

Furthermore, when constructing a questionnaire, the researcher always should consider the ethical aspects of research regarding the questions that ask the respondent to provide personal information such as age, education and occupation. This kind of information can identify a respondent, especially if there are many questions like this and there are options that few respondents choose. It is therefore important to only ask for the personal information that could be of interest for analysis. In both surveys, this theme is called *About me* and in order to avoid risk of identification, we only asked for gender, occupation and geographical area in Region Skåne in which the respondent worked.

Study 3 indirectly involves people since one of the artifact that was analyzed is the online community PatientsLikeMe.com that contains a wealth of data about patients' health conditions that normally are confidential. In order to analyze the materiality of the online community, I collected information about PatientsLikeMe. This information was gathered from public portions of their website. However, no data from specific patient communities or individual patients is included in the study.

Summary of appended papers

This chapter presents a summary of the six appended papers. Three of them are published, two are submitted for publication and one is a working paper under preparation for submission to a journal. The title for each paper is presented, followed by a brief introduction, the aim, an overview of the methods and a summary of the results. An outline is presented under the heading "Appended papers" at the beginning of the thesis as to where in the submission process each of the six papers are, and my contribution to the respective papers.

Paper I

Configurational Boundary Work – Narratives from the Implementation of Open Notes in Two Swedish Regions

There is an ongoing development in healthcare with an increased focus on and a striving for patient empowerment and participation. In many cases, the vision is that patients should be more involved in their care and empowered with the support of digital technology. This ambition can also be identified in the implementation of the civic health technology Open Notes. The Open Notes service is aimed at the patients, and the technical solution enables them to get online access to their electronic health records. In 2012, Region Uppsala was the first in Sweden to implement the service in non-psychiatric healthcare. In 2014, Region Skåne became the second, and today, it has been implemented in non-psychiatric care in all regions in Sweden. However, there were differences in the implementation processes in the first two regions that offered the service to citizens. Thus, we were curious about if, and then how, the two regions differed in their reasoning about the implementation of the Open Notes service per se on the one hand, and their view of the service impact on the work of healthcare professionals on the other.

The process of empowering patients can challenge healthcare professionals because it can change the boundaries between them and their patients. Changes in professional boundaries may result in boundary work. Most of the research in this field deals with boundary work between different professions. Still, this is a field in which there is a need for more knowledge in cases when someone from outside an

organization is conducting boundary work in order to change the boundaries for someone inside an organization or a social setting. This is called “configurational boundary work” and means that someone outside an organization changes the boundaries of professional work to make space, for example, for patient empowerment. This paper aims to describe and analyze how those creating the configuration view their boundary work and the way this affects the professionals concerned.

Sixteen semi-structured interviews were conducted with key actors in the implementation processes in both regions in order to gain insight in this matter. Eight key actors in each region were identified by means of snowball sampling. The interviews were conducted in 2014 and 2015 and were recorded, transcribed and analyzed with a qualitative content analysis and according to the theoretical concept of configurational boundary work. The empirical material from the respective regions was presented as a narrative. These narratives were then compared and analyzed with support of the theoretical concept of configurational boundary work.

The results show that the key actors, or “distant actors” (because they are acting from outside) in the two regions are conducting configurational boundary work and that they are arranging boundaries at different levels in order to make space for the empowered patient in healthcare. These actors exist at different hierarchical levels in a complex network in the two regions. The results also show that the configurational boundary work that they conducted can be both unintentional and intentional. There are differences between the narratives from the two regions regarding how the implementation was framed, but political decisions are the most important framing of the implementation in both regions.

Paper II

How to Communicate the Indirect Implementation of Open Notes

The literature on how to communicate reforms, such as the implementation of new technology like eHealth, has mainly focused on how to communicate to different hierarchical levels in an organization, and thus has ignored the variety of professionals that exist in the organization. The focus of the research presented in this paper is on the strategies used in the information and communication activities directed at professionals in adult psychiatry in Region Skåne before the implementation of Open Notes. The paper also focuses on whether various professional groups demonstrate different patterns regarding the media through which they receive information, and the issues they perceive as important for the implementation of eHealth (such as Open Notes). Thus, two related questions arose in relation to implementing eHealth: 1) What media are best used to inform and

change the perceptions of professional groups during the implementation phase? 2) What aspects do the professionals perceive as important for the implementation? The issues that arose in the professionals' answers to these two questions were analyzed using theories on communication in the processes of implementation. The overall aim of the paper was to answer these questions by investigating the media used and the important aspects in relation to the implementation of an eHealth reform.

To gain insight into these questions, we attended meetings, studied documents and conducted observations. We did this to determine the strategies behind decisions about the information and communication it was expected that the professionals would need before implementation, and the media they could use to access it. The following data from the baseline survey are reported in this paper: demographic data on the participants' professions and the results from two of the fixed-choice questions in the baseline survey (one about the communication process, and one about the implementation process).

The results indicate the strategies behind the information and communication activities before the implementation. Altogether, patient safety was the focus and the information given to the professionals about the implementation was based on that. The activities were: to provide information on the intranet, send e-mails, arrange educational events and give information at workplace meetings. In addition, the unions arranged professional staff meetings on information and communication concerning the implementation. The educational events were considered important. A major communication challenge was that neither the full technical prerequisites nor the implementation date were clearly determined when the events took place.

The results from the baseline survey (29%, 871/3017) show that different professional groups utilized different media for gathering information before the implementation. Forty-nine per cent of the respondents stated that they received information at a workplace meeting, 25% from colleagues, and 14% at an educational meeting held in the spring of 2015. Forty per cent got information from the intranet and 38% from e-mail. It is noteworthy that 7% claimed they had not received any information at all about the implementation of Open Notes. The doctors distinguished themselves when we looked at the differences between professional groups. They got significantly more of their information from professional meetings and informal conversations than the rest of the respondents, and significantly less from workplace meetings. The medical secretaries got significantly more of their information from the intranet than the other respondents. Psychologists and socio-therapists received information from workplace meetings to a significantly higher degree than the others. Assistant nurses took part in educational activities to a significantly lower degree and got significantly more of their information from e-mail than the other respondents.

The second question in this paper deals with the aspects the professionals perceived as important for the implementation. Overall, the results show that the most frequently chosen factor was “Evaluation of Open Notes”, but “Patient safety” was the factor with the highest total score and also the highest mean value. The differences between the different professional groups, though, are small. The medical secretaries diverge most from the general picture because they rank “Information to employees” as the most important factor.

The results indicate that there are challenges regarding information and communication in the implementation process of a health technology such as Open Notes. The implementation can be described as “indirect” because the reform as such did not aim to affect the work of the professionals, even though it increased transparency between the patients and the healthcare professionals. The primary aim of the Open Notes service was thus patient empowerment without risking patient safety. Consequently, the information and communication activities for the healthcare professionals were accommodated to this aim. The paper highlights that professional communities matter when it comes to the choice of information media and the sense-making of the message that comes from a higher level in an organization. Therefore, it is necessary to consider the composition of the employees in a healthcare practice when choosing the media and message for the implementation of the Open Notes service. In relation to earlier studies with a media selection theory perspective, these results emphasize the importance of considering both the hierarchical levels and the different status of professional groups in an organization.

Paper III

Open Notes in Swedish Psychiatric Care (Part 1): Survey Among Psychiatric Care Professionals

Psychiatric care was exempted when the Open Notes service was introduced in hospitals for primary care and specialized care in Region Uppsala in 2012. This was because psychiatric notes were considered too sensitive for patient access. Region Skåne was the first region in Sweden to add adult psychiatry to its Open Notes service and did so on October 5, 2015. Little was known about the perceptions of healthcare professionals about the service in this context. Thus, the introduction of Open Notes in psychiatry provided an opportunity for us to carry out a unique baseline study in adult psychiatry in Region Skåne before the service became available to patients.

The aim of the study was to describe, compare, and discuss how different healthcare professionals in adult psychiatric care in Region Skåne expect Open Notes to impact their patients and their own practice.

A web-based survey was distributed to healthcare professionals in adult psychiatric care in Region Skåne. The entire population of healthcare professionals (n=3017) in adult psychiatry in the region who meet patients were invited to participate. The survey closed before patients were given online access to the Open Notes service so that all the material in the baseline study could be collected before the implementation. The response rate was 29% (871/3017). A statistical analysis examined the relationships between the different professionals and attitudes to the Open Notes service.

Many of the respondents were pessimistic in their expectations of the impact of Open Notes on their patients in adult psychiatry. Almost 60% (488/840) believed that their patients would worry more after reading their notes, and 63.2% (529/837) expected that their patients would disagree with the content in their notes. Only 11.2% (93/833) believed that the service would inspire their patients to take better care of themselves. The chi-square tests showed that there were differences in opinions among the different groups of professionals, especially regarding whether patients would be satisfied with the content in their notes and if Open Notes would increase the patients' trust for the healthcare professionals.

The results also show that the psychiatric healthcare professionals were generally of the opinion that the service would negatively affect their own practice. Approximately 40% of the respondents believed that visits would take longer (299/852), that they would have to take care of patients' questions in addition to the visits (343/845), and that patients would be offended when they read their notes online (376/844). Thirty-six per cent (302/849) believed that the relationship between their profession and the patient would change and nearly half of the respondents (386/846) believed that the implementation of Open Notes would increase the risk for threat and violence. Approximately one-third (231/835) of the respondents agreed that Open Notes in adult psychiatric care was generally a good idea. The statistical analysis shows that people in different professional groups vary concerning their misgivings about how the service will affect their own work: doctors, psychologists, and medical secretaries in many cases were more negative to the service than the other professional groups. The most striking result was that more than 60% of doctors (80/132, 60.6%) and psychologists (55/90, 61%) were concerned that they would be less candid in their documentation in the future. Thus, the results indicate that the Open Notes service could affect the working life of primarily the doctors and psychologists, but also that the service might not meet the intentions of the implementers, that is, to provide patients with full information about their health conditions.

Overall, the results of the baseline survey show that the healthcare professionals expect the implementation of Open Notes to have mainly a negative impact on their patients and on their own working life. The main concern seems to be connected to the enhanced transparency that the service offers to the patients.

Paper IV

Open Notes in Swedish Psychiatric Care (Part 2): Survey Among Psychiatric Care Professionals

This is the second of two papers presenting the results from a study of the implementation of Open Notes in adult psychiatric care in Sweden. The study contributes an important understanding of both the expectations and concerns that existed among healthcare professionals before the introduction of the Open Notes service in psychiatry and the perceived impact of the technology on their own work and patient behavior after the implementation. The study design also enabled the comparison of expectations and experiences between different groups of healthcare professionals.

The aim of the study was to describe and discuss how health care professionals in adult psychiatric care in Region Skåne experienced the influence of Open Notes on their patients and their own practice, and to compare the results with those of the baseline study.

A web-based survey was distributed to healthcare professionals in adult psychiatric care in Region Skåne in the spring of 2017, which was one-and-a-half years after the implementation of the service. The entire population of healthcare professionals (n=2521) in adult psychiatry in Region Skåne who meet patients were invited to participate in this post implementation study. The response rate was 27.73% (699/2521). A statistical analysis examined the relationships between health professional groups and attitudes to the Open Notes service.

