

Digital Culture

Master Thesis

**“An Ethical Evaluation of Three Digitization Measures in
the Health Sector: How to Better Accommodate Patients
Suffering Chronic Diseases”**



Universitetet i Bergen

Det humanistiske fakultet

Institutt for lingvistiske, litterære og estetiske studier, LLE

Name: Pål Kjelkenes

Abstract

This thesis intends to analyze and describe three different cases of digitization within the health sector. Even though all three cases discuss accommodating patients suffering a chronic disease, it is important to state that each respective case is different. Case One is a research project with the intent to integrate digital tools and cognitive behavioral therapy to better accommodate war veterans suffering chronic low back pain. Case Two is a review of peer-reviewed literature focusing on instances of digitization measures of treating cardiovascular disease and the presentation of the findings and implications of applying this to low- and middle-income countries. Lastly, Case Three is an app-supported research project targeted at a variety of users, medical personnel, relatives of patients, and the general public that intends to simulate what it's like to live with Inflammatory Bowel Syndrome through the use of a mobile health tool that inform patients of typical IBD situations. Central to this thesis will also be discussing literature and providing information about the symbiotic relationship between recent developments within artificial intelligence and medical ethics, and the importance of these fields evolving both in unison and tension. The purpose for this will be to highlight why ethics may and should play a significant role in the designing process of artificially intelligent tools used in the health sector, as these tools may have a direct impact on our health and well-being and should, ideally, be designed to reflect ethical values. However, there is a diversity of approaches to ethics in general, and more specifically to medical ethics. Following this line of thought, the thesis will discuss various issues that arise when combining the fields of medicine, ethics and technology into one thesis, taking into consideration that these fields, individually and combined, are extensive and complex. Another central part of this thesis will be to address to some extent the historical context, e.g., the view on the "patient" and on chronic illness, in terms of ethics being a dynamic and evolving principle. We will look, among other things, at how medicine and health care in industrial and post-industrial societies have moved from a historical beneficence model that focused primarily on the act of researching and curing diseases to an autonomy model which gradually has emphasized the patients' right to be involved in accommodating their disease. Central to this work, we will uncover four ethical principles that will act as a framework to evaluate the ethical implications in the three cases we have analyzed. The ethical evaluation towards the end of the thesis will present ethical implications and evaluate these using the four ethical principles in medical ethics as a framework.

Sammendrag

Denne masteravhandlingen er en kvalitativ beskrivelse og etisk analyse av tre digitaliseringstiltak som er gjort for å følge opp pasienter som lider av kroniske sykdommer. Masteroppgaven gir en historisk innføring i den etiske utviklingen av forholdet mellom pasient og lege, med fokus på de fire etiske prinsippene; velgjørenhet (beneficene), ikke skade (non-maleficence), rettferdighet (justice) og respekten for selvbestemmelse (autonomy). Disse fire etiske prinsippene vil være rammeverket som utgjør den etiske analysen av de tre digitaliseringstiltakene oppgaven tar for seg. En sentral del av masteravhandlingen vil være å belyse at det kreves et tverrfaglig samarbeid mellom flere fagfelt for at teknologi og helse skal følge etiske normer. Masteravhandling diskuterer hvilke etiske implikasjoner vi møter når etikk og digitalisering møtes i et symbiotisk forhold innenfor medisinske oppfølgingsmetoder. Noen eksempler på etiske implikasjoner vil være generasjons gap i forbindelse med brukervennlighet av digitaliserte medisinske tiltak, rettferdig fordeling av medisinske tiltak og ressurser uavhengig av økonomisk og geografisk bakgrunn og stigmatisering av enkelte pasientgrupper som lider av kroniske sykdommer. De tre digitaliseringstiltakene er forskjellige i deres metodiske gjennomføring som utspiller seg i ulike etiske utfordringer relatert til de fire etiske prinsippene. Oppgaven belyser viktigheten i at gode etiske retningslinjer må gjenspeiles i utviklingen og gjennomføringen av digitaliserte tiltak for oppfølging av pasienter med kroniske sykdommer.

