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## HEALTH DATA AS AN ENABLER OF DIGITAL TRANSFORMATION

A SINGLE HOLISTIC CASE STUDY OF CONNECTED INSURANCE

UNIVERSITY OF OULU GRADUATE SCHOOL; UNIVERSITY OF OULU, FACULTY OF INFORMATION TECHNOLOGY AND ELECTRICAL ENGINEERING



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## HEALTH DATA AS AN ENABLER OF DIGITAL TRANSFORMATION

A single holistic case study of connected insurance

Academic dissertation to be presented with the assent of the Doctoral Training Committee of Information Technology and Electrical Engineering of the University of Oulu for public defence in the OP auditorium (L10), Linnanmaa, on 8 May 2020, at 12 noon

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#### Abstract

The use of digital technologies is driving the mass creation and collection of health data, fuelling disruptions in the healthcare ecosystem, and shifting the competitive landscape of health service provision. In response to this paradigm shift, the insurance industry is exploring new avenues of value creation as part of the digital health economy. Connected insurance has emerged as a strategy to leverage digitalization efforts for preventative and proactive health services. As insurance organizations strive towards implementing novel data-driven services, they are grappling with organizational and legislative challenges surrounding four necessary health data factors: *access*, *control*, *sharing*, and *use*.

The research followed a qualitative methodological approach that was conducted in two phases as part of a single holistic case study of a transforming Finnish insurance organization. In the first phase, five empirical studies have been conducted which ascertain four case study boundaries: the health data environment in the Nordic countries, governance within the EU, insurance organizations as processors and controllers of health data, and customers as data subjects. In the second phase, a theory-driven narration of digital transformation in the insurance organization has been developed. The narration is a synthesis of data collected from interviews, ethnography, and a survey. The four health data factors - access, control, sharing, and use - were thematically analyzed and content-driven themes were empirically crafted to produce an inductive framework of health data mechanisms.

The resulting framework of eleven health data mechanisms provides tactics for the design and development of proactive digital health services, stressing the importance of *culture*, *interoperability*, and *transparency* for service provision. How health data can be utilized as a resource for value creation requires key strategic decision-making practices by policymakers, organizations, and management and is informed by the conditions inherent in the boundaries of health data. Theoretical contributions indicate the capacity of health data as part of digital transformation. More holistic research is required to expand the mechanisms of health data which support fair, equal, and open value creation among stakeholders in the digital health economy.

*Keywords:* connected insurance, digital transformation, health data, health data framework, health informatics, information systems, insurance, mechanisms, proactive digital health services, qualitative research, single holistic case study

## Grundstrom, Casandra, Terveysdata digitaalisen transformaation mahdollistajana. Yhden tapauksen kokonaisvaltainen tapaustutkimus digitaalisesta vakuutuspalvelusta

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#### Tiivistelmä

Digitaalisilla teknologioilla voidaan tuottaa ja kerätä terveysdataa, mikä vauhdittaa terveydenhuollon ekosysteemin murrosta ja muuttaa terveydenhuollon palveluiden kilpailuasetelmaa. Paradigman muutoksen ansiosta vakuutussektori etsii tapoja luoda lisäarvoa osana digitaalisten terveyspalvelujen markkinoita. Digitaalinen vakuutuspalvelu on uusi strategia, ja se hyödyntää digitalisaatiota ennaltaehkäisevissä ja ennakoivissa terveyspalveluissa. Ottaessaan käyttöön uusia dataan perustuvia palveluja vakuutusyhtiöt kohtaavat organisatorisia ja lainsäädännöllisiä haasteita. Nämä liittyvät neljään terveysdatan elementtiin: *saavutettavuus, hallinta, jakaminen* ja *käyttö*.

Tutkimuksen metodologiseksi lähtökohdaksi valittiin kvalitatiivinen lähestymistapa ja se tehtiin kahdessa vaiheessa osana yhden tapauksen kokonaisvaltaista tapaustutkimusta, jossa tarkasteltiin muuttuvaa suomalaista vakuutusorganisaatiota. Ensimmäisessä vaiheessa toteutettiin viisi empiiristä tutkimusta, joiden perusteella määritettiin neljä tapaustutkimuksessa tarkasteltavaa osa-aluetta: pohjoismainen terveysdataympäristö, EU-ohjaus, vakuutusorganisaatiot terveysdatan käsittelijöinä ja hallinnoijina ja asiakkaat rekisteröityinä henkilöinä. Toisessa vaiheessa kehitettiin teoriapohjainen kertomus digitaalisesta transformaatiosta vakuutusyhtiössä. Kertomus yhdistelee haastattelujen, etnografisten menetelmien ja kyselyiden avulla kerättyjä tutkimusaineistoja. Neljä terveysdatan elementtiä – saavutettavuus, hallinta, jakaminen ja käyttö – analysoitiin temaattisesti ja niistä laadittiin empiirisesti sisältölähtöiset teemat. Näin luotiin terveysdatan mekanismeja kuvaava induktiivinen malli.

Syntynyt malli käsittää yksitoista terveysdatan mekanismia ja tarjoaa keinoja ennakoivien digitaalisten terveyspalvelujen suunnitteluun ja kehittämiseen painottaen *kulttuuria*, *yhteensopivuutta* ja *läpinäkyvyyttä* palvelujen tarjoamisessa. Terveysdatan hyödyntäminen lisäarvon tuottamiseksi vaatii strategisen päätöksenteon avainkäytäntöjä päättäjiltä, organisaatioilta ja johdolta. Siihen vaikuttavat myös terveysdatan osa-alueiden reunaehdot. Teoreettiset tulokset osoittavat terveysdatan potentiaalin osana digitaalista transformaatiota. Kokonaisvaltaista tutkimusta tarvitaan laajentamaan terveysdatan mekanismeja, jotka tukevat reilua, tasa-arvoista ja avointa tapaa luoda lisäarvoa eri osapuolille digitaalisten terveyspalvelujen markkinoilla.

Asiasanat: digitaalinen transformaatio, digitaalinen vakuutuspalvelu, ennakoivat digitaaliset terveyspalvelut, kokonaisvaltainen tapaustutkimus, kvalitatiivinen tutkimus, mekanismit, terveysdata, terveysdatamalli, terveysinformatiikka, tietojärjestelmät, vakuutus



## Acknowledgements

I have seen and heard conflicting reports about the acknowledgements section of a dissertation. Some have told it is the only part of a Ph.D. that people read (unless they *have* to read the rest), while others suggest it is merely glossed over or ignored completely. This situates me in kind of a writer's paradox, the Schrödinger's cat of acknowledgements if you will, but without the radioactive part. So, I invite you to consider below my musings, reflections, and appreciations to those who have knowingly (or possibly unbeknownst to them), shaped my Ph.D. journey. No hard feelings if you decide to skip ahead though.

With my work visa all sorted, tickets booked, and two suitcases which I had been living out of, I boarded my first of many flights from Vancouver, Canada on my way to Oulu. It was rather a leap of faith to blindly move to a new country for work, but it is one I am so grateful to have jumped at. My new supervisor picked me up in my haggard traveller's state from the airport and gave me a tour (albeit brief) of Oulu city center. If you live here in Oulu, you know February is not the best month for making first impressions.

Regardless, I settled into the new circumstances quite quickly. As you might expect when starting a position, the first few days at the University at Oulu were somewhat of a whirlwind. The third day required a trip to Helsinki to meet a dozen or so board members of an insurance organization to discuss what I planned to do as part of my research. Despite being somewhat underdressed for the formal board setting, my suggestions for research were eagerly received and I clumsily and quite accidentally found my way into an academic role. The madness of the first week of work was only a precursor of what was to come. As anyone who has been through this process knows, the work is compounding, and you just seem to get busier and busier.

The first few months of the Ph.D. flew by. Quite by chance, I received some rather unexpected and slightly confusing advice which has nevertheless stuck with me throughout. *Professor Kari Kuutti* shared with me a secret to research which was to "find my people". At the time, I wasn't sure exactly what he meant. Weren't *my* people those in the INTERACT unit? A short time later however, I became a part of the MyData community, and I was enlightened—I had found my people. MyData represents everything I was working for in the Ph.D., creating and advocating for a human-centric data economy where value derived from personal data should be for mutual benefit and never compromise the privacy of an individual. In these uncertain times, this holds true now more so than ever. I'm very

grateful for the warm welcome I received from the community and look forward to taking part in the many positive effects in MyData's future.

Many people played an important role in my Ph.D. but perhaps none so significant as my supervisors. Therefore, it should come as no shock that I would first and foremost like to express my sincerest gratitude to my two supervisors. There are many kind things expressed in other acknowledgements (all of which are true) about my primary supervisor *Professor Minna Isomursu*. Your unwavering support, guidance, and friendship over these past few years has been invaluable. I am also grateful to my secondary supervisor *Dr. Karin Väyrynen*. Thank you for your practical advice, hands on approach, and reassurances that my stressful experiences were not outside of the norm. You might have heard the idiom 'you can't choose your family, but you can choose your friends.' The same is true of supervisors. While this was not something that I had the foresight to consider, I feel very lucky to have fortuitously come into the care and supervision of both Minna and Karin.

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February 25th, 2019

Casandra Grundstrom

<sup>&</sup>quot;Why are there so many barriers for getting access to my own data? No one really sees the problems involved with getting access to your own data until you are in the hot seat." Steven Keating Ph.D.

## Glossary of abbreviations and acronyms

**CHESS** Connected Health Early-stage researcher Support System

COST Cooperation in Science and Technology CRM Customer Relationship Management

DPO **Data Protection Officer** 

exempli gratia e.g. Electronic Health eHealth

**EHRs** Electronic Health Records

**ENJECT** European Network for the Joint Evaluation of Connected health

Technology

etc. et cetera

EU European Union

General Data Protection Regulation **GDPR** HIT Health Information Technology Insurance Distribution Directive IDD

IS Information Systems IT Information Technology IoT

Internet of Things

ITN **Initial Training Network** 

Mobile Health mHealth

**PAEHRs** Patient Accessible Electronic Health Records

**PROs** Patient Reported Outcomes **OES** Qualitative Evidence Synthesis

Quality of Life QoL

SET Social Exchange Theory

**VPHI** Voluntary Private Health Insurance

## **Original publications**

This thesis is based on the following publications, which are referred throughout the text by their Roman numerals:

- I Grundstrom, C., Väyrynen, K., & Isomursu, M. (2018). Dimensions of Accessibility and Interoperability for Electronic Health Records in the Nordic Countries: A Qualitative Evidence Synthesis of Facilitators and Barriers. In Proceedings of the 22nd Pacific Asia Conference on Information Systems (PACIS), 287.
- II Grundstrom, C., & Karampela, M. (2018). A Transforming Insurance Company and the 4 Types of Health Data Challenges that Arise. In *PervasiveHealth'18* (pp. 310–317). https://doi.org/10.1145/3240925.3240950
- III Grundstrom, C., Väyrynen, K., Persson, M., & Isomursu, M. (2018). Health Data Access Barriers in a Finnish Insurance Company: A Case Study. In *Proceedings of the* 27th International Conference on Information Systems Development (ISD2018 Lund, Sweden). https://aisel.aisnet.org/cgi/viewcontent.cgi?article=1198&context=isd2014
- IV Grundstrom, C., Väyrynen, K., Iivari, N., & Isomursu, M. (2019). Making Sense of the General Data Protection Regulation—Four Categories of Personal Data Access Challenges. In *Proceedings of the 52nd Hawaii International Conference on System Sciences (HICSS)*. https://doi.org/10.24251/hicss.2019.605
- V Grundstrom, C., Korhonen, O., Väyrynen, K., & Isomursu, M. (2020). Insurance Customers' Expectations for Sharing Health Data: Qualitative Survey Study. *JMIR Medical Informatics* 8(3):e16102. https://doi.org/10.2196/16102

As the main author of all publications in this doctoral dissertation, I was responsible for the study design, data collection, data analysis, article writing, publication, and overall management of each article.

## **Contents**

A١	ostra	ct		
Ti	iviste	elmä		
A	knov	wledge	ements	9
$\mathbf{G}$	lossai	ry of a	bbreviations and acronyms	13
O	rigina	al pub	lications	15
C	onten	ts		17
1	Intr	oducti	ion	19
	1.1	Backg	groundground	. 19
	1.2	Objec	etive and research questions	. 22
	1.3	Struct	ture of the thesis	. 26
2	Rela	ated re	esearch	27
	2.1	The d	ligitalization of insurance	. 27
		2.1.1	A brief history of insurance	. 28
		2.1.2	The traditional insurance organization	. 28
		2.1.3	Digital transformation	. 29
		2.1.4	Connected insurance.	. 32
		2.1.5	Proactive health services	. 33
	2.2	Healtl	h data	. 34
		2.2.1	Health data access	. 36
		2.2.2	Health data control	. 38
			Health data sharing	
		2.2.4	Health data use	. 42
3	Res	earch :	approach and methodology	45
	3.1	Resea	rch domain	. 45
	3.2	Case	study	. 46
		3.2.1	Single holistic case study	. 46
			Selection of case study research site	
	3.3		arch method for data collection of articles	
		3.3.1	Case study data collection	. 50
		3.3.2	Health data environment	. 53
		3.3.3	Data governance	. 56
			Health data processors and controllers	
		3.3.5	Health data subjects	. 59
	3.4	Data a	analysis of articles	. 60
		3.4.1	Research methods for data analysis	. 60
		3.4.2	Health data environment.	. 60

		3.4.3	Health data governance	61
		3.4.4	Health data processors and controllers	61
			Health data subjects	
	3.5		e holistic case study overview	
	3.6	Comp	oosing the single holistic case study findings	66
		3.6.1	Theory-driven digital transformation narration	66
		3.6.2	Content-driven health data mechanisms	68
		3.6.3	Presenting the case study findings	69
	3.7	Ethica	al considerations	71
		3.7.1	Informed consent and ethical declaration	71
		3.7.2	Personal data processing	72
		3.7.3	Research funding	73
4	Fin	dings		75
	4.1	Backg	ground about Omega and the role of health data	75
	4.2	Digita	al transformation momentum	78
		4.2.1	Use of digital technologies	79
		4.2.2	Digital technologies fuelling disruptions	84
		4.2.3	Triggering a strategic response	90
	4.3	Digita	al transformation	93
		4.3.1	Enabling changes in value creation paths	94
		4.3.2	Structural changes affecting the value creation paths	99
		4.3.3	Organizational barriers affecting value creation paths .	108
		4.3.4	Generating negative impacts	113
		4.3.5	Generating positive impacts	115
	4.4	A fran	nework of health data mechanisms	120
5	Disc	cussior	1	125
	5.1	Overv	view of contribution	125
	5.2	Healt	h data in digital transformation	126
	5.3	Healt	h data mechanisms for proactive health services	129
	5.4	Validi	ity and research limitations	134
		5.4.1	Validity	134
		5.4.2	Reliability	136
		5.4.3	Research limitations	136
6	Cor	ıclusio	ns	139
Li	st of	refere	nces	141
Aj	ppen	dices		157
O	rigin	al nuh	lications	169

## 1 Introduction

## 1.1 Background

Across the contemporary frontiers of healthcare, a variety of relevant stakeholders require access to health data for various purposes. Healthcare professionals access the health data of patients through electronic health records (EHRs) for decision-making purposes, whereas individuals use data-driven applications for the self-management of health and wellness. Health data are generated through a myriad of novel technological artifacts: smartphones, tablets, computers, wearable fitness devices, etc. The increasing use of digital technology is generating an abundance of health data, prompting changes in how health-oriented organizations are empowered in their provision of healthcare through the development of data driven digital health services. This phenomenon, colloquially understood as "digital transformation" in academia, is "... a process that aims to improve an entity by triggering significant changes to its properties through combinations of information, computing, communication, and connectivity technologies" (Vial, 2019, p. 118).

The digital transformation of healthcare is a globally emergent process that is slated to decrease costs, help prevent chronic diseases, and empower patients (Agarwal, Gao, DesRoches, Jha, & Press, 2010). In the healthcare industry, leveraging health data is useful for realizing a myriad of different benefits for various stakeholders, such as public health research, big data analytics, and preventative interventions for chronic conditions (Raghupathi & Raghupathi, 2014). Similarly, the insurance industry is motivated to leverage data-driven proactive healthcare to improve the factors of workers' compensation programs, provide preventative interventions, and assist customers with their health and wellness (Hüppe et al., 2017; Pikkarainen, Pekkarinen, Koivumaki, & Huhtala, 2018).

In Finland, voluntary private health insurance (VPHI) has seen a recent upswing, from 15% coverage of the population in 2009 to 21% coverage of the population in 2016 (Tynkkynen et al., 2018). Insurance customers are leveraging VPHI for increased access to specialized services, for decreased waiting times, and in the interest of peace of mind (Anderson & Agarwal, 2011; Tynkkynen, Chydenius, Saloranta, & Keskimäki, 2016). However, as Finland is traversing its second healthcare reform, the boundaries between public and private healthcare services are becoming increasingly blurred (Saltman & Teperi, 2016). Reform plans were in place early in 2019; however, a new left-centre government change

waylaid the existing proposal. As a result, an increased pressure is placed on the insurance industry to change their business models to meet new and emergent demands, such as proactive digital health services (Persson, Grundstrom, & Väyrynen, 2018). The lack of digital transformation research in the insurance industry is surprising, considering the social and economic influence embodied in the ecosystem: a lack that may result in neglecting important ethical conversations (Eling & Lehmann, 2017; Vial, 2019).

A strategic means to embrace the shift toward data-driven healthcare services is through leveraging the concept of connected health. Connected health aims to empower stakeholders with the means to leverage their health data for different uses at the right time through data-driven digital health services and platforms (Caulfield & Donnelly, 2013). As part of the mimetic force of connected health, connected insurance has emerged as a term to describe "an evolution of the insurance business model based on the adoption of the Internet of Things (IoT) technologies which allow the direct connection between all actors of the ecosystem: customers, insurers, and players from other industries" (Silvello & Procaccini, 2019, p. 2). This term has, however, not been readily adopted in academic circles despite its descriptions in theory (Eling & Lehmann, 2017) or industry studies (Bieck & Tjioe, 2015).

Historically, insurance companies have battled a negative stigma, hindering their entrance into the healthcare industry, despite their interest in new competitive markets (Eling & Lehmann, 2017). This stigma preserves the negative perceptions of insurance organizations owing to concerns of trust, ultimately affecting how these companies can access and use health data, even for the benefit of the customer (Grundstrom, Väyrynen, Persson, & Isomursu, 2018; Martinez-Hume et al., 2017; Moon, 2017). Further evidence of distrust toward the insurance industry is evident in the unwillingness of individuals to share health data for fears of health profiling being used to increase insurance costs or deny coverage (Caine & Hanania, 2013; Patil, Lu, Saunders, Potoglou, & Robinson, 2016; Soni et al., 2019; Weitzman, Kaci, & Mandl, 2010; Weitzman, Kelemen, Kaci, & Mandl, 2012; Whiddett, Hunter, Engelbrecht, & Handy, 2006). A common complaint when sharing health data is the lack of granular control that individuals possess to make privacy decisions and ensure their ability to dictate who has access to their sensitive health information (Caine & Hanania, 2013; Wetzels et al., 2018). Despite the role of individuals and patients in creating health data and consuming health-related products and services, "... they do not yet have the power to act as drivers for accessing and exchanging their own health information" (Kouroubali & Katehakis, 2019, p. 2).

Leveraging health information technology (HIT) is one approach for advancing the power of individuals in the healthcare ecosystems, while still ensuring the privacy and security of their health data (Anderson & Agarwal, 2011). HIT is also valuable for improving the quality of health services and reducing costs (Agarwal et al., 2010). The efficacy of HIT is evident in the design and development of patient-accessible electronic health records (PAEHR), underlining the empowered factors of individuals with access and control of their health data (Moll et al., 2018), while facilitating the medical exchange of health records for sharing and use (Patil et al., 2016). One of the major barriers for HIT adoption is regulation because policy makers shape the governance of healthcare (Agarwal et al., 2010). Sensitive information related to personal and health data is contemporarily regulated in the pan-European region through the General Data Protection Regulation (GDPR). All processors and controllers of health data are, as an inextricable part of their organization, required to be compliant with the regulation, with heavy penalties for non-compliance (Marelli & Testa, 2018). Insurance organizations fall within the processor and controller category because their core business activities relate to storing and processing health data.

Compliance to the GDPR is a heavy burden for practices of governance because any data that can identify a natural person as a data subject were bestowed with elevated rights through this legislation (De Hert, Papakonstantinou, Malgieri, Beslay, & Sanchez, 2018). The GDPR governs the empowerment of data subjects through emergent factors of access, control, sharing, and use of health data. These factors are evident in the requirements for processors and controllers of health data: enabling data subjects to access their data, exert control over the content of their data, share health data through portable and interoperable channels, and ensure transparency regarding the use of their health data through informed consent (European Commission, 2016; Grundstrom, Väyrynen, Iivari, & Isomursu, 2019; Lindqvist, 2018; Marelli & Testa, 2018; O'Connor, Rowan, Lynch, & Heavin, 2017; Tikkinen-Piri, Rohunen, & Markkula, 2018).

Aligning with the need for enhancing the role of individuals in healthcare environments and motivated by the considerations of governance, are data subjects whose agency over their health data is dependent on the support of mechanisms (Rappaport, 1987). Mechanisms can be leveraged to bring about change when considered in configuration with the increased availability of health data and the entangled organizational contexts (Dalkin, Greenhalgh, Jones, Cunningham, & Lhussier, 2015; Pawson & Tilley, 1997). However, the particular mechanisms affecting the necessary factors of access, control, sharing, and use of health data

are not adequately described in contemporary academia. For example, conditions that facilitate sharing health data in the public sector, such as the current infrastructure intended to support health information exchange through HIT, are not contextually transferrable to the private insurance industry (Anderson & Agarwal, 2011).

The opacity of a mechanism aligns with the realist interpretation of causation: hidden entities that are influenced by various contexts and are the driving force generating desired factors (Astbury & Leeuw, 2010; Pawson & Tilley, 1997). Using mechanisms to explain how a particular phenomenon can occur captures the required conditions, which in turn will bring about the desired outcome (Dalkin et al., 2015). If the mechanisms informing health data factors can be empirically described, the need to understand the under-researched implications of desirable health data factors on the digital transformation of health insurance becomes evident (Grundstrom, Väyrynen, & Isomursu, 2018). Therefore, ratifying and contextualizing the mechanisms of health data is of considerable importance for insurance organizations; as it informs their ability to enact digital transformation strategies, empower their customers, align with legislative compliance, and develop mutually beneficial digital health services.

## 1.2 Objective and research questions

The objective of this dissertation is to advance the understanding of health data as part of the digital transformation of connected insurance. The dissertation further explores what mechanisms support the desired health data factors of access, control, sharing, and use.

In this thesis, I ascribe to Astbury and Leeuw's (2010) realist definition of mechanisms. This conceptualization characterizes mechanisms as the "underlying entities, processes, or structures which operate in particular contexts to generate factors of interest" (Astbury & Leeuw, 2010, p. 368). In this case, the factors of interest are access, control, sharing, and use, which are intrinsic to the digital transformation of connected insurance and parallel to the empowerment of individuals. Therefore, this thesis is specifically focused on answering the two following two research questions:

Research question 1: How can health data enable digital transformation for an insurance organization?

Research question 2: What mechanisms support health data factors required for proactive digital health services?

To answer these questions, a health data framework will be empirically crafted based on a single holistic case study of a Finnish insurance company given the moniker Omega. This is achieved through the synthesis of five articles and further substantiated through additional empirical evidence. A single holistic case study among a selection of qualitative research methods was chosen for the purposes of this research (see Table 1 for an overview). The following qualitative methods selected were selected: a literature review, a case study with semi-structured interviews, an ethnography, and a survey (Denzin & Lincoln, 1994; Grant & Booth, 2009). Each article exists within and informs the boundary of the single holistic case study because mechanisms require context to frame how emergent factors facilitate desirable factors (Dalkin et al., 2015).

Table 1. Summary of the five articles' main and secondary objectives, and their research approach.

Article	Research approach	Main objective	Secondary objective
I	Literature review	Synthesize existing research on EHR	Set the boundary for the health
		accessibility and interoperability in the	data environment
		Nordic countries	
II	Semi-structured	Develop an understanding of the health	Set the boundary for processors
	interviews	data challenges for the insurance case	and controllers of health data
		organization	
Ш	Semi-structured	Identify the barriers to accessing health	Set the boundary for processors
	interviews	data for the insurance case organization	and controllers of health data
IV	Ethnography	Understand the challenges with GDPR	Set the boundary for the health
		compliance for insurance organizations in	data governance
		Europe	
V	Survey	Generate insights into customer	Set the boundary for health data
		expectations for sharing health data with	subjects
		insurance organizations	

The context of health data in the case study is informed by four complementary boundaries: the health data ecosystem of the Nordic countries (environment), policy and other legal considerations of health data (governance), the case organization itself (processors and controllers), and its customers (data subjects). The contributions of this thesis are twofold. First, it examines how health data could enable digital transformation at Omega through the concept of connected insurance.

Second, it provides a framework for *what* mechanisms for insurance organizations enable the four health data factors. Digital strategies are identified that point to the necessary conditions for the health data factors—access, control, sharing, and use—for proactive digital health services.

Article I present the results of a literature review in the context of the aforementioned single holistic case study. The barriers and facilitators of EHR accessibility and interoperability were synthesized by healthcare stakeholder groups within the Nordic countries (Finland, Sweden, Norway, Denmark, and Iceland). EHRs were chosen as the core of the study because they represent the largest source of health data available. The article synthesized the available evidence into the dimensions of accessibility and interoperability that either act as a barrier toward or as a facilitator of health data for healthcare stakeholders. Furthermore, the article identified that the role of insurance organizations as healthcare stakeholders as well as the roles of Nordic insurance customers in the health insurance context are under-researched. It concludes that policymakers should focus on stakeholder inclusion within health record platforms for increasing accessibility and enabling interoperability. The article acts as an impetus for the current study to fill this research gap and identifies the dimensions of accessibility and interoperability that served to guide research in the subsequent articles.

Article II presents the results of semi-structured interviews from a single insurance organization in Finland. Further, it outlines the processor and controller boundary context of the single case study. The results were generated through a bottom-up, deductive thematic approach. The results point to the challenges in four areas of health data as the organization transforms from reactive to proactive healthcare service provision: access, ownership, sharing, and use of health data. The article discusses how a focus on customer experience is needed to manage these challenges and enable value creation pathways.

Article III presents the results of the semi-interviews from the same single insurance organization in Finland. Similar to Article II, this article further outlines the processor and controller boundary context of the case study. The case data was analyzed with a top-down, inductive approach for identifying the barriers that the insurance organization faces when processing or controlling health data for its digital health services. The three areas are institutional (facing stigma and misunderstanding of the customers), legislation (motivation for understanding the extensive policy context), and use and participation (customer engagement with the organization). The article discusses these barriers in the context of aligning

traditional insurance approaches away from the reactive notions to proactive providers of health insurance services.

Article IV presents the results of an ethnographic study conducted to characterize the governance of health data in the insurance ecosystem by observing 20 insurance professionals (split among the roles of representative and consultant of insurance organizations) from six European countries. The Finnish case organization participated in the study, which took place during a turbulent period of Europe-wide policy change: the enactment of GDPR. Studying the effects of this far-reaching regulation on processors and controllers represented a fortuitous opportunity. The study was enacted within a European-wide insurance organization summit held to build an understanding of the challenges represented by GDPR for processors and controllers (of which the case organization is both a processor and controller). A sense-making lens was used to interpret the study data to inform the challenges of GDPR and the responses set in motion to overcome those challenges. The findings highlight four areas of compliance that are related to procedure, proliferation, privacy, and protection for personal data access. Personal data was studied as a whole because health data is a subcategory of personal data. The discussion provides a checklist for the challenges other processors and controllers may face and further equivocates the concepts of personal data and big data. Furthermore, the study elucidates the importance of organizational culture for adopting privacy-oriented practices and grounds it as a concern that requires longterm commitment while simultaneously not being guided by any GDPR principles. The discussion comes full circle in regard to the agency that the GDPR grants the customer over their personal data and the strategic necessity this creates for enacting customer involvement in insurance organizations.