The results show that 41.5% (285/687) of the health care professionals reported that none of their patients stated that they had read their Open Notes. Few healthcare professionals agreed with the statements about the potential benefits for patients from Open Notes. Slightly more of the healthcare professionals agreed with the statements about the potential risks. In addition, the results indicated that there was little impact on practice in terms of longer appointments or health care professionals having to address patients' questions outside of appointments. Of the 699 healthcare professionals, 212 (30.3%) responded with free text to the question, "For which patient groups or diagnoses in adult psychiatry may Open Notes be an asset?" There were many different responses to this open-ended question, and the most common

ones were “everyone” (63/212, 29.7%), “I do not know” (26/212, 12.3%), and “no one” (21/212, 9.9%). Of the 699 healthcare professionals, 276 (39.5%) responded with free text to the question “For which patient groups or diagnoses in adult psychiatry may Open Notes be particularly problematic?” The most common answers to this question were “patients with a personality disorder” (88/276, 31.9%), “patients with psychosis” (82/276, 31.1%), and “patients with paranoia” (47/276, 17.0%). Thus, the pattern of answers to the question about Open Notes being problematic differed from that of Open Notes being an asset.

Generally, the results indicate that there was little actual impact on practice after the implementation of Open Notes in terms of longer visits or more questions from patients about the content in the health record. On the other hand, the results also indicate that changes had taken place in clinical documentation. Psychologists (39/63, 62%) and doctors (36/94, 38%) in particular stated that they were less candid in their documentation after the implementation of Open Notes. Since the implementation, all healthcare professionals who enter documentation in health records need to carry out a confidentiality check each time they make an entry, since the patient has immediate access to the content. One-third (231/664, 34.8%) of the respondents reported that they did a confidentiality check. However, there were differences between the professional groups; most of the psychologists (39/62, 63%) and doctors (51/94, 54%) answered that they conducted a confidentiality check when writing in the health records, compared to 30.9% of the nurses (58/188) and 20.6% of the assistant nurses (33/160). At the same time, few healthcare professionals (43/667, 6.4%) used the Specific Information template in Open Notes, which is where a professional can enter content that is hidden from the patient online. Few healthcare professionals (95/642, 14.8%) agreed that it changed the relationship between their profession and the patient. However, 22.8% (146/639) stated that it increased the risk for threats and violence. Nearly 40% of the healthcare professionals (239/650, 36.8%) reported that the Open Notes Service in psychiatry was a good idea. The general tendency in the comparisons between the answers from the baseline survey and the post-implementation survey is that in the latter, approximately half as many respondents in some way agreed with the statements. Thus, the comparison of the results shows that both hopes about benefits and worries about risks for patients were higher before the Open Notes implementation than after.

The results show that few health care professionals who responded to the post-implementation survey experienced that the patients had become more involved in their care after the implementation of Open Notes. The results also indicate that the clinical documentation had changed after the implementation of Open Notes.

Paper V

A Theoretical Twist on the Transparency of Open Notes: Qualitative Analyses of Health Care Professionals' Free-Text Answers

From the beginning of the 1990s and onwards, the New Public Management (NPM) movement in the public sector has striven for transparency so that politicians and citizens could gain insight in the work and performance of, for example, the healthcare sector. Thus, as electronic health records (EHRs) started to diffuse, a base was laid for enhanced transparency within and between healthcare organizations. Right now, we appear to be experiencing a new kind of transparency in the healthcare sector, as many healthcare providers give patients online access to their electronic health records through Open Notes systems. The Open Notes system enables and strives for a transparency between the healthcare organization and the individual patient. This paper investigates the healthcare professionals' perceptions of Open Notes and deepens the understanding of the transparency that Open Notes implies. Building on a theoretical framework of transparency, we analyzed the results according to seven factors of trade-offs and synergies with transparency.

The aim of this paper was to deepen the academic writing on the type of transparency connected to Open Notes based on two survey studies of healthcare professionals' perceptions of Open Notes.

Healthcare professionals in adult psychiatry in Region Skåne in Sweden were surveyed before and after the implementation of Open Notes. The empirical material consists of 1,554 free-text answers from two web surveys. Web surveys make it easy to give respondents an opportunity to tell researchers what is on their minds about the subject of the survey. It is still uncommon, though, that free-text answers are systematically coded and analyzed. In this study, qualitative content analysis was used to analyze the empiric material, and all free-text answers from the baseline survey and the post-implementation survey were included. The theoretically-informed analysis pivots around the following factors connected to transparency: effectiveness; trust; accountability; autonomy and control; confidentiality, privacy, and anonymity; fairness, and legitimacy.

The results show that the free-text answers can be sorted under these factors as trade-offs with transparency. The main concerns of the healthcare professionals both before and after the implementation is the loss of effectiveness when writing notes in the health record. The professionals became more candid in the way they wrote, the care meeting became less efficient, and the health records became a less efficient work tool for themselves as they were watered down and thus less informative. The comments about trust or distrust show that the healthcare professionals are concerned about how the patients will interpret the content of the health record and in the post implementation survey, they express doubts about the patients' ability to

understand the notes. The healthcare professionals state that they have to be accountable to different stakeholders and that it is difficult to know whom to please the most as different stakeholders may have different needs and/or standards for what is accountable. In both surveys, the healthcare professionals express their worries/experiences of loss of autonomy in how to write their notes and control over their work tool (i.e., the health record). The healthcare professionals that have experiences of Open Notes are frustrated about not being able to control what information is visible to the patient and when it becomes visible. The professionals thus oppose that they themselves cannot control and alter the technical features of the Open Notes service. The healthcare professionals are concerned about the loss of privacy for the patients towards their relatives in both surveys, but they also express fear for the loss of anonymity for their own sake because their full name will be exposed in the entries in the notes.

It is seen as positive in the professionals' comments, that patients in psychiatric care have the same possibility as patients in non-psychiatric care to use the Open Notes service. However, there is a distrust on the part of the healthcare professionals of the patients' ability to understand and make use of the information in the health record. In the last survey, the professionals stated that many of the psychiatric patients do not have the material resources to access their health record, and/or the cognitive ability to understand and manage the information in it. Finally, the healthcare professionals questioned the legitimacy of the Open Notes service. They think that the implementation was not sufficiently prepared, that other efforts had been more necessary and that the enhanced transparency negatively influences their work tool (the health record). However, there are also comments from the respondents that the service may imply possibilities.

The results presented in this paper increase our understanding of the transparency that the Open Notes service implies. They also indicate that the implementation of Open Notes is policy driven while demanding, what we have chosen to call it *governed individual real-time transparency*, on behalf of citizens/patients. Thus, when healthcare professionals react to the transparency by changing their ways of writing notes, it can negatively affect the efficiency of the work of healthcare professionals and the service itself. The results show that the reactions from the healthcare professionals are aimed primarily at protecting patients and their relatives as well as their own relationship with the patients, and secondly at protecting themselves.

Paper VI

New Boundaries for the Physician Profession in the Digitalized Healthcare Sector – Why Materiality Matters

The healthcare sector is undergoing a digital transformation as issues related to health and medical conditions are increasingly being handled with the support of digital health technology. The Internet has transformed conditions regarding information and knowledge about health. This raises questions about how the boundaries that have traditionally existed between health professions and patients regarding matters of information and knowledge are being transformed by technology. Thus, digitalization has transformed the conditions for people's knowledge development and this paper highlights the consequences. I argue here that an important factor in the transformation of healthcare involves the materials from which health technologies are developed and how the materiality of these artifacts transforms the traditionally established boundaries around the knowledge of physicians vis-à-vis patients and others.

The aim of this conceptual paper is to describe and analyze how the design of three different digital health technologies (artifacts) can transform the boundaries of physicians' work and how these change processes are possible through the design of the artifacts.

The study is based on three digital health technologies that in different ways have a materiality that offers patients information, and in some instances, knowledge about their health. This enables changes to the existing boundaries between physicians and patients. The artifacts were selected because they constitute deviant examples, not because they are representative for digital health technologies in general. Two of the artifacts in the study consist of civic health technology, promoted and developed by the Swedish authorities, and aimed at Swedish citizens (Open Notes and HealthForMe). The third artifact consists of a digital patient support platform initiated and developed by an American company and aimed at patients all over the world (PatientsLikeMe). Building on a theoretical framework of materiality and professional boundaries, I analyzed the three artifacts. An analytical model enabled comparisons between the three artifacts. In the paper, there is a presentation and analysis of each artifact focused on how the materiality in the digital health technologies changes the boundaries around the physicians' work. The results from these analyses are presented in Table 4.

The first five rows in the table describe the materials out of which the three artifacts are created. Row six describe the materiality of the artifacts, and the last two rows describe the processes in healthcare where the affordances materialize into practice.

Table 4:
A summary of how the materiality of three artifacts changes the boundaries of the work of the physician profession in relation to patients.

		Open Notes	PatientsLikeMe	HealthForMe
1	Who took the initiative to develop the artifact?	Civil servants at a public agency.	Owners of a private company.	Politicians through a remit to a public agency.
2	What are the apparent underlying visions?	Transparency and well-informed patients.	Democratization and self-management.	Transparency and self-management.
3	What Internet generation is the artifact based on?	Medicine 1.0	Medicine 2.0	Medicine 1.0
4	Who contributes information?	Healthcare provider through the information it has received from the patient.	The patient, healthcare provider through the information it has received from the patient, other patients with the same diagnosis, and Artificial intelligence (AI).	The patient, healthcare provider through the information it has received from the patient and Artificial intelligence (AI) through the apps.
5	Who has access to the information?	Healthcare provider and patients.	The patient, other patients with the same diagnosis, researchers, and the company.	The patient, healthcare provider (to a certain extent), and the companies that own the apps.
6	What are the affordances to the patient?	Information and access to the physician's work tools, with registered knowledge about the individual's health.	Processing, analyses, comparisons and visualizations of information, ability to create a personal knowledge bank, technical support, community, and psychological support.	Information and access to the physician's work tools, with registered knowledge, and the ability to build a personal knowledge bank (Personalized Health) through Artificial intelligence (AI) in the apps.
7	How does the artifact transform the boundaries of the physician profession´s jurisdiction?	No changes.	Changes regarding diagnosis and inference.	Changes regarding diagnosis and inference.
8	How do the professional boundaries change?	The artifact opens the boundaries.	The artifact closes the boundaries.	The artifact creates and dissolves the boundaries.

The summary in Table 4 shows that all three artifacts have a materiality that alters the boundaries surrounding professional knowledge, albeit in different ways. This indicates that the organization that controls the materiality of an artifact has power over the behavior of the affected individuals (both the patients/citizens and the physicians). The consequence is a transfer of power over physicians' work from the profession to the owner of the technology (public agencies and private companies). By analyzing these three artifacts with the support of theories on materiality and professional boundaries, we have increased our understanding of how the development of digital health technologies changes the conditions in healthcare for the creation of boundaries, professional work, and the organization of healthcare.

Discussion and conclusions

In this chapter, I return to the four research questions presented in the Introduction. The answers to the questions are supported by the theoretical framework presented in chapter 3. I go on to clarify the most important findings in the appended papers and the conclusions drawn based on the results. Finally, I discuss methodological considerations, present the thesis conclusions, the implications for practice and suggest areas for future research.

Returning to the research questions

The overall aim of the thesis research was to explore and analyze how the transparency that eHealth technology affords patients changes the boundaries in healthcare.