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Piette et. al. "Patient-Centered Pain Care Using Artificial Intelligence and Mobile Health Tools: Protocol for a Randomized Study Funded by the US Department of Veterans Affairs Health Services Research and Development Program." *JMIR Research Protocols* 5, no. 2 (2016):1-16. [10.2196/resprot.4995](https://doi.org/10.2196/resprot.4995)

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Piette et. al. "Mobile Health Devices as Tools for Worldwide Cardiovascular Risk Reduction and Disease Management." *Circulation* 132, no. 21 (2015): 2012-027.

<https://doi.org/10.1161/CIRCULATIONAHA.114.008723>.

“A society grows great when old men plant trees in whose shade they know they shall never sit in”

Greek Proverb

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1 Introduction

Imagine an inverted triangle. Going from top to bottom, it starts out broad and then gets more pointed towards the end. Building on that analogy, I intend, in a first phase, to approach the thematic issues raised in this thesis broadly, and, in a second phase focus specifically and with greater detail on highlighted issues and perspectives. The general approach will build upon insights that the digitization of health measures and the ethical implications surrounding these digitized measures involve many layers of the notion of “technology”, which will be addressed in due time in these pages.

The title of this thesis “*An Ethical Evaluation of Three Digitization Measures in the Health Sector: How to Better Accommodate Patients Suffering Chronic Diseases*” suggests modestly how difficult it may be to fathom at once the complexity of addressing various encounters between healthcare and networked technologies and Artificial Intelligence. Analyzing and assessing such encounters requires dealing with fields of research stretching across a wide spectrum. For instance, because the thesis is “an ethical evaluation”, the field of philosophical ethics cannot be avoided fully when designing the research approach in this thesis. However, dealing with the complexity behind the topic of this thesis does not end there. One can still peel off further layers of “the onion’s skin” and propose that the thesis does not only concern itself with the general field of philosophy, but needs to involved the more specialized domain of *moral* philosophy, taking into account recent development within its subfield of ‘ethics of health’, ‘healthcare ethics’ and ‘medical ethics’, while including dimensions specific of the recent development of networked information and communications technology (ICT) and, e.g., social media, privacy and individual rights. Moreover, we can apply this same approach to other parts of the thesis title, e.g., “*How to Better Accommodate Patients Suffering Chronic Diseases*”, one understands that invoking the research field of *medicine* is crucial in the process of writing this thesis, with *bioethics* (not totally reducible to ‘medical ethics’) being another layer of complexity. The last part of the title – “*three digitization measures within the health sector*” adds another layer of complexity, namely the various dimension of applications of digital technologies in the health sector, e.g. mediated interaction and Artificial Intelligence. Correspondingly, one can also peel the metaphorical onion in this case and discover that digital is a rather general term that can describe hardware such as digital electronics, socio economic phenomena such as digital

culture and other uses like digital data, digital media, digital radio and television, and so forth. The list is seemingly endless. We will from there endeavor in this thesis, to focus on specific aspects of digitization exemplified through three cases studies.

Going back to our inverted triangle analogy, the intention is to offer the reader a contextual understanding justifying an initial broad approach to be followed by a more detailed analysis. This is imitating this work by describing the contextual setting is crucial. We cannot speak of context without using the metaphorical “zoom button” and zooming all the way out so that we may see the big picture. Therefore, the intention of this next section will be to give thought to the idea of The Fourth Industrial Revolution, as proposed by Klaus Schwab. This is the ultimate big picture, as it describes everything within the title of this thesis. It is as far as we can “zoom out”, in order to understand what is going on in this era of where technology seems to be a key factor in our day-to-day life.

In this section I want to take some time to write about the almost perplexing reality that has begun to take shape in front of us. We’re talking about the idea of the Fourth Industrial Revolution (4IR). This term was coined by Schwab (2016) to capture the discourse going on across emerging technological fields such as robotics, artificial intelligence, nanotechnology, quantum computing, biotechnology, the Internet of Things, the Industrial Internet of Things, fifth-generation wireless technology (5G), additive manufacturing/3D printing and fully autonomous vehicles, to name some. One can argue that a term like “The Fourth Industrial Revolution” allows us to “zoom out” from the ongoing discourse in all these technology-infused fields and capture them all under one term, much like an umbrella. This conceptual umbrella allows us to include synergies and possible convergences between various fields of research, development and industry and address these using a collective term. Using such a collective term may challenge one to see the big picture, namely the historical context and realizing the changes that we’re currently going through, and ultimately leading us to understand better the specific implications this may have in regard to ‘digitized accommodation systems’ (this will, hereinafter, be used as a generic term) in the health sector.