Article V presents the results of a customer survey regarding health data sharing within the Finnish case organization and establishes the health data subject boundary of the case study. Health data sharing is an important part of the digital health economy and is contingent on individuals who are empowered to take informed decisions about their health data. A social exchange theory framework is used to determine the customers' expectations for commitment, power, reciprocity, and trust. Customers expect the insurance organization to treat their health data in a certain manner (commitment) and to not use their health data against them in decision-making (power). They also require something they deem valuable in return such as personalized health services (reciprocity) and wish to establish an emotional connection for transparent actions between them and the organization (trust). This article explores the power of health data and a need for equalizing

power to incentivize the customer to share their health data as part of digital health services. How this shift may occur is discussed in the article based on the customers' expectations such as providing personalization of their health data. The article elucidates how these conditions for health data sharing are actionable points for the insurance organization and offer insight into the perceived values of the customer in regard to their health data.

#### 1.3 Structure of the thesis

This thesis is divided according to the content focus. The first chapter (above) contains the introduction to the thesis, leading to the research questions and a brief overview of the content of the articles.

Chapter 2 contains the related research for the thesis topic and is presented in a structured manner. Topics relevant to the setting of this thesis are presented along with further justification of the research questions.

Chapter 3 contains the research approach and methodology for this thesis. It presents the single holistic case study, motivating the case study organization, the process for data collection and analysis, and discussion of the ethical aspects of conducting research.

Chapter 4 contains the findings of the single holistic case study that is categorized into four parts. The first part contains the overview of the case study, providing background details and the current status of the organization. The second part concerns the moment of the organization leading up to its digital transformation. The third part concerns the role of health data in supporting proactive health services and its impact on digital transformation in the case organization. The fourth and final part regards the health data mechanisms that support the shift toward proactive health services and the creation of new value paths in the case organization.

Chapter 5 contains the discussion, wherein the findings are examined through the lens of the research questions, which in combination with further analysis of previous literature serve as a canvas on which to discuss the practical implications of the thesis. The first research question develops an understanding of how health data could create value for insurance organizations and their customers. Both research questions cumulatively consider how the mechanisms support health data factors for proactive health services. Further, the discussion suggests that access, control, sharing, and use of health data should be considered as core functionalities for empowering individuals in a private organization setting

## 2 Related research

This section aims to outline the relevant concepts for the thesis by grounding them in scientific literature. The scope of the related research includes the description of the insurance industry and connected insurance, changes occurring in the industry owing to the technologies and practices that drive digital transformation, and how insurance is moving toward proactive digital health services. Another objective of this section is the characterization of health data, its current practices of governance, the central role of different data mechanisms and their definitions, and its evolving relationship to the shifts happening within the insurance sector.

## 2.1 The digitalization of insurance

An overarching context within this thesis is the insurance industry, given its role as the focus of the single holistic case study. As part of the related research, the history and role of insurance in society is briefly described before presenting the contemporary shape of the insurance sector, the changes that are occurring, and the strategic movements being made with an emphasis on health-related insurance. The insurance industry is a global setting; therefore, to present more contextually significant and relevant research as a background, the Nordic context forms the narrower focus of this thesis. The Nordic countries are of particular interest to research owing to their high digitalization rating in electronic health (eHealth) for provision of digital public services, including but not limited to medical data exchange such as electronic networks for EHR sharing as well as e-prescription use (Mateus, 2016). Barring evidence available within the Nordic context, more broad European evidence is used in its stead. This is neither to say that other insurance sectors are not experiencing similar paradigm shifts nor to say that they are not relevant contexts in which to study these phenomena. The complexity of each individual European insurance context is a minefield of national policies and regulations in addition to the European-level considerations. As such, any inclusion of a non-Nordic instance represents a potential scope creep that cannot be justified from within the confines of this dissertation. Limiting the focus to the Nordic context allows a higher resolution for narrowing down the gaps in existing research and determining where the contributions of this thesis fit in theory and practice.

### 2.1.1 A brief history of insurance

Insurance is a risk management approach to mitigate undesirable factors. The etymology of the word insurance is from Old French and means to provide assurance or a guarantee in the face of adversity. Present day insurance as a private institution does not significantly deviate from the traditional conceptions of insurance in early 3000 BC, where proto-Chinese merchants systematized a shared risk of goods loss to reduce the impact on an individual (Vaughan & Vaughan, 2014); similar conceptions of risk transfer are further interspersed throughout history. Life-oriented insurance has been traced back to 2500 BC when Egyptian stonemasons collectively supported burial practices for funeral processions, and similar practices were observed in Greek and Roman societies (Vaughan & Vaughan, 2014).

### 2.1.2 The traditional insurance organization

Traditionally, insurance organizations and the insurance sector have been very reactive; by definition, insurance assures support in the face of unpredictable setbacks. Traditional industries may be "stuck" in their ways because their dependence on core products or processes as part of business practices is incumbent (Remane, Hanelt, Wiesboeck, & Kolbe, 2017). For example, workers' compensation in occupational health is built on the very concept of risk being intrinsic to employment, risk which in turn requires management. Insurance industries exist throughout Europe and internationally as a result of taxation as well as public, social, private, or out-of-pocket funding schemes (Magnussen, Vrangbæk, & Saltman, 2012). Although there are other types of insurance providers, such as reinsurance, private insurance organizations are typically either proprietary or mutual organizations. Proprietary insurance organizations are owned by "stockholders" who purchase a stake in the company, whereas in mutual organizations, the customers own the company and act as fundholders (Letza, Hardwick, & Kowalski, 2001).

These organizations cover a wide range of insurance classifications: automotive insurance, property insurance, liability insurance, and legal insurance; however, these are also more broadly classified to fall within the purview of three principal groups: life, non-life, and occupational health. Health insurance is present in all three of the aforementioned groups in its role as "a generic term applying to all types of insurance indemnifying or reimbursing for losses caused by bodily

accident or sickness or for expenses of medical treatment necessitated by sickness or accidental bodily injury" (Vaughan & Vaughan, 2014, p. 656). To offer an example, car insurance has health-related components because injuries such as whiplash are a frequent result of car accidents and can require rehabilitation.

Insurance sales are heavily regulated in the European Union, and one of its highest instances of governance is the Insurance Distribution Directive (IDD). The IDD has recently repealed the insurance Directive 2002/92/EC and amended Directive 2016/97/EU to more holistically consider all insurance stakeholders, in effect as of February 23<sup>rd</sup>, 2018. Furthermore, the definition of what constitutes insurance distribution is being expanded to include "to sell, propose to sell, advise on or carry out other work before concluding an insurance contract including dealing with claims after an insurance event" (European Commission, 2016). These new rules for insurance providers emphasize the importance of insurers being more transparent with the products and services being purchased, including premiums, purposes, and policies for insurance products (Köhne & Brömmelmeyer, 2018). In addition, Finland has a supplementary legislation enforced as of January 1st, 2018 that compels data processing to be considered as a special category in the context of insurance. Section 6 of the Finnish Data Protection Law "Tietosuojalaki" denotes that data collected over the course of insurance business practices on the health status of an individual are an exception to processing to determine liability for claim-related decision-making (Finlex, 2018).

## 2.1.3 Digital transformation

Digital transformation has garnered an increasing amount of attention in academic disciplines such as information systems (IS) for leveraging digital technologies as a catalyst for societal and organizational change (Morakanyane, Grace, & O'Reilly, 2018; Vial, 2019). The concept describes the gradual and technologically motivated shift of organizational processes, culture, and practices, resulting in new business models and service offerings and altering the customer experience and value creation paths in the use of new products and services. Despite the presence of research and obvious academic interest in digital transformation, it has been indicated that "...there is very little scientific research published on digital transformation, as most published work is related to digitizing information, not the transformation of an organization or the ability to use digital means in the organization" (Parviainen, Tihinen, Kääriäinen, & Teppola, 2017, p. 65). However, research within the field is on an upswing in a wider range of publications

(Henriette, Feki, & Boughzala, 2015). In Finland alone, digital transformation is being researched within the taxi industry (Väyrynen, Lanamäki, & Lindman, 2018), the banking sector (Grym, Koskinen, & Manninen, 2018), and insurance organizations (Persson et al., 2018).

Several academics have attempted to provide a comprehensive and meaningful definition of digital transformation (Morakanyane et al., 2018; Van Veldhoven & Vanthienen, 2019). However, this has only added to the disorganization of what digital transformation actually means. Most notable is the definition provided by Vial (2019) as a result of a large-scale literature review (n = 282): "a process that aims to improve an entity by trigging significant changes to its properties through combinations of information, computing, communication, and connectivity technologies" (p. 118). This definition suggests that there are many dimensions of digital transformation, some of which an organization can only plan and respond to. Furthermore, it has been shown that the application of digital technologies has to be embedded in the business process, organizational culture, and services and experiences for customers to create value, such as preventative health services for customers (Eling & Lehmann, 2017) and better market share for insurance organizations (Bohnert, Fritzsche, & Gregor, 2019). The impact and influence of the use of digital technologies represent a multitude of pressures for the organizations undergoing digital transformation. Internal efficiency transforms organizational processes, external opportunities leverage digital technologies to create new business capabilities, and disruptive changes in the extant ecosystems necessitate the radical alteration of business models (Parviainen, Tihinen, Kääriäinen, & Teppola, 2017). Figure 1 illustrates the impact of digital transformation on organizations (Parviainen et al., 2017).

The digital transformation of healthcare is accelerating and has critical implications for healthcare stakeholders, including insurance organizations (Agarwal et al., 2010). Eling and Lehmann (2017) identify four major tasks for the insurance industry created by digital transformation: competing in new industries, offering new products and services, developing the customer experience, and improving business processes. These tasks create challenges during the planning, execution, and sustainable phases of strategic implementation (Gebayew, Hardini, Panjaitan, Kurniawan, & Suhardi, 2018). Because digital transformation is not organization-centric (Vial, 2019), the insurance sector faces pressures to depart from traditional, organization-centric business models and instead look to new models that allow them to establish themselves in a health-related ecosystem (Iivari, Pikkarainen, & Koivumäki, 2017). These new models transform the role of

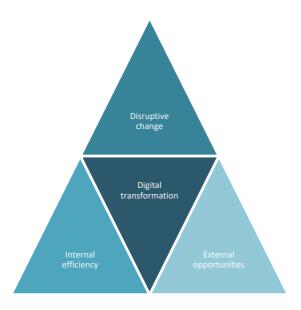


Fig. 1. Digital transformation impact.

insurance organizations as strict insurers into a position as healthcare providers. The Nordic MyData model for human-centric data management and processing is one such example of an applicable business model, decentralizing the organizations model and ratifying the boundary of traditional insurance organizations (Iivari, Pikkarainen, & Koivumäki, 2017; Koivumäki et al., 2017; Poikola, Kuikkaniemi, & Honko, 2015).

Digital transformation partly relates to the leveraging and adoption of digital technologies for the creation of value. Developing the customer experience in insurance results in a shift in the role of customers and insurers related to communication and delivery of services. Automatization of business processes such as claims reporting and decision-making regarding claims settlement are two examples of how digital technologies can be leveraged to alter the value creation pathway and therefore challenge the role of the customer (Eling & Lehmann, 2017). Service design is an approach that embraces disruption, enables competitive customer-centric solutions, involves products into service delivery, and enacts the digital transformation strategy in organizations (Warg, Weiß, Engel, & Zolnowski, 2016). For example, a case study in Basque country using service design to change how customers experience the insurance company found the approach to more holistically consider the customer as part of the strategy for organizational change

(Iriarte, Alberdi, Urrutia, & Justel, 2017). Despite the apparent opportunities for service design (among others), there are barriers to navigating digital transformation owing to the velocity of its emergent complexities that are both internal and external to the organization. At the stakeholder level, individual, organizational, and environmental characteristics can all act as barriers to digital transformation, such as failure to incentivize data sharing (Vogelsang, Liere-Netheler, Packmohr, & Hoppe, 2019).

#### 2.1.4 Connected insurance

An established and a rapidly growing movement in the healthcare ecosystem is connected health (Karampela, Isomursu et al., 2019). Connected health leverages digital technologies from various sources and acts as follows (Caulfield & Donnelly, 2013, p. 704):

"a conceptual model for health management where devices, services or interventions are design around the patient's needs, and health related data is shared, in such a way that the patient can receive care in the most proactive and efficient manner possible. All stakeholders in the process are 'connected' by means of timely sharing and presentation of accurate and pertinent information regarding patient status through smarter use of data, devices, communication platforms and people."

As insurance organizations are key stakeholders in healthcare, their needs in developing connected insurance business models mirror the connected health movement. Through leveraging personal and health data, their capacity to prevent the onset of disease or injury, assist in the management of chronic conditions, and contribute to the wellness of individuals becomes clear. This service provision represents a radical departure from traditional insurance business models, requiring commitment throughout the organization to embrace a proactive mindset and the essence of digital transformation (Giannopoulou, Yström, & Ollila, 2011; Iivari, Pikkarainen, & Koivumäki, 2017). Strategically, an insurance organization should aim to develop key partnerships in health to overcome the legislative barriers for insurance in healthcare ecosystems (Grundstrom, Väyrynen, Persson et al., 2018) and invest in predictive analytics for health interventions and management (Patil & Seshadri, 2014) while simultaneously facilitating to build an innovative bridge between patients or individuals and their healthcare providers (Iivari, Pikkarainen, & Koivumäki, 2017; Numerof, 2016).

Health insurance operates on risk-based principles with the magnitude of consequence and the probability of incidence. A core theme in the traditional notions of insurance is to react after an event has occurred by mitigating risk-based loss. The traditional role of health data in insurance practices is for decision-making in claims and compensation practices. However, connected insurance is steering the insurance sector toward embracing the mass creation of health data as a basis for pattern recognition, behaviour change incentives, cost reduction, improving quality of life (OoL), and holistic healthcare (Silvello & Procaccini, 2019). The future direction of the data-driven landscape points to "the most successful health innovations [which] will use data from different sources regarding the needs of individuals in a manner that is highly personalized and supportive" (Pikkarainen et al., 2018, p. 72). This future direction requires the advancement of digital transformation within the insurance sector to overcome challenges and shift the reactive mindset of the industry: to enact a polar shift from being a payer to becoming a proactive service provider for the customer and their wellbeing (Silvello, 2017).

#### 2.1.5 Proactive health services

A paradigm shift in the healthcare industry has been leaning toward a human-centric orientation that empowers individuals and facilitates proactive health and wellness (Länsisalmi, Kivimäki, Aalto, & Ruoranen, 2006; Prilleltensky, 2005). Digital health services are slated to manage and help prevent a range of health concerns that are strongly correlated with the development of chronic diseases, such as age, weight, behaviours, and medical history. Digital technologies have been proven successful in preventing obesity and related comorbidities through education and intervention by assessing risk in infancy (Redsell et al., 2017); they have also proven efficacious in decreasing or improving cognitive function in atrisk elderly individuals through behaviour change interventions and platform-based therapy (Ngandu et al., 2015). Because traditional insurance organizations operate on the basis of risk, such as risk of developing diabetes owing to weight, mitigating risk for customers is of mutual interest. Blocker et al. (2011, p. 217) argue that:

"proactive customer orientation refers to a provider's capability to continuously probe customers' latent needs and uncover future needs, possibly offering ideas even before customers realize they had such a need; from the customer's perspective, it reflects customers' perceptions that providers have

proactive processes and skills to successfully anticipate their latent and future needs."

For insurance organizations to engage in proactive services, progress is required in the customer experience element of digital transformation (Eling & Lehmann, 2017). A need (whether latent or future) of individuals is access to healthcare, and in Finland, there has been an increase in waiting times for primary and specialized care services among other issues (Tutkimusosasto, 2014). In addition, a large portion of the working force in Finland has access to private healthcare through occupational health systems, establishing a benchmark for satisfaction and customer experience that the public system may not be able to meet (Tynkkynen et al., 2018).

This context of occupational health could offer a partial explanation of why all Nordic countries reported an increase in VPHI purchased by individuals (Kullberg, Blomqvist, & Winblad, 2019; Tynkkynen et al., 2016). Although the freedom of choice to purchase insurance is grounded in a democratic movement for private service provision, evidence suggests that individuals of privilege and "good risk" customers are the only beneficiaries of such health insurance services (Häkkinen & Lehto, 2005; Kullberg et al., 2019; Wasem, Greß, & Okma, 2004). Other challenges (with less emphasis on an ethical perspective) also act as barriers for insurance organizations to facilitate proactive health services. For the purposes of enabling connected insurance, overcoming these barriers is of great significance because proactive health services are data-driven and require access to health data to create value and provision health-related services (Caulfield & Donnelly, 2013; Eling & Lehmann, 2017; Grundstrom, Väyrynen, Persson et al., 2018; Huhtala, Pikkarainen, & Saraniemi, 2015; Wiese, Das, Hong, & Zimmerman, 2017).

### 2.2 Health data

Healthcare is information-intensive and relies on numerous channels of health data proliferation, gathered in a multitude of forms. The most traditional channel for health data collection is the interaction between a healthcare professional and a patient. With the upswing in adopting pervasive technological artifacts and the ever-expanding IOT, individuals have become more engaged in self-managing health and wellness, resulting in an abundance of health data created through wearables and mobile applications as part of the quantified self (Groves, Kayyali, Knott, & Kuiken, 2016). Contrary to the paternalistic setting of healthcare,

individuals are becoming more empowered to individually act on their health and data through governance measures such as the GDPR (European Commission, 2016; Grundstrom et al., 2019; Karampela, Ouhbi, & Isomursu, 2019; McKay et al., 2018), human-centric movements such as MyData (Poikola et al., 2015), and personalized telemedicine-based digital health services (Korhonen, Väyrynen, & Isomursu, 2018). The European strategy for data calls for a health data space that is central for "advances in preventing, detecting, and curing diseases as well as for informed, evidence-based decisions to improve the accessibility, effectiveness, and sustainability of the healthcare" (European Commission, 2020, p. 22). This promotes a more in-depth understanding of the infrastructures that support factors such as access and control of health data.

Health data falls under the special categories of European regulation and encompasses any data even tangentially related to health. It is defined by the GDPR as "personal data related to the physical or mental health of a natural person, including the provision of health care services, which reveal information and his or her health status" (European Commission, 2016, p. 114). This definition includes any and all biometric and genetic data. Any person to whom health data is bound can be referred to as a "data subject" or a "natural person." Furthermore, any and all entities that process or control health data must clearly justify the purpose for doing so (European Commission, 2016).

These regulations demand insurance organizations to facilitate the empowerment of data subjects as part of compliance, which in turn determines the boundaries of how organizations can gather and leverage health data. Table 2 represents nine articles from the GDPR that are mapped against four factors of health data: access, control, sharing, and use. They represent the emphasis on organization compliance in recent research and the prominence of each health data factor (European Commission, 2016; Khajuria, Sørensen, & Skouby, 2017; Marelli & Testa, 2018; O'Connor et al., 2017; Tikkinen-Piri et al., 2018).

In traditional insurance organizations, health data are used for decision-making in claims and compensation practices. However, connected insurance is shifting the insurance sector toward embracing the mass creation of health data as a basis for pattern recognition, behaviour change incentives, cost reduction, QoL, and holistic healthcare (Silvello & Procaccini, 2019). Managing compliance is a heavy burden for insurance organizations as processors and controllers of health data, and data subjects are empowered to perform various actions that have direct influence on the ability of the organization to utilize health data. A few examples of such rights are the "right to be forgotten" (RTBF) that demands measures to personal data

erasure on demand, accountability of any processor and controller who accesses their information (and why), and transparency in informed consent (Tikkinen-Piri et al., 2018). This is not an exhaustive list but a synthesized representation of the emphasis on compliance in recent research for access, control, sharing, and use of health data (European Commission, 2016; Khajuria et al., 2017; Marelli & Testa, 2018; O'Connor et al., 2017; Tikkinen-Piri et al., 2018).

Table 2. Summary of health data factors part of GDPR compliance.

Factor	GDPR articles	Practical Application in GDPR Compliance for Health
		Data
Access	Article 15 – Right of access	- Allowing data subject's access to their health data
	Article 6 – Lawfulness of processing	- Justification of processors and controllers for
		accessing health data
	Article 34 – Notification of data breach	- Notification of unlawful health data access
	Article 25 – Data protection by design	- Preventing or filtering access to health data
Control	Article 16 – Right to rectification	- Allowing data subjects to control the accuracy of
		their health data
	Article 18 – Right to erasure	- Allowing data subjects to delete their health data
Sharing	Article 20 – Right to data portability	- Facilitating data subjects to share their health data
Use	Article 7 – Conditions for consent	- Discloses the purpose for using health data
	Article 12 – Source of data collection	- Discloses the sources of collection and use of
		health data

#### 2.2.1 Health data access

Access to health data is described as "an abstruse and intrinsic property of data that is enacted in various contexts by different stakeholders. These contexts, involving varying levels of complexity, emerge through stakeholder and technical interactions" (Grundstrom et al., 2019, p. 2040). The concept of governance, as described in Article 15 of the GDPR, declares the right of data subjects to access data from processors and controllers and to sanction different rights such as requesting the purposes of processing the data (European Commission, 2016). According to a Pan-European survey, over 90% of citizens expect to be able to access their own health data through the use of digital technologies (Europa, 2018). Providing access to health data through HIT has been proven to be beneficial for patients to advance patient-centric care (Baldwin, Singh, Sittig, & Giardina, 2017; Giardina, Menon, Parrish, Sittig, & Singh, 2014), save a life (Kushniruk, 2019), encourage patients to be more engaged with their health (Bergevi, Lendahls, Crang-

Svalenius, & Oscarsson, 2018; Hägglund & Scandurra, 2017), and facilitate transparency (Adler-Milstein, Sarma, Woskie, & Jha, 2014; Lehnbom, McLachlan, & Brien, 2013). However, access to health data has a darker side and can taint a data subject's experience and perceived value depending on the presentation format of the health data (Karampela, Grundstrom, & Isomursu, 2018), the results that might be troubling or alarming (Baldwin et al., 2017), the validity of content being inaccurate (Scandurra & Hägglund, 2017), or the pressure on stakeholders for the responsibility of privacy and security (Lehnbom et al., 2013).

Access to health data is a fundamental, strategic, and value creating process for all stakeholders. Advancement in proactive health services is dependent on access to health data as a resource (Huhtala, 2018). Benefits from the processing power of insurance organizations for preventative insights in claims data affords a great opportunity to provide insights into long-term chronic diseases, how resources are used, and the frequency of hospitalizations in certain demographics (Bhatt et al., 2015). However, it is challenging to facilitate access to health data to the right stakeholder at the right time while keeping in mind privacy and protection (Commission of the European Communities, 2004).

In the Finnish context, insurance organizations have rights to access health data through central systems such as the public database OmaKanta when insurance claims are being made or to aid in decision-making processes. Because insurance is a complex healthcare stakeholder, there exist distinctions between the workers' compensation legislation and VPHI legislation, with the latter being more restrictive toward health data access. Moreover, abundant health data are collected in insurance organizations through diagnoses, treatments, and claims. However, it is unclear if insurance organizations will have access to the abundant health data being generated through digital technologies, and this is a potential source for value depreciation (Eling & Lehmann, 2017). Solving this conundrum is imperative for connected insurance because access to health data is the driving force behind connectedness (Caulfield & Donnelly, 2013.

The accessibility of health data in the healthcare industry is largely underresearched owing to the limitations for research in practice (Karampela, Ouhbi, & Isomursu, 2018). Studies that address access to data tend to emphasize the accessibility for patients and healthcare professionals or the general public, overlooking the role of payers as part of the healthcare ecosystem (Grundstrom, Väyrynen, & Isomursu, 2018). Figure 2 is a visualization of available evidence for accessibility to health data for different healthcare stakeholder groups. "Administrators" represents research that includes the insurance sector in the Nordic countries for accessibility to health data.

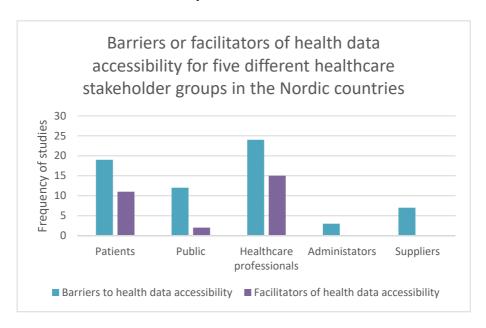


Fig. 2. Visualization of accessibility research on insurance organizations.

Despite the clear need for access to health data as a resource, insurance organizations are under-researched as healthcare stakeholders. There is a lack of understanding of how to overcome the challenges of accessing health data. Furthermore, access to health data is not valuable in itself because health data requires integration, presentation, and interpretation to create value for the relevant stakeholders (Anderson & Agarwal, 2011; Grundstrom & Karampela, 2018; Harjumaa et al., 2016; Karampela, Grundstrom et al., 2018).

#### 2.2.2 Health data control

Although individuals should be in control of their own health data, they are given limited functionality to control the details of their health data through actions such as managing information accuracy or enacting erasure measures (Poikola et al., 2015; Sjöberg et al., 2017). Control over health data influences business models and provides benefits for the healthcare market, which should interest all processors

and controllers of health data (Kemppainen, Koivumäki, Pikkarainen, & Poikola, 2018; Vescovi, Moiso, Pasolli, Cordin, & Antonelli, 2015). Creating an emphasis on the control of health data has been shown to cause individuals to become more active and engaged with their own health and wellbeing (Mandl, Simons, Crawford, & Abbett, 2007). Moreover, control can be beneficial for privacy considerations because individuals could enact granular control over who sees their health data, when, and why (Munns & Basu, 2015; O'Connor et al., 2017). However, some red flags are apparent when patients can limit access to health data, which may be a necessary part of their healthcare at a later time or during emergency situations (Caine & Hanania, 2013; Schwartz et al., 2015).

Organizations that process and control health data as part of their central business practices need to empower individuals with the agency to control their health data. Controlling health data is tedious and difficult when digital means are not utilized. In the case of Finnish insurance organizations, the time between issuing a health data request and receiving the printed documents can approach 50 days for a customer, and half of the times, the request is outright ignored (Gencoglu, Simila, Honko, & Isomursu, 2015). This delay represents a breach of GDPR compliance because it exceeds the 30-day window for responding to requests related to an individual's information (European Commission, 2016; Tikkinen-Piri et al., 2018). However, this particular study was conducted before the GDPR compliance was enforced.

As part of the value delivery process, control of health data can be automated using artificial intelligence and big data analytics on health service platforms (Eling & Lehmann, 2017). GDPR functionalities such as the right to erasure (or the RTBF) or the right to manage and change the content of health data serve to empower customers with the means to control their health data (European Commission, 2016; Steinbart, Keith, & Babb, 2017). Individuals will continue to shape proactive digital health services because they control their health data (Pikkarainen et al., 2018). Empowering customers is not a finite resource; instead it expands the capabilities of digital technologies as a sustainable resource (Rappaport, 1987). Providing mechanisms to enhance individuals' control over health data has been linked to increasing trust between stakeholders (Bietz et al., 2016; Schwartz et al., 2015). Because insurance companies are highly distrusted and carry a negative stigma (Anderson & Agarwal, 2011; Martinez-Hume et al., 2017; Vaughan & Vaughan, 2014), it is of interest for insurance organizations to provide customers with expedient and independent control of their health data.