More specifically the research questions of the thesis are:

> *RQ1: What kind of boundary work do key actors behind the Open Notes service conduct to make space for the empowered patient in healthcare?*
>
> *RQ2: What are the supposed and experienced effects of Open Notes in adult psychiatry from the healthcare professionals' perspective?*
>
> *RQ3: How do visions of the empowered patient change the boundaries in a healthcare practice and what kind of boundary work do healthcare professionals describe that they conduct to meet these changes?*
>
> *RQ4: In what ways can the materiality of health technologies aimed at patients reconstruct boundaries between patients and healthcare professionals?*

Paper I described the kind of configurational boundary work key actors in Region Uppsala and Region Skåne conducted to make space for the empowered patient in

healthcare. Paper II showed that professional belonging mattered in the choice of media for receiving information about the implementation of the Open Notes service and that there are challenges regarding information and communication in an indirect implementation process of an eHealth technology such as Open Notes. Papers III and IV showed that professional belonging also mattered in the expectations and experiences regarding the impact that Open Notes would have on the patients and the practice. Paper V described how the governed individual real-time transparency offered by Open Notes could affect the healthcare professionals and the service per se in negative ways. Finally, Paper VI showed that the materiality of technologies can change the boundaries between doctors and patients, and that developers of technology aimed at citizens have the power to transform healthcare. The results from Paper I mainly contribute to the first research question; findings from Papers II, III, IV and V mainly contribute to the second research question; the results from Papers III, IV and V contribute to the third research question; and the findings from Papers IV, V and VI mainly contribute to the fourth research question. The following discussion is initially structured around the four research questions. I then discuss and analyze the overall results of the thesis research with support of the theoretical model presented in chapter 3.

RQ1: What kind of boundary work do key actors behind the Open Notes service conduct to make space for the empowered patient in healthcare?

The findings in Paper I indicate that the key actors in Region Uppsala and Region Skåne are conducting what Langley et al. (2019) describe as *configurational boundary work*. The idea behind configurational boundary work is to reshape the spaces and boundaries for others and the boundary work can be conducted through *the arranging of boundaries*, which aims to reconfigure interaction patterns in relation to existing boundaries (Langley et al., 2019). The results in Paper I show that the key actors arrange boundaries through the implementation of the Open Notes service. Their configurational boundary work is performed in order to change other individuals' behavior, and thus give patients the possibility to do new things when they have online access to their health records. However, when the key actors are in the process of arranging the boundaries in healthcare to accommodate the empowered patient, this also changes the boundaries of the healthcare professionals. The Open Notes service aims to empower patients and the healthcare professionals can thus be described as the group that are "pushed aside" by the new space that the key actors create for patients during the boundary work process. This is an example that shows that various stakeholders can change the conditions for professional work (Brante, 2014) and that the boundaries around professional work always are flexible (Fournier, 2000). Configurational boundary work can be described as work through boundaries in order to deliberately change and rearrange the existing boundaries and

thereby influence the behaviors of others (Langley et al., 2019). Consequently, when the key actors are arranging boundaries, they also change the healthcare professionals' behavior. The results in Paper I, however, indicate that the changes of the healthcare professionals' space can be both intentional and unintentional when the key actors are conducting the boundary work. The boundary work is thus not always done in order to deliberately change the professional boundaries.

The results of the Paper I study show that the key actors in both regions are arranging boundaries through the implementation of the Open Notes service in different ways in order to create space for transparency for someone else: the empowered patient. The main framing was that this is a political decision. There are also arguments that are examples of what Morley and Floridi (2019ab) call *the empowerment narrative*. The authors describe this as the rhetoric and narrative around the impact of technology on patients' health. The findings indicate that the majority of the key actors in both regions frame the Open Notes service as a technical solution that will empower the patients and make them more informed, compliant and active in their care. However, one key actor also wonders if the Open Notes service can contribute to this development or if there are other solutions and work processes, that may be more expensive and work demanding, that could be used to achieve this. These reflections can be seen as an example of the reframing of the empowerment narrative that Morley & Floridi (2019a, 2019b) are asking for. They claim that it often is unclear exactly how access to data will empower patients and argue that there is a need for a reframing of the empowerment narrative. The contribution of Paper I is that we show that the key actors in the two regions are conducting configurational boundary work and their argumentation for the implementation can be described as empowerment narratives that rely on the presumed positive impact of the Open Notes service on patients' health. The Paper I study results are a point of departure for other papers, since the rhetoric of the empowered patient affects the design of the Open Notes service and thus the healthcare professionals that work in settings were the service is implemented.

In configurational boundary work, the agency clearly comes from outside the boundaries and spaces are created in order to influence others' activities (Langley et al., 2019). This can be related to what Leonardi (2010) refers to as the" material agency". He argues that digital artifacts have material agencies that can be found in the design of the technology (Leonardi, 2010). In other words, the key actors behind the Open Notes service are the ones that can affect the design and thus the material agency of the artifact. The findings from Paper I show that the Open Notes service was intended to give patients transparency into their health records. Transparency efforts always involve selectivity, directionality and interpretation (Flyverbom, 2016). The key actors selected the content in the health records that should be transparent to the patients and when; the flow of information was from healthcare to the patient (it was the content in the health record that should be visible) and the interpretation was that the patients would be an active audience that used the Open

Notes service. Finally, Langley et al. (2019) argue that configurational boundary work often involves multiple stakeholders and they refer to processes that evolve over a long period. They state that configurational boundary work is a force that drives competitive boundary work. This reasoning can be applied to the implementation of the Open Notes service, because since the first steps towards the service were taken in the Uppsala Region in the late 1990s, many stakeholders have been involved over the years. Additionally, the thesis research results show that the configurational boundary work that was conducted by the key actors in Study 1 drove the competitive boundary work that was conducted by the healthcare professions in Study 2. The configurational boundary work in Study 1 is conducted from the outside with the agency to make space for the empowered patient. The key actors did not want to affect the healthcare professionals' behavior, but they did want to affect the behavior of the patients. However, the results in Paper I indicate that the key actors may have hoped that the Open Notes service would lead to what Langley et al. (2019) call collaborative boundary work and that the technology would *work at boundaries* and contribute to interactions between the empowered patients and healthcare professionals. The Open Notes service could thus be described as a tool aimed at changing healthcare and paving the way for a transparency that will empower patients by making the content in the health record visible to them. Thus, the results of Papers III, IV and V show that there are signs of collaborative boundary work, but even more indications of competitive boundary work.

RQ2: What are the supposed and experienced effects of Open Notes in adult psychiatry from the healthcare professionals' perspective?

An eHealth implementation is a complex process that can change healthcare professionals work, their practice and the patients (Cucciniello et al., 2015; Doolin, 2016). The results presented in Study 2 showed that this applies when the Open Notes service is implemented in adult psychiatric care in Region Skåne. The findings in Papers II, III, IV and V provide descriptions of the healthcare professionals' expectations and experiences of the implementation. Implementing new technology involves processes that change both the healthcare organization and the work of the healthcare professionals (Mair et al., 2012). Paper III illustrated how healthcare professionals in adult psychiatry anticipated the effects of the Open Notes service before implementation by presenting the results from the baseline survey. This was, to the co-authors knowledge, the first study that examined how adult psychiatric healthcare professionals working in public care expected Open Notes to affect their work and how these expectations varied between different professional groups.

In summary, the Paper III results showed that the Region Skåne healthcare professionals in psychiatric care expected the implementation of Open Notes to have

mainly a negative impact on their patients and on their own work. Many were pessimistic in their expectations. A majority believed that their patients would worry more after reading their notes, and few believed that the service would inspire their patients to take better care of themselves. A majority of both doctors and psychologists were also worried that they would be less candid in their documentation in the future. Nearly 30% of the healthcare professionals reported that the Open Notes Service in psychiatry was a good idea. Generally, the respondents were more negative to Open Notes than the respondents in previous baseline studies in non-psychiatric settings in the United States (Walker et al., 2011). One explanation can be that the service is obligatory in Sweden; healthcare professionals cannot opt out from participating, and they cannot exclude patients. Another explanation could be that this was the first implementation of the service in a psychiatric setting in Sweden and this may have generated uncertainty among the healthcare professionals since they had no previous experience to rely on. The same explanations can be applicable for the initial implementation in non-psychiatric care in Region Uppsala in 2012, and this can be one reason behind the conflicts that arouse around the development and implementation of the service.

The post-implementation survey was, to the best of the authors' knowledge, the first follow-up survey of its kind. In summary, the Paper IV results showed that many healthcare professionals reported that none of their patients had read their Open Notes. Few professionals agreed with the statements about the potential benefits for patients from Open Notes. Slightly more agreed with the statements about the potential risks. These results indicate that the visons that Open Notes will contribute to empowered patients that came forward in Study 1 may not come true according to the healthcare professionals that responded to the post-implementation survey. The results confirm the evidence presented by Ammenwerth et al. (2012) showing that the impact of the information from Open Notes services available through patient portals such as *1177 Vårdguiden* is limited when it comes to increased patient empowerment. The results also indicate that there was little impact on practice in terms of longer appointments or healthcare professionals having to address patients' questions outside of appointments. However, the results indicated that changes had taken place in clinical documentation. Psychologists and doctors, in particular, stated that they were less candid in their documentation after the implementation. This could be because the boundaries around the healthcare professionals changed with the implementation of the Open Notes service. Fournier (2000) claims that it is important for the professions that the boundaries between them and laypeople be maintained. Because the implementation of the Open Notes service makes space for the empowered patient, it thus changed these boundaries.

In the post-implementation survey, nearly 40% of the healthcare professionals reported that the Open Notes service in psychiatry was a good idea, an increase compared to the baseline survey were nearly 30% of the respondents agreed. Paper IV also presented a comparison between the results from the two surveys on the

effect on patients. The tendency was that approximately half as many respondents in some way agreed with the statements in the post-implementation survey as in the baseline survey. Hopes about benefits and worries about risks were higher before the service was implemented. One explanation for the results regarding the positive outcomes of the service could be that patient empowerment was an important argument for the implementation of Open Notes, which was shown in the Paper I results. Thus, there may have been expectations among the healthcare professionals that the patients should be empowered and active because of the implementation. However, the result in the post-implementation survey showed that few healthcare professionals had met a patient who told them that they had read their notes online and this might explain the results in Paper IV. Additionally, the Open Notes service enables and strives for a transparency between healthcare and the individual patient in order to empower him or her. Pursuits for transparency in healthcare can be problematic because the work that is performed by healthcare professions can be difficult for laypeople to understand (Levay, 2016). However, the Paper V results indicate that there were trade-offs with this transparency. The healthcare professionals were concerned, both before and after the implementation, that the writing in the health record would be less effective. The comparisons thus show that the uncertainty about the effects of Open Notes that came forward before the implementation developed into experiences one-and-a-half years after the implementation. Because of these experiences, healthcare professionals in Paper V described that they were changing their way of working.

The results in Papers II, III and IV also show that there are differences between the occupational groups in adult psychiatry. Paper II reported differences between occupational groups on how they received information about the implementation. The pattern of and between professional groups reveals that a scale of social status came forward with the doctors and the medical secretaries at the endpoints. Consequently, professional belonging matters both for choice of media for information and for sense making of the message sent from higher levels of the organization. Those professions known as classic professions (Brante, 2013) and with higher professional status (i.e., the doctors) preferred to be informed amongst peers, while semi-professions (Brante, 2013) and other groups of professionals found other ways to get informed. Furthermore, the comparisons in Paper IV reveal that there were differences between the two surveys: doctors, psychologists, and medical secretaries were in many cases more negative toward the service than were nurses and assistant nurses in the baseline survey. In the post-implementation survey, though, there were fewer such differences in opinions between the various professional groups. One explanation of this result can be the uncertainty before the implementation. On the one hand, the medical secretaries did not know how their work in the front line with the patients would change due to the implementation. On the other hand, the doctors and the psychologists did not know what would happen with their work tool, the health record, and how this would affect their work.

RQ3: How do visions of the empowered patient change the boundaries in a healthcare practice and what kind of boundary work do healthcare professionals describe that they conduct to meet these changes?

The work of the healthcare professions, by tradition, is surrounded by boundaries. The creation and maintenance of boundaries surrounding a field of knowledge make up a fundamental part of the growth and development of professions (Abbott, 1988; Fournier, 2000). Thus, boundaries around the jurisdiction of the work of healthcare professionals (Abbott, 1988) existed long before the implementation of any kind of eHealth solution in healthcare practices. Consequently, it is of interest to examine how professional boundaries change when digital technology that affects their work is implemented (Eriksson-Zetterquist et al., 2009). In the case of Open Notes, the eHealth technology that is implemented in the healthcare practice aims to empower the patients, and this adds yet another interesting dimension to the implementation. Traditionally, many studies in this field have focused on boundaries between different professional groups (Lamont & Molnár, 2002); in this case, however, the focus is on the boundaries between professional groups and patients. The implementation can thus be described as a change of the boundaries around the professions that ensued as a consequence of the empowered-patient vision.

"Jurisdiction" in this context is a profession's control over the boundaries of a given field of knowledge and the right to perform certain tasks in that field (Abbott, 1988). Actors outside of an organization can play an active role in shaping professional jurisdiction by opening and closing boundaries (Liu, 2017). Paper VI, however, illustrates that the boundaries around the jurisdiction are not changed by the Open Notes per se, but by the outcome of the jurisdictional work (i.e., when the content in the health records became visible through the service). This could alter the relationship between professionals and patients since the authority of a professional, according to Fournier (2000), is based on the existence of such boundaries in matters related to their professional field of knowledge.

Consequently, the boundaries of professions in the healthcare sector and the balance of power between the profession and the patient may both change when the health record documentation makes information about professional judgements accessible to patients through civic health technologies such as Open Notes. The Paper V results illustrate that professionals reported that they had changed their way of writing entries in the health records; they sometimes used words that would be easier for the patient to understand, for example. This could be problematic since, according to Abbott (1995), it is important for professionals to be able to express themselves in a purely professional language that is based on scientific knowledge. If this is not possible there is a risk for "professional regression".

When the conditions around the professionals work change (due to the implementation of a digital artifact, for example), the boundaries around professions also change. This calls for boundary work in order to manage these changes.

Langley et al. (2019) describe this as *work for boundaries* and they call it *competitive boundary work*. It is worthwhile to gain more knowledge about how healthcare professions describe the competitive boundary work they conduct when a digital artifact that makes their work visible is implemented in a healthcare practice. Technology-enabled digital visibility makes transparency possible (Stohl, Stohl, & Leonardi, 2016); and according to the results in Papers IV and V, the professionals changed their behavior to meet the transparency in the Open Notes service that made their work visible. This result in Paper V thus show one consequence of the transparency vision that was put forward in Paper I. The Open Notes service has a materiality (Leonardi, 2010) that affords transparency towards the patients, and the results in Paper V illustrate that the healthcare professionals described that they were conducting competitive boundary work to meet these changes. Flyverbom (2016) argues that our understanding of transparency can be enhanced if we pay attention to the constraints and opportunities that are provided by technology. The results in Paper V thus contribute to an increased understanding of how the affordance of transparency to patients results in competitive boundary work that reduces transparency when healthcare professionals change their way of writing entries in the health record.

The results in Papers IV and V indicate that the professionals conducted competitive boundary work in order to deal with the transparency in the Open Notes service that made their professional work visible. The findings from Paper IV show that many employees stated that they never met a patient who had read their health record via the Open Notes service. However, one important result from Papers IV and V is that the employees acted as if the patients had read their notes online and changed their way of making entries in the health record accordingly. The results in Paper V reveal that the professionals did this in order to protect patients, relatives of patients and themselves. One explanation can be that the materiality of the service is configured for a rational patient who can meet these requirements and expectations. The results show that the professionals do not experience that all of their patients in adult psychiatry meet these expectations. The findings in Paper V thus reveal that according to the professionals, they changed their way of making entries, in other words, they conducted boundary work to protect their patients, the relatives of patients and themselves. This result show the challenges that arise in the implementation of a civic health technology that is designed for rational patients in a healthcare setting where some of the patients are vulnerable because of their diagnoses. In Paper IV, healthcare professionals thus report that the Open Notes service can be particularly problematic for patients with personality disorders, psychosis, and paranoia. This finding confirms that the worries and concerns that resulted in psychiatric care being exempted when the Open Notes service was initially implemented in Region Uppsala may be relevant. The descriptions in chapter 2 of the regulatory framework also reveal that the technical prerequisites for Open Notes were adjusted when the service was implemented in adult psychiatry in Region Skåne; currently there is a delay for inpatients in adult psychiatric care that

exempts them from immediate access to the service. The description in chapter 2 also shows that since the implementation in 2015, the affordances for and responsibilities of the healthcare professionals have changed, and due to that, the tendency now is that the changes in the materiality of the Open Notes is increasingly affecting the healthcare professionals' daily work. Thus, the boundaries around the healthcare practices are flexible and change when the technical prerequisites of the Open Notes service change.

The Open Notes service seems to have changed clinical documentation irrespective of whether the patients were active or not; this indicates a risk for watered-down health records. This result is supported by research on the OpenNotes Project in the United States where Walker et al. (2014) have expressed similar concerns. Mental health clinicians in the VA System claim that they are also more careful about what they write to protect the patients and themselves (Denneson et al., 2017).

RQ4: In what ways can the materiality of health technologies aimed at patients reconstruct boundaries between patients and healthcare professionals?

Open Notes is a civic health technology that enhances transparency and through its materiality (Leonardi, 2010), it makes the work of healthcare professionals visible to the patients. The technical prerequisites of the service that are presented in chapter 2 can be described as affordances and constraints for the patients but also for the healthcare professionals. Affordances and constraints have a basis in the underlying visions and ideas and that affect what is possible to do with the support of the digital artifact (Leonardi, 2010). In Paper VI, I argue that the organization or group of individuals that controls the materiality of a health technology aimed at patients has power over the behavior of the affected individuals (i.e., the patients and the professionals). Thus, the design of the Open Notes service can be seen as an practical example of how the visions and ideas from key actors in the two regions about patient empowerment(presented in Paper I) are realized in a digital artifact. This is why the materiality of the Open Notes service is significant because it governs what is possible for patients and healthcare professionals to do with the support of technology. Individuals are, depending on their role, introduced to an artifact whose materiality is already preconfigured for them (Leonardi, 2013; Lindberg et al., 2017). The materiality of Open Notes determines what can be done, by whom and when it can be done (see the technical prerequisites presented in chapter 2). It is noteworthy that over time, new technical prerequisites in the Open Notes system have been developed that better afford healthcare professionals the ability to conduct their work. The arguments that can be found in Paper I (that the service should not affect the healthcare professionals' work) is thus not applicable today.

The main concerns from the healthcare professionals in Papers III, IV and V appear to be linked to the enhanced transparency that is afforded the patients through the Open Notes service. As discussed above, the professional jurisdiction does not change according to Paper VI, but the jurisdictional work is made visible through the Open Notes service because the artifact opens the boundaries. Visibility is the combination of three attributes according to Stohl, Stohl and Leonardi (2016): availability of information, approval to disseminate information, and accessibility of information to third parties; transparency is achieved when there are high levels of these attributes. Paper I reports that all three of these attributes are fulfilled in the Open Notes service: written information is available in the electronic health record, there are key actors who have approved sharing of the information, and the information is accessible to the patients via the Open Notes service.

Transparency is often connected to desired things like efficacy (Levay, 2016). The results from Paper V, however, show that the governed individual real-time transparency that is provided by the Open Notes service may have the intended positive effects, but can also result in negative trade-offs between the transparency and the efficiency of the actual healthcare practice. In fact, Stohl et al. (2016) argue that increased visibility can result in reduced transparency and that this can create opacity instead. In other words, the authors question the assumption that higher visibility results in more transparency and calls this the "transparency paradox". The Paper V results support this argumentation, the materiality of the Open Notes service affords governed individual real-time transparency for the patients and the affordance to the patients increases the visibility of the health record. As a result, healthcare professionals claim that they change their entries, they are more candid when they write, and that this results in health records have become a less effective work tool because they are watered down and do not contain as much information as before. This is an example of the transparency paradox (Stohl et al., 2016): the increased visibility of the content in the health record reduces the transparency. When healthcare professionals change their way of writing entries there is less visible information, and this results in opacity instead of transparency.

Summary of the results discussion

The overall aim of this thesis is to explore and analyze how the transparency that is afforded to patients by eHealth technology changes the boundaries in healthcare. The main example of eHealth technology examined was the Open Notes service, to which the Paper I, II, III, IV and V results are related. Paper VI presents a comparison of the Open Notes service to two other eHealth technologies in terms of changes in the boundaries of the doctors' work.

I use the analytical model that was presented in Figure 1 in chapter 3, to sum up the discussion. The model illustrates the different processes that occur between the ones to the left that influence the behavior of others, and the ones to the right that are influenced, and how the theoretical concepts can explain these processes. Altogether, the results show that the key actors in Region Uppsala and Region Skåne conducted configurational boundary work in order to make space for the empowered patient. The configurational boundary work is framed by the vision about the empowered patient and the main argument behind the service is that it is a political decision. The configurational boundary work is connected to the material agency and this governs the materiality of the Open Notes service. The materiality affords transparency to the patients, which opens up the boundaries around the healthcare professionals work. The consequence is that they are conducting competitive boundary work to primarily protect the patients and their relatives, and secondly to protect themselves. However, there are also signs of collaborative boundary work between the patients and the healthcare professionals.