### 2.2.3 Health data sharing

Sharing of health data involves the exchange or transmission of data across digital sources. The sharing process may be triggered by data subjects who wish to share their personally collected health data online. Data sharing can take place through various functions, such as mobile personal health records (mPHRs), where individuals enact self-management through the digital technologies that provide appropriate functions for sharing health information (Ouhbi, Idri, Fernandez-Aleman, & Toval, 2016). It can also take place via platforms such as *Open Humans* and PatientsLikeMe to catalyze data sharing autonomy for decision-making, data harmonization, or participation in community-centric ecosystems (Greshake Tzovaras et al., 2019; Wicks et al., 2010). Clinical trials are being performed to more assertively explore the potential of patient reported factors (PROs) through telehealth pilot studies. Questionnaires answered by patients to indicate the QoL changes in chronic disease management have been studied as a potential indicator of exacerbation (Gaveikaite et al., 2019). Data subjects may also wish to share their health data with healthcare professionals; however, this is difficult owing to lack of data integration capabilities in existing services and mobile health (mHealth) applications not being medically sanctioned despite their potential value (Zhu, Colgan, Reddy, & Choe, 2016).

Sharing health data has become more possible through the quantified selfmovement and availability of self-tracking devices such as the Fitbit. Notwithstanding the predicted benefits for different health actors when sharing data, there are intrinsic trepidations, especially in the context of notoriously sensitive health data (Otjacques, Hitzelberger, & Feltz, 2007), suggesting that data sharing functions should ensure privacy and security (Europa, 2018). Barriers to sharing health data can range from motivational, where no incentives may exist, to political, due to the lack of trust from information asymmetry; they can also be attributable to technical reasons, where no interoperable capacity may be available (Anderson & Agarwal, 2011; Joiner & Lusch, 2016; Van Panhuis et al., 2014). Health data does not automatically flow from self-collected sources to organizations. However, a need for sharing mechanisms such as interoperability can aid in the ventilation of data silos while also contributing to core business practices for improved financial factors (Tang, Plasek, & Bates, 2018). Interoperability allows for health data to be accessed and shared in a timely and cost-efficient manner while improving the delivery of care across health stakeholders (Kouroubali & Katehakis, 2019).

However, despite the willingness of patients to share their data with primary healthcare providers such as medical doctors, patients are not so willing to share that same data with insurance organizations in fear of reduced or denied coverage (Weitzman et al., 2012). The public appears to be significantly opposed to sharing health data in the context of insurance, as reported in a European survey for public preferences. Central European countries such as Slovakia and the Czech Republic were very averse to sharing data with private insurance organizations, whereas France and Ireland were comparatively less averse, with Finnish citizens being more neutral to the idea. Finnish near-neutrality on data sharing resonates with the findings from a Finnish insurance organization where approximately 57% of customers were unwilling to share their health data (S. Patil et al., 2016; Persson, Grundstrom, & Giunti, 2019). The purpose for sharing health data is also a crucial element for individuals. Research has shown that patient care is most positively affiliated with willingness to share health data and marketing is the least (Anderson & Agarwal, 2011). On this scale, proactive digital health services are considered to be more closely aligned with patient care than marketing; however, research on health services through health data sharing is rather limited.

Processors and controllers also have the capability of data sharing as well as the responsibility to facilitate it. Article 20 of the GDPR aligns with the factor of sharing through the right to data portability. Portability allows data subjects to request their personal data (including health data) in a compatible, structured, and commonly used machine readable format that can then be transmitted across systems, including being received by the data subject without prejudice (European Commission, 2016; Tikkinen-Piri et al., 2018). Health data sharing is important for insurance organizations because it provides them with access to said data. Other benefits are slated for insurance organizations, such as being included in the patient-provider data-sharing loop that "could contribute to increased health and wellbeing through preventive healthcare, and result in e.g. lower insurance costs, bringing added value to the individual client" (Iivari, Pikkarainen, & Koivumäki, 2017, p. 324). Health data sharing is an uncommon phenomenon requiring a more in-depth understanding, as it is the key resource for shifting traditional business models toward sustainable data-driven proactive health services (Caulfield & Donnelly, 2013; Iivari, Pikkarainen, & Koivumäki, 2017).

A core consideration of connected insurance is to be "connected" with customers throughout their lives, not limiting interaction with them to periods of illness or elevated risk; this underlines the need for provisioning and sustaining both active and passive communication between insurers and customers. This can be achieved through digital health services as long as conditions can be created that incentivize customers to share health data and mechanisms are in place to support exchange. What these are in particular is rather opaque for the insurance industry owing to the contemporary stigma and other interconnected barriers to health data sharing.

#### 2.2.4 Health data use

The digitization of health data through HIT has surged over the last two decades, largely owing to an increase in medical record-keeping in healthcare systems such as EHRs, which are widely adopted and implemented across Europe (Codagnone & Lupiañez-Villanueva, 2013). Health data is mainly used in the traditional clinical setting between patient and provider for improving healthcare delivery and decision-making (Adler-Milstein et al., 2014). Digital footprints contribute to the abundance of health data available for use from individuals' self-collected data through wearable technologies and other wellness devices; however, these are seldom considered in patient care (Gencoglu et al., 2015; Harjumaa et al., 2016).

Difficulties in health data use are sometimes derivative of the manner in which the health data are created. Structured health data that follows a standardized approach to create, store, collect, and maintain health data is universally valuable for use because it can be easily exchanged across IS and information contexts. Some examples of structured health data are coded data, uniform data terminology, and data templates. Unstructured health data, however, has no clear standards for capture and is organized according to source rather than outcome. For example, two fitness devices may record the same data on heartbeat, but the output could be incompatible owing to the capture devices. Further, an abundance of unstructured health data is being created by healthcare professionals in the form of note taking, paper charting, imaging, or recording devices. With so much health data being created in an unstructured manner, leveraging the power of big data analytics for proactive health services requires blending of structured and unstructured data to interpret health factors in a meaningful way and is increasingly difficult (Raghupathi & Raghupathi, 2014).

With the role of healthcare stakeholders expanding beyond the traditional settings, the primary use of health data can be considered to occur when "the organization or entity that produced or acquired these data in the process of providing real-time, direct care of an individual" (Safran et al., 2007, p. 4). Use of health data as part of information exchange should include insurance organizations

because they expedite health-related value for individuals through personalized services (Huhtala et al., 2015; Iivari, Pikkarainen, & Koivumäki, 2017). Health data collected in primary contexts would benefit from a common structure, facilitating the secondary use of health data (Vuokko, Mäkelä-Bengs, Hyppönen, Lindqvist, & Doupi, 2017). Secondary use of health data is considered to occur when the health data are repurposed for something other than the initial health data assemblage but are still valuable for the individual, society, and research purposes (Bietz et al., 2016). Recent emphasis has been placed on the reuse of health data for the benefit of society; this requires an increase in public awareness regarding the advantages afforded by the secondary use of health data (Safran et al., 2007).

Finland has embraced the potential of secondary use of health data for social wellbeing, for the prevention of chronic illness, and to support research. A new legislative act aims to leverage the comprehensive health resources readily available in Finland and support the secondary use of this data through secure means (Lähesmaa, 2019). Insurance organizations fall under the purview of "special use" in legislation as a business necessity for decision-making in cases such as claims and compensation (Grundstrom, Väyrynen, Persson et al., 2018). What health data the insurance organizations should be allowed to reuse brings to light ethical considerations and highlights customers' distrust in insurance practices (Eling & Lehmann, 2017; King, Brankovic, & Gillard, 2013).

To maximize the benefit of health data from insurance sources that include information on resource utilization, hospitalization rates, efficacy of interventions, and long-term health factors, support from customers must be rallied (Bhatt et al., 2015; Hripcsak et al., 2014). Transparency between insurance organizations and their customers is one such mechanism suggested to win customer support for the secondary use of their health data (Grundstrom & Karampela, 2018; Safran et al., 2007). Transparency is a compounding need emphasized by the GDPR for processors and controllers and by human-centric data movements such as MyData (European Commission, 2016; Poikola et al., 2015). Other similar mechanisms, such as informed consent, require customers to be educated on and to agree to the intended primary use of their data during data collection as well as potentially secondary uses before health services commence. However, both of these approaches have fundamental flaws in achieving meaningful agreement from customers because it is becoming increasingly challenging to ensure individual understanding of the terms being agreed to and for what purpose (O'Connor et al., 2017). Proactive digital health services require primary and secondary use of health data as a means of processing and creating value for customers through service improvements such as personalization. Connected insurance practices should employ tactics that ensure compliance with regulations while consensually using health data to build mutual trust.

# 3 Research approach and methodology

This section provides details on the research approach and methodology adopted in this dissertation. The sections are organized as follows. First, the research domain is explained, followed by the details of the case study design and research setting. Second, the research method for data collection and analysis of the articles is presented. Next, the composition of the case study, analysis process, and findings of the case are presented. Last, the ethical components of the research are disclosed.

#### 3.1 Research domain

This doctoral thesis is interdisciplinary; it connects two academic disciplines that are linked by the focal approach to the single holistic case study. The interdisciplinary nature of this dissertation is evident in the social, technical, and organizational components that comprise both IS and HIT (Hersh, 2009). Although IS and HIT are separate disciplines the sociotechnical shifts increasingly taking place in academia are permutating traditionally well-established disciplines and blurring boundaries (Lyytinen & Newman, 2008). Fundamentally, informatics can be understood as "the discipline focused on the acquisition, storage, and use of information in a specific setting or domain" (Hersh, 2009, p. 2). Health data is an intrinsic component in the health informatics discipline as part of EHRs and data exchange (Agarwal et al., 2010). Therefore, the domain in this case study is health informatics because health data is the specific setting that ultimately links the research domains of IS and HIT. Figure 3 is a Venn diagram that visualizes the connection between IS and HIT where the health informatics domain exists. The

articles in this dissertation have been targeted for conferences and journals within these disciplines.

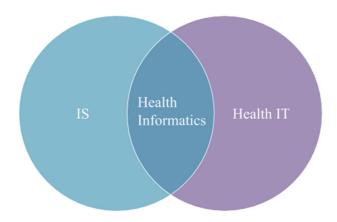


Fig. 3. Research domains of doctoral dissertation.

# 3.2 Case study

This section details the case study performed as the core of this doctoral thesis. *Case Study Research: Design and Methods* by Yin (2014) was the scripture that frequented the research approach and process over the last three years. Hence, it is heavily referenced and relied upon below to guide the structure, justification, and related decision-making for the case study methodology.

# 3.2.1 Single holistic case study

This thesis is designed as a single holistic case study that was exploratory in nature. Unpacking these terms, we turn to the arguably most predominant case study researcher, Robert Yin for a definition (Yin, 2014, p. 23).

"A case study is an empirical inquiry that:

investigates a contemporary phenomenon within its real-life context;
 when

- the boundaries between phenomenon and context are not clearly evident' and in which
- multiple sources of evidence are used."

A qualitative case study was chosen as a suitable approach to support the research questions stated in section 1.2 because the study was conducted in a real-life situation wherein the relevant phenomena were explored in detail utilizing different yet complementary sources for obtaining empirical evidence. This provided a potent underpinning for structuring the study as a holistic conceptual generalization of a single case (Toomer, Bowen, & Gummesson, 1993; Yin, 2013). A case study protocol was developed in the early phases of the research process to describe the iterative process anticipated within the case study, the selection of research instruments that were appropriate for collection and analysis, and the conduct of the research direction to adhere to (Yin, 2013). As part of the case study protocol, the critical realist perspective was adopted to scrutinize the ambiguity part of research and the fallibility of selected research approaches (Fleetwood, 2005; Iosifides, 2018). Critical realism is a useful ontological conception commonly used in social sciences for understanding intangible constructs and how they cause observable or "real" events in the social, organizational, and technological settings (Fleetwood, 2005). In practice, the critical realist perspective was applied for the interpretation and separation of unobservable phenomena (health data) and the emergent influence (digital transformation) (Iosifides, 2018). Table 3 provides a brief overview of the holistic case study of this dissertation.

Table 3. Overview of the single holistic case study research approach.

Single holistic case study

Study design: single holistic case study

Approach: exploratory

The case: Omega - an insurance organization

Setting: Finland

Boundaries of case study: environment, governance, processors and controllers, and data subjects

Data collection: qualitative

Main limitations: generalization and subjectivity

The primary types of case studies include single-case design and multiple-case design studies and are distinguished by their contextual conditions for either a single or multiple unit of analysis (Yin, 2014). The holistic case study follows the notion of boundedness for a specific unit of analysis over a period of time (Gerring, 2004). In this case study, health data is the specific unit of analysis, while the insurance organization in Finland (denominated "Omega") is the specific case setting. The boundaries of the specific unit of analysis in the case setting are as follows: environment (Article I), governance (Articles III and IV), processors and controllers (Article II and III), and data subjects (Article V). Throughout the dissertation, reference to the boundaries of the case study are denoted with (E) for environment, (G) for governance, (PC) for processors and controllers, and (DS) for data subjects.

An argument could be made that this thesis contains embedded units of analysis. However, the unit of analysis and the core tenet of health data remained the same; only the framing was shifted through different analytical approaches and further by definition and context of the case study scope (Miles & Huberman, 1994). This is in alignment with Gummeson (2000), who advocates that the holistic view of a case study is not formed through the sum of its parts but through centralizing the phenomenon of the study interest to frame the whole picture. The motivation to frame a core phenomenon in a case study through different milieus aligns with the motivation to develop an understanding of what triggers mechanisms in different contexts (Dalkin et al., 2015; Pawson, 2002). Moreover, digital transformation is not organization-centric and includes societal-, industrial-, and individual-level implications (Vial, 2019). Figure 4 illustrates the single holistic case study in this dissertation, where the blurring of the boundaries between the context and the case within it are represented by the dashed line.

Case studies are strategically preferable for research settings that ask "how" or "why" questions; "what" questions are also suitable for cases that are exploratory in nature (Yin, 2014). However, these concepts should not be conflated because "many social scientists still deeply believe that case studies are only appropriate for the exploratory phase of an investigation" (Yin, 2009, p. 6). All articles that constitute this thesis asked a "what" question related to health data as part of the research question in an exploration of the case organization. However, when considered holistically, the case provided a broader appreciation of the health data phenomenon while facilitating the understanding of something else: in this case, digital transformation (Crowe et al., 2011). Investigations of case studies should not be considered mutually exclusive—if it is "x," then it cannot ever be "y"—but should be thought to have flexibility to respond to the stimuli of the case and emerging evidence of the phenomena being studied (Crowe et al., 2011).



Fig. 4. Single holistic case study design.

### 3.2.2 Selection of case study research site

The single holistic case study takes place over the course of three years with a Finnish mutual insurance company, Omega. As part of the Marie-Skłodowska Curie fellowship that funded the majority of this Ph.D. project (more details in section 3.7.3 for research funding), Omega represented both the host and the secondment institution. A secondment is a temporary relocation between organizations to conduct work practices in a host organization. I was part of Omega as a host institution for six months, from August 2017 to January 2018. Omega can be considered a particularly suitable case study because it fits into two of the three rationales for single case study criteria (Yin, 2014). The first is "revelatory" (partially described above), which is the somewhat limited access to particular phenomena, usually owing to it being secretive or sensitive. This results in constrained academic knowledge of the constituent phenomena, which in this case is represented by insurance organizations; the identified constrained knowledge outlines a clear gap in literature in Article I. Revelatory cases are interesting to study because they generate insights into the somewhat pervasive presence of digital transformation research but within more unique case settings, marking the second rational (extreme or unique case) (Yin, 2014). This justifies the use of the single case approach because it is both unique and well-suited to answer the research question.

#### 3.3 Research method for data collection of articles

In this section, the research method for the case study is presented in regard to the data collection process. Details of the theoretical underpinnings of the approaches as well as the overall data collection in the case study are guided by the articles. The need to collect data was driven by the health data boundaries: environment, governance, processors and controllers, and data subjects.

# 3.3.1 Case study data collection

Data collection in qualitative studies describes the "who, what, and where of events of experiences, of their basic nature and shape" (Sandelowski, 2000, p. 338). Strategies for data collection in case study research are purposeful and should align with the research question(s) in the case. There are six different sources of evidence: documentation, archival records, interviews, direct observations, participant observations, and physical artifacts (Yin, 2014). Each of these sources contains its own set of strengths and weaknesses such as degree of obtrusiveness, intensity of collection, time required for data collection, and relevance of case purpose. More details are provided in Table 4. Some form of evidence was collected during the case study for each of the six different sources. However, the richest sources of data in this case study were interviews and direct observations. Using a variety of data sources was a mindful strategy employed in the pursuit of rigour when collecting evidence for the holistic case study (Baxter & Jack, 2016).

Table 4. Six sources of evidence of case study data collection.

Definition of evidence	Evidence	Details
	collected	
Documentation: digital or physical evidence from		
the case study setting.		
Personal documents such as letters, notes, and	No	
emails		
Reports such as agendas and meeting minutes	No	
Administrative such as progress reports and internal proposals	Yes	- PowerPoint presentations - GDPR documentation
Formal documentation from the same case conducted by other actors	No	
Social documentation in newspapers or on social media	Yes	- Social media posts - Online blogs

collected  Archival records: digital or physical evidence from the case study setting.  Public census and statistical data Yes - Online Finnish databases  Service records such as publicly presented No reports  Organizational records such as quarterly Yes - Annual mutual reports reports or budgets - Financial statements  Maps or charts of geographic details No
he case study setting.  Public census and statistical data  Service records such as publicly presented  reports  Organizational records such as quarterly  reports or budgets  No  - Annual mutual reports  - Financial statements
Public census and statistical data  Yes  - Online Finnish databases  Service records such as publicly presented  No reports  Organizational records such as quarterly reports or budgets  - Annual mutual reports - Financial statements
Service records such as publicly presented No reports  Organizational records such as quarterly Yes - Annual mutual reports reports or budgets - Financial statements
reports  Organizational records such as quarterly Yes - Annual mutual reports reports or budgets - Financial statements
Organizational records such as quarterly Yes - Annual mutual reports reports or budgets - Financial statements
reports or budgets - Financial statements
Maps or charts of geographic details No
1 0 0 1
Internal statistical data collected by the Yes - Customer statistics reports
organization
nterviews: conversations conducted with case
tudy stakeholders guided by a purpose.
In-depth: an interview where a detailed Yes - Articles II and II blended both in-depth
discussion of the event is inquired with key and focused interview evidence collection
actors in the case study, may persist beyond approaches
just one interview and for a longer period of
time, and points to further sources of
information from other actors
Focused: actors are engaged in shorter, Yes - Articles II and II blended both in-depth
conversational questions directed by the case and focused interview evidence collection
study purpose and more open to reduce approaches
leading bias
Survey: a more formal and rigid series of Yes - Article V surveyed customers through an
questions pertinent to the case online platform
Direct observations: interpretations recorded in the
natural case study setting:
Visual evidence such as photos or videos Yes - Photos taken during interviews
- Photos taken during secondment
Journaling observations Yes - Article IV used ethnography to observe
sensemaking of the case study for the
GDPR
- Researcher journal kept throughout case
study documenting thoughts, reflections,
and action points
Participant observations: active research in case
tudy to influence or participate in shaping the
events in a case study.

Definition of evidence	Evidence collected	Details
Observations of case participants occur in organic settings such as social interactions at lunch, or discussion in meetings.	Yes	- Unpaid member of the staff during secondment - Observed and recorded workings of organization - Engaged with staff in social scenarios
Physical artifacts: sources of physical evidence pertinent to the case, can be digital artifacts.		
Technological device	Yes	- Observed, experienced, and interviewed around digital health platform as artefacts
Tool or instrument	No	
Art	No	

Yin (2014) has connected the six sources of evidence to three principles that maximize the potential value of the data collected in the case study and control the quality of the case study. The first principle is the justification of using multiple sources of evidence. Triangulation is the compounding of multiple evidence sources to point to and empirically substantiate facts in a case study (Gaya & Smith, 2016; Yin, 1999, 2013). Despite the increased burden of using various sources of evidence owing to time and scope concerns, the convergence of the empirical data part of triangulation helps to minimize issues of construct validity (discussed in more detail in section 5.4.1).

Over the course of the research process, multiple incursions to the Omega campus in the metropolitan area of Helsinki, Finland, were conducted, including an early-stage initial meeting, day trips for initial interviews, and a six-month secondment. The secondment allowed for majority of data collection to take place through interviews, ethnography, and a survey. Interview Participant 1 acted both as gatekeeper and insurance domain mentor, as the mentor has both a Ph.D. and M.D. in Occupational Medicine and a high-ranking position in Omega. The insurance domain mentor enabled the access to the company, campaigned for involvement from employees, suggested the necessary persons to connect with, and facilitated the environment for conducting the research, such as booking meeting rooms.

The second principle is the approach to managing the collected data. Organization and documentation of the evidence is necessary for handling the sheer volume of rich data collected, especially over a three-year period. A database has been created by compiling all of the six data sources collected and indexed

according to type and purpose, contributing to the reliability of the case study (section 5.4.2). A data management plan was created to guide the administration of the personal data collected and accommodate data analysis through indexing. Further, the analysis of the data is also part of the data collection and is catalogued for ease of access. This dissertation can be considered as the second type of study database, as it is a collection of research articles synthesized to represent the case study.

The final principle that connects the six sources of evidence and contributes to the reliability of the case study contribution is the forensic notion of chain of evidence. This principle is addressed in the case study through transparency, such as in Table 4, to enforce the idea that the data being analyzed are from the data collected and accurately presented as such. The six sources of evidence and three principles of data collection were followed throughout the case study process, setting the stage for the analysis process detailed in section 3.4.

#### 3.3.2 Health data environment

As part of the case study, the environment was considered necessary to establish the boundaries of health data. To develop this understanding, a literature review of the available academic sources was conducted. Article I presents a literature review that explores health data in the Nordic countries for accessibility and interoperability with five types of healthcare stakeholders. EHRs are chosen because they are the primary source of health data in the healthcare setting.

Because health data has many uses for many different international purposes, narrowing down the environment relevant to the case was essential. Only the Nordic countries were focused upon because the case organization, Omega, is in Finland. Nordic countries are currently among the highest ranked countries—all five having above 80% occurrence—for the use of EHRs as part of health service provision such as digital prescriptions (Mateus, 2016). The Nordics are also unique in that they have established agreements and treaties that support eHealth and health data sharing across borders in the interest of public health crises: for example, the prenatal use and exposure to antidepressants (Ehrenstein, Nielsen, Pedersen, Johnsen, & Pedersen, 2017; Nordic Co-Operation, 2018). They are also typically grouped together as part of the Nordic welfare state for discussion and comparison (Köhne & Brömmelmeyer, 2018; Tynkkynen et al., 2018).

Accessibility and interoperability among the Nordic countries are the core functional needs for EHRs to meet user demands (Aanestad, Grisot, Hanseth, &

Vassilakopoulou, 2017; Commission of the European Communities, 2004; Essén et al., 2017). Stakeholders represent those who need health data, ranging from patients to designers. Health data should be accessible to the right stakeholder at the right time through interoperable functionalities and with highest regard for security and privacy (Commission of the European Communities, 2004; European Commission, 2017). Five principal stakeholder groups are considered to be part of the healthcare sector: patients, the public, healthcare professionals, administrators, and suppliers (Singleton, Pagliari, & Detmer, 2009).

In the first phase of data collection, because the purpose was to collect data that amalgamate these different components together—health data, Nordic countries, accessibility, interoperability, and stakeholders—a qualitative evidence synthesis (QES) approach was selected. QES is a method to interpret a wider phenomenon meant to:

"explore barriers and facilitators to the delivery and uptake of services; for an exploration of user views; to investigate perceptions of new roles, from the point of view of either those filling the roles or those with whom stakeholder interacts; and to inform the prioritization of services where evidence on effectiveness is equivocal and preferences and attitudes thus become the determining factors" (Grant & Booth, 2009, p. 100).

A selective sampling approach was applied to systematically search three online databases: Scopus (Elsevier), PubMED, and EBSCOhost (Academic Search Premier). A Boolean phrase that was sensitive to spelling, acronyms, and capitalization was applied to the abstract, title, and keyword sections of the databases, searching for "electronic health records" and "access\*" OR "interop\*" within the names of the Nordic countries. The total number of articles included after filtering for only the articles in English, arriving at a count of n = 143.

The second phase of data collection included filtering the articles based on the following five criteria to ensure that the data being extracted was relevant: 1) removal of duplicates, 2) removal if the study was not conducted in Finland, Sweden, Norway, Denmark, or Iceland, 3) removal if the study did not clearly outline at least one healthcare stakeholder, 4) removal if EHRs were not the primary focus of the study, and 5) removal if the study did not have a qualitative component. Of the 143 articles filtered, 19 were found to be suitable for data extraction. In preparation for data analysis, qualitative findings from the 19 papers were extracted as excerpts into an Excel file and the author and stakeholders were labelled. Figure 5 is a flow diagram of the literature review.

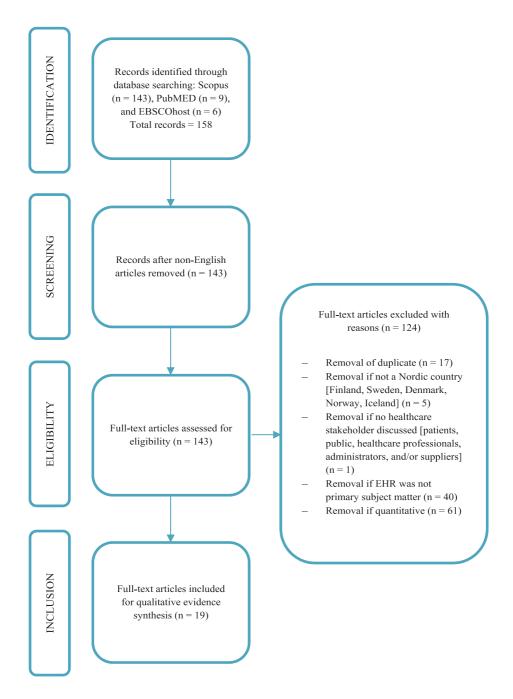


Fig. 5. Qualitative evidence synthesis flow diagram.

### 3.3.3 Data governance

Given that health data comprises information about an individual's private health status, how these data are governed through legal entities is a boundary of critical relevance to this case study. On May 25<sup>th</sup>, 2018, approximately halfway through this case study, the GDPR came into force, replacing the existing Data Protection Directive 95/46/EC from 1995 (European Commission, 1995, 2016). Omega, like all processors and controllers of personal data, was swept up in the wake of GDPR compliance demands. Although the focus of this thesis is on the special classification of health data, personal data is the wider group of this special data type. All identifiable health data falls within the same purview as personal data (European Commission, 2016).

Navigating Omega's traversal of the practical challenges that emerged owing to the introduction of GDPR was the focus of Article IV. The GDPR components heavily emphasize access to personal data. For example, portability of data requires processors and controllers to facilitate access and control to data subjects for data sharing (Vanberg & Ünver, 2017). Another requirement is accountability, which is the justification for having access to personal data that must be made transparent to data subjects (Lindqvist, 2018).

Data about the GDPR compliance challenges were collected using a qualitative descriptive study leveraging an ethnographic data collection methodology (Sandelowski, 2000). Omega is part of a coalition of mutual insurance organizations who coordinate challenge-solving events without the complication of competition. A two-day workshop on GDPR compliance was conducted in Sweden, where the research participation consisted of a "fly on the wall" method, gathering ethnographic data in the form of colour-coded field notes. Additional data was gathered from presentation slides, notes from participant discussions during breaks and travel times, and other participant interactions. Table 5 describes the characteristics of the participants, including the approximate European region that is not more specific in interest of protecting the identity of the participants. Using this method to understand Omega's compliance facilitated the identification of governance challenges for health data and the associated burden on organizations.