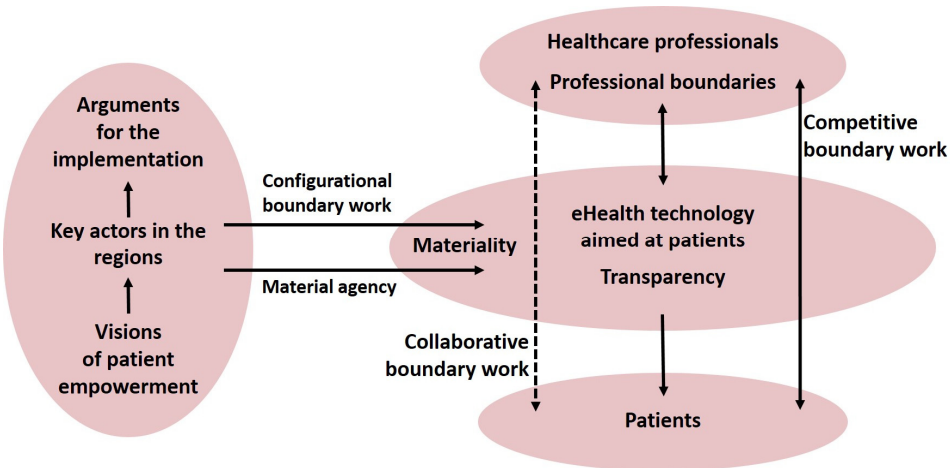


Figure 1:
Theoretically informed analytical model

Methodological considerations

Research design considerations

This thesis consists of three studies and has an exploratory sequential design with mixed methods using both qualitative and quantitative approaches. This kind of research often starts with a qualitative phase followed by a quantitative phase (Creswell & Creswell, 2018). The research design in this thesis starts with a

qualitative phase, since Study 1 is an interview study. Study 2 has a sequential mixed design: it begins with a qualitative phase followed by a quantitative phase that consist of two surveys. Finally, Study 3 has a qualitative approach. I believe that the methods that were used in the respective studies were suitable for the research questions.

The term "triangulation" can be used to describe validation between different findings or it can describe a process of studying an issue using different methods to gain a more complete picture; the latter approach is most common in mixed methods studies (O'Cathain, Murphy, & Nicholl, 2010). The latter approach to triangulation is used in this thesis and the different methods were chosen because we wanted to get complementary information from different empirical materials. The three studies are connected to each other and each study has contributed knowledge to the next study. In a mixed method study, the qualitative and quantitative findings should be integrated and discussed in relation to each other (Bryman, 2016). In this thesis, the results from the three studies have been integrated in the discussion.

An interview study with key actors

The key actors that were interviewed were identified through snowball sampling and pre-knowledge. This was an appropriate technique to use when we were trying to find out who the key actors were that we should talk to in the respective regions. At the end of the interviews, all key actors were asked to provide the names of other key actors that had been involved in the implementation process. In the last of these interviews, all of the names were of key actors who already had been interviewed. We may not have interviewed all the key actors that were involved in the implementation in the two regions, but I believe we interviewed most of them, and that they thus were able to answer the questions about the implementation of the Open Notes service in their respective region.

Because the interviews were conducted in 2014 and 2015, it is impossible to know if the answers to the questions would be the same if the interviews were conducted today or at an earlier stage. The narratives around the Open Notes service could very well have changed during this time due to increased experiences from healthcare settings that had implemented the service.

Two full population web surveys

When we were planning the research design of Study 2, there were no surveys available in Swedish in this field. The OpenNotes project in the U.S., however, had developed surveys. We decided to translate these surveys and use them in our study. This methodological choice made it possible for use to compare the answers from the baseline survey and the post-implementation survey with results from settings

in the U.S. that have used the OpenNotes project surveys. As mentioned above, I also attended educational events, read the risk analysis and conducted focus groups in order to validate the areas of interest in the questionnaire used in the baseline survey.

An important starting point for Study 2 was to include all healthcare professionals within the practice who meet patients in their daily work. Both the baseline survey and the post-implementation survey were thus full population surveys. The response rate was 28.86% to the baseline survey and 27.73% to the post-implementation survey. The explanations for the response rates obtained are probably the same for both surveys: some professionals may have been absent during the timeframe in which they could respond to one or both of the surveys; some may not have opened their e-mail during that timeframe, or they simply were not interested. Still, the group distribution among the respondents in the two surveys corresponds well with the percentage of employees in each profession, which indicates that we have good representation of all professional groups.

There was no way of knowing whether the same individuals answered the baseline survey and the post-implementation survey. Both surveys were programmed so that it was not possible to track specific respondents' answers, since the connection between the email address and the answers were deleted when the respondent send the answers to the server. In addition, it was not possible to send the survey to the same individuals because of the study design: during the one-and-a-half years between the two surveys, new employees started working in adult psychiatric care and others left. Thus, it is only possible to compare the results from the two surveys on a group level. We do not know if and how individual healthcare professionals have or have not changed their perceptions of the Open Notes service.

Should only those healthcare professionals who had met patients who had read their Open Notes been able to answer the post-implementation survey? No. This would not have been the best methodological decision. The results in Papers IV and V show that there would have been changes in documentation patterns, for example, regardless of if the healthcare professional has met such a patient or not. Thus, the professionals were acting as if the patients were reading their health records through the Open Notes service. This is an interesting result that would not have otherwise been obtained.

The baseline and post-implementation surveys were designed in different ways, resulting in different numbers of open-ended questions in the two surveys. To permit comparisons between the expectations before the implementation and the experiences after, the post-implementation survey was based on the baseline survey. However, to be able to capture the experiences of the healthcare professionals in the post-implementation survey, both fixed-choice questions and open-ended questions were added. This methodological choice resulted in a different number of free-text answers in each survey. In addition, it was not possible to conduct chi-square tests

on as many answers in the post-implementation survey as in the baseline survey. This was due to the answer options "not relevant" and "I do not know" for some of the questions. Thus, it was not possible to carry out statistical analyses to the same extent as in the baseline survey.

A conceptual study that includes three health technologies

Study 3 is a conceptual study in which I describe and theoretically analyze how the work of doctors changes due to the development of health technologies. To carry out this analysis, make comparisons, and determine if the results from Studies 1 and 2 (that technology aimed at patients can change the boundaries between the doctors and patients) were valid, I gathered material about technologies other than Open Notes. The main source of data about the respective technologies came from content on the web sites that described them. The three technologies were not chosen because they were representative of health technologies in general, but rather because they differed from each other and it was thus possible to reveal similarities and differences in their materiality.

Knowledge contribution

The knowledge contribution of the thesis pivots around the results in the respective papers, and the previous discussion in this chapter where the results from the three studies have been integrated.

As stated previously, psychiatric care was initially exempt from the Open Notes service in Sweden due to the sensitive nature of the content in the records and due to the risk that patients may be specifically vulnerable (Åkerstedt, Cajander, Moll, & Ålander, 2018). Adult psychiatry in Region Skåne was the first psychiatric healthcare setting in Sweden where the service was implemented. Papers II, III, IV and V have contributed knowledge about the supposed and experienced effects of Open Notes from the healthcare professionals' perspective.

One contribution is that three different kind of boundary work are analyzed and integrated in the thesis discussion. The results of this integration show that the configurational boundary work conducted by the key actors in Paper I is the driving force for the competitive boundary work that is conducted by the healthcare professionals in Papers IV and V. However, there are also signs of collaborative boundary work between patients and healthcare professionals. These results add knowledge to the research field of boundary work presented in Langely et al. (2019) since it confirms that the three different kind of boundary work can exist at the same time and that various actors can conduct boundary work from both outside and inside a healthcare practice. In addition, the results contribute knowledge about how

the materiality of new technology can be related to different kinds of boundary work; this is a research field were Langley et al. (2019) call for more knowledge.

Another important contribution is the report of watered-down records in Papers IV and V. This issue has been discussed previously by Walker, Meltsner, & Delbanco (2015) and Klein et al. (2016) and they argue that there is a need for more knowledge about how Open Notes changes the documentation praxis in the health record. Paper V in particular contributes important knowledge in this field, because the paper is, to our best knowledge, the first of its kind to analyze free-text answers in which healthcare professionals describe how the transparency that is afforded by Open Notes changes their work. Paper V contributes methodological knowledge about the analyses of free-text answers in web surveys, theoretical knowledge about the kind of transparency that is offered to patients by Open Notes, and empirical knowledge about the trade-offs with governed individual real-time transparency in a healthcare setting.

Paper VI is a conceptual paper in which I analyzed and compared the Open Notes service with two other health technologies that changes boundaries around healthcare professionals in general, and doctors in particular. This paper contributes knowledge about the effect the materiality of artifacts can have on the boundaries around doctors' work. The three artifacts were chosen because they illustrate examples of how the significance of the materiality is related to changes around professional boundaries. The results are presented in a table that gives an overview of how the materiality of Open Notes, PatientsLikeMe and HealthForMe change the boundaries of the doctors' work. The factors that are identified in the analysis and presented in the table can be used as a point of departure for future empirical studies of how the materiality of artifacts, aimed at patients, can change the boundaries of professional work.

Conclusions

The Open Notes service is being implemented in more and more healthcare settings, and large groups of patients in both non-psychiatric and psychiatric care have online access to their health record on both national and international levels. However, there is a need for more knowledge about how this civic health technology affects the patients, the professionals and the organization of healthcare. This thesis contributes to an increased understanding of how the transparency that is afforded to patients by eHealth technology changes the boundaries and work in healthcare.

The main conclusions from the research presented in this thesis are:

- Open Notes is aimed at empowering the patients, but the results show that in addition the service also may change healthcare practice and the relations between professionals and patients, and that there seems to be changes regardless of whether the patient uses the service or not.
- The idea of the Open Notes system is to create a transparent healthcare practice that empowers patients and enables them to be more involved in their care. Thus, Open Notes can be described as an artifact that is primarily designed for a rational patient who can meet these requirements and expectations. The results show that the professionals do not experience that all of their patients in adult psychiatry meet these expectations. This indicates that governed individual real-time transparency may not always be the best choice either for the patients or for the healthcare professionals work. The results thus indicate that full transparency may not always be the best choice.
- The work of the healthcare professions is, by tradition, surrounded by boundaries. On the one hand, the results show that key actors behind the Open Notes service conducted configurational boundary work in order to make space for the empowered patient. On the other hand, the healthcare professionals conducted competitive boundary work to regain control over their professional boundaries. The results indicate that the professionals change their behavior in order to meet the transparency in the Open Notes service that made the professional work visible. The professionals reported that they did this primarily to protect the patients and their relatives and secondly to protect themselves.
- Because of the implementation of the Open Notes service, an important work tool of the healthcare professionals, the health record, becomes visible. Altogether, the results from adult psychiatry show that psychologists and doctors in many cases seem more negative to this visibility than other groups of professionals. The materiality of Open Notes thus seems to challenge professional values and the reactions seem to be strongest from the psychologists and the doctors. The reason for this could be that the content in their entries are more sensitive than the content in other professionals' entries. It also came forth that their primarily reason for being skeptical of the transparency afforded by the Open Notes service is that they believe it may not always be the best and safe solution for all their patients.

Implications for practice and future research

Implications for practice

The results show that there is a need for information and communication to healthcare professionals when eHealth technologies that are aimed at patients are implemented in healthcare. The Paper II results indicate that it is preferable to use different communication activities because different professional groups gather information from different media sources.

It is also important to keep in mind that the implementation of Open Notes is never complete. The Paper IV and V results show that there is a need for information about the service in general and the technical prerequisites in particular. This can be described as an ongoing implementation; there are always new patients that may be using the service for the first time and their ability to do so as it is intended can vary, which in turn can affect the healthcare professionals' work. New healthcare professionals are regularly employed in a healthcare practice were patients already have online access to their electronic health record, and the regulatory framework and the technical prerequisites change over time. It is thus not sufficient to provide information and training when the service is implemented for the first time.

The Paper V results show that the governed individual real-time transparency offered to patients by the service may not be the most efficient for the healthcare professionals or for the service as such. The results thus indicate that it may be important to discuss how the Open Notes service should be designed in order to be valuable for both patients and the healthcare professionals.

Suggestions for future research

There is a need for more knowledge about the Open Notes service. There is a need for studies with both qualitative and quantitative data. The results presented in this thesis have contributed suggestions for future research.

One interesting result from Papers IV and V is that there are healthcare professionals in adult psychiatry who claim that the clinical documentation changed after the implantation of the Open Notes service. To gain more knowledge about this important issue, interviews and observations can be conducted with healthcare professionals to deepen the understanding of how they actually conduct this work and the reasons why the documentation patterns change.

There is also a need for more surveys of healthcare professionals in other clinical settings in both non-psychiatric and psychiatric care to be able to compare the results from Papers II, III, IV and V with results from other settings on both the national and international levels.

The results from Papers IV, V and VI indicate that there is a need for more studies on how the materiality in health technologies aimed at patients can change the boundaries around healthcare professionals work in both positive and negative ways.

Finally, it would be interesting to carry out studies that explore how knowledge about materiality can be used in development and implementation of eHealth technology to make it more sustainable for both patients and healthcare professionals.

References

Abbott, A. (1988). *The System of Professions. An essay on the division of expert labour*. London: The University of Chicago Press.

Abbott, A. (1995). Boundaries of Social Work or Social Work of Boundaries?: The Social Service Review Lecture. *Social Service Review*, 69(4), 545-562.

Albu, O. B., & Flyverbom, M. (2019). Organizational Transparency: Conceptualizations, Conditions, and Consequences. *Business & Society*, 58(2), 268-297. doi:10.1177/0007650316659851

Alvesson, M., & Sköldberg, K. (2009). *Reflexive methodology: new vistas for qualitative research*. Los Angeles: SAGE.

Ammenwerth, E., Schnell-Inderst, P., & Hoerbst, A. (2012). The Impact of Electronic Patient Portals on Patient Care: A Systematic Review of Controlled Trials. *Journal of Medical Internet Research*, 14(6), e162. doi:10.2196/jmir.2238

Barello, S., Triberti, S., Graffigna, G., Libreri, C., Serino, S., Hibbard, J., & Riva, G. (2015). eHealth for Patient Engagement: A Systematic Review. *Frontiers in Psychology*, 6, 2013. doi:10.3389/fpsyg.2015.02013

Bell, S. K., Mejilla, R., Anselmo, M., Darer, J. D., Elmore, J. G., Leveille, S., et al (2017). When doctors share visit notes with patients: a study of patient and doctor perceptions of documentation errors, safety opportunities and the patient-doctor relationship. *BMJ Qual Saf*, 26(4), 262-270. doi:10.1136/bmjqs-2015-004697

Blumenthal, D., & Abrams, M. K. (2019). Ready or Not, We Live in an Age of Health Information Transparency. *Annals of Internal Medicine*. doi:10.7326/m19-1366

Brante, T. (2010). Professional Fields and Truth Regimes: In search of Alternative Approaches. *Comparative Sociology* (9), 843–886.

Brante, T. (2013). The Professional Landscape: The Historical Development of Professions in Sweden. *Professions and Professionalism*, Vol 3, Iss 2 (2). doi:10.7577/pp.558

Brante, T. (2014). *Den professionella logiken : hur vetenskap och praktik förenas i det moderna kunskapssamhället*. Stockholm: Liber.

Brante, T., Johnsson, E., Olofsson, G., & Svensson, L. G. (2015). *Professionerna i kunskapssamhället : en jämförande studie av svenska professioner*. Stockholm: Liber.

Brodersen, S., & Lindegaard, H. (2015). Empowering patients through healthcare technology and information? The challenge of becoming a Patient 2.0. *International Journal of Healthcare Technology and Management* 15(1):73-88. doi:10.1504/ijhtm.2015.070518

Bryman, A. (2016). *Social research methods*. Oxford: Oxford University Press.

Cajander, A., Moll, J., Englund, S., & Hansman, A. (2018). Medical Records Online for Patients and Effects on the Work Environment of Nurses. *Studies in Health Technology and Informatics*, 247, 271-275.

Cajander, Å., & Grünloh, C. (2019). *Electronic Health Records Are More Than a Work Tool : Conflicting Needs of Direct and Indirect Stakeholders*. Paper presented at the ACM Conference on Human Factors in Computing Systems (CHI '19). http://urn.kb.se/resolve?urn=urn:nbn:se:kth:diva-235847

Carlhed, C. (2013). The Rise of the Professional Field of Medicine in Sweden. *Professions & Professionalism* (2), 562. doi:http://dx.doi.org/10.7577/pp.562

Cehis. (2013). *Handlingsplan 2013-2018. Landstings, regioners och kommuners samarbete inom eHälsoområdet*. Retrieved from https://www.inera.se/globalassets/om-inera/styrdokument-och-rapporter/strategi-och-handlingsplan/handlingsplan_2013_2018.pdf

Charmaz, K. (2014). *Constructing grounded theory*: Thousand Oaks, CA: Sage Publications.

Creswell, J. W., & Creswell, J. D. (2018). *Research design: qualitative, quantitative, and mixed methods approaches*. Los Angeles: SAGE.

Cromer, R., Denneson, L. M., Pisciotta, M., Williams, H., Woods, S., & Dobscha, S. K. (2017). Trust in Mental Health Clinicians Among Patients Who Access Clinical Notes Online. *Psychiatric Services*, 68(5), 520-523. doi:10.1176/appi.ps.201600168

Cucciniello, M., Lapsley, I., Nasi, G., & Pagliari, C. (2015). Understanding key factors affecting electronic medical record implementation: a sociotechnical approach. *BMC Health Services Research*, 15, 268. doi:10.1186/s12913-015-0928-7

Czarniawska, B. (1998). *A narrative approach to organization studies*. Thousand Oaks, Calif.: Sage.

Czarniawska, B. (2014). *Social science research: from field to desk*. Los Angeles: SAGE.

David, N., McNutt, J., & Justice, J. (2018). Smart Cities, Transparency, Civic Technology and Reinventing Government. In R. B. M. (Ed.), *Smart Technologies for Smart Governments. Public Administration and Information Technology* (Vol. 24, pp. 19-34): Springer.

de Lusignan, S., Mold, F., Sheikh, A., Majeed, A., Wyatt, J. C., Quinn, T., et al.(2014). Patients' online access to their electronic health records and linked online services: a systematic interpretative review. *BMJ Open*, 4(9), e006021. doi:10.1136/bmjopen-2014-006021

Dedding, C., van Doorn, R., Winkler, L., & Reis, R. (2011). How will e-health affect patient participation in the clinic? A review of e-health studies and the current evidence for changes in the relationship between medical professionals and patients. *Social Science and Medicine*, 72(1), 49-53. doi:10.1016/j.socscimed.2010.10.017

Delbanco, T., Walker, J., Bell, S. K., Darer, J. D., Elmore, J. G., Farag, N., et al. (2012). Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. *Annals of Internal Medicine*, 157(7), 461-470. doi:10.7326/0003-4819-157-7-201210020-00002

Delbanco, T., Walker, J., Darer, J. D., Elmore, J. G., Feldman, H. J., Leveille, S. G., et al. (2010). Open notes: doctors and patients signing on. *Annals of Internal Medicine*, 153(2), 121-125. doi:10.7326/0003-4819-153-2-201007200-00008

Denneson, L. M., Cromer, R., Williams, H. B., Pisciotta, M., & Dobscha, S. K. (2017). A Qualitative Analysis of How Online Access to Mental Health Notes Is Changing Clinician Perceptions of Power and the Therapeutic Relationship. *Journal of Medical Internet Research*, 19(6), e208-e208. doi:10.2196/jmir.6915

DesRoches, C. M., Bell, S. K., Dong, Z., Elmore, J., Fernandez, L., Fitzgerald, P., et al. (2019). Patients Managing Medications and Reading Their Visit Notes: A Survey of OpenNotes Participants. *Annals of Internal Medicine*. doi:10.7326/m18-3197

Dobscha, S. K., Denneson, L. M., Jacobson, L. E., Williams, H. B., Cromer, R., & Woods, S. (2016). VA mental health clinician experiences and attitudes toward OpenNotes. *General Hospital Psychiatry*, 38, 89-93. doi:10.1016/j.genhosppsych.2015.08.001

Dobscha, S. K., Denneson, L. M., Pisciotta, M. K., Bourne, D. S., Chen, J. I., Philipps-Moses, D., & Woods, S. S. (2018). Predictors of viewing progress notes among users of VA's electronic health portal who receive mental health care. *JAMIA Open*, 1(1), 122-127. doi:10.1093/jamiaopen/ooy007 %J JAMIA Open

Dobscha, S. K., Kenyon, E. A., Pisciotta, M. K., Niederhausen, M., Woods, S., & Denneson, L. M. (2019). Impacts of a Web-Based Course on Mental Health Clinicians' Attitudes and Communication Behaviors Related to Use of OpenNotes. *Psychiatric Services*, appips201800416. doi:10.1176/appi.ps.201800416

Doolin, B. (2016). Implementing E-Health. In E. Ferlie, K. Montgomery & A. Reff Pedersen (eds). *The Oxford Handbook of Health Care Management*. Oxford University Press.

Elo, S., & Kyngas, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107-115. doi:10.1111/j.1365-2648.2007.04569.x

Eriksson-Zetterquist, U., Lindberg, K., & Styhre, A. (2009). When the good times are over: Professionals encountering new technology. *Human Relations*, 62(8), 1145-1170. doi:10.1177/0018726709334879

Erlingsdóttir, G., & Lindholm, C. (2015). When patient empowerment encounters professional autonomy: The conflict and negotiation process of inscribing an eHealth service. *Scandinavian Journal of Public Administration* (2), 27.

Erlingsdottir, G., & Sandberg, H. (2016). eHealth for better for worse, in sickness and in health. In G. Erlingsdóttir, Sandberg, H. (Ed.), *eHealth Opportunities and Challenges* (pp. 4-8). Lund: Lund University.

Essén, A., Scandurra, I., Gerrits, R., Humphrey, G., Johansen, M. A., Kiergegaard, P., et al. (2017). Patient access to electronic health records: Differences across ten countries. *Health Policy and Technology* (7), 1.

Eysenbach, G. (2001). What is e-health? *Journal of Medical Internet Research*, 3(2), E20-E20. doi:10.2196/jmir.3.2.e20

Farrell, H. M. (2012). Transparency in psychiatric care. *Asian Journal of Psychiatry*, 5(3), 273-274. doi:10.1016/j.ajp.2012.07.011

Feilzer, M. Y. (2009). Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm. *Journal of Mixed Methods Research*, 4(1), 6-16. doi:10.1177/1558689809349691

Flyverbom, M. (2016). Digital Age| Transparency: Mediation and the Management of Visibilities. *International Journal Of Communication*, 10, 13.

Flyverbom, M., Leonardi, P. M., Stohl, C., & Stohl, M. (2016). The Management of Visibilities in the Digital Age. *International Journal of Communication*, 10, 98-109.

Fournier, V. (2000). Boundary work and the (un)making of the professions. In N. Malin (Ed.), *Professionalism, Boundaries and the Workplace* (pp. 67–86). London: Routledge.

Freidson, E. (2001). *Professionalism: the third logic*. Chicago: University of Chicago Press.