Table 5. Ethnographic participants' characteristics.

Participant	Role	Participant	Role
Western Europe 1		Northern Europe 2	
E1	Consultant	E12	Lawyer
Northern Europe 1		E13	Lawyer
E2	Compliance Officer	E14	Lawyer
E3	Compliance Officer	E15	Product Manager
E4	Lawyer	E16	Project Manager
E5	Lawyer	E17	Project Manager
E6	Program Manager	E18	Project Manager
E7	Project Manager	E19	Project Manager
Southern Europe		Central Europe	
E8	Project Manager	E20	Compliance Officer
Western Europe 2			
E9	Consultant		
E10	Department Head		
E11	Project Manager		

### 3.3.4 Health data processors and controllers

Omega is both a processor and controller of health data, which establishes a clear boundary for this case study. Because Omega was shifting its focus from offering reactive products in a traditional insurance setting to offering proactive digital health services for a holistic customer experience, understanding the role of health data to sustain its strategic vision was imperative. Thus, the focus of Article II and Article III was to unravel the health data threats as part of the larger transformation process.

Semi-structured interviews were used as the empirical data collection approach. In qualitative research, interviews are a fundamental tool for data collection (Myers & Newman, 2007). The interviews conducted provided the largest source of evidence collected, providing rich description of Omega's behaviour and intentionality for health data events (Schultze & Avital, 2011). The interview format was semi-structured to allow for flexibility during the interviews while ensuring the homogeneity of the collected data. The designed interview guide adhered to the case study protocol (Yin, 2014). The interviews were conducted following the dramaturgical model of interviewing. This approach considers interviews to be "a drama, and therefore interviewers should prepare themselves

with that in mind. In other words, they should aim for an excellent performance..." (Myers & Newman, 2007, p. 16).

The interviews were conducted in two phases. The duration of all interviews was approximately 60 minutes, and they were conducted in English. The first phase was from May to July, 2016 and included interviews with 10 Omega employees having varying levels of expertise and different job descriptions. In this part of the interviewing process, details about Omega's organizational structure and attitudes or perceptions of health data were gathered. The second phase was from August 2017 to January 2018 as part of my industrial secondment with Omega. Twentyfour interviews were conducted together with another researcher at Omega's headquarters in Helsinki, Finland. This part of the interviewing process aimed at probing deeper into health data, digital health services, the shift from reactive to proactive, value creation activities, and the changes taking place in the organization. All interviews were audio-recorded, transcribed following a denaturalization procedure in Dictapad (Davidson, 2009), and familiarized with in preparation for data analysis (Oliver, Serovich, & Mason, 2005). Table 6 describes the participants' characteristics, the numbers used to refer to them throughout the findings, and the phase(s) of the interview process that they participated in. Interview guides for both phases can be found in Appendices 5 and 6.

Table 6. Interview participants' characteristics.

Participant	Phase	Phase	Position	Area of Expertise
ID	1	2		
I1	X		Unit Director <sup>a</sup>	Medicine Occupational Health
12	x	x	Unit Director	Business Workplace Health and Safety
13	x		Business Director	Digital Health Services
14	x		Manager	Human Resources
15	x	x	Development Manager	Data Business Intelligence and Analysis
16	x	х	Unit Director	New Business Development
17	x		Manager	Business Claims
18	x		Department Head	Customer Relationship Development
19	x		Unit Director	Business Claims
I10	x	х	Development Manager	Digital Health Services
l11		х	Unit Director	Business Worker's Compensation
l12		x	Development Manager	Customer Experience Research
I13		x	Chief Digital Officer	Digital Health Services
114		x	Program Director	Digital Health Services
I15		x	Communications Manager	Public Relations
I16		х	Development Manager	Corporate Business Worker's Compensation

Participant	Phase	Phase	D 38	A
ID	1	2	Position	Area of Expertise
l17		х	Unit Director	Claims
I18		x	Analyst	Data
I19		x	Development Manager	Customer Experience
120		x	Development Manager	Non-life Company
I21		x	Senior Consultant	Traffic Prevention
122		x	Unit Director	Research and Development
123		x	Unit Director	Strategy and New Services
124		x	Program Manager	Data Security
125		x	Strategic Technologist	Solution Architecture
126		x	Lawyer	GDPR
127		x	Unit Director	Customer Relationship Development
128		x	Leading Expert	Customer Development
129		x	Department Head	Social Media
130		x	Unit Director	ICT and Risk Management

a: The Unit Director of Occupational Health acted as the insurance domain mentor as well as the main gatekeeper to Omega, guiding the interview process through direction and company-wide networks.

# 3.3.5 Health data subjects

Including the customers' perspective (customers are also referred to as the data subjects) in the single holistic case study was significant to establish a boundary in the case study. This is apparent from Articles II, III, and IV, which emphasize the governing factors that influence processors and controllers as part of compliance. Article V represents the customer perspective of control for the individual as the point of integration for enacting control-related choices over their health data.

To collect data from the customers of Omega, a large-scale survey was designed with mixed quantitative and qualitative components. A survey was selected as the data collection method because it can reach a large number of customers and Omega could facilitate this process through its existing channels. The survey was designed following an iterative process with feedback from pilot testing and was made in three languages: Finnish, Swedish, and English. It comprised four subject areas: customer characteristics, health data, customer participation, and social media; moreover, it could be filled out through an online platform facilitated by Omega (Webropol). The survey was sent on January 30<sup>th</sup>, 2018 in an email to a simple random sample of 5,000 Omega customers to ensure that probabilistic sampling biases were kept to a minimum (Fricker Jr, 2016). A simple random sample was deemed to be the most suitable for survey distribution

because it is an unbiased surveying technique for selecting customers at random. Other sampling techniques such as cluster sampling or stratified random sampling would have been unnecessarily restrictive because the survey had few requirements for the target population (Fricker Jr, 2016). The only constraints of the survey were that the participant must be over 18 years of age, be an existing customer of Omega, and have an email address on file. The survey was live until March 15<sup>th</sup>, 2018 for a total of six weeks.

# 3.4 Data analysis of articles

In this section, the research method is presented in the purview of conducting data analysis in a case study context. The data analysis process was qualitative in nature and utilized analytical processes typical of qualitative research. Each approach is justified on the merit of its suitability, and the analysis process is further explained.

# 3.4.1 Research methods for data analysis

Analysis of the substantial and holistic case study evidence was approached using a general qualitative strategy (Yin, 2014), which is reflected in all of the articles. The complexity of the analysis should not be exchanged for the clarity of the case, which is why the focus points of the data analysis consider health data using different analytical approaches. The analysis draws from three core qualitative approaches: theming (Article I, III, and V), framing (Article II), and content analysis (Article IV); digital tools are used to manage the analysis, such as Dedoose and Excel. Health data was prioritized throughout the data analysis process, which guided the investigation process and prevented scope creep. The analysis approach was designed to strategically exhaust the available evidence, consider contrary interpretations, decipher the most substantiated and interesting parts of the case, and utilize my extensive knowledge on health data in the insurance case study to demonstrate holistic awareness (Gummesson, 2000; Yin, 2014). The three analysis approaches are detailed below within their relevant boundaries to imbue rigour and evidence of quality analysis in regard to the articles.

#### 3.4.2 Health data environment

The data for the health data environment was collected using QES, the process of which is described in more detail in section 3.3.2. After the data from the 19 papers

was collected, extracted, and collated, data analysis was performed. First, a coding process was applied to assign excerpts with labels such as accessibility or interoperability and stakeholder group; insurance organizations are classified as payers, which are part of administrators. To holistically synthesize the coded data, a thematic analysis approach was used to inductively construct themes and subthemes for building the dimensions of accessibility and interoperability. The thematic analysis approach was chosen to describe the synthesized findings and to identify the patterns of health data and gaps in stakeholder research (Braun & Clarke, 2012; Vaismoradi, Jones, Turunen, & Snelgrove, 2016). The synthesis results of the health data environment for this case study point to the barriers and facilitators of health data and healthcare stakeholders.

# 3.4.3 Health data governance

The qualitative data collected through ethnography for Article IV was initially analyzed using the content analysis approach to elucidate the themes of challenges for GDPR compliance interpreted by the ethnography participants from a processor and controller perspective (Braun & Clarke, 2012; Vaismoradi et al., 2016). These themes were subsequently further grouped using the lens of sense-making. Participant sense-making of the GDPR occurred both before and after the workshop, bringing individual insurance organization challenges together for a holistic interpretation of compliance for mutual insurance organizations. Sense-making seeks to obtain a shared understanding of what an organization is doing and how the interpretation is represented in practice (Choo, 1996; Gioia & Chittipeddi, 1991; Wrzesniewski, Dutton, & Debebe, 2003). In this case, this relates to the observed understanding of the participants toward the GDPR and its impacts on Omega in terms of health data compliance.

# 3.4.4 Health data processors and controllers

Abundant data was collected through the interviews at Omega, approximating 167,000 words in total. Coming in at over 360 pages of text, this dataset can be considered "rich" (Oliver et al., 2005). Two analytical approaches were selected for the data analysis of the interviews.

The first approach, which was content-driven, was applied in Article II; no lens or theory was applied to the raw data. A systematic qualitative analysis approach called the framework method was used (Gale, Heath, Cameron, Rashid, &

Redwood, 2013). Transcription of the interviews and familiarization with the interview data are the first two steps in the framework method (as described in the data collection process for health data processors and controllers). The remaining five steps are as follows: coding, developing a working analytical framework, applying the analytical framework, charting the data into a framework matrix, and interpreting the data. The interview data was first inductively and openly coded, followed by deductive coding to narrow down the health data—related areas. An analytical framework was built on four challenges of health data: access, control, sharing, and use. These four challenges were re-applied to the interview data to substantiate the evidence related to them. Next, the data was charted to further structure the four challenges, followed by the interpretation of what these challenges meant. The four challenges helped ascribe the key health data areas in the organization that Omega was navigating as a processor and controller in insurance: access, control, sharing, and use of health data.

The second approach, in Article III, was theory-driven by applying the open data barrier framework proposed by Janssen, Charalabidis, and Zuiderwijk (2012). Using the same rich interviews as a source, the data was analyzed following a thematic analysis process, abstracting barriers through the identification of key themes and typologies and encapsulating them as aligned with the framework (Braun & Clarke, 2012; Vaismoradi et al., 2016). As a processor and controller of health data requiring access to health data for data-driven proactive health services, Omega is facing barriers in three areas: institutional, legislation, and use and participation.

### 3.4.5 Health data subjects

Article V uses qualitative data collected from the customer survey for analysis. Of the 5,000 surveys distributed to customers, 452 (9.0%) were completed and all were determined to be appropriate for analysis. A single open-text question was translated from Finnish to English and analyzed using an inductive coding process to prevent quasi-content analysis (O'Cathain & Thomas, 2004). The question asked customers "If you were to share your health data with Omega, what would you expect in return?" This question was driven by the need for Omega to access health data (Article II) and the conflation of customer understanding for data sharing (Article III).

Once the coding of data was saturated, open-text answers that were similar were grouped together using content-driven analysis and framed using a social

exchange theory (SET) framework. SET is an interdisciplinary framework that deciphers values in the exchange of goods and services and is equated by a philosophy of equivalent exchange (Wu, Chuang, & Hsu, 2014). Omega's customers realize the value of their health data and place a premium on conditions for incentivizing health data sharing for mutually beneficial health-related outcomes. Quantitative components obtained from a co-researcher on the project are used as part of the case study findings. They are indicated with the reference customer survey 2018 and are connected to the corresponding article with the descriptive statistics of the survey (Persson et al., 2019). Table 7 presents the participants' demographics from the customer survey 2018.

Table 7. Customer survey 2018—participants' demographics (n = 452) (V, published in JMIR Medical Informatics and in accordance with Creative Commons Attribution License).

Characteristics	Customers, n (%)	
Gender		
Female	227 (50.2)	
Male	224 (49.6)	
Other	1 (0.2)	
Age range (years)		
18–24	11 (2.4)	
25–34	43 (9.5)	
35–44	87 (19.2)	
45–54	99 (21.9)	
55–64	104 (23.0)	
65–74	86 (19.0)	
≥75	22 (4.9)	
Highest level of education		
Primary or comprehensive school	32 (7.1)	
High school or vocational school	145 (32.1)	
Some college credit, no degree	30 (6.6)	
Bachelor's degree	146 (32.3)	
Master's degree	98 (21.7)	
Doctoral degree	1 (0.2)	

### 3.5 Single holistic case study overview

Below (Table 8) is a summary table intended to provide a bird's eye view of the methodology and research approach used in this dissertation.

#### Table 8. Overview of single holistic case study.

Single holistic case study

Context: the increased use of digital technologies is generating an abundance of health data, prompting healthcare organizations to transform and ultimately changing business models to leverage new value creation channels.

Objective: investigate the phenomenon of health data in an insurance organization undergoing digital transformation.

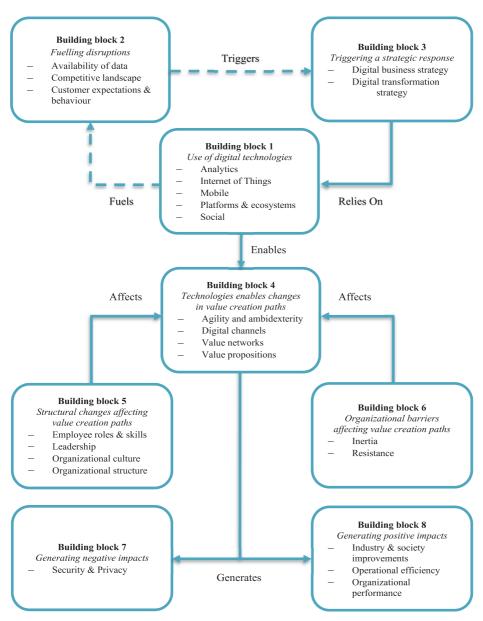
Study design: single holistic case study; exploratory.

The Case: focused on health data in proactive digital health services as part of the digital transformation of omega.

Boundaries of case study: environment (Article I): accessibility and interoperability of health data in the Nordic countries for health stakeholders. Governance (Article III and IV): GDPR affects the processors and controllers of health data in Europe; Finnish legislation standardizes insurance industry practices. Processors and controllers (Article II and III): employees of a single insurance organization in Finland share attitudes and practices of health data—related activities. Data subjects (Article V): customers of the same insurance organization share insights into the perceived value of their health data.

Data collection: Article I—literature review to situate Nordic and academic contexts. Articles II and III—semi-structured interviews with insurance organization employees. Article IV—ethnography of the sense-making activities of European insurance organizations. Article V—qualitative survey of insurance customers.

Data analysis: Article I—qualitative evidence synthesis of literature through thematic analysis. Article II—inductive open coding of interviews, followed by deductive coding via the framework method. Article III—thematic analysis of interviews. Article IV—content analysis of ethnography, followed by application of the sense-making lens. Article V—thematic analysis of survey data framed by the social exchange theory. Main limitations: Reliability of case study process: unique circumstances of Omega make for an interesting study, but it is difficult to replicate.



Key: Dashed arrows represent the trends seen globally in the industry and society Solid arrows represent the digital transformation of an organization

Fig. 6. Digital transformation framework.

# 3.6 Composing the single holistic case study findings

For this dissertation, to generate the description of the holistic case of Omega as well as synthesize the extensive work performed in the articles, Vial's (2019) digital transformation framework is utilized. Figure 6 illustrates this framework and is the referral archetype moving forward. At the time of writing, no academic research was found to follow this extensive framework for reporting case studies. Figure 7 is an example of the description of the naming schema of the digital transformation framework. Building blocks are given a reference number ranging from one to eight, have a descriptive title based on the building block concept, and are composed of several elements that are part of the digital transformation concept. Throughout the thesis, the framework refers to the building blocks, their descriptive titles, and the elements within the building blocks by their names.

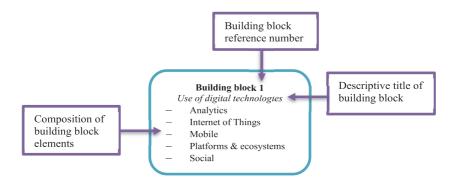


Fig. 7. Clarification of digital transformation framework components.

Vial's (2019) digital transformation framework was selected for two reasons. First, it is the most extensive attempt to synthesize digital transformation into a cohesive whole by inductively crafting a framework from 282 articles. Second, the framework is suitable for this single holistic case study because all its building blocks and their elements were present in my data, which was not driven by this particular framework during data collection and analysis; this marks a very significant match.

### 3.6.1 Theory-driven digital transformation narration

The digital transformation framework comprises eight building blocks and characterizes the structure for guiding the narration of the case (Figure 6). Each

building block has inductive properties that are elementary of digital transformation. The reporting of the case study is not presented as a narrative analysis; the narration is theory-driven by Vial's (2019) theory-building structures of digital transformation and relies on theoretical propositions to guide the thematic case study analysis and presentation (Braun & Clarke, 2012; Yin, 2014). Theory-building structures is one of the six reporting types suggested by Yin (2009, p. 177), where "the logic will depend on the specific topic and theory, but each chapter or section should reveal a new part of the theoretical argument being made." A strength (and weakness) of case studies is that there is no prescribed and perfected method for reporting a case study, which this thesis takes advantage of. Because the overall analysis of the case study is theory-driven, an inductive thematic process was applied to build each element of the building block if it was not already part of my existing articles (Braun & Clarke, 2012; Vaismoradi et al., 2016). This process helps in ensuring that the contributions of this case were not lost in the volume of gathered information and further focusing the findings of the case study.

The elements within Vial's (2019) digital transformation framework are ranked in order of importance for enabling health data in digital transformation; the degree of importance is a principal contribution of this thesis for research question 1. The elements were ranked via their post hoc comparison within each of the building blocks. The ranking analysis considered the logical relationship between health data and the digital transformation elements for proactive digital health services, thus ranking the elements in order of importance from the most important element for health data to the least important within that building block. Importance was contingent on three areas for health data: i) necessity for proactive digital health services, ii) frequency of element depicted in the interview, ethnographic, and survey data, and iii) representation in Articles I–V. Figure 8 illustrates this process using building block 2 as an example, establishing a modus operandi for health data to provide proactive digital health services.

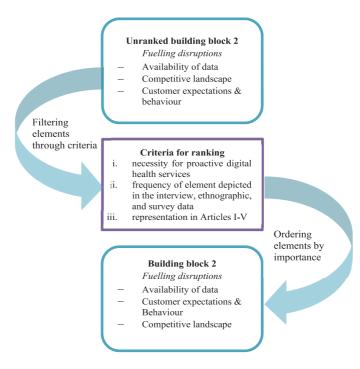


Fig. 8. Example of the analysis process when ranking building block elements for degree of health data importance in the digital transformation narration.

#### 3.6.2 Content-driven health data mechanisms

To determine the mechanisms of the four health data factors—access, control, sharing, and use—a critical realist perspective was applied to the theory-driven presentation of the digital transformation narration (Martela, 2015). Identification of mechanisms in IS research has been useful in explaining the relationship of change between the different organizational structures entangled with contextual considerations to identify empirical facts (David et al., 2016; De Haes & Van Grembergen, 2005; Hedström & Ylikoski, 2010). This prescription aligns with the structure of this case study and should be thought of as a blueprint for the analysis process. Because mechanisms require certain conditions and contextualization to frame the result, the mechanism is the bridge that enables the outcome (Dalkin et

al., 2015). For example, the security of sensitive health data could be leveraged by a double encryption mechanism that tackles the challenge of providing security on the cloud (Hamrioui et al., 2017). Another example is the mechanism of stakeholder participation that supports the structures and processes of IT governance (De Haes & Van Grembergen, 2005). Both these examples illustrate the mechanism as a driver to generate the desired outcome factor.

Identifying which health data mechanisms are suitable for supporting the emergent digital transformation processes being enacted in the case study is necessary for the development of proactive health services. To construct the mechanisms, the emergent health data factors were clustered with the organizational elements of digital transformation to understand the effect of interest (Hedström & Ylikoski, 2010). It is already established that a desired outcome of health data are the four health data factors of access, control, sharing, and use and that the boundaries of the case study construct the context; mechanisms are the missing element. Each mechanism that emerged from the content-driven thematic analysis was recorded and described according to its boundary and health data factors to inductively construct a framework (Braun & Clarke, 2012). Figure 9 is an overview of the data arrangement, analysis, and presentation for health data mechanisms.

# 3.6.3 Presenting the case study findings

The findings of this thesis are presented in three sequential stages. First, the specifics about Omega, Omega's history, details about the insurance organization, and justification for them as a suitable case study are provided as a background to the narration in section 4.1.

Second, the findings of the narration of this case study are guided by the building blocks of Vial's (2019) digital transformation framework (Figure 6). Each building block is presented as part of the resulting whole to narrate the digital transformation of Omega. Within each of the eight building blocks is descriptive text summarizing the narration and presenting the order of the elements to reflect the degree of their importance for health data, forming a critical path. The first three building blocks represent the momentum of Omega leading up to digital transformation, presented in section 4.2. The remaining five building blocks focus on data-driven proactive digital health services for connected insurance, presented in section 4.3. Each section includes evidence substantiating the findings from the interviews, ethnographic observations, or survey data and is denoted as such.

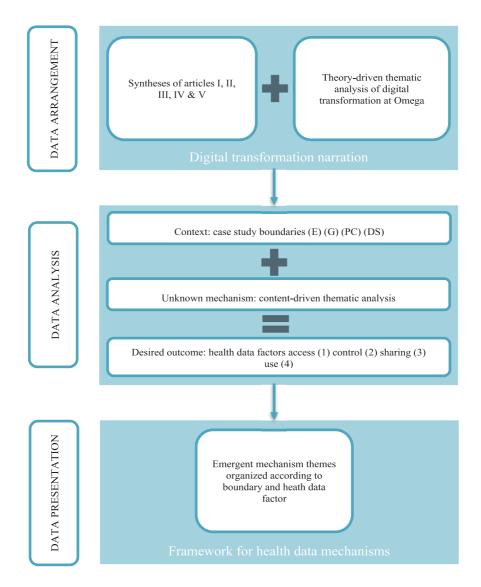


Fig. 9. Overview of content-driven analysis process for mechanisms of health data.

Third, the health data factors and the mechanisms that support the data-driven proactive health services are presented in section 4.4. The health data factors are synthesized from all articles and extant literature and are further situated in the digital transformation narration as part of how to facilitate the health-related

impacts from both the customer's (data subject) and the organization's (processor and controller) perspective within the landscape (environment) and legislative (governance) contexts. To more clearly connect these three aspects, indicators are provided in text. Context is represented according to environment (E), governance (G), processors and controllers (PC), or data subjects (DS). The health data factors are denoted with numbers: access (1), control (2), sharing (3), and use (4). These indicators are followed by the mechanisms by name: for example, (G1: Mechanism) identifies an access mechanism in the governance context. The indicator connects the narration evidence to the summary at the end of the section. Each mechanism is labelled to enable changes in the value creation path for the health data factors in the corresponding building blocks.

#### 3.7 Ethical considerations

Important for the reliability of research is the clear description of the research process. The integrity of a researcher is driven by their values, ethical responsibilities, and moral compass (Green & Thorogood, 2018). For that reason, and in the interest of full disclosure on par with the topic of this thesis, the ethical considerations describe the process of informed consent for the case study as well as how any personal data was collected and processed. For transparency reasons, the funding information of this doctoral dissertation is also disclosed.

## 3.7.1 Informed consent and ethical declaration

Autonomy to decide whether to participate is an ethical principle, not only in healthcare but also in society. Philosophically, informed consent respects the autonomous rights of a person and supports a voluntary and an un-coerced decision. Throughout this study, no participants at Omega were threatened with consequences such as loss of potential income if unwilling to participate. Every interviewee and some ethnography participants in this study were supported by Omega in the sense that data collection took place during normal working hours: part of dedicated paid working time. Other ethnography participants were from other European mutual insurance organizations.

No informed consent was required for Article I because it was a literature review and no actual participation took place. However, for the remaining four articles, there was a variety of participants and channels through which they participated: 30 interview participants for Articles II and III, 20 ethnography

participants for Article IV, and 5,000 potential participants in the customer survey. All participants in this study either signed informed consent forms or digitally acknowledged them. The disclosing of informed consent met all the requirements set forth by both the Marie-Skłodowska Curie project as the funding agency and the University of Oulu's Ethics Committee of Human Sciences. The informed consent forms detailed information about the study and contact information and were provided ahead of time to allow for any questions or withdrawal from the study.

The Ethics Committee of Human Sciences at the University of Oulu mandates six statements as criteria to explicitly declare your ethical status and need for review. My study did not require a review from an ethical committee because 1) the study did not intervene with the physical integrity of subjects, 2) the study did not deviate from the principle of informed consent, 3) the study did not involve any participants under the age of 18, 4) the study did not expose participants to strong stimuli, 5) the study did not expose the research subjects to risks beyond everyday life, and 6) the study did not explore risks to subjects for mental or physical purposes.

# 3.7.2 Personal data processing

This study commenced before the GDPR came into force; thus, a majority of the personal data processing originally fell under the purview of Data Protection Derivative 95/46/EC. Despite the less comprehensive rules of the directive than the GDPR, a stringent data processing plan was followed for this research. A data management plan was designed and declared according to the Horizon2020 guidelines. Details of personal data collection and processing were disclosed, the method for pseudonymization was declared, the details about metadata and recordings were addressed, and the intentions for data sharing both inside and outside of the project consortium were strictly defined. The personal data was stored only on password protected work laptops and the intranet of the University of Oulu for research purposes. Every effort was made to accommodate and respect the privacy and security of participants in this case study. In addition, Omega reviewed all articles before publication to confirm satisfaction regarding anonymization.

## 3.7.3 Research funding

This doctoral thesis was funded from February 2016 for three years by the Connected Health Early Stage Researcher Support System (CHESS) project and Initial Training Network (ITN). CHESS ITN is a European Union Horizon2020 Programme under the Marie Skłodowska-Curie grant agreement No. 676201. The final year was funded by the M3S unit in the Faculty of Information Technology and Electrical Engineering at the University of Oulu.

Supplementary funding was awarded through different research and training activities. One source was the European Network for the Joint Evaluation of Connected health Technology (ENJECT) under the grant agreement TD1405 as part of Cooperation in Science and Technology (COST). Short-term funding from the Information Technology and Electrical Engineering Doctoral Programme (ITEE-DP) at the University of Oulu was also awarded. The last source to award funding was the Finnish Vakuutustiedon Kehittämissäätiö (Insurance Information Development Foundation).

# 4 Findings

The findings of the thesis are presented in four sections. The first section contextualizes Omega and the manner in which health data are interwoven with its business practices. The second and third sections outline the structure and narration of the digital transformation framework. The final section presents a framework and elaborates on the synthesized health data mechanisms affecting digital transformation in terms of the access, control, sharing, and use of health data.

## 4.1 Background about Omega and the role of health data

The advent of Finnish insurance, termed "vakuutus," has historical roots in Finland that go back to the 18<sup>th</sup> and 19<sup>th</sup> century. The German King of Sweden (whose domain presided over Finland at that time), King Adolf Fredrik, enacted the development of fire associations within regional communities, a form of mutual risk protection where a community would come together to help extinguish fires and rebuild damaged homes. Similar associations exist today all over the world, relying on the efforts of local volunteer firefighters.