Gieryn, T. F. (1983). Boundary-Work and the Demarcation of Science from Non-Science: Strains and Interests in Professional Ideologies of Scientists. *American Sociological Review*, 48(6), 781-795. doi:10.2307/2095325

Gilson, L. L., & Goldberg, C. B. (2015). Editors' Comment: So, What Is a Conceptual Paper? *Group & Organization Management*, 40(2), 127–130.

Graneheim, U. H., Lindgren, B. M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, 56, 29-34. doi:10.1016/j.nedt.2017.06.002

Gravetter, F. J., & Wallnau, L. B. (2013). *Statistics for the behavioral sciences*. Australia: Wadsworth Cengage Learning.

Greenhalgh, T., Stones, R., & Swinglehurst, D. (2014). Choose and Book: A sociological analysis of 'resistance' to an expert system. *Social Science and Medicine*, 104, 210-219. doi:https://doi.org/10.1016/j.socscimed.2013.12.014

Grunloh, C., Cajander, A., & Myreteg, G. (2016). "The Record is Our Work Tool!"-Physicians' Framing of a Patient Portal in Sweden. *Journal of Medical Internet Research*, 18(6), e167. doi:10.2196/jmir.5705

Grunloh, C., Myreteg, G., Cajander, A., & Rexhepi, H. (2018). "Why Do They Need to Check Me?" Patient Participation Through eHealth and the Doctor-Patient Relationship: Qualitative Study. *Journal of Medical Internet Research*, 20(1), e11. doi:10.2196/jmir.8444

Grünloh, C. (2018). *Harmful or Empowering? : Stakeholders' Expectations and Experiences of Patient Accessible Electronic Health Records*: KTH Royal Institute of Technology.

Hagglund, M., & Scandurra, I. (2017a). Patients' Online Access to Electronic Health Records: Current Status and Experiences from the Implementation in Sweden. *Studies in Health Technology and Informatics*, 245, 723-727.

Hagglund, M., & Scandurra, I. (2017b). A Socio-Technical Analysis of Patient Accessible Electronic Health Records. *Studies in Health Technology and Informatics*, 244, 3-7.

Heald, D. (2006). Transparency as an Instrumental Value. In: Hood C, Heald D, editors. *Transparency: The Key to Better Governance*. Oxford: Oxford University Press.

Hewson, C., Vogel, C., & Laurent, D. (2016). *Internet Research Methods*. (2nd ed). London: Sage.

Hill, J. W., & Powell, P. (2009). The national healthcare crisis: Is eHealth a key solution? *Business Horizons*, 52(3), 265-277.

Hollmark, M., Lefevre Skjoldebrand, A., Andersson, C., & Lindblad, R. (2015). Technology Ready to be Launched, but is there a Payer? Challenges for Implementing eHealth in Sweden. *Studies in Health Technology and Informatics*, 211, 57-68.

Inera. (2019a). *About Inera*. Retrieved from https://www.inera.se/om-inera/about-inera/

Inera. (2019b). *Journalen*. Retrieved from https://www.inera.se/tjanster/journalen/Journalen/

Inera. (2019c). *Statistik om Journalen*. Retrieved from https://www.inera.se/aktuellt/statistik/journalen_statistik/

Jilka, S. R., Callahan, R., Sevdalis, N., Mayer, E. K., & Darzi, A. (2015). "Nothing About Me Without Me": An Interpretative Review of Patient Accessible Electronic Health Records. *Journal of Medical Internet Research*, 17(6), e161. doi:10.2196/jmir.4446

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed Methods Research: A Research Paradigm Whose Time Has Come. *Educational Researcher*, 33(7), 14-26. doi:10.3102/0013189X033007014

Kahn, M. W., Bell, S. K., Walker, J., & Delbanco, T. (2014). A piece of my mind. Let's show patients their mental health records. *JAMA: Journal of the American Medical Association*, 311(13), 1291-1292. doi:10.1001/jama.2014.1824

Kajbjer, K., Nordberg, R., & Klein, G. (2011). Electronic Health Records in Sweden: From Administrative Management to Clinical Decision Support. In L. P. Impagliazzo J., Wangler B. (Ed.), *History of Nordic Computing 3*. HiNC 2010. IFIP Advances in Information and Communication Technology (Vol. 350, pp. 74-82). Berlin: Springer.

King, G., O'Donnell, C., Boddy, D., Smith, F., Heaney, D., & Mair, F. S. (2012). Boundaries and e-health implementation in health and social care. *BMC Medical Informatics and Decision Making*, 12, 100-100. doi:10.1186/1472-6947-12-100

Klein, J. W., Jackson, S. L., Bell, S. K., Anselmo, M. K., Walker, J., Delbanco, T., & Elmore, J. G. (2016). Your Patient Is Now Reading Your Note: Opportunities, Problems, and Prospects. *American Journal of Medicine*, 129(10), 1018-1021. doi:10.1016/j.amjmed.2016.05.015

Klein, J. W., Peacock, S., Tsui, J. I., O'Neill, S. F., DesRoches, C. M., & Elmore, J. G. (2018). Perceptions of Primary Care Notes by Patients With Mental Health Diagnoses. *Annals of Family Medicine*, 16(4), 343-345. doi:10.1370/afm.2287

Lamont, M., & Molnár, V. (2002). The Study of Boundaries Across the Social Sciences. *Annual Review of Sociology*, 28, 167-195.

Lamont, M., Pendergrass, S., & Pachucki, M. C. (2015). Symbolic Boundaries. In W. James (Ed.), *International Encyclopedia of Social and Behavioral Sciences* (2 ed., pp. 850-855). Oxford: Elsevier.

Langley, A., Lindberg, K., Mork, B. E., Nicolini, D., Raviola, E., Walter, L. (2019). Boundary work among groups, occupations and organization: From Cartography to process. *Academy of Management Annals*, 13(2): 704–736.

Leonardi, P. (2009). Crossing the Implementation Line: The Mutual Constitution of Technology and Organizing Across Development and Use Activities. *Communication Theory*, 19(3), 278-310. doi:10.1111/j.1468-2885.2009.01344.x %J

Leonardi, P. (2010). Digital materiality? How artifacts without matter, matter. *First Monday*, 15(6).

Leonardi, P. (2011). When Flexible Routines Meet Flexible Technologies: Affordance, Constraint, and the Imbrication of Human and Material Agencies. *MIS Quarterly*, 35(1), 147–167.

Leonardi, P. (2012). Materiality, Sociomateriality, and Socio-Technical Systems: What Do These Terms Mean? How Are They Different? Do We Need Them? In: Leonardi P.M.,

Nardi B.A. and Kallinikos J. (eds). *Materiality and Organizing: Social Interaction in a Technological World*. Oxford Scholarship Online.

Leonardi, P. (2013). Theoretical foundations for the study of sociomateriality. *Information and Organization*., 23(2), 59–76.

Leonardi, P. (2015). Materializing Strategy: The Blurry Line between Strategy Formulation and Strategy Implementation. *British Journal of Management*, 26(S1), S17-S21. doi:10.1111/1467-8551.12077

Leonardi, P. (2017). Methodological Guidelines for the Study of Materiality and Affordances. In M. Raza & S. Jain (Eds.), *The Routledge Companion to Qualitative Research in Organization Studies*: Routledge Handbooks Online.

Leonardi, P., & Barley, S. (2008). Materiality and change: Challenges to building better theory about technology and organizing. *Information and Organization*, 18, 159–176.

Levay, C. (2016). Health Care Transparency in Organizational Perspective. In E. Ferlie, K. Montgomery & A. Reff Pedersen (eds). *The Oxford Handbook of Health Care Management*. Oxford University Press.

Leveille, S. G., Walker, J., Ralston, J. D., Ross, S. E., Elmore, J. G., & Delbanco, T. (2012). Evaluating the impact of patients' online access to doctors' visit notes: designing and executing the OpenNotes project. *BMC Medical Informatics and Decision Making*, 12, 32. doi:10.1186/1472-6947-12-32

Liljegren, A. (2008). *Professionellt gränsarbete : socionomexemplet*. Göteborgs universitet, Göteborg.

Lindberg, K., Styhre, A., & Walter, L. (2012). *Assembling health care organizations. Practice, materiality and institutions*. Basingstoke: Palgrave Macmillan.

Lindberg, K., Walter, L., & Raviola, E. (2017). Performing boundary work: The emergence of a new practice in a hybrid operating room. *Social Science and Medicine*, 182, 81-88. doi:https://doi.org/10.1016/j.socscimed.2017.04.021

Liu, S. (2017). Boundaries and professions: Toward a processual theory of action. *Journal of Professions and Organization*, 5(1), 45-57. doi:10.1093/jpo/jox012 %J Journal of Professions and Organization

Lupton, D. (2018). *Digital Health. Critical and Cross-Disciplinary Perspectives*. New York: Routledge.

Läkartidningen. (2015). *Nätjournalerna öppnas för psykiatrins patienter i Skåne*. Retrieved from http://www.lakartidningen.se/Aktuellt/Nyheter/2015/03/Skane-gor-natjournalerna-tillgangliga-for-psykiatrins-patienter/

Mair, F., May, C., O'Donnell, C., Finch, T., Sullivan, F., & Murray, E. (2012). Factors that promote or inhibit the implementation of e-health systems: an explanatory systematic review. *Bulletin of the World Health Organization*, 90(5), 357-364. doi:10.2471/BLT.11.099424

McNutt, J., Justice, J., Melitski, J., Ahn, M., R. Siddiqui, S., T. Carter, D., & D. Kline, A. (2016). The diffusion of civic technology and open government in the United States. *Information Polity*, 21, 153-170. doi:10.3233/IP-160385

Mellgren, F. (2013). *Nätjournal kan vara farligt*. Retrieved from http://www.svd.se/nyheter/inrikes/natjournal-kan-vara-farlig_8461500.svd

Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: a methods sourcebook*. Los Angeles: Sage.