The concept of insurance is traditionally modelled based on a risk-and-react scenario where protection is retroactively provided to the event. While the Omega organization has roots that go back to the early 20th century, its contemporary shape emerged in 2012. Two large insurance groups comprising a total of 20 regional insurers and nearly 300 offices interspersed throughout Finland and Åland joined forces in a merger, strengthening their position in the Finnish insurance ecosystem. The regional insurers enjoy the benefits of a central strategic direction while retaining the freedom to run their businesses and develop their service offerings in an independent and agile manner. Within the main organization of Omega are four satellite organizations: general insurance, life insurance, real estate insurance, and asset management. These divisions primarily exist owing to the national legislative requirements that prevent insurance companies from offering more than one specific category of insurance: life, non-life, and pension. As a workaround, Omega established the aforementioned satellite organizations under the main umbrella organization to be able to offer services in each category. As such, Omega offers insurance services for life, non-life, and pension for a wide range of customers, both private and corporate. A multitude of different insurance services are offered by Omega, including coverage for homes and motor vehicles, personal insurance (such as travel and accident), forest insurance, and corporate insurance for statutory personnel, property, business, and finance.

Together with two other competitors, Omega makes up almost 81% of the insurance market in Finland, making them one of the top three largest insurers with a market share approximating 25%. Among the big players on the Finnish market, Omega is unique in being a mutual insurance organization, with its approximately 1.6 million customers mutually owning the business. Outside of the strict insurance ecosystem, Omega has also invested in and partnered with other actors. In 2013, Omega bought roughly a quarter of a large Finnish bank, and between 2016 and 2017, it further expanded into the health and wellness ecosystems by acquiring actors on the private healthcare market. These acquisitions and partnerships coincide with and inform the movements toward digital transformation as Omega initiated the development of its proactive health and wellness services.

The vision and mission of Omega have changed in accord with the evolution of organizational values; the current statements are provided in Table 9. Today, the key component of its vision is the provision of connected insurance. Omega has given an actual Finnish name for the connected insurance philosophy; owing to concerns of anonymity, the real name will not be used and the philosophy will be called connected insurance. Connected insurance aims to proactively mitigate the risk to customers in areas such as accidents or avoidable illnesses, shifting the core tendency of insurance away from being purely reactive and risk-based and toward a mutually beneficial and proactive service. In traditional insurance thinking, the emphasis is on reacting after an event and offering financial security to a customer if, for example, their house burns down. Omega is shifting away from this archaic paradigm by seeking to evolve its capacity to predict the event and proactively intervene to prevent it. In the context of a house fire, it is clearly more valuable for both Omega and its customer if the fire never starts in the first place.

Table 9. Omega's vision and mission statements.

Vision	Mission
Omega's vision is to offer Finns a safer and	Omega's mission is to safeguard the lives and
healthier life. Connected insurance means	businesses of our customers.
providing a proactive service to our customers.	

Omega considers prevention and proactive services to exist within two separate configurations. Prevention is an actionable risk-oriented intervention perpetuated by the insurer to stop something undesirable from happening to its customer. This

can occur at a larger scale, with examples including flu vaccinations, campaigns against drunk driving, and wearing correct personal protective equipment on a construction site. The majority of these services are provided through public campaigns using mixed media, corporate and customer training sessions, and direct customer contact. The proactive configuration is more complex because the provision of proactive health and wellness services is data-driven and therefore depends on access to the comprehensive data that can be used to create a holistic representation of the customer and their risk factors. To motivate the customers to share their data, Omega intends to provide both personalized and aggregate proactive services for customers in the categories of health, safety, and management of finances. Thus, health-related services can be tailored according to individual needs and can also provide overarching collective benefits through the emergence of population-level risk models and analytics.

Both preventative and proactive services are mutually beneficial for Omega and its customers for several reasons. First, as the principal portion of customer payments at Omega are health-related claims, including occupational healthcare and reimbursement of private healthcare costs, Omega is financially incentivized to reduce the likelihood of accidents and illnesses for the customer, ultimately improving the bottom line of the organization. The benefit of decreased costs in a mutual company is that the added value is funnelled back to its customers. Second, and more intuitively, successful preventive and proactive services represent positive impacts on several dimensions of the services: improved QoL through preventing accidents and injury, improved support of customer health and wellness, and improved customer experience.

The digital transformation of an actor inhabiting a notoriously archaic and rigid service industry makes for a very compelling case study. Omega offers a remarkable context for studying how the internal mechanisms of health data enable new modes of value creation and how the impacts of data-driven innovation practices reverberate throughout its organizational landscape. The intrinsic reimagining of the customer—organization relationships in the emergent data economy has the potential of creating positive health outcomes both in the short and long terms. In Omega's shift away from traditional forms of insurance and toward the provision of proactive data-driven health services, a necessity for frameworks that elucidate the impact of health data in digital transformation processes becomes apparent. Thus, implementing the mechanisms of health data—access, control, sharing, and use—should be a priority within the digital

transformation processes of Omega. Figure 10 schematizes the scope of this thesis and how digital transformation is associated with health data.

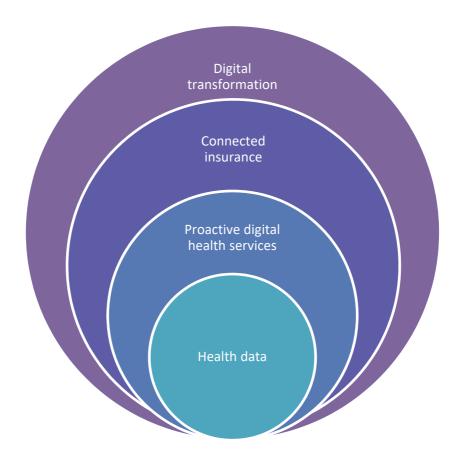
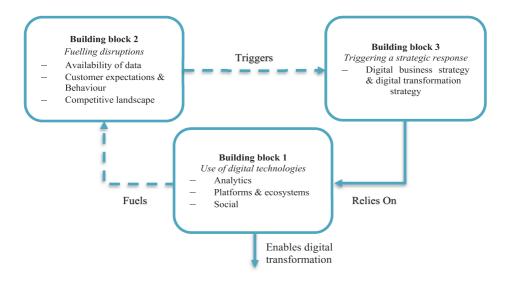


Fig. 10. Visualization of the role of health data in digital transformation.

## 4.2 Digital transformation momentum

The beginning of this narration describes the momentum leading up to the digital transformation that is currently transpiring within Omega. Figure 11 represents the first three building blocks of the digital transformation framework at Omega (Vial, 2019). The importance of the health data building block elements in the

presentation of both the narration and the visualizations are ranked by order of importance for health data.



Key: Dashed arrows represent the trends seen globally in the industry and society Solid arrows represent the digital transformation of an organization Elements ranked by order of importance for health data

Fig. 11. Digital transformation momentum: building blocks 1, 2 & 3.

# 4.2.1 Use of digital technologies

This section provides important context for the technologies that exist at the core of Omega's digital transformation processes. Figure 12 offers an overview of building block 1, use of digital technologies. It represents the ubiquitous practices that enable the digital transformation processes through the emergence of digital health platforms and healthcare ecosystems, big data analytics, and social networks. These digital technologies are being explored by Omega various areas and for different purposes. In the figure below, the key source areas of importance to Omega are empirically discussed and ranked in order of necessity for health data: use of digital platforms and ecosystems, use of analytics, and use of social media. Not all of the elements of Vial's (2019) framework in this building block are presented in the figure; mobile and IoT are interwoven throughout the other three

elements. For instance, mobile applications are used in connection with healthcare platforms at Omega. Therefore, mobile and IoT are simply considered to be part of use of digital technologies. Further, not all of the presented elements are tightly bound to health-related aspects. Instead, they set an important stage for future building blocks by providing important context.

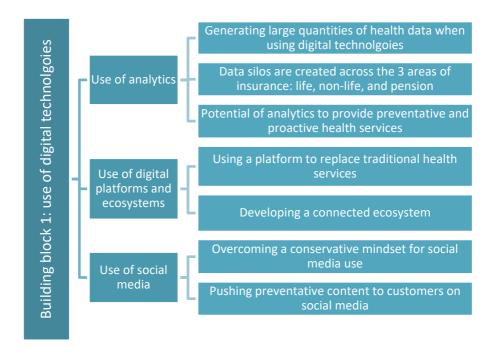


Fig. 12. Overview of building block 1: use of digital technologies.

## Use of analytics

The use of analytics in organizations is motivated by the promise of big data analytics. Omega, like many other organizations, understands the importance of accessing health data to analyze data as part of organizational processes and for the customer's benefit. Because the use of digital technologies leaves behind digital footprints, Omega generates and manages large databases of health data across its three main areas of business: life, non-life, and occupational health. All of these areas are rich sources of personal and health data that require storage and

maintenance. Life and occupational health are somewhat self-explanatory regarding why they include health data as part of their core purposes; non-life includes coverage for vehicles or homes and cottages. Car accidents, for example, have the potential to generate health-related data through vehicle-related claims because personal injuries such as whiplash are a common outcome even from low-speed accidents.

A common health data phenomenon arises owing to the discrepancy between company purposes (which is a legislative demand explained in section 4.1); the isolation of data groups creates silos between life, non-life, and pension services. This means that a customer who has health and car insurance at Omega could file a claim for macular degeneration requiring corrective lenses from health insurance while the non-life car insurance sector would not receive details about the new driving requirements.

"I'm actually personally more worried about silos between these different business areas. They use completely different systems; for example, the data that we are utilizing is mainly related to the insurance area. So, we don't really have a 360° view of the person. It is actually quite important that we have some holistic picture, of both the person as a person but also as a customer for our company." (Interview 25—strategic technologist: solution architecture).

This notion suggests both an internal need for interoperability mechanisms across the three areas of insurance to aid in the ventilation of internal data silos (PC1: Interoperability/PC3: Interoperability) as well as the access to additional data for generating a more holistic picture of customers through analytics (PC1: Reuse).

Interview participant 5 works as a Development Manager in the Data Business Intelligence and Analysis area of Omega. Their main area of expertise is grounded in mathematical training, and they primarily guide Omega in decision-making through the use of analytics. Analytics of health data aids Omega in areas such as prevention and proactive activities and is key in advancing Omega's capacity to help customers with acting before an accident or illness through artificial intelligence and machine learning. Occupational health and safety strive to prevent accidents or injury in the workplace, such as ensuring that hard hats and steel-toed boots are worn on construction sites. With advanced analytics and tools such as artificial intelligence, Omega would be capable of more intuitive responses to manage and change unsafe workplace practices; the illustration of a proactive service is made possible by leveraging the increased amount of personal data. Participant 5 shared a vision of supporting workers who send digital photos of

unsafe working conditions to Omega, whose services could subsequently analyze the content for potential risks and provide reports to the company, intervening if necessary—an example of analytics-powered personalized prevention.

# Use of digital platforms and ecosystems

The use of digital platforms at Omega falls short of ubiquity. Traditionally, or at least in the sense of traditional insurance in the digital age, customers filing claims or requiring healthcare services were channelled through telephone systems. Filing a claim at the time of the study required manually calling or filling out a non-dynamic online PDF form, a so-called old-fashioned method.

"We are working on the new system, and we have our old web services, our old forms in our web. They are kind of old-fashioned, and our customers are not happy with them; we get a lot of feedback all the time about them." (Interview 19—development manager: customer experience).

Awareness of the potential usefulness of digital platforms is evident in the plans for the "virtual hospital." The virtual hospital is an online resource for insurance customers to engage with medical professionals such as nurses and doctors. The platform is described as a technical support phone line but for your health. Nurses act as the first line of support to help with a majority of the customer health needs and doctors are available as the second line of support. Decision-making by the nurses to handle the majority of episodic health-related issues is directed through digital means; this is preferred over the tendency to always and mostly unnecessarily make an appointment. Omega estimates that approximately 60% of the appointments made to see healthcare professionals could be managed through digital channels.

"We have recognized we need different [health services] because most cases are short episodes, maybe 1 or 2 contacts. And we think that 60% of these contacts could be managed by digital phone or digital channel. So, there are going to be big Euros to spare if we can change this one." (Interview 10—development manager: digital health services).

Using digital means prevents the unnecessary use of healthcare resources, decreases waiting time for health services, reduces costs, and solves health-related problems for customers more quickly.

"In Finland and in other countries as well, the whole industry asks people to visit [healthcare centers] multiple times for the same reason, and people are tired of that." (Interview 22—unit director: research and development).

Because Omega is the result of a merger between two insurance organizations in Finland, the use of digital platforms for work processes is experiencing radical change. Internal digital platforms (not customer facing) are considered prehistoric, from the '80s and '90s.

"[Our] IT systems are dinosaurs. We have systems where we handle claims from the eighties and then we have [different] systems from the nineties. Now they are making a new [system] that would somehow be [evolving] everything." (Interview 5—development manager: data business intelligence and analysis).

Despite the difficulties and costs of navigating new IT projects, Omega is using the need to advance its systems as an opportunity to orient its work process toward a connected ecosystem. Omega's current ecosystem comprises organizations outside of its scope of insurance business, including a bank and a grocery store chain. More recently, a hospital has been imbued as part of the ecosystem in the form of satellite clinics throughout Finland.

#### Use of social media

Initially, the use of social media at Omega was strictly banned. Uncertainty about the value of social media and concerns of repercussions kept Omega from exploring this avenue of digital technologies.

"Companies were more restrictive in using social media channels; back then it was mainly the question about Facebook, and how companies should be presented in Facebook, and at least in Finland in 2010 it was like "don't tell anything" type of policy." (Interview 15—communications manager: public relations).

However, in 2018, Omega took steps toward exploring social media avenues and hired a team.

"We will do some new recruitment for social media and start to invest more in that social media presence." (Interview 15—communications manager: public relations).

Omega has made the leap to engage social media channels for different purposes and now has a presence on mostly Facebook, Twitter, Instagram, and LinkedIn. About 10.8% of Omega's customers self-reported following Omega on at least one social media channel. The majority of these (9.2%) are on Facebook according to the *customer survey 2018*. Omega is also supporting the use of social media internally and encouraging employees to engage in these channels.

"Actually, Omega is encouraging us to use Twitter, Facebook, and LinkedIn." (Interview 16—development manager: corporate business worker's compensation).

Despite the evolution of its attitude toward social media, the communication channels are not utilized for bi-directional functionality. Instead, various types of content are pushed toward customers with limited customer interaction.

# 4.2.2 Digital technologies fuelling disruptions

The use of digital technologies fuels the increased availability of health data, change in customer expectations and behaviour, and change in competitive landscape. Along the path to digital transformation, these three key areas have radically disrupted Omega's role in the insurance sector. Below, each of these three areas is narrated to describe Omega's mimesis and momentum leading up to its strategic response and gateway into digital transformation. Figure 13 represents building block 2.

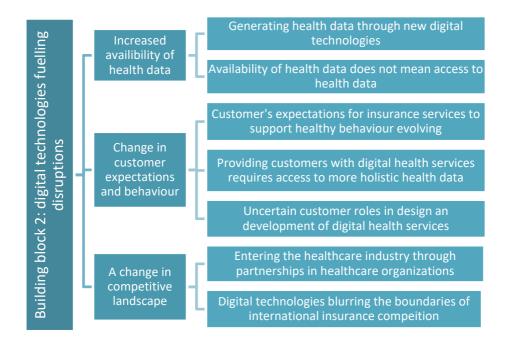


Fig. 13. Overview of building block 2: digital technologies fuelling disruptions.

#### Increased availability of health data

A fortunate and rich by-product of the use of digital technologies is the generation of personal and health data. Omega, like many other organizations, is largely data-driven and thus requires access to data at an operational level.

"Without data we have no company." (Ethnography 4—lawyer).

The healthcare industry generates huge volumes of health data through the nature of their business. However, health data are increasingly being created by individuals through IoT-enabled devices such as activity trackers and mobile phone applications. Increased availability of health data does not necessarily mean that the data are accessible to Omega; it merely means that data are being generated at an unprecedented rate. The increased availability of health data is also disrupting the role Omega has as a processor and controller of personal data.

"The biggest challenge is to manage the data in a quick way and everyday more and more data comes in. We don't have time to control the data like a conductor." (Ethnography 8—project manager).

In Finland, there exist restrictive legal policies that apply to insurance organizations and their access and use of health data. Omega has the right to acquire health data when they are related to a claim being processed (G1: Legislation), including existing health data from the public sector (G4: Legislation). But individual data is not readily available to Omega.

"In Finland, there's a law that data is available in those certain cases, for example, [claims]. And legal healthcare data, which is mainly what happens if you get hurt or get sick on your way to work or during the worktime or in traffic. That healthcare data is available already for the insurance company." (Interview 22—unit director: research and development).

To access customers' health data, permission is required by the data subject, who is empowered to choose how, when, and if they will share health data with Omega (DS1: Legislation/PC2: Management/DS2: Management).

## A change in customer expectations and behaviour

Omega is a unique case example because they are a mutual insurance organization, meaning that customers are also owners and that valuable factors for Omega are valuable factors for the customer. The expectations of customers are challenging the traditional insurance models, and customers are looking for experiences beyond reactive insurance. Fuelled by the use of digital technologies such as the virtual hospital at Omega, how the customer—payer relationship plays out is evolving. A change in customer expectations and behaviours is pushing service development to embrace these new needs by incorporating behaviour change models. These service-driven behaviour changes aim to create value for the customer by improving their health outcomes with proactive management of disease and chronic illness and for Omega by reducing the burden of claim payment, which represents the largest cost at Omega.

"We are creating all kinds of tools and ideas [which] people can understand [their health]. We basically show them a mirror; that's how you look like right now. If you want to do something, it's time to behave differently. So, they will

[treat themselves better]. That's the main idea as well." (Interview 22—unit director: research and development).

However, to match or transcend the customer expectations for proactive health services, Omega require greater access to customers' health data. Customers are empowered to share health data through legal sanctions (G3: Legislation/DS3: Legislation) but lack interoperable capabilities in the landscape (E3: Interoperability), and Omega (PC3: Interoperability) is not yet capable of providing such a mechanism (DS3: Interoperability).

Healthy behaviour expectations related to the digitalization of services is evident in the customer behaviour, although it is not fully understood by Omega.

"Definitely, we should have interviews for our customers; we should observe how they behave in certain channels, try and understand some of the behavior in general, and design services together. All of this." (Interview 12—development manager: customer experience research).

However, approximately 75% of customers from the *customer survey 2018* report that they do not feel there are opportunities for their involvement in the development of new services; in contrast, there is about equal interest and disinterest in participating with Omega should the opportunity arise, according to *customer survey 2018*. This serves as an indication that customers are more willing to participate in the design and development of digital health services with Omega than there are available opportunities to do so (DS4: Engagement).

The virtual hospital allows Omega to provide remote health-related services to its customers, but the healthcare experience differs from a simple healthcare professional and patient interaction. Some cases demand medical examination and are strictly tied to Omega's perception of providing good customer experience, which is only possible when all the health details are available (PC1: Engagement). An example of how not having all the details led to a poor customer experience was provided by the unit director of new business development (Interview 6), who acknowledges that accessing additional data to make a difference is a tricky process. A female health insurance customer of Omega called to ask for advice in treating her daughter's suspected ear infection. The nurse guided the mother to help treat the pain and the case was closed. However, the mother did not disclose that they had planned to travel in the coming days and only used painkillers to help alleviate her daughter's ear pain. Her daughter's persisting pain motivated the mother to seek medical attention elsewhere, and both the problem of the ear infection and the

worry of travelling with ear pain were alleviated. Omega followed up with the case only to learn that the mother actually wanted to know if it was safe for her daughter to travel as well as what could be done to treat her daughter. While the customer might have had a straightforward case from the nurse's perspective, one that did not even require a prescription, the whole picture proved more complex than could be solved within the current confines of the digital service. This dichotomy between the customer's expected service outcome and experience and the ability of the service to match that expectation represents an issue that needs to be resolved. Being able to offer and being able to experience engaging and holistic services are values echoed by both Omega (PC1: Engagement) and its customers (DS1: Engagement).

## A change in competitive landscape

A change in competitive landscape is both a result of Omega's decision-making and the disruption to the competitive market in Finland. Omega's ecosystem alliances with non-insurance organizations (such as a bank and a grocery chain) have segued into previously uncharted waters. By purchasing 10% shares of one of the largest hospitals in Finland, Omega entered as a competitor in the health sector and not just as a payer but as a player.

"We bought ten percent of the second largest private hospital in Finland. Right now, the biggest thing concerning health and service development is happening with [them]." (Interview 2—unit director: business workplace health and safety).

By the end of 2018, Omega had increased its share to 20%. Because digital technologies represent critical disruptions of the competitive landscape, insurance providers (Omega included) are contemplating the value of digital delivery services over traditional products. All products provided by Omega are being converted into digital services wherever possible: for example, the filing of claims, shopping for and purchasing insurance, and/or contacting insurance advisors. Health is the most complex of these processes owing to the nature of providing healthcare (for example, performing surgery).

Traditionally, in Finland, the insurance sector was clearly defined and regulated; however, the aligning of the private sector with healthcare is challenging how insurance can operate in these new ecosystems. The chief digital officer of digital health services expressed one sure difficulty as policy:

"There is nothing in our current services that would require physical form of anything. The only thing being physical is actually our health business. We are doing everything we can to be as digital as possible. So, we really would appreciate [it if] the competitive environment would enable us to operate with reasonable terms and conditions which would be shared with everybody and not creating this unhealthy situation." (Interview 13—chief digital officer: digital health services).

Because access to health data is fundamental for proactive health services, Omega in its role as a business requires policy to support its transition across traditional insurance boundaries and into the healthcare sector (G1: Legislation).

Omega's entry into healthcare is creating competitive pressure in the existing healthcare markets; the reverse is also happening in the insurance sector. Previously non-insurance companies such as banks are now entering into the insurance market to provide more holistic services, including underwriting, meaning that market boundaries are no longer clearly defined between the insurance sector and the banking sector. Consequently, a banking organization that was previously outside of Omega's scope now represents its main competition.

"Yeah, they are our primary competitor. Originally a bank, but they have bought an [insurance company] and now they are all within the [competitor] branch." (Interview 12—development manager: customer experience research).

Omega is experiencing the effects of the change in the competitive landscape not only within Finland but also internationally, with international actors blurring the traditional boundaries of insurance provision and making it increasingly difficult for Omega to navigate the change in digital competition. The digitalization of insurance has enabled customers to seek insurance services from outside of Finland, such as from international competitors in Norway and Sweden. A perilous consequence of an increasingly global competition is the increased plurality of insurance services driving down market rates. Insurance markets in Finland are currently being oversaturated, with over 700 new companies every year.

"There is, at the moment, a lot of competition: for example, a company from Norway which is operating as [an international] model. Their expense ratio is seven point something. And in Finland, insurance companies' expense rates are eighteen to twenty-five, between [those numbers]. When you have this kind of advantage, [as the] expense ratio, you could put the prices down and win

the battles in [company insurance]. And we're facing that battle at the moment, and we have a pressure to put the prices down." (Interview 17—unit director: claims).

To differentiate itself, Omega is focusing on a customer experience superior to that of its competitors because the core concepts of insurance are quite similar. Cost of insurance is one of the first considerations a potential customer has, and where Omega cannot overcome the cost obstacle, it can create value for its customers by providing a stellar customer experience.

"We are not that much different from the insurance companies. The products and services are quite [similar in prices], and it's the service that we should use [to compete]. That our service is the best service." (Interview 19—development manager: customer experience).

# 4.2.3 Triggering a strategic response

The use of digital technologies that is fuelling the disruptions is the momentum leading up to the initiation of the digital transformation process in Omega. These conditions have necessitated Omega to develop strategic digital responses to stay competitive and gain market resilience. Omega's digital transformation strategy and digital business strategy are narrated in this section, and they act as the helm for the remaining five building blocks. Vial (2019) outlined that within building block 3, triggering a strategic response, there are two elements, the digital transformation strategy and digital business strategy. The digital business strategy builds on the optimal use of digital resources to create value, whereas the digital transformation strategy represents the organizational changes caused through the use of digital technologies. The narration of these two triggers has found them to be fundamentally entangled, and they are therefore considered as an interwoven whole for triggering a strategic response. Because this building block is a single element, having a strategic response is considered as a critical point for the initiation of digital transformation in this case study. Figure 14 provides an overview.

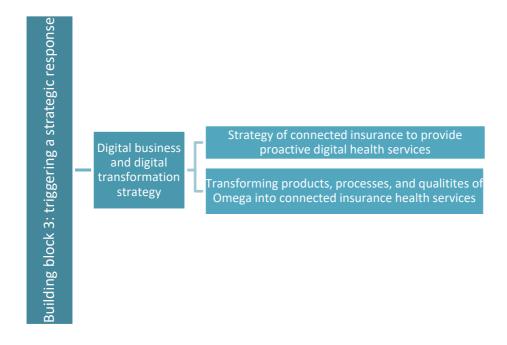


Fig. 14. Overview of building block 3: triggering a strategic response.

Prompted by the use of digital technologies and disruptions such as availability of data, Omega is transforming its business model through the formulation of a clear digital strategy: connected insurance. This strategy encompasses both the digital business angle for the advantageous use of digital technologies as well as digital transformation to guide the changes taking place in a bid to leverage its breadth of digital resources. The connected insurance strategy formulated by Omega in its vision and values (mentioned in section 4.1) trickles throughout its decision-making and guides the digital transformation.

"Our long-term goal is to move this connected insurance in the company. Try to secure people living a life in a healthier way and less risky and so on. Of course, that's our group strategy and it will be a 10-year journey. And we will [navigate] through that goal. That means that we move from a product company to a service company and extend our business to healthcare and smart homes or [car sharing]. These kinds of things." (Interview 6—unit director: new business development).

As already explained in-depth, the complex and competitive service ecosystem of Finland is shifting, and Omega's digital strategy represents its efforts to weather the storm. In line with this goal, Omega is aiming to differentiate itself from its roots as a traditional insurance provider by transforming its value propositions to support data-driven service provision, associate its processes with good customer experience outcomes, and therefore evolve the fundamental qualities of the organization.

"The insurance industry right now in Finland, it's [a] pretty... old type of business. It's very traditional, and we are changing that, so basically, my duty here is to change us as a product-type of company, to switch that to the service type company." (Interview 22—unit director: research and development).

Part of Omega's strategy is to alter its market position through leveraging strategic alliances and investing in existing organizations that represent its vision and values, with a heavy emphasis on healthcare-related stakeholders. Its new strategic partner, dubbed Epsilon, one of the largest private healthcare companies in Finland, possess existing digital technologies as part of its healthcare services. Omega plans to leverage these digital health data resources to further sustain the ideation and development of novel proactive health services (PC4: Reuse). In a nutshell, Omega plans to benefit customers via service platforms that collate the customers' required services under one roof, connecting the different parts of its value creation pathways with all its partners, including a bank and a grocery chain.

To complement this digital business strategy, Omega will also be transforming the digital services of its new healthcare partner to more closely align with its vision.

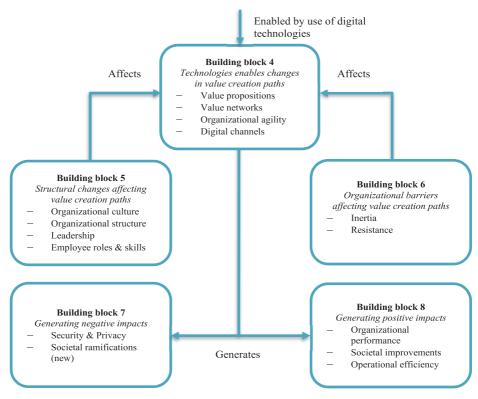
"Every day, I have a meeting with the private hospital, the directors of the private hospital. So, we go through services and products that we want to offer the customers." (Interview 2—unit director: business workplace health and safety).

The unit director went on to explain how an existing service dubbed "workplace compass" was developed by Epsilon and further adapted by Omega for corporate customers such as HR, occupational health teams, and supervisors. The workplace compass gauges employees' risks for workplace accidents and sick-leave patterns, alerting management to intervene to deal with elevated risks when appropriate. Having corporate customers use these sorts of services allows Omega to generate health data for use in ongoing sustainability services and the development of digital health services (PC4: Sustainability).