Moll, J., & Cajander, A. (2019). Oncology health-care professionals' perceived effects of patient accessible electronic health records 6 years after launch: A survey study at a major university hospital in Sweden. *Health Informatics J*, 1460458219881007. doi:10.1177/1460458219881007

Moll, J., Rexhepi, H., Cajander, A., Grunloh, C., Huvila, I., Hagglund, M., . . . Ahlfeldt, R. M. (2018). Patients' Experiences of Accessing Their Electronic Health Records: National Patient Survey in Sweden. *Journal of Medical Internet Research*, 20(11), e278. doi:10.2196/jmir.9492

Morgan, D. L. (2014). Pragmatism as a Paradigm for Social Research. *Qualitative Inquiry*, 20(8), 1045-1053. doi:10.1177/1077800413513733

Morley, J., & Floridi, L. (2019a). Enabling digital health companionship is better than empowerment. *The Lancet Digital Health*, 1(4), e155-e156. doi:10.1016/S2589-7500(19)30079-2

Morley, J., & Floridi, L. (2019b). The Limits of Empowerment: How to Reframe the Role of mHealth Tools in the Healthcare Ecosystem. *Science and Engineering Ethics*. doi:10.1007/s11948-019-00115-1

Nielsen, K. D., & Langstrup, H. (2018). Tactics of material participation: How patients shape their engagement through e-health. *Soc Stud Sci*, 48(2), 259-282. doi:10.1177/0306312718769156

Nilsson, L. (2014). *Social Challenges when Implementing Information Systems in a Swedish Healthcare Organization*. (Doctoral thesis, comprehensive summary), Blekinge Tekniska Högskola, Karlskrona. Retrieved from http://urn.kb.se/resolve?urn=urn:nbn:se:bth-00602 DiVA database. (14)

Nøhr, C., Parv, L., Kink, P., Cummings, E., Almond, H., Nørgaard, J. R., & Turner, P. (2017). Nationwide citizen access to their health data: analysing and comparing experiences in Denmark, Estonia and Australia. *BMC Health Services Research*, 17(1), 534-534. doi:10.1186/s12913-017-2482-y

O'Cathain, A., Murphy, E., & Nicholl, J. (2010). Three techniques for integrating data in mixed methods studies. *BMJ*, 341, c4587. doi:10.1136/bmj.c4587

O'Cathain, A., & Thomas, K. J. (2004). "Any other comments?" Open questions on questionnaires - a bane or a bonus to research? *BMC Medical Research Methodology*, 4, 25. doi:10.1186/1471-2288-4-25

Oh, H., Rizo, C., Enkin, M., & Jadad, A. (2005). What Is eHealth (3): A Systematic Review of Published Definitions. *Journal of Medical Internet Research*, 7(1), e1. doi:10.2196/jmir.7.1.e1

OpenNotes. (2019). Our History: Fifty Years In the Making. Retrieved from https://www.opennotes.org/history/

Palen, T. E., Ross, C., Powers, J. D., & Xu, S. (2012). Association of online patient access to clinicians and medical records with use of clinical services. *JAMA*, 308(19), 2012-2019. doi:10.1001/jama.2012.14126

Parsons, T. (1939). The Professions and Social Structure. *Social Forces*, 17(4), 457–467.

Parsons, T. (1974). Profession. In D. Sills (Ed.), *International Encyclopedia of the Social Sciences* (pp. 536–547). New York: Macmillan.

Peck, P., Torous, J., Shanahan, M., Fossa, A., & Greenberg, W. (2017). Patient access to electronic psychiatric records: A pilot study. *Health Policy and Technology*, 6(3), 309-315. doi:https://doi.org/10.1016/j.hlpt.2017.06.003

Petersson, J. (2014). *Geographies of eHealth: Studies of Healthcare at a Distance*. (Diss.), Göteborgs Universitet, Göteborg.

Pisciotta, M., Denneson, L. M., Williams, H. B., Woods, S., Tuepker, A., & Dobscha, S. K. (2019). Providing mental health care in the context of online mental health notes: advice from patients and mental health clinicians. *J Ment Health*, 28(1), 64-70. doi:10.1080/09638237.2018.1521924

Region Skåne (2019). *Journalen via nätet*. Retrieved from https://vardgivare.skane.se/patientadministration/journalhantering-och-registrering/journalhantering/journalen-natet/

Rennstam, J. & Wästerfors, D. (2015). *Från stoff till studie. Om analysarbete i kvalitativ forskning.* Lund: Studentlitteratur.

Reumatikerförbundet. (2013). *Nätjournaler är ett demokratiskt verktyg*. Retrieved from https://reumatikerforbundet.org/press-1/debattartiklar/natjournaler-ar-ett-demokratiskt-verktyg/

Rexhepi, H., Åhlfeldt, R.-M., Cajander, Å., & Huvila, I. (2016). Cancer patients' attitudes and experiences of online access to their electronic medical records: A qualitative study. *Health Informatics Journal*, 24(2), 115-124. doi:10.1177/1460458216658778

Rich, J. L., Chojenta, C., & Loxton, D. (2013). Quality, rigour and usefulness of free-text comments collected by a large population based longitudinal study - *ALSWH. PloS One*, 8(7), e68832-e68832. doi:10.1371/journal.pone.0068832

Risling, T., Martinez, J., Young, J., & Thorp-Froslie, N. (2017). Evaluating Patient Empowerment in Association With eHealth Technology: Scoping Review. *Journal of Medical Internet Research*, 19(9), e329. doi:10.2196/jmir.7809

Ross, J., Stevenson, F., Lau, R., & Murray, E. (2016). Factors that influence the implementation of e-health: a systematic review of systematic reviews (an update). *Implementation science: IS*, 11(1), 146. doi:10.1186/s13012-016-0510-7

Roth, L. H., Wolford, J., & Meisel, A. (1980). Patient access to records: tonic or toxin*? American Journal of Psychiatry*, 137(5), 592-596. doi:10.1176/ajp.137.5.592

Scandurra, I., Jansson, A., Forsberg-Fransson, M.-L., & Ålander, T. (2017). Patient Accessible EHR is Controversial: Lack of Knowledge and Diverse Perceptions Among Professions. *Int. J. Reliab. Qual. E-Healthc.*, 6(1), 29-45. doi:10.4018/ijrqeh.2017010103

Scandurra, I., Jansson, A., Forsberg-Fransson, M.-L., & Ålander, T. (2015). Is 'Patient's Online Access to Health Records' a Good Reform? – Opinions from Swedish Healthcare Professionals Differ. *Procedia Computer Science*, 64, 964-968. doi:https://doi.org/10.1016/j.procs.2015.08.614

Scandurra, I., Lyttkens, L., & Eklund, B. (2016). Implications of Swedish National Regulatory Framework of the Patient Accessible Electronic Health Record. *Studies in Health Technology and Informatics*, 228, 695-699.

Scandurra, I., Pettersson, M., Eklund, B., & Lyttkens, L. (2017). Analysis of the Updated Swedish Regulatory Framework of the Patient Accessible Electronic Health Record in Relation to Usage Experience. *Studies in Health Technology and Informatics*, 245, 798-802.

Schulz, P. J., & Nakamoto, K. (2013). Health literacy and patient empowerment in health communication: the importance of separating conjoined twins. *Patient Education and Counseling*, 90(1), 4-11. doi:10.1016/j.pec.2012.09.006

Seale, C. (2012). Sampling. In C. Seale (Ed.) *Researching society and culture* (pp. 134-152). London: SAGE.

Shah, S. G. S., Fitton, R., Hannan, A., Fisher, B., Young, T., & Barnett, J. (2015). Accessing personal medical records online: A means to what ends? International *Journal of Medical Informatics*, 84(2), 111-118. doi:https://doi.org/10.1016/j.ijmedinf.2014.10.005

Shenkin, B. N., & Warner, D. C. (1973). Sounding board. Giving the patient his medical record: a proposal to improve the system. *New England Journal of Medicine*, 289(13), 688-692. doi:10.1056/NEJM197309272891311

Silverman, D. (2011). *Interpreting Qualitative Data*. London: SAGE.

Singer, E., & Couper, M. (2017). Some Methodological Uses of Responses to Open Questions and Other Verbatim Comments in Quantitative Surveys. *Methoden, Daten, Analysen*, Vol 11, Iss 02, Pp 115-135 (2017)(02), 115. doi:10.12758/mda.2017.01

SKL. (2014). *Invånartjänster*. http://skl.se/halsasjukvard/ehalsa/invanartjanster.1741.html

SKL. (2015). *Ny patientlag 2015 ska stärka patientens ställning*. http://skl.se/halsasjukvard/patientinflytande/patientlagen.2083.html

SKL. (2016). *Vision for eHealth 2025 www.ehalsa2025.se* Retrieved from https://ehalsa2025.se/wp-content/uploads/2017/10/vision-for-ehealth-2025.pdf

SKL. (2019). *Swedish Association of Local Authorities and Regions*. Retrieved from https://skl.se/tjanster/englishpages.411.html

Socialdepartementet. (2010). *National eHealth – the strategy for accessible and secure information in health and social care*. Retrieved from https://www.regeringen.se/contentassets/632b4d05795549bc98a45cc5321db1c8/national-ehealth---the-strategy-for-accessible-and-secure-information-in-health-and-social-care-s2011.023

Socialdepartementet. (2014). *Rätt information på rätt plats i rätt tid.* www.regeringen.se Retrieved from https://www.regeringen.se/49bbb9/contentassets/909ca5e5ee2a48609b25824e228d6486/ratt-information-pa-ratt-plats-i-ratt-tid-sou-201423-del-1-hela

Stohl, C., Stohl, M., & Leonardi, P. M. (2016). Managing Opacity: Information Visibility and the Paradox of Transparency in the Digital Age. *International Journal of Communication*, 10, 123-137.

Swedish Research Council (2017). *Good Research Practice*. Retrieved from https://www.vr.se/download/18.5639980c162791bbfe697882/1555334908942/Good-Research-Practice_VR_2017.pdf

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: integrating quantitative and qualitative approaches in the social and behavioral sciences*. Los Angeles, Calif.: SAGE.

Walker, J., Darer, J. D., Elmore, J. G., & Delbanco, T. (2014). The road toward fully transparent medical records. *New England Journal of Medicine*, 370(1), 6-8. doi:10.1056/NEJMp1310132

Walker, J., & Delbanco, T. (2013). Interval examination: moving toward open notes. *Journal of General Internal Medicine*, 28(7), 965-969. doi:10.1007/s11606-013-2407-3

Walker, J., Leveille, S., Bell, S., Chimowitz, H., Dong, Z., Elmore, J. G. et al. (2019). OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians' Outpatient Visit Notes. *Journal of Medical Internet Research*, 21(5), e13876. doi:10.2196/13876

Walker, J., Leveille, S. G., Ngo, L., Vodicka, E., Darer, J. D., Dhanireddy, S. et al. (2011). Inviting patients to read their doctors' notes: patients and doctors look ahead: patient and physician surveys. *Annals of Internal Medicine*, 155(12), 811-819. doi:10.7326/0003-4819-155-12-201112200-00003

Walker, J., Meltsner, M., & Delbanco, T. (2015). US experience with doctors and patients sharing clinical notes. *BMJ*, 350, g7785. doi:10.1136/bmj.g7785

Wass, S. (2017). *The importance of eHealth innovations : Lessons about patient accessible information.* (Doctoral thesis, comprehensive summary), Jönköping University, Jönköping International Business School, Jönköping.

Wass, S., & Vimarlund, V. (2018). The Role of PAEHRs in Patient Involvement. *Journal of Medical Systems*, 42(11), 210. doi:10.1007/s10916-018-1070-y

Werbrouck, A., Swinnen, E., Kerckhofs, E., Buyl, R., Beckwee, D., & De Wit, L. (2018). How to empower patients? A systematic review and meta-analysis. *Translational Behavioral Medicine*, 8(5), 660-674. doi:10.1093/tbm/iby064

WHO. (2016). *Global diffusion of eHealth: Making universal health coverage achievable. Report of the third global survey on eHealth.* Retrieved from https://www.who.int/goe/publications/global_diffusion/en/

Åkerstedt, U. S., Cajander, Å., Moll, J., & Ålander, T. (2018). On threats and violence for staff and patient accessible electronic health records. *Cogent Psychology*, 5(1), 1-11. doi:10.1080/23311908.2018.1518967

Printed by Media-Tryck, Lund 2020 NORDIC SWAN ECOLABEL 3041 0903

Ergonomics and Aerosol Technology
Department of Design Sciences
Faculty of Engineering, Lund University

ISSN 1650-9773, Publication 65
ISBN 978-91-7895-410-0