Part of Omega's guiding vision for the future of its proactive insurance is to provide customers with holistic support for health and wellbeing, ultimately requiring access to customers' health data. The strategic response of Omega relies on the contextual use of digital technologies to further enable the digital transformation processes. The shift away from reactive toward proactive digital health services presents a fundamental requirement of proliferating health data to achieve the value proposition set forth in the connected insurance strategy.

# 4.3 Digital transformation

The remainder of this narration will be more focused on the health data roles in Omega and their digital transformation. At the end of the narration is the framework that synthesizes digital transformation as mechanisms for health data factors, offering a structured approach for how to navigate through the building blocks of digital transformation. These blocks elucidate why certain approaches are critical for Omega and its customers, what are the legal considerations of policies such as the GDPR, and which properties of health data catalyze the transformation process. Figure 15 represents the digital transformation in regard to the remaining five building blocks (Vial, 2019).



Key: Dashed arrows represent the trends seen globally in the industry and society Solid arrows represent the digital transformation of an organization Elements ranked by order of importance for health data

Fig. 15. Digital transformation: building blocks 4, 5, 6, 7, & 8.

## 4.3.1 Enabling changes in value creation paths

The changes in value creation paths are enabled by the three previously mentioned building blocks that are part of Omega's digital transformation momentum. Figure 6 provides an overview of the entire process. This section will focus on the latter half as seen in Figure 15. The changes in value creation paths for health-related digital transformation activities at Omega are described via four key elements: value propositions, value networks, digital channels, and organizational agility. The "ambidexterity" part of the element "organizational agility" from Vial's (2019)

framework is not presented because Omega's inability to exploit their existing resources (of health data) limit how the bimodality can be explored and thus is not included. The overview is presented in Figure 16.

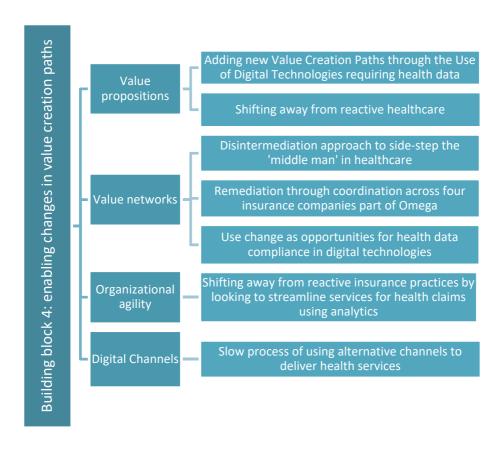


Fig. 16. Overview of building block 4: enabling changes in value creation paths.

## Value propositions

Omega's strategic change to provide holistic services instead of insurance products creates new value propositions or methods for generating value. Traditional models of healthcare require the individual to go to a clinic or hospital to receive medical care from healthcare professionals. Certain processes of these models cannot be

changed owing to the needs for proximity and medical expertise, such as surgery. However, Omega is offering digital health services that allow customers to use digital technologies to be diagnosed by healthcare professionals—or further referred. The implementation of the virtual hospital is creating a new path for value by moving services away from patient—clinician interaction and offering a means for customers to engage with healthcare professionals regardless of location. The addition in the care pathway for insurance customers decreases costs for Omega by reducing the number of customers visiting healthcare professionals for health-related needs that can be supported digitally, thus decreasing pressure on valuable healthcare resources and expertise.

"Nurses in the first contact decide what this is and what is the need for this service and for this customer. Now it goes like this; I call and almost every nurse gives [a] doctor's appointment. So, if you think about euros or think about the customers' time, why does he have to go to the doctor's appointment if [there is no need to go the nurse] can handle it by phone or by digital network or something? This is quite a new thinking and it's a very big thing to change the nurses you know; they don't just give the doctor's appointment [to every customer who calls]." (Interview 10—development manager: digital health services).

However, the service implementation requires holistic health data pulled from internal data silos (PC3: Interoperability) as well as from sources outside of Omega's access, prompting the need for customers to be incentivized to share their health data (DS3: Reciprocity).

#### Value networks

The digital transformation of Omega is altering the value networks in the organization in two distinct areas: competitively and internally. Omega is using a disintermediation approach to build a value network among healthcare competitors by side-stepping the health "middleman" and creating direct contact with the customer, in line with its insurance—health strategy. To achieve this, Omega has had the foresight to partner and purchase a significant share of the healthcare organization Epsilon that acts as the medical branch of the insurance organization, effectively removing the need to outsource health services and leveraging existing intermediaries to bring the customer's health concerns closer to Omega. As part of its strategic vision, the disintermediation has wedged Omega into the competitive

Finnish healthcare market. Furthermore, this partnership enables Omega to use Epsilon as a processor of health data, allowing access to customers' health data as a part-owner and partner (E1: Procedure).

Value networks are also being internally transformed at Omega. The remediation approach enables coordination among the four different insurance companies under the Omega umbrella (general, life, asset management, and real estate insurance). Because Omega is the result of a 2012 merger between two organizations, the incompatibility of their legacy systems combined with the need to distinguish between the four areas of insurance has created significant data silos within Omega (PC3: Interoperability). To remedy this shortcoming, a new digital platform, Lava, is being developed by an American company to connect and support a new value network of companies within Omega.

"The scope of the Lava project is really focused on changing the core insurance system. A new initiative which is still at least to some extent within the Lava umbrella is the customer experience layer, which is then responsible for, for example, building the sales and services applications that Lava will utilize when it comes to selling these new insurances or providing services related to those. But the key thing is that it is not within the insurance silo. All in all, I think it is mainly about building the customer-facing applications, whether it's [in the form of a] web site, web shop, self-service portal, or mobile application." (Interview 25—strategic technologist: solution architecture).

Omega also sees the expensive need to create and implement Lava as an opportunity for GDPR compliance (PC1: Legislation/PC2: Legislation/PC3: Legislation/PC4: Legislation) and for creating a new customer-centric layer to improve the customer experience, leaning heavily on the future use of digital technologies. The new system would include data-centric capabilities such as enabling customers to have access to and control over their health data (PC1: Accessibility/DS1: Accessibility/DS1: Management/PC2: Management/DS2: Management/DS1: Legislation/DS2: Legislation), facilitating health data sharing through a portal (PC3: Interoperability), and ensuring transparency around the use of health data at Omega (PC4: Transparency).

## Organizational agility

Changing the value creation paths at Omega will require an increased focus on agility, especially regarding customer-related concerns. Data-driven claims services can minimize the time duration but require the customer's consent.

"[We are making] the services quite adjustable so that you can move things in different ways. We are offering this, but if you don't [want to share your data, check the box], and [maybe the service won't be that good], but it's your choice. You can't use our automated [processes], and you can get the compensation [in] the same day, or you can write us a postcard, and you get the compensation [after] one month. Your choice—fast or slow. But you have to [facilitate for both of those services]." (Interview 26—lawyer: GDPR).

Data-driven decision-making for sales is the most advanced and agile form of transformation currently being enacted at Omega using algorithms and predictive analytics both to target potential customers as well as retain current customers.

"At the moment, we use data, perhaps, the most in sales analytics. I think that's the main thing. The progression has been, you know... we're furthest ahead in the sales analytics: which customers we should contact." (Interview 2—unit director: business workplace health and safety).

Being agile is part of the connected insurance strategy because it changes the traditional means Omega uses to create value and brings the customer closer as a whole. In summary, being proactive means offering the right intervention at the right time, which necessitates access to customer health data to respond in a significant manner (PC4: Engagement) (Article II).

## Digital channels

Through the use of digital technologies, Omega is altering the channels through which they distribute health insurance. Part of the digital transformation process at Omega has forced reflection on the traditional notions of insurance organizations as slow-paced and unable to respond with any capacity for agility. The development manager for customer experience at Omega compares the capabilities of Omega with a similar organization in the Netherlands, noting that the Dutch insurance company can respond to customers through WhatsApp within 20 minutes, whereas

Omega is stuck using slow traditional channels (2 days instead of 20 minutes) and therefore is unable to create a good customer experience.

"Because we are such a big company, things [run] a little bit slow. Now we have the traditional service channels for our customers: phone, our web service, and the office. Why can't we serve customers using WhatsApp, for example? I think it was our partner from the Netherlands; they had the service promise that they answer within 20 minutes. We are so far [away] from that." (Interview 19—development manager: customer experience).

The use of digital technology for digital channels is a limiting factor for Omega to access health data in its current, underdeveloped state.

# 4.3.2 Structural changes affecting the value creation paths

Transforming the value creation paths affects the structural changes taking place at Omega and is guided by the connected insurance strategy. This building block (five) explores four areas of structural change for Omega: organizational culture, organizational structure, leadership, and employee roles and skills. In addition, with contributions from Articles II, III, VI, and V, further insights are provided into certain critical structural changes at Omega, such as the need for employees with certain skills to accommodate value co-creation activities between Omega and its customers. Figure 17 presents the overview.

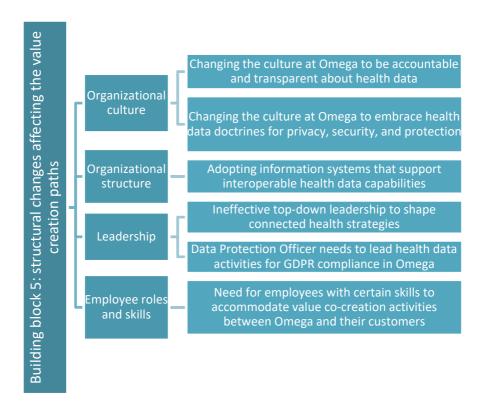


Fig. 17. Overview of building block 5: structural changes affecting the value creation paths.

## Organizational culture

While organizational culture is always in a state of flux, it is especially disrupted by the changes introduced by digital transformation. An intentional and focused effort is required to develop a common understanding of what connected insurance means to the organizational culture as well as the mechanisms through which those values manifest in everyday practice. How an organization transforms its culture is arguably the key activity Omega must undertake to meet the expectations of its strategic response.

"It's not a question of discipline; it's a question of culture." (Ethnography 8—project manager).

Some organizational culture changes have taken place at Omega, such as its attitude toward the use of social media. With the common vision of connected insurance, three primary shifts need to take place to support a proactive culture at Omega: creating a culture of accountability, a culture sensitive to the data doctrines of privacy, security, and protection, and a culture of transparency. Articles II, III, IV, and V pointed to organizational culture as part of what necessitates digital transformation at Omega. In contrast, Article I delineated how culture facilitates or hinders access to health data. All articles are synthesized below, elucidating the need for accountability, a data doctrine, and transparency in Omega's organizational culture to support its transformation into a proactive health service provider.

Accountability culture is the ability of Omega to facilitate moral culpability for its actions such as claims decision-making processes and when access to health data occurs (PC1: Accessibility). Accountability has been shown to be beneficial for healthcare professionals and patients when accessing their health data (E1: Accessibility) (Article I). Facilitating accountability is demanded by the customers as a prerequisite for sharing their health data with Omega. Customers require the ability to see who has accessed their health information and why (DS1: Transparency/ DS3: Culture) (Article V).

"I must have the right to see who has accessed my insurance and health information; I must be able to see what has been logged in my data file." (Customer survey—customer 195: female aged 45–54 years).

Accountability is further necessitated by the GDPR for processor and controller compliance of health data (PC1: Legislation). It is challenging for Omega to provide proof of compliance and is a burden of obligation (Article IV).

"The culture, you have to bring the new culture for accountability. That accountability is a new one. So, you have to inform everything that you do, and there's quite much paperwork to be done." (Interview 26—lawyer: GDPR).

In an attempt to facilitate the formation of accountability culture toward health data, informed consent is being employed to apprise customers of how their health data will be used in, for example, the virtual hospital (PC2: Management/DS2: Management). Informed consent also aligns with the GDPR functionalities, where

data subjects develop an accurate and detailed understanding of the intended purpose of collecting or using their data (G4: Legislation/DS4: Legislation) and customers are empowered to decide if that service is responsible for using the health data and control the outcome (DS2: Management).

"We have to be clear enough to tell the customers what data we are using and for what purposes. We have to make a lot of documents and information for our customers, and I think it's a good thing, because... If you can't understand what we are using your data for, how can you give consent? And how can you make any decisions? So, it should be accountability." (Interview 26—lawyer: GDPR).

A data doctrine culture is Omega's state-of-mind, guiding its actions toward the creation of an environment optimized for encapsulating data as part of a digital culture change. Security, privacy, and protection are all components of a data doctrine culture that are necessitated by customer expectations (Article V), by legal requirements such as the GDPR (Article VI), and for supporting the organizational goal of connected insurance (Articles II and III). Although the three concepts overlap, they should not be conflated. Security is preventing external access to health data using digital technologies (PC1: Accessibility) to provide storage and utilization functionality while securing the health data (G1: Legislation/PC1: Legislation/PC1: Culture). Privacy is allowing access to health data but only via authorized persons (PC1: Accessibility). Privacy of health data also allows for data subjects to control how their personal information is used (DS2: Management). Protection is preventing unauthorized access to health data internally at Omega (PC1: Accessibility). Security of health data is heavily reliant on how Omega uses digital technologies to safeguard data. Omega has a long history of managing very sensitive information, and connected insurance increases the breadth of sensitive data being controlled and processed, thus requiring more flexibility in testing the IT solutions in place (PC2: Culture) (Article II). The unit director of ICT and risk management at Omega is steering Omega's attitude toward preventing negative security events by hosting Hackathons for skilled hackers to test existing systems for flaws and points of vulnerability, offering financial incentives as rewards.

"Information security in Finland has been very old school. It's quite typical; you write policies, you fix the firewalls, and things like that. But we started a hack day event once per year. This year, we have two of those kinds of events;

that's sort of an introduction." (Interview 30—unit director: ICT and risk management).

Customers at Omega consider information security as a primary concern that affects their decision to share health data with Omega and demand security-related criteria in return when sharing their health data with Omega (DS4: Reciprocity) (Article V). Some of the customers state in no uncertain terms that Omega should be:

"Taking care of information security." (Customer survey—customer 234: male aged 35–44 years).

Issues of privacy are more nuanced, relying on both digital technology functionality as well as the actions of Omega's employees to access health information (PC1: Culture/PC1: Accessibility). Patients and healthcare professionals have negative inclinations toward health data being accessible owing to the risks associated with privacy (E1: Culture) (Article I). Omega, in alignment with the GDPR, should therefore orient organizational culture around the privacy of health data (G1: Culture) (Article V).

"We need to teach our organization what privacy really means." (Ethnography 4—lawyer).

Protection of health data requires the internal IS at Omega to prevent unauthorized access, such as employees looking through family members' claims (PC1: Accessibility). Because individual health data is sensitive by its very nature, only those with authorization to access this data should be able to do so, and IS should prevent access and use otherwise (PC1: Culture/PC4: Culture). Moreover, IS should maintain a detailed log of health data access for accountability purposes. Privacy (allowing internal access) and protection (denying internal access) are complementary to a digital culture change, where access is an expression of power. Customers understand that their data is a source of power and strongly emphasize that Omega should act in a way that provides professional confidentiality as part of the conditions to be met when sharing health data (DS3: Reciprocity/DS3: Culture) (Article V). Privacy and security are predominantly important for mitigating negative impacts as part of digital transformation in section 4.3.4.

Creating a culture of transparency in organizational practices promotes trust with customers (Articles II, III, & V). Access to health data has been associated with positive benefits for patients because it facilitates transparency through active

participation (E1: Transparency) (Article I). Further, transparency is a core principle in the GDPR and ties to the responsibility of processors and controllers for access (PC1: Transparency), control (PC2: Transparency), sharing (PC3: Transparency), and use (PC4: Transparency) of health data by promoting trust (Articles II, III, IV, & V). How Omega intends to use a customer's health data remains generally unclear from the customer perspective (PC4: Culture/PC3: Culture/DS: Culture), despite the descriptive sources available online and the required signing of informed consent forms (Article V). Connected insurance seeks to rise above the disconnect between customers' understanding and the use of health data (PC4: Reciprocity).

"I think we have a smart insurance service available to some customers and the way that it is done is it is targeted toward customers that are okay with a company using their data, so it is very explicit, very clear that with optional service, we use your data to provide better services." (Interview 12—development manager: customer experience research).

The access and use of health data remain imperative for providing proactive health services. Without these mechanisms, no data-driven generation of personalization or health-related interventions can take place (Article II).

"We don't have the data, and to have that data, we have to have the trust of the customers. We have to give birth to trust for the customers and they have to see the value [in the services] that [makes them want to share their data]." (Interview 22—unit director: research and development).

Creating a culture of transparency requires Omega to promote trust through customer participation (PC3: Transparency/DS3: Culture) (Articles II and III). Imbuing honest and open values as part of Omega's organizational culture supports internal transparency and sets the tone throughout the company to focus on iterative change by acting on employee feedback in an agile manner (Article III). Employee values, initially driven by the strategic response, require the continuous embrace of a proactive mindset in day-to-day activities and translating the new value creation paths into digital technologies. Service design can be a tool to support the change in mindset from reactive to proactive and represents a part of the organization culture change needed at Omega (Article II).

## Organizational structure

To operate within the legal requirements for insurance organizations to only sell one of three possible insurances (life, non-life, and pension), Omega has 22 companies under its umbrella. Owing to this, the creation and collection of health data in all three insurance categories has generated data silos, requiring collaboration across the companies to transform the organizational structure of Omega through the use of digital technologies.

"As you won't get the full benefit if you don't break down data silos." (Ethnography 11—project manager).

Omega's new value network tool, Lava, affords the opportunity to facilitate the cross-functionality required for life, non-life, and pension insurances to communicate (PC3: Interoperability). The Lava IS should be adequately designed, allowing accessibility and interoperability of data across the many insurance companies under Omega's organizational umbrella (PC3: Interoperability) (Article III). Interview 25, strategic technologist for solution architecture, highlighted this need for organizational structure, especially to enable proactive health services through data. They further emphasized that Lava will not be the solution to engaging the customer in such a way that it provides a holistic picture; instead, access to health data will be through interoperability of all the Omega companies to help break the silo walls internally (PC1: Interoperability).

"Lava is something that happens within the insurance area. It doesn't really touch anything that happens outside. And, of course it will fix some issues but only within the insurance business area." (Interview 25—strategic technologist: solution architecture).

#### Leadership

As the digital transformation process advances throughout Omega, flexible leadership is needed to respond to emergent disruptions while also keeping Omega's shift toward the strategic targets represented by connected insurance. Leaders at Omega are blurring organizational boundaries to smooth out connected insurance throughout business practices and affect digital technologies in a strategic manner. In January 2018, a new director (interview participant 22) was hired to manage the research and development at Omega. As a result of their arrival, they halted all ongoing projects, delaying the intended release date of a Chatbot in

the virtual hospital from March to summer. In Finland, most of the country slows down to take vacation; therefore, the newly planned implementation in summer faced numerous difficulties, ultimately delaying the release by another four months. Across the levels of the organizational hierarchy, looking upward, interview participants mostly at the middle management or operational level indicated a gap. Leaders of Omega are perceived to not fully comprehend what they are committing to when guaranteeing the launch of a service.

"Our leaders make promises, and the promises are "We will have four launches this year." And when they make these promises, they don't even know what the launches are. But there is a gap [between] designers and leaders, and project owners." (Interview 28—leading expert: customer development).

This calls into question the communication of Omega's leadership. All interview participants were aware of connected insurance and its purpose, but not everyone understood the implications and requirements for its implementation. Health data is highly sensitive and strictly regulated; thus, a unique position of leadership is required to guide how Omega should act.

"The DPO is the strategic role at the heart of everything; they must be part of the organization, trusted, and at a high level." (Ethnography 1—consultant).

The DPO, interview participant 26, spoke nothing of being a leader but understood their role in imbuing current and future digital technologies with GDPR-compliant elements and reflecting the culture of privacy in everyday practices (PC1: Culture); this indicated that the current leadership at Omega may not be effective from a top-down perspective and that there is a clear need for one or several digital transformation champions to lead the transformation of digital technologies in a pragmatic fashion. Leadership is also needed to inform and champion strong practices of access to health data because the creation of proactive health services, and by extension the entire digital strategy, hinges on Omega safely navigating data concerns.

#### Employee roles and skills

Digital transformation is an ongoing and disruptive process that distorts the boundaries of employee work-roles, thrusting employees into new positions and challenging their skills and capabilities. Where traditional roles of employees may have organically changed, digital transformation is altering employee roles to also

include the culture of privacy and accountability. As part of connected insurance, involving the customer to influence the changes in value paths, which is strategically important for designing and developing health services required by customers, ultimately incentivizes health data sharing (PC3: Reciprocity). Customer value co-creation is understood to be "the" approach to take; however, enacting customer involvement beyond traditional co-creation practices is mystifying for employees, largely owing to a lack of skills to complement the strategic goals of connected insurance.

"I feel that even the top management welcomes this idea of customer cocreation. But people here, the way I see it, don't really have the skill set or they don't really know how to involve the customers. Is it okay to bother them and ask them to answer our questions and really create these services together? There is no resistance, but people here just don't know how to do it." (Interview 12—development manager: customer experience research).

Furthermore, the list of skills required for healthcare professionals employed by Omega is evolving to fit connected insurance requirements. Healthcare professionals who embody the desirable mindset are being hired, such as doctors and nurses working under the umbrella of insurance, albeit through the virtual hospital platform. Doctors are working as the second line of support, much like a technical support line, for nurses to provide digital care.

"So basically, the whole digitalization [process] will change those old types of models where doctors will run the business. Now, we are trying, as an insurance company, to run the business. And that's why we have found the doctors who understand how to do that; how to give the best services without the [customer having to go anywhere else]. And they save time and money, we save time and money, and everybody wins in the long run. And that's why we have been hiring such great doctors who are now working here by the nurses." (Interview 22—unit director: research and development).

The development manager of digital health services (interview participant 10) understands that the digital workforce at Omega is very demanding and advocates for the expansion of existing employees' skills as well as hiring more to meet the requirements of digital transformation.

"We have both, because in-house we have very nice, very skilful persons, but we don't have enough, so we have to [hire more]." (Interview 10—development manager: digital health services).

## 4.3.3 Organizational barriers affecting value creation paths

A significant amount of the transformation taking place at Omega is hindering its capacity and changing the value creation paths. Building block 6 investigates these barriers in greater detail through the concepts of inertia and resistance. Articles II—IV have generated considerable in-depth insight into these areas for health data–related barriers during the transition from reactive to proactive at Omega and are narrated below. Figure 18 is an overview of this building block.

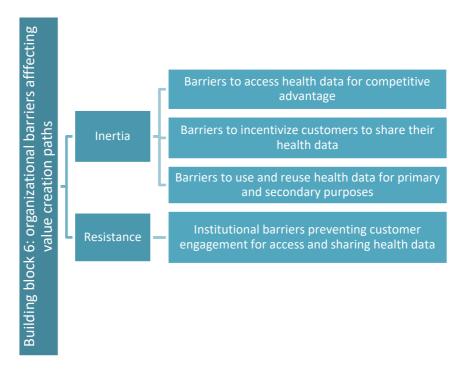


Fig. 18. Overview of building block 6: organizational barriers affecting value creation paths.

#### Inertia

At Omega, proactive capabilities are rendered inert without sufficiently sourced health data fuelling the holistic digital health services being utilized. The pervasive use of digital technologies, such as fitness trackers, is catalyzing change in mainly owing to the quantity of health data available. Barriers to health data as a resource require identification and flexible management during digital transformation. Discussed below are a synthesis of Article II and the inertia of four health data barriers at Omega: access, control, sharing, and use. Article V is also used to complement the customer perspective for health data sharing.

Access to health data is necessary to sustain digital health services, sustain Omega in competitive healthcare markets, and generate value for customers (PC1: Procedure).

"We should be proactively present for the customer [during] the whole relationship that we have with them. And basically, the only way we can do that is that we have the data and that we really use [it]." (Interview 27—unit director: customer relationship development).

However, challenges of accessing health data are grounded in unstable digital technologies for access, a need for trust between Omega and its customers, and the customers' needs for protection from unwanted access.

These factors tie into the second barrier, control. Omega understands that customers own their own data and therefore have the control over it. In certain situations, however, health data is made available for use through public services in Finland such as if a claim is filed (G2: Legislation/DS4: Legislation). The customers may not be aware of this legislation.

"It's in the law that we as an insurance company can ask the doctor to give that data and people don't know that we have the right already to get that." (Interview 9—unit director: business claims).

As an alternative to legislative rights to data, individuals can share their health data (DS3: Legislation). The *customer survey 2018* revealed that customers mostly believe they are familiar with their health data rights, with approximately 30% reporting a level of unfamiliarity with their data rights.

Sharing (the third barrier), is a complex issue at Omega owing to the existing concerns held by customers, such as the data being used against them to profile their health and increase their health insurance costs (Article V). This practice

would represent a transgression against Finnish law because insurance organizations are forbidden from leveraging unjust power against customers, such as using health data to change insurance pricing (PC3: Transparency/ DS3: Legislation). Customers sharing their health data with Omega would increase its access to pure customer data but requires incentivizing customers to do so. Through the development of digital technologies and services that customers consider valuable, Omega can affect the willingness of individuals to share health data (PC3: Reciprocity).

"It's yet to be seen that we are able to give the carrots [and] try to increase the number of people sharing data. And of course, we try to build the service that will lower the barrier to give the data. But it's very difficult at this point to say that." (Interview 6—unit director: new business development).

The services Omega's customers have described as valuable to them in the context of sharing health data are personalized health-related services (Article V). Personalization of health services should include supporting health needs such as medication, wellness and lifestyle choices, and proactively motivating the customer to enact preventative activities (DS3: Engagement/DS3: Reciprocity) (Article V).

Along the same lines, the use and reuse of health data is problematic for Omega owing to the existing silos across the different companies within the organization. As an example, the use of health data from the pension area cannot be transferred to life insurance, which renders the available sources of data inert (PC4: Interoperability). This notion is further reinforced by the *customer survey 2018*, where three out of four customers (74.6%) reported that they did not know how Omega will use their health data, an indication that a significant majority do not possess in-depth understanding of how their health data will be used by Omega (Figure 19). A lack of transparency regarding the intended purposes of health data use was identified as a source of unwillingness to share health data (DS3: Transparency/DS4: Transparency) (Article V). However, some customers reported wanting Omega to use their health data to help with their health and wellness (DS4: Reciprocity).

"Naturally, there are different kinds of customers who have different kinds of expectations, but at least in some customer segments, it's like really clear expectations from them that they are like really saying "use the data that you have about me and use it so that you are actually helping me!" For example,

to live a healthier life." (Interview 27—unit director: customer relationship development).

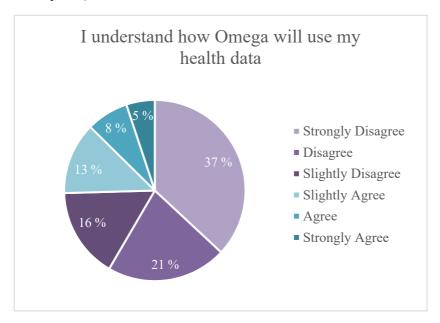


Fig. 19. Customer survey 2018: customers' understanding of Omega's use of health data.

This trend indicates that customers are in the process of aligning with Omega's vision of connected insurance, given a provision of desirable health services.

These barriers of inertia present complex and multifaceted challenges; at the same time, they mirror Omega's vision for transformation. The rigidity of traditional insurance would render the capacity of managing these barriers useless. Digital transformation affects Omega's tangible and intangible qualities, and careful steps are required to overcome the loss of momentum restricted access to health data would entail. Access, control, sharing, and use are detailed as part of the mechanisms for health data in section 4.4.

### Resistance

Resistance is a complementary digital transformation barrier to inertia but focuses on the internalization of disruptions at Omega. Resistance is experienced when the digital transformation processes are not balanced with organizational constructs such as organizational culture. Article III explores two barriers that create resistance for accessing health data, which is a requirement for sustaining proactive health services such as the virtual hospital. These barriers are described as institutional or use and participation.

The utilization of health data for proactive digital health services fundamentally necessitates access to the aforementioned health data. Having customers share their health data is a strategy to gain access to their health data outside of legislative channels and claims (DS3: Legislation). However, Omega's interpretation of the customers' willingness to share heath data is inconsistent. During the case study, a distinctive and split picture was painted that dichotomized the employee perceptions of their customers to be either conservative or progressive: either their customers would be entirely unwilling to share health data with Omega or conversely entirely willing.

"My perception is that the average Finn is very scared of giving out any data at all." (Interview 12—development manager: customer experience research).

#### Contrasted with:

"I have not yet seen that that the customer would say that they don't want to share the data; that I haven't seen." (Interview 6—unit director: new business development).

Willingness is partially explainable by the negative public perception of insurance organizations. The stigma of providers is an institutional barrier because it creates friction between the internal view of their societal role and the external perception of their customers.

The use of digital technologies to forge new value creation paths at Omega initially met resistance owing to a lack of employee roles and skills. Recently, however, new positions have been created in an effort to embrace the potential value of social media for the use and participation of the customer. These unclear roles have also created resistance around customer ownership. Employees at Omega are not taking ownership of the overall customer experience, leading to ambiguous ones. Part of the connected insurance strategy is to change the role of the customer, pushing for activation and engagement in their health while supported by Omega throughout their life. This is achieved without delineating the responsibility of employees through organizational activities such as workshops, thus controlling the customer experience risks fragmentation.

## 4.3.4 Generating negative impacts

Generating negative impacts is an unintended consequence of digital transformation, bringing to light concerns about privacy and security. Vial's (2019) framework has synthesized only privacy and security as part of negative impacts, requiring a focus on exploring health data—specific negative impacts. For Omega as well as its growing dependence on health data, the potential societal impacts are included as a mirror of positive impacts. To enlighten what Omega considers the chief negative impacts or risks, emphasis is placed the sustainable access and use of health data. When considering the sensitivity of health data in particular, it is imperative for Omega to aim to mitigate and manage these negative impacts to their full capacity, ideally to channel them into positive impacts instead. Articles I, IV, and V examine the negative impacts of health data from a policy (IV), organizational (IV), and customer (I and V) perspective. Figure 20 presents an overview.

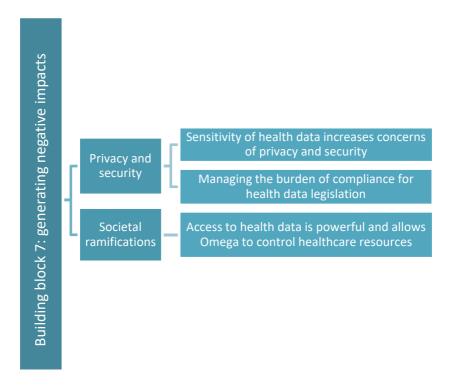


Fig. 20. Overview of building block 7: generating negative impacts.

## Privacy and security

An increased availability of data has unintended consequences for the processors and controllers of data as well as the data subjects themselves. The ever-increasing quantity of data by definition causes amplified extents of privacy and security risks. Access to health data was seen as a risk for customers and patients owing to concerns about privacy and security (E1: Accessibility/DS1: Accessibility) (Article I). Customers require Omega to provide technical measures to store and secure their data against external attacks (Article V).

"The more health data moves around on the internet, the more likely it is that it won't stay private anymore and instead make possible at least some sort of data mining or some inappropriate search for data." (Customer survey—customer 117: male aged 55–64 years).

Despite the capabilities of digital technologies, no IS can ever provide a bulletproof certainty of security or a guarantee of privacy. Organizational compliance to GDPR demands for improved privacy and security is challenging for Omega owing to costs, the need for continued justification to access health data, the enacting and enforcing of privacy policy throughout the organization, and the proactive designing of privacy into IS such as Lava to manage the authorization of data access (Article IV). In such cases, an IS could enact privacy-related actions through authorization.

"You should prevent the worker from accessing certain data." (Ethnography 4—lawyer).

While security can be considered to be IS-intensive, privacy is more abstract to manage. Mitigation of these risks is discussed previously as part of organizational culture (section 4.3.2). Besides the awareness of privacy and security, owing to passive awareness, Omega is active in selecting partners that share its data-doctrine values and strict adherence to health data privacy and security in an attempt to mitigate negative impacts.

"Every kind of [devices with which] we can collect data from [their] home, vehicles. We have to be sure that the equipment is secure. And that's the IT point of view; but we always ask where you bought it from, who is our partner, how [do] they keep the data secure, what is the channel [through which] we transport this data. Who [has] access to [the] data in our system, or in our partner's system?" (Interview 24—program manager: data security).

#### Societal ramifications

The changing competitive landscape in Finland has enacted pressure on the healthcare sector and disrupted Omega's role in it. Part of Omega's strategic response, connected insurance, has societal ramifications. Access to data is access to power. Customers perceive that Omega wields a lot of power and has the potential to exert its power to deny claim compensation or healthcare coverage (PC1: Accessibility) (Article V).

"Customers, they don't love these insurance products. Actually, they hate them. Because [they feel that there's a small clause somewhere], which means that we don't cover [their claim] if that happens, and so on. With customers, they have to have [insurance], but they don't love it." (Interview 22—unit director: research and development).

Some customers even report being scared to share their health data in fears of negative repercussions.

I wouldn't be ready to share my data because I believe that the issue would always be flipped around to be the customer's fault by using their health data, if compensation was required. (Customer survey—customer 127: male aged 65–74 years).

A potential negative impact of connected insurance calls into question the ethical quandaries of having access to vast information sources in tandem with controlling healthcare resources. Because insurance premiums are calculated on risk-based equations, having additional sources of information to input into that calculation affects the output. Privatization of health impacts Finland's healthcare ecosystem by exerting pressure on public healthcare systems and resources and increasingly blurring data subjects' agency over their health data; therefore, a balance is required between privatization of health and health benefits for Finnish society.

## 4.3.5 Generating positive impacts

Positive impacts through digital transformation are echoed for both internal and external factors. Societal improvements, organizational performance, organizational compliance, and operational efficiency represent the four data-driven instances of value creation emerging from the digital transformation at Omega. Synthesized below from Articles I–V is an explanation of how health data

used in the shift from reactive to proactive at Omega is generating positive impacts. The "industry" part of the element "societal improvements" from Vial's (2019) framework is not presented as the scope of this case study did not extend to the insurance industry at large. Figure 21 is an overview of this building block.

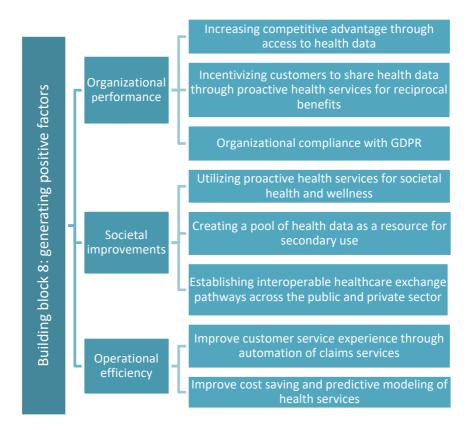


Fig. 21. Overview of building block 8: generating positive factors.

### Organizational performance

The performance of Omega is of reciprocal benefit for customers as well as the organization in their capacity as a mutual company. This means the positive impacts for organizational performance are of common interest to Omega and its customers. Although Omega's digital transformation can still be considered to be in the early

stages of maturity, positive impacts are evident in several dimensions of organizational performance. Leveraging digital technologies to provide proactive health services is innovating healthcare delivery while simultaneously increasing their competitive advantages by amassing their access to health data (PC1: Procedure). Having access to health data improves Omega's capabilities for providing personalized and proactive digital health services through digital technologies such as the virtual hospital (Article II). With a greater capacity for providing valuable digital services to customers, further enhancements to organizational performance can be identified in Omega's sustained growth over the last three years of strategic movements to enter, remain, and compete in the healthcare market.

"If we look at the core insurance business, that is not a growth business, long term. So, we have to figure out something else if we want to be in the business as the same for the next 100 years. And then, of course, if we look at what could be the options, health is definitely a growth business." (Interview 25—strategic technologist: solution architecture).

Desirable services also incentivize customers to be more active in their engagement with those services. Article V explores this phenomenon as a benefit for both Omega and its customers through health data sharing. When customers share their health data, Omega can provide better health-related digital services by processing that data and can return the value to the customers through perceived benefits such as online consultations in the virtual hospital, personalized wellness feedback, and reduction in health insurance prices (PC3: Reciprocity/DS3: Reciprocity) (Article V). Reputation of insurance organizations has historically been highly stigmatized, and a central aspect of Omega's connected insurance is to challenge that stigma by changing the role of the customer and evolving from "just" an insurance company into a life-long health and wellness partner. Positive performance in this regard can transform this stigma into a positive impact by challenging the negative customer perceptions about Omega through a focus on customer experience and co-creation of value (Articles II and III).

International regulations such as the GDPR are imposing cost compliance for processors and controllers of personal data. The digital transformation of health is data-driven and therefore is forcing the hand of processors and controllers to be compliant with personal data regulations. Hence, compliance is a fundamental part of organizational performance during digital transformation. Legislation enacts restrictions on Omega, including limitations for heath data use and different rules

for insurance organizations. Despite the burden of compliance on Omega, embracing the negative impacts such as privacy and security (both part of the GDPR) and funnelling them into desirable factors provides the most benefit. The attitude of Omega was found to lean toward embracing the compliance demands from organizational barriers as an opportunity to imbue digital values into connected insurance through changes in value creation paths as well as into organizational culture through structural changes. The full benefits of compliance remain to be seen, but at the very least, it helps mitigate the risk for security breaches and support the strategic response to facilitate benefits for Omega and its customers as an alternative pathway (Article IV).

### Societal improvements

Societal improvements as a result of Omega's digital transformation outline the reverberation of its efforts on a societal level. Health and related care approaches are a massive economic aspect in aging populations such as Finland's, with chronic diseases and long-term care consuming most of the resources. Powered by health data, connected insurance proactively aims to prevent diseases or illnesses, mitigate the worsening of chronic disease, and support better QoL. Connected insurance allows Omega to have a voice in society, advocate for the healthcare paradigm shift away from reactive thinking, and contribute to a societal alignment with proactive health and wellness. Health data can be used at both a granular level for personalization as well as an aggregate level for social impacts. Much like in the conception of the traditional insurance (everyone pitches in a little), health data can be pooled.

"We are collecting the data, specific data for the customer, for her good. And we get the anonymized data for the masses, and we can think about how this information can be used. It differs. But this is the thing that we have to tell our customers." (Interview 26—lawyer: GDPR).

From the pool of health data, Omega can provide beneficial interventions for its stakeholders despite the non-participation of some, and the reduced stress on the healthcare system stands to benefit even non-customers.

"If our customer [doesn't] want to give the data, it's okay; they will have the service from us, but the benefits that they will receive come from the other people sharing their data. So, let's take the smart phone [as] an example; half

of our customers share their data, and half of the customers don't share their data. And with the information we get from half of our customers, we are able to do analytics and prediction about the things that might happen and have this kind of [intervention]." (Interview 6—unit director: new business development).

Maintaining the health of Omega customers is part of a societal improvement because it decreases the healthcare resource demands on the public sector and improves the overall health of the customers participating in the value creation processes in society. Digital technologies such as the virtual hospital are enabling access to healthcare resources that might have otherwise taken a longer time or been difficult to access owing to regional differences and geographic distance. Services such as medical notes for illness reduce the need for individuals to travel to health centres unless necessary, further decreasing the risk of contagious transmission.

"Because you need a paper for where you work, and you have to go [to the doctor when] sick. So, it's a little bit stupid. If you could have a video connection with your doctor and have discussions digitally, we give that." (Interview 10—development manager: digital health services).

Wellness is another factor that requires holistic subtleties of data to determine actionable wellness interventions, such as smoking cessation.

An unintentional societal improvement for health data is grounded in the barriers being broken down by Omega for interoperable data pathways as part of its digital transformation (E3: Interoperability). Data siloed in different private organizations such as Epsilon are being connected owing to Omega's strategic response. Adjacent to the practice of customers sharing their data (Article I), increasing Omega's level of access to health data is evolving the value networks in place and reducing the time constraints for decision-making.

"We wouldn't have to [acquire information from private hospitals or public sector hospitals anymore]." (Interview 2—unit director: business workplace health and safety).

Health research from insurance organizations has been overlooked for its potential to sustain the reuse of anonymized health data for societal benefit (PC4: Reuse). Large quantities of private data afford the opportunity for researchers to generate substantial health-related societal benefits through the reuse of health data (Article

I). Data sharing from public healthcare sources such as the central public healthcare repository in Finland, OmaKanta, supports public and private crossing of health data, enabling interoperability in a scope yet unseen in Europe and representing a great stride for the advancement of healthcare in society.

## Operational efficiency

Using digital technologies such as Lava to improve Omega's operational efficiency impacts its capacity to automate claims services, reducing the cost for processing and improving timelines for decision-making. Also, the unit director of business workplace health and safety predicts this automation to cascade down the business supply chain, acting as a sales pitch for Omega's corporate customers and enabling better safety and prevention activities for its employees.

"By doing these services, and renewing services, this way it will certainly lower the claims costs; it might create new jobs [because of] automation and robotization. It will create [value] for [corporate customers]. New ways of advising, being proactive, and so on." (Interview 2—unit director: business workplace health and safety).

Improving business processes is another enhancement point for Omega; in this case, it is prompted by the GDPR to transform how health data is processed and controlled. Omega's access to an existing pool of data and additional data being generated through digital technologies can be considered big data owing to the volume, velocity, variety, and veracity of data. This affords the opportunity to leverage big data analytics to improve operational efficiency for further cost savings and the enhancement of predictive modelling used in proactive digital health services and preventative interventions (Article IV).

## 4.4 A framework of health data mechanisms

Mechanisms for health data are the driving force behind proactive health services as part of connected insurance in digital transformation. In this case, because the focus is on proactive digital health services, data is the core of what drives Omega's digital transformation. A brief summary is provided for the different mechanisms identified in each of the four desired factors and according to boundary context. Not all mechanisms are described in detail in favour of a more detailed exposition of the most frequently occurring mechanisms.

In Table 10, the overview of each framework and its mechanisms is presented for access, control, sharing, and use of health data. An overview of the defining characteristics of the mechanisms is presented in Table 11. More detailed framework findings are available in Appendices 1—4. The mechanisms characterize the factors of health data (access, control, sharing, and use) for proactive digital health services within the health data environment (E), governance (G), processors and controllers (PC), or data subjects (DS).

Table 10. Framework of health data mechanisms.

	Accessibility	Culture	Engagement	Interoperability	Legislation	Management	Procedure	Reciprocity	Reuse	Sustainability	Transparency
Health Data Access	Х	Х	Х	Х	Х	Х	Х		Х		Х
Environment	Х	Х					Х				Χ
Governance		Х			Х						
Processors and Controllers	Х	х	х	X	х		X		X		Х
Data Subjects	Х		Х		Х	Х					X
Health Data Control		X			X	X					X
Environment											
Governance					Х						
Processors and		Х			Х	Х					Х
Controllers		^			^	^					^
Data Subjects					Χ	Χ					
Health Data Sharing		X	X	Х	X			X			X
Environment				Χ							
Governance					Х						
Processors and		Х		Х	Х			Х			Х
Controllers		^		^	^			^			^
Data Subjects		Χ	Χ	Χ	Χ			Χ			X
Health Data Use		X	X	X	X			X	X	X	X
Environment											
Governance					Χ						
Processors and		Х	Х	Х	Х			Х	Х	Х	Х
Controllers		^	^	^	^			^	^	^	^
Data Subjects			Χ		Χ			Χ			Х

The most saturated of the four health data factors was access, indicating its distinctive importance for the purposes of successful digital transformation in the

context of connected insurance. Access was highly represented within the processors and controllers of health data. Accessibility as a mechanism is the attribute to access and was present in three of the four boundaries. Accessibility allows health data access to processors and controllers as well as data subjects while accounting for the sensitivities related to health data that warrant security, protection, and privacy. The accessibility of health data is complementary to interoperability as a mechanism. Interoperability for processors and controllers can enable the health data silo ventilation that is internal to the organization. Culture as a mechanism further reinforces the need for nuanced qualities in the health data environment, governance, and processors and controllers whose work necessitates ethical conduct related to the sensitive nature of health data. To increase trust between the processors and controllers and the data subjects, the mechanism of transparency can enable access to health data. Transparency allows data subjects to understand who has access to their health data and for what purpose. The legislation mechanism provides a legal basis for processors and controllers to access health data, who should leverage the use of digital technologies to ensure compliance. Procedure is a mechanism for strategizing access to health data throughout the extended healthcare ecosystem because access is a requirement for processors and controllers to remain competitive.

Table 11. Description of mechanisms and their characteristics.

Mechanism	Defining Characteristics
Accessibility	Availability of health data through authorized actions using digital tools and services
Culture	Attitudes and perceptions of health data that influence actions of actors
Engagement	Influential outcomes achieved through digital actions prompted by health data
Interoperability	Technical capability of porting health data across infrastructures
Legislation	Policies that stimulate health data compliance for a variety of factors
Management	Ensuring actors are given decision-making powers using digital tools and services
Procedure	Process by which health data as a resource can be consumed
Reciprocity	Expectations for equivalent exchange of health data across actors
Reuse	Repurposing health data for an unplanned action
Sustainability	Using health data to support ongoing action in a digital service
Transparency	Developing trust by disclosing actions or choices made regarding health data

Control represents the least saturated of the health data factors. Control functionalities that meet the needs of data subjects should enable control exertion over their health data in all digital services. Emphasis on the processors and controllers points to the need to allow data subjects control of their data as part of

the mechanism of management. The legislation mechanism further supports the control factor because processors and controllers embrace legislation for controlling health data using digital technologies as part of compliance. It is important to emphasize the need for processors and controllers to enact trust from their data subjects through the transparency mechanism.

The desired factor of sharing health data is required for the design and development of proactive digital health services, thus enabling service development. Sharing of health data from data subjects emphasizes the mechanism of reciprocity that is required for processors and controllers to incentivize health data sharing from data subjects. In correlation, willingness of data subjects to share their health data can be increased if intrinsic and extrinsic motivations for sharing can be met through reciprocal mechanisms. Measures of security and privacy are required, not only to meet data legislation but also to instill trust with the customers. The mechanism of interoperability was present as part of the health data environment as a means to establish a pathway for health data sharing across health industries. Processors and controllers can leverage interoperability mechanisms to support data subjects with the technical capability to share health data while providing digital health services in exchange. With digital technologies in place to facilitate health data sharing, processors and controllers will also be compliant with legislation mechanisms for the portability of health data.

Health data is leveraged to power digital health services. The mechanism of reciprocity enables processors and controllers to provide improved digital health services to data subjects, as better services inspire increased use; this in turn yields more data, increasing the benefits and predictive abilities of the services through a positive feedback loop. Secondary use of health data through the reuse mechanism contributes to a holistic picture of data subjects in the provision of health services. Interoperability can enable the use of health data across data silos to further contribute to the holistic picture of data subjects while allowing for the reuse mechanism to take advantage of the primary data collected for secondary use purposes. Data subjects are required to consent to the secondary use of health data, and the transparency mechanism suggests that the use of health data by processors and controllers can increase trust of data subjects through informed consent. The legislation mechanism mandates the legal basis for the use of health data for processors and controllers under special circumstances, effectively requiring digital technologies to be compliant with prescribed governance. The engagement mechanism allows processors and controllers to more readily respond to healthrelated situations when using health data. For data subjects, engagement means a

more active role in helping to develop and design valuable digital health services to use health data.

# 5 Discussion

The discussion section presents the contributions of this thesis drawn from the research articles and the findings. I discuss the contributions to theory and practice, pointing to the different research questions being answered within previous theoretical work and real-world implications for healthcare organizations. Finally, I present the limitations of this dissertation.

#### 5.1 Overview of contribution

The contributions of this dissertation are health data—centric in the health informatics domain, which is the composite of the IS and HIT research disciplines. The use of an interdisciplinary approach to address the gap in the current body of knowledge offers a distinctive approach to encapsulate the qualities from these disciplines and shape the contribution. Further, it provided context for the boundaries that influence health data in transforming insurance organizations.

The practical contributions of this doctoral thesis are oriented around the research question "How can health data enable digital transformation for an insurance organization?" The identification of the most important elements for health data throughout Vial's (2019) framework shaped a "critical path" of health data changes that implicates management decision-making. Moreover, creating service-based value through health data requires certain organizational changes that are emphasized in the critical path. Because digital transformation is an emergent process and owing to the relatively recent impacts of dramatic disruptions in private health organizations, the implications of this dissertation are valuable to those stakeholders. Advancing the theoretical contributions to IS in particular, Vial's (2019) digital transformation framework, is suggested as a method for unravelling the key elements of health data-dependent changes to guide the narration of a single holistic case study. All areas of the digital transformation framework were cohesive with the case study data and empirically substantiated. Additional theoretical insights were generated in the negative impacts of digital transformation for health data, further adding scientific merit to this thesis for contributions in research.

The research contributions of this doctoral thesis for theory are made by addressing the gaps in the current literature on the access, control, sharing, and use of health data for proactive digital health services. Holistic considerations of the actors and the contexts that shaped the health data mechanisms in the environment (Article I), the governance (Articles III & IV), for processors and controllers

(Articles II & III), and data subjects (Article V) were used to answer the research question 2: "What mechanisms support health data factors required for proactive digital health services?" The mechanisms offer insights into the complexity of health data for data-driven services by drawing together the constellation of health data contexts and depicting the activities that are brought about and their corresponding changes. Proactive digital health services shift the organizational mindset away from reactive and toward proactive thinking. The mechanisms have real-life implications for management in health-related fields in the digital transformation process and for private organizations requiring access to health data to drive proactive health services. The mechanisms are conditions that private organizations in the health sector need to consider in their role as processors and controllers of health data. They also need to consider the impact on strategic decision-making from the contexts of environment, governance, and data subjects, which have considerable influence on health data.

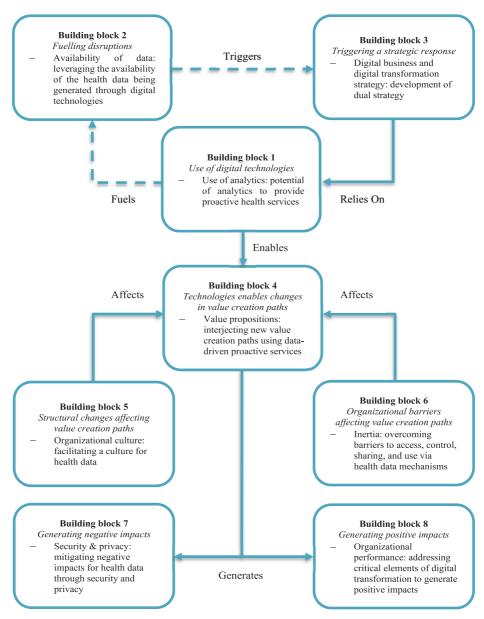
# 5.2 Health data in digital transformation

The critical path identified using Vial's (2019) framework contributes to literature and has implications for healthcare organizations. The elements within the building blocks were ranked according to their importance for proactive digital health services, frequency in empirical data, and overall representation in Articles I-V, serving to identify the crucial transformative areas for organizations relying on health data as well as the potential areas for improvement or change. Much like a harmonogram that is typically used in project management, the ranking process allowed for the identification of dependency elements for health data pathways through the digital transformation process, establishing a critical path of health data. More specifically, the critical path represents the minimum requirements for insurance organizations to enable health data-centric digital transformation. Figure 22 illustrates an overview of the most important elements of health data through the eight building blocks. For the benefit of organizational decision-makers and management, this section elucidates the fundamentals of data-related concerns in digital transformation, allowing for an increased understanding and the ability to make informed choices in their change work.

The use of analytics (building block 1) for health data is the primary means for interpreting health data through the extrapolation of actionable insights. In turn, using analytics contributes to the availability of health data (building block 2) through the sustained use of data-creating services. This process is adjacent to the

concept "data begets data" because the production of health data further contributes to the availability of health data for further holistic analysis in a positive feedback loop (Huhtala, Pikkarainen, & Saraniemi, 2019). The abundance of health data requires an organization to form a strategic response (building block 3) to leverage the rich source of information into business practices. However, "data does not bring value if it is not integrated with customer value through the business model" (Huhtala et al., 2015, p. 3475). Altering value creation paths (building block 4) is part of the connected insurance shift toward the provision of services instead of the provision of goods. The introduction of new health services disrupts the existing value pathways, thus leading to the structural changes (building block 5). Organizations should embrace health data culture as part of their everyday practices to influence the business infrastructure and activities that must take place in a tactical manner (Fritzsche & Bohnert, 2019). Management should keep in mind that the culture in organizations is an emergent phenomenon that requires ongoing and intuitive administration and may have unintended consequences (Iivari, 2006, 2010). Failure to shape culture around health data-oriented mannerisms may result in the breakdown of the capacity to deliver proactive services, as has been the case in other healthcare contexts (Davies & Mannion, 2013).

Payers will need to overcome the health data barriers (building block 6) that render their business practices inert. Access to and sharing of barriers are largely the result of the negative perceptions of insurance built over many years of stigmatization (Grundstrom, Väyrynen, Persson et al., 2018; Martinez-Hume et al., 2017; Moon, 2017). To eliminate customer unwillingness to provide access or share health data, insurance organizations need to develop trust with their customer. Signalling engagement in the health data sharing phenomenon is not an ethical or a legal gateway for insurance organizations to increase costs or deny coverage (Caine & Hanania, 2013; Patil et al., 2016; Soni et al., 2019). Owing to the highly sensitive nature of health data, insurance organizations should strive to mitigate the negative impacts through privacy and security as an enabling activity (building block 7). Privacy by design approaches imbues customers as partners to help mitigate negative factors, improving transparency while protecting health data (O'Connor et al., 2017). Addressing the critical elements of health data in digital transformation culminates in positive factors (building block 8) for organizations, leading to improved organizational performance, increased competitive advantage through access to health data, advancement in the capabilities of proactive digital health services, and the further incentivization of customers to share health data for valuable data-driven services.



Key: Dashed arrows represent the trends seen globally in the industry and society Solid arrows represent the digital transformation of an organization

Fig. 22. Critical path for health data in digital transformation.

In answering the first research question, this dissertation provides a set of strong indicators that health data enables the digital transformation of insurance organizations. Some identified key elements deserve special attention from policymakers and managers, in particular the elements that outline the strategic importance of healthcare actors in facilitating valuable proactive health services within digital transformation (Blocker et al., 2011). A more in-depth understanding of the various roles played by individual customers and/or patients in the digital transformation process could elucidate critical success factors. Future research should aim to disentangle the complexity of actor roles and other emergent mechanisms of digital transformation as an ongoing process, including (but not limited to) the continued digitalization process of Omega.

## 5.3 Health data mechanisms for proactive health services

This thesis makes a clear contribution to the need for the identification of critical factors of digital transformation such as the mechanisms that facilitate positive outcomes for data-driven health services and impact organizations and business models (Huhtala et al., 2019). The findings of digital transformation in different contexts of health data appeal to businesses with health-oriented services as they promote the mechanisms that can be employed to achieve a health data factor such as access. The access of health data for organizations is of particular interest to understand the data-associated mechanisms as it "provides new opportunities to tap into such data to examine the central topics of interest for researchers in organization and innovation studies, such as the conditions for change and development among different types of organizations" (Hedström & Wennberg, 2017, p. 98).

Many inductively deduced mechanisms are advocated in the European strategy for data as part of the common European health data space (European Commission, 2020). As a means to actualize this goal, movements such as MyData offer a philosophy to advance data-driven services by promoting human-centric principles aligned with actions of transparency, culture, sustainability, and the individual as the point of integration (Poikola et al., 2015). Organizations existing within larger and more complex ecosystems, such as insurance providers, are collectively facing challenges owing to policies such as the GDPR that dictates how they can operate in the health data space (Grundstrom et al., 2019). The proposed mechanisms are a source of tools empirically established to promote health data factors such as access.

The mechanisms themselves are present as part of the GDPR, such as transparency and interoperability (European Commission, 2016).

A mechanism is a form of push and pull system, which in this case study set the environment, governance, and data subjects on one side and organizations on the other. Not focusing on the organization-centric applications is especially critical because digital transformation is not solely about the organization and instead has internal and external components (Vial, 2019). Therefore, drawing from the boundaries of health data creates more comprehensive mechanisms to enable processers and controllers of health data to leverage tactics for targeting strategic factors (Hedström & Ylikoski, 2010). Particular attention toward a few of the most saturated mechanisms in Table 10 shows that interoperability, culture, and transparency are dominant. It is evident from the framework that these mechanisms describe the tactics for private organizations, such as insurance companies, that are used to guide strategic planning.

The availability and abundance of health data is creating health data silos across the different healthcare domains (Groves et al., 2016). Silos represent highly unfortunate outcomes of data segregation, and motivations for enabling a flow of information between health silos are abundant in stakeholder benefits (Grundstrom, Väyrynen, & Isomursu, 2018; Schneeweiss, 2014; Zheng, Sun, Mukkamala, Vatrapu, & Ordieres-Meré, 2019). Organizations within the healthcare domain should aim to ventilate these silos or, in other words, provide access, encourage sharing, and facilitate the use of data resources. Processors and controllers provide sustainable access to health data through sharing from data subjects and across traditional boundaries. Interoperability may facilitate the acceleration of digital transformation and has implications for a healthier and more proactive society (Kouroubali & Katehakis, 2019).

There is, however, an abundance of interoperability-related challenges, particularly for health-related harmonization because health data is highly sensitive and requires extreme caution for privacy, security, and protection (Grundstrom, Väyrynen, & Isomursu, 2018; Kierkegaard, 2015; Otjacques et al., 2007; Schreiweis et al., 2019). Implementation of interoperability solutions currently remains in its infancy owing to the heterogeneity of data layers, actor networks, and technical challenges that must be harmonized. Approaches such as the European interoperability framework have begun to unravel the complexity of interoperability by offering recommendations for health service delivery, thus defining interoperability as follows (European Commission, 2017):

"The ability of organizations to interact towards mutually beneficial goals, involving the sharing of information and knowledge between these organizations, through the business processes they support, by means of the exchange of data between their ICT systems."

The approach further points to the advancement of interoperability as a partial responsibility of the organization, which needs to act in the interest of harmonizing capabilities for doing so through technical and organizational measures (Kouroubali & Katehakis, 2019).

In part, health data silos in insurance organizations are created to comply with legislation for the provision of insurance services because in most regions, only one type of insurance can be provided by any one company. Policymakers should recognize the effect of this limitation on insurance organizations as a contributor to the interoperability difficulties within the Nordic context. In digital transformation, the arrangement of the organizational structure can leverage IS to accommodate interoperability (Vial, 2019). In this case study, a new underwriting system is being developed, offering a transitive state during which careful consideration should be placed on introducing infrastructure to sustain the access and sharing of health data both internally and externally to the organization as well as its adjacent health sectors. Using the interoperability mechanism as a means to facilitate health data sharing from data subjects for health-related services aims to improve the customer experience, empowering data subjects (Eling & Lehmann, 2017; Kouroubali & Katehakis, 2019; Otjacques et al., 2007) as well as contributing to the harmonization of the public and private health sectors for health data spanning and securely providing health data to the right actor at the right time (Commission of the European Communities, 2004; Essén et al., 2017). These concerns are also partially mirrored in the fields of connected insurance (Battistella & Burchfield, 2000; Silvello, 2017; Silvello & Procaccini, 2019) and connected health (Caulfield & Donnelly, 2013; Karampela, Isomursu et al., 2019).

Culture is another mechanism identified in the findings and was extensively evident in all of the articles of this thesis. Furthermore, it was identified as a key element in building block 5 for structural changes to the organization that are health data—centric (Vial, 2019). Organizational culture is not universally defined, and the meaning largely depends on the theoretical grounding. However, "at the heart of many definitions is that culture consists of the values, beliefs, and assumptions shared by occupational groups" (Davies & Mannion, 2013, p. 1). Organizational culture has been identified by Morakanyane et al. (2018; Morakanyane, Reilly, &

Mcavoy, 2020) as a point of success to accommodate the changes in organizations in different organizational sectors. Including omnichannel retailers (Hansen & Sia, 2015), banking (Schuchmann & Seufert, 2015), and as part of an everyone-to-everyone economy (Berman & Marshall, 2014); demanding radical shifts in organizational culture cannot accommodate the changes enacted by digital transformation.

For health data, culture should be oriented around three areas: accountability, transparency, and a data doctrine of security, privacy, and protection. Of these, the most intrinsic to health data is the culture of a data doctrine. The data doctrine suggests that culture in organizations should be sensitive to health data through means of security, privacy, and protection. Security, privacy, and protection are all common themes in the context of health data owing to the sensitivity and incumbent necessity to protect identification and potential harm to individuals.

Adapting organizational culture to be in compliance with the GDPR is challenging for organizations because they have to change the mindset of the organization and reflect the values of security, privacy, and protection in their practices (Grundstrom et al., 2019). Transparency is also significant for organizational culture, to the degree that it is considered a mechanism in itself. Transparency in actions has been found to bolster trust between actors when sharing health data (Smith, Grande, & Merchant, 2016). Transparency as a mechanism aims to increase trust between actors: in this case, between the insurance organization and its customers. Insurance organizations in particular carry a negative stigma, tainting individuals' expectations of insurance companies for health provision and further confounding the sensitivity of health data (Martinez-Hume et al., 2017). Fears of insurance organizations using health data to prevent compensation of health coverage costs or to increase premiums through profiling of health are evident (Article V). Therefore, insurance organizations should explore transparency mechanisms to foster trust and subsequently generate prosperity. Using HIT to enable transparency leads to improved value creation in health scenarios because it clarifies the roles that different actors should fulfil (Nyende, 2018).

At the forefront of data concerns within digital transformation is the creation of a culture of privacy: to value the sanctity of individual privacy while still maintaining authorized access to health data. This can be enacted by creating technological solutions to monitor and enable authorized data access on request. The Nordic MyData model leverages privacy through a human-centric health data business management approach (Iivari, Pikkarainen, Ylén, & Gomes, 2017;

Poikola et al., 2015). Organizational performance is tightly bound to culture for the efficacy of employees expressing values and attitudes through everyday practices and even predicates positive factors in the short term (Gordon & DiTomaso, 1992). Negative factors of digital transformation significantly emphasize security and privacy; radical and disruptive changes in the business models and ecosystems combined with the presence and proliferation of an abundance of health data makes for a very volatile data security environment. This uncertainty is reflected upon in the form of the question: "how security and privacy can be effectively turned from a potential issue into a source of positive impacts for an organization as well as society?" (Vial, 2019, p. 131). Understanding the "how" behind organizational culture is imperative to develop insights into the effectiveness (Gregory, Harris, Armenakis, & Shook, 2008). In this case, the "how" is through cultural mechanisms to develop accountability, transparency, security, privacy, and protection in organizational culture and practice regarding health data. In other words, it involves labouring to transform the negatives associated with health data through the cultural interventions that could then further inform the conditions of customers in their capacity as actors in digital health.

Access to health data is the most frequently reported need by individuals, which is an important factor for increasing healthcare quality (European Commission, 2020), and is described as a key factor for creating competitive advantages for organizations (Eling & Lehmann, 2017; Huhtala et al., 2015). However, the accessibility of health data calls into question the ethics for insurance organizations (Boyd & Crawford, 2012) and as an outcome for digital transformation (Vial, 2019). Of notable interest is the apparent absence of ownership discourse. This should not be taken to suggest that this thesis does not advocate for data subjects as owners of their health data. In fact, the GDPR has made abundantly clear who is the owner of their health (European Commission, 2016), which is reflected in the agenda of Omega. This is further reinforced by Safran et al. (2007) and Wiese et al. (2017), who argued that an emphasis should be put on the access and sharing of health data because there is no longer a need to question ownership as data subjects are in control. However, other studies show a bleaker image of ownership, wherein despite the alleged control and importance offered to individuals in healthcare systems, power was not been fully realized toward individual agency, further perpetuating data asymmetries which persist in the contemporary health landscape (Greshake Tzovaras et al., 2019; Grundstrom, Väyrynen, & Isomursu, 2018; Kouroubali & Katehakis, 2019). Health data factors facilitate proactive digital health services through mechanisms that connect the

boundary-spanning elements. The desirable factors of health data (access, control, sharing, and use) aim to remedy the asymmetries of health data by advocating for their presence in the infrastructure of the healthcare economy, much like power, heat, and other utilities that exist in our modern society; this is similar to how previous suggestions in literature assert that the IT itself is not what enables competitive value, but how and why it is used (Carr, 2003). Social, technological, and governing infrastructure should aim to include these heath data factors to empower individuals beyond GDPR compliance and as a step toward an innovative, fair, and sustainable health data space.

## 5.4 Validity, reliability, and research limitations

Ensuring that the extensive research work intrinsic to a case study is not wasted requires comprehensive thought and planning toward translating the quality of the research into the quality of the results. There are strengths and weaknesses to every decision, from the type of case study, to the particular implementation of data collection, to the selected lenses of analysis. To address the core research decisions made within this case study, a discussion and disclosure of the enacted research strategy will follow below. This is presented as a companion piece to ascertain the construct validity, external validity, and reliability of this single holistic case study. In this study, internal validity is an unnecessary criterion for quality assessment in the research design owing to the case study classification being exploratory; internal validity is typically more important for explanatory cases (Rowley, 2002; Yin, 2009).

## 5.4.1 Validity

Construct validity is primarily necessitated in case study research as a form of correctness of the study. The aim is to minimize subjectivity through the justification of research questions to the data collection procedures (Rowley, 2002). Construct validity can be tactically designed into the case study approach early on during the planning of data collection. Two of the three tactics for ensuring the construct validity of a case study were employed during data collection. These are triangulation and chain of evidence (mentioned in section 3.3.1). The triangulation in this holistic case study is grounded in the multiple sources of evidence gathered as part of data collection and used in triangulating the empirical findings. Chain of evidence, much like forensic science, is a tactic achieved through the transparency

and disclosure of the case study process. Table 4 divulges the evidentiary collection in this case study in an effort to delineate which data sources were used during the analysis process, ultimately contributing to the findings.

In addition, construct validity can be enforced through key informants who validate the content of draft-versions of the case study reports. This form of validity took place with the insurance domain mentor (Interview participant 1) in Articles II–V. No validation was required in Article I because it was a literature review and not a case report. The insurance domain mentor reviewed all draft versions, including this thesis, and provided feedback on and approval for the content of the draft case reports. In Article IV, ethnographic participant 6 also reviewed and provided feedback on the draft of the case study article.

External validity is concerned with the generalization and applicability of the case study and is the most commonly criticized weakness of case studies (Baxter & Jack, 2016; Gerring, 2004; Rowley, 2002; Yin, 2013, 2014). Both tactics suggested to mitigate these criticisms were employed in the research design phase of the case study. However, because this is not a multiple case study, the replication logic does not apply here. Instead, single case studies rely on analytic generalization to draw and externalize the conclusions of the scientific findings to outside of the single case study. Fundamentally advantageous to the single case study approach is to build holistic insight that comprises the centralized phenomena of the study (Gummesson, 2000). However, because one of the primary motivations for selecting a single case is that the case is unique or special, it will by definition pose a challenge to generalize the findings outside of the case context (Crowe et al., 2011).

Private organizations in the Nordic countries requiring access to health data, who act as processors and whose data subjects are customers, would suit the broader generalizable theory. Furthermore, all personal data processing companies within the European Union are required to provide the four factors (access, control, sharing, and use) of personal data to their customer for regulatory purposes. Evidence of mechanisms outside of the insurance and health context is prevalent in, for example, the sophistication of customer relationship management tools to build trust using transparency mechanisms (Nguyen & Mutum, 2012) or through the cultivation of a digital culture in e-banking as a success factor (Liu, Chen, & Chou, 2011).

## 5.4.2 Reliability

Reliability tactics are part of the data collection phase and are necessary to manage concerns of reproducibility and minimize bias (Yin, 2014). Reliability can be considered a recipe that should ideally guide subsequent researchers to similar conclusions if they closely adhere to the presented conditions. To build the "recipe for reliability" in the single holistic case study, both suggested tactics of case study research were followed: following case study protocol and developing a case study database (Rowley, 2002). The case study protocol herein was guided by the case study questions (complementary to the research questions of this thesis), with the sub-questions reflected in the articles, the data collection plan for different data sources and health data components, and an overview of the case study project. The case study database was created to manage the volume of data collected in an organized and easily accessible manner. More details are available in section 3.3.1 of this thesis.

Replicability of this case study and its design is a fallible point of this dissertation. As even with access to all of these materials, another researcher returning to the same organization following my case study protocol will not return to the insurance organization captured in this study. Part of what makes Omega a unique case to study is that I was present during the early-stage of the digital transformation process of the organization, a condition which cannot be easily replicated, if at all. In addition, the shift from reactive to proactive service provision, particularly in regard to health services, was a core part of the motivations for strategic changes being enacted at Omega, as was the pre- and post-GDPR implementation and compliance. For these reasons, the weakness of reliability is countered in this research through the accountability and transparency of process, ergo, the documentation of choices in "as many steps as possible, as operational as possible, and to conduct research as if someone were always looking over your shoulder" (Yin, 2014, p. 45).

### 5.4.3 Research limitations

The case study itself is a source of several limitations in this research. First is owing to the shifting nature of an organization. Because a longitudinal case study was conducted, the exploration of the phenomenon of health data over the course of the research resulted in emergent evidence. For example, the GDPR was enforced in the Pan-European area partway through data collection, causing in no small part

the second limitation because the collection of data was guided by sensing Omega's boundaries in practice and through theory. As such, the mechanisms are more tightly bound to organizational tactics in the push and pull of health data. If, for instance, the single holistic case study was around data subjects, more individual-centric mechanisms would be evident. However, this thesis does not claim the mechanisms to be an exhaustive list. Rather, it presents the logic behind the empirical connections to the mechanisms within the utilities of health data. Future research should aim to validate these mechanisms and further expand and emphasize health data boundary tactics.

Third is the limitation of the overdetermined value of digital transformation constructs overshadowing the role of health data, leading to the emergence of interesting yet potentially erroneous case details. This limitation could also be considered an instance of scope creep because the resounding effects of digital transformation at Omega were evident in all aspects of data collection. The final limitation is attributable to the human factors of research. The ontological influences—or subjectivity—that researchers carry owing to the epistemology of knowledge affect both major streams of research. No researcher, including myself, is exempt from the need to self-reflect on the subjectivity and objectivity as part of their research (Fleetwood, 2005). During the course of this single holistic case study, the social, material, technological, and other aspects the human context could (and likely did) affect the deliberate actions performed as part of the case study. For example, the degree to which participants were comfortable with expressing themselves in English could have been influenced by their perceptions of me and thus shaped their responses. In an attempt to mitigate the subjectivity of this research, a critical realist perspective has been adopted for the ontological and epistemological methodologies, for the data collection techniques, and during data analysis. The critical realist philosophy is a function lens of which to consider ambiguity and errors as part of the social influences in research and the fallibility of selected research approaches (Iosifides, 2018).

# 6 Conclusions

The objective of this dissertation was to advance the understanding of access, control, sharing, and use of health data as part of digital transformation. In particular, this study explored the boundaries of a Finnish insurance organization as a processor and controller of health data, unravelling its role in the environment of health data, implications for compliance in the governance of health data, and the relationship with data subjects.

The results of this thesis address "how" health data can be utilized as a resource for value creation in the digital transformation of insurance: identifying a critical path of importance that health data follows and pointing to crucial areas for managers, organizations, and policymakers to consider in the context of digital transformation. Strategic planning is better informed by the conditions that health data necessitates as part of the data-driven health economy.

The results of this thesis also contribute to the "what" concealed in health data in the form of mechanisms for the design and development of proactive digital health services. These services are the future of connected insurance, seeking to prevent accident, injury, or illness for customers. A framework was empirically constructed, representing the desirable factors of health data (access, control, sharing, and use) and the mechanisms that would enable these factors across different boundary contexts. The framework is a pragmatic contribution to research and an extensive synthesis of a single insurance organization's journey through digital transformation. Future research should build on mechanisms as part of a framework for empowering equality, overcoming information asymmetry, and challenging the stigma of insurance as a healthcare provider.

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# **Appendices**

Appendix 1: Details of the access mechanisms part of the health data framework

Appendix 2: Details of the control mechanisms part of the health data framework

Appendix 3: Details of the sharing mechanisms part of the health data framework

Appendix 4: Details of the use mechanisms part of the health data framework

Appendix 5: Phase I semi-structured interview content guide

Appendix 6: Phase II semi-structured interview content guide

Appendix 1: Details of the access mechanisms part of the health data framework.

Mechanism	Environment (E)	Governance (G)	Processors and Controllers (PC)	Data Subjects (DS)
Accessibility	- access to health data is beneficial for actors - access to health data has security risks		- enable data subjects' access to their health data through digital technologies - accountable to data subjects when accessing health data - secure health data against unwanted external access - protect health data from unwanted internal access - filter health data for authorized access - access to health data has unintended consequences	- secure and protected access to health data through digital technologies
Culture	- privacy of health data has perceived risks	- foster a culture of privacy that is compliant with governing factors for health data privacy	- secure data subjects' health data against external	
Engagement			<ul> <li>enable a holistic health understanding of the data subject through access to health data</li> </ul>	- provide access to health data, allowing for a more holistic health experience
Interoperability			- enable organizational access across health data silos	
Legislation		- provide a legal basis for access to health data - create an equal playing field for access to health data - prevent unwanted access to health data	- leverage digital technologies to be compliant with governing factors - support a culture of compliance with governing factors	- provide a legal basis to decide who and how access health data takes place

Management			ensure access to health data is provided through digital technologies
Procedure	- strategize access to health data in the landscape through boundary spanning	<ul> <li>access to health data is strategically valuable for competing</li> </ul>	
Reuse		- allow the reuse of health data from other areas of the organization to create holistic customer representations	
Transparency	- facilitate active engagement in health data	- increase trust to access health data	- enable data subjects to see who has accessed their health data - enable data subjects to see the purpose of accessing their health data

Appendix 2: Details of the control mechanisms part of the health data framework.

Mechanism	Environment (E)	Governance (G)	Processors and Controllers (PC)	Data Subjects (DS)
Culture			- facilitate a culture of sensitivity to health data control	
Legislation		- rights for processors and controllers to control health data under special circumstances	- enable data subjects' control over their health data through digital technologies - leverage digital technologies to be compliant with governing factors	- provide a legal basis to control health data through digital technologies
Management			- ensure control of health data is given to data subjects through informed consent - enable data subjects' control over their health data through digital technologies	- ensure control of health data is provided through informed consent - ensure control of health data is provided through digital technologies
Transparency			- enable trust to control health data	

Appendix 3: Details of the sharing mechanisms part of the health data framework.

Mechanism	Environment (E)	Governance (G)	Processors and Controllers (PC)	Data Subjects (DS)
Culture			- foster an organizational culture that supports data sharing through various mechanisms	- participate in the data sharing culture as long as certain conditions are met
Engagement				- technical measures such as personalization that incentivize healthy lifestyle choices
Interoperability	- provide technical resources to facilitate health data sharing - establish a path for health data sharing across sectors		- enable sharing of health data across health data silos - provide technical means for data subjects to share health data	<ul> <li>facilitate health data sharing in exchange for health-related services</li> </ul>
Legislation		- support data subjects with the right to share health data	leverage digital technologies to be compliant with governing factors	- data subjects can supersede processor and controller restrictions through sharing - provide a legal basis to decide how health data is shared
Reciprocity			- increase willingness of data subjects to share health data through incentives	- sharing health data should have either extrinsic or intrinsic motivations - require security measures in place to incentivize health data sharing - require privacy measures in place to incentivize health data sharing
Transparency			- enable trust to share health data	- require transparency to increase willingness to share health data

Appendix 4: Details of the use mechanisms part of the health data framework.

Mechanism	Environment (E)	Governance (G)	Processors and Controllers (PC)	Data Subjects (DS)
Culture			- create a culture of appropriate health data use for considerations of privacy for data subjects - use health data to respond to health-related situations more readily	- facilitate the design and development of digital health services using health data - personalize digital health services for
Interoperability			- enable the use of health data across data silos	customers to be actively involved in their health
Legislation		- provide a legal basis for the use of health data - provide a legal justification for the use of health data - rights for processors and controllers to control health data under special circumstances	- leverage digital technologies to be compliant with governing factors - provide a legal basis to use health data for business purposes	- provide a legal basis to decide who and how health data is used
Reciprocity		urcumstances	- provide data subjects with better services through the use of health data	- require the use of health data through valuable digital technologies and services - personalize digital health services for customers
Reuse			- use health data from a secondary source in a collective whole	cusiomers
Sustainability			ruse health data from a provided primary source to continually sustain digital health services	
Transparency			- clarify how health data will be used in business processes to foster trust	- understand how health data will be used for providing digital services

# Appendix 5: Phase I semi-structured interview content guide.

The following section presents the interview guide from the semi-structured interviews in Phase I of data collection. The interview questions have been deidentified.

#### Part I: 30 Minutes

### General Ouestions

- 1. Could you tell me a little about yourself, what is your background (education/experience)?
- 2. What is your role and title in Omega?
- 3. How long have you work here, in this position?
- 4. Could you describe what your work entails on a day-to-day basis?

#### Health Data and Services

- 1. Do you have any direct interactions with (depending on work description): patients/physicians?
  - a. If so, please characterize your interactions) with them.
- 2. Do you deal with sensitive information?
  - a. If so, please generalize details about the information (where do you gain access to it, what form does it take, how is it involved in your work, do you share with others, do you have to adhere to any guidelines etc.)
- 3. Do the patients and/or customers have tools to access their healthcare related data?
  - a. If so, please describe the available tools. If not, how do patients/customers access their healthcare related information?
- 4. What rights that you know of, do patients/customers have to their healthcare data in Omega?

#### Healthcare System

- 1. As it stands now, how would you characterize the existing system of healthcare data? For you? For customers/patients?
- 2. Are you aware of any existing definition from Omega about a model towards patients and their data?
  - a. If so, could you explain how it is defined?
  - b. AND/If not, what do the terms mean to you personally and/or for your work?

#### Part II: 30 Minutes

#### Role Focus

# Human Resources/Legal

- 1. Who is considered to own the healthcare data in Omega?
- 2. What are the legal requirements for you to provide or share healthcare data?
  - a. Internally?
  - b. Externally (3rd party organizations)?
  - c. Other private organizations?
  - d. The public sector?
  - e. To the customers?
- 3. How is healthcare data controlled in Omega?
- 4. What influences your decisions around healthcare data? (Government, internal policies, EU Directives etc.)
- 5. Do you have any thoughts about healthcare data you would like to share?

# Medical Staff/Patient-Services/Customer Care

- 1. What access do you have to a patient's healthcare data?
- 2. What access does the patient have?
- 3. How do you access a patient's information?
  - a. Do you use mixed mediums to access patient's information (paper in ad hoc situations, digital services etc.)?
- 4. Have you encountered issues in accessing a patient's healthcare data?
  - a. If so, please explain the problem(s) in a general sense. Could you say something more about this?
- 5. In terms of healthcare data, who do you understand to own the information?
- 6. How do you feel the existing system incorporates the role of patients in their healthcare/lifestyle choices and general wellness?
- 7. Do you have any thoughts about healthcare data you would like to share?

#### IT and Support Services

- 1. What are your technical requirements for managing data within the organization?
  - a. How about more specifically healthcare data?
- 2. Could you characterize the distinctions between healthcare data and other data?
  - a. How are these different streams of data treated differently?

- 3. What tools are available for a customer or patient to access their healthcare data?
  - a. How about physicians or case workers?
- 4. What are your thoughts on a patient or customer's ability to access their healthcare information?
  - a. What is good, what could be improved?
- 5. What external factors influence what information you are able to provide and how you are able to provide it to:
  - a. Customers
  - b. Patients
  - c. Internal Support
  - d. External Sector
- 6. Do you have any thoughts about healthcare data you would like to share?

# Appendix 6: Phase II semi-structured interview content guide.

The following section presents the interview guide from the semi-structured interviews in Phase II of data collection. The interview questions have been deidentified.

#### **Areas of interest:**

- Healthcare data perceptions and barriers
- Digital healthcare services
- Prevention and proactiveness: Processes and semantics
- Omega attitudes towards inclusion of customers into practice
- Networking / exposure to company culture
- Probing for further research opportunities

#### General Part I: 1-2 Hours

Purpose: To re-connect with key individuals

- 1. Ask for any information about policy changes in Omega that they believe we should be aware of
- 2. What changes have occurred in the last year in the workplace (Worker's Compensation)
- 3. To gather information about the current status of digital healthcare projects in Omega
- 4. To discuss benefits or positive outcomes of previously ended projects (within the last year) or ongoing project
- 5. To discuss drawbacks or negative experiences with previously ended (within the last year) projects or ongoing projects
- 6. Inquire about further opportunities to conduct research and data gathering

#### Part II

- 1. Could you tell me a little about yourself, what is your background (education/experience)?
- 2. What is your role and title in Omega?
- 3. How long have you worked here, in this position?
- 4. Could you describe what your work entails on a day-to-day basis?
- 5. Who do you think owns healthcare data?
  - a. Why do you think that is?
- 6. What do you feel is the role of health data in insurance services?

- 7. What do you think is the biggest barrier to integrating healthcare data into Omega's services today?
- 8. What are the effects of the aforementioned barrier in the implementation of new services at Omega?
- 9. Explain to me your idea of the relationship between prevention and proactiveness.
- 10. What do you think about the current proactive direction in which Omega is moving?
- 11. How does Omega use prevention related activities in digital healthcare services?
- 12. How does Omega use prevention related activities in digital healthcare services?
- 13. What do you think will be the effect of prevention-based policy in the worker's compensation department?
- 14. How is social media used in prevention related activities?
- 15. Have there been any changes in the inclusion of customers in the design process of digital healthcare services/tools?
  - a. Are there any policies that you believe to be limiting customer involvement in healthcare technology development? If so, why?
  - b. Why do you think that customers are limited in their involvement?
- 16. What do you think will be the effect of prevention-based policy in the worker's compensation department?
- 17. How is social media used in prevention related activities?
- 18. What do you see is the biggest pressure for change? From the perspective of your individual work and the company at large?
- 19. Are there any policies that you believe to be limiting customer involvement in healthcare technology development? If so, why?
- 20. Why do you think that customers are limited in their involvement?
- 21. Where in the Omega hierarchy, can customers be found?
- 22. Has this position in the hierarchy changed over time?
- 23. Why do you think the hierarchy looks the way it does?
- 24. Where do you think Omega will be in 2 years? What will have happened?

# **Original publications**

- I Grundstrom, C., Väyrynen, K., & Isomursu, M. (2018). Dimensions of Accessibility and Interoperability for Electronic Health Records in the Nordic Countries: A Qualitative Evidence Synthesis of Facilitators and Barriers. In *Proceedings of the 22nd Pacific Asia Conference on Information Systems (PACIS)*, 287.
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