A closer look at the notion of 4IR will highlight contextual aspects of ‘digitized accommodation systems’ in the health sector. As stated above, the 4IR vision has been promoted by Klaus Schwab, Founder and Executive Chairman of the World Economic

Forum, who has been a central actor and contributor to global affairs for over four decades. In his book, 'The Fourth Industrial Revolution' (Schwab, 2016) the author exposes his theory that we are currently living in what is termed the Fourth Industrial Revolution, which he characterizes by a range of new technologies that are fusing the physical, digital and biological worlds, impacting all disciplines, economies and industries, and even challenging ideas about what it means to be human (Schwab, 2016, p. 6). More concretely, Schwab (2016), explains how the digital dimension is changing healthcare and ventures into outlining the potential this evolution has:

“Many of our intractable health challenges, from heart disease to cancer, have a genetic component. Because of this, the ability to determine our individual genetic make-up in an efficient and cost-effective manner (through sequencing machines used in routine diagnostics) will revolutionize personalized and effective healthcare. Informed by a tumours genetic make-up, doctors will be able to make decisions about a patient’s cancer treatment” (Schwab, 2016, p. 26)

Schwab’s sentiment that cost-effective and sufficient digitized treatments in health care is visible through the various ways that society has become deterministic in the sense that they not only use technology for practical reasons but *thrive* on technology. However, thrive is a strong word and should not be used unless it fits the context, but it is the word that I personally would use to describe our increasingly digitized culture. An example of just how much we “thrive” on technology would be the inherent obsession with self-surveillance through mobile health tools. In fact, there are as much as 48 companies investing in mobile health tools as of 2017, highlighted by Terry (2017) in a quite recent article about companies investing in the mobile health market. While this number may not be particularly high, it is mentioned because all these 48 different companies have different technological approaches to digitized health, e.g., medically oriented apps using artificial intelligence, mobile health to collect big data samples, image detection technology, molecular technology, AI chatbots to retrieve information and counsel patients, social media approaches for information awareness, reinforcement learning through adaptive processes, to mention only a few.

The fact that the statistics, going back one year to 2017, show this amount of companies investing in a wide spectrum of digitized health accommodating systems could be argued as a sign of a progressively more autonomous culture. We have come so far on the spectrum of

investing resources into the technology and digitization that one may even entertain the idea of human beings being an extension of technology (and vice versa), as suggested by Lawson (2010), which adds a more radical and possibly disturbing scene to Schwab's vision of the Fourth Industrial Revolution.

Because such a fundamentally impactful movement of technological development in our society has led to what Schwab refers to as the Fourth Industrial Revolution, it is fair to say the general population might have noticed that this revolution affects so many areas that it ultimately challenges what it means to be human, because the combining of ethics into machinery raises some problematic moral and ethical issues, e.g., questions of this nature: What are the implications of creating algorithmic machinery that will impact us physically, mentally, socially on a day-to-day basis? In which aspects should pre-defined algorithmic code define a mechanic behavior? These are crucial challenges that humanity must face, according to Creighton (2016) in her contribution about "The Evolution of AI: Can Morality be Programmed?". Answering such questions become difficult because, optimally, one would want machine behavior to reflect moral values if it is responsible for tasks such as treating patients, however, the variables that determine what moral values a person will follow are relying on too many factors. Such variables could be culture, orientation, socio-economic background or thousands of different factors, according to Creighton (2016). Such challenges are almost impossible to solve, unless there is a collaboration between different disciplinary areas to ensure that The Fourth Industrial Revolution will not end with a future dystopia, abundantly imagined in literature and films.

Taking the measure of these challenges, and relating these to various initiatives aiming at improving the life of patients suffering from chronic diseases through various technological measures, one has to incorporate fields such as neuroscience, psychology, moral philosophy, digital culture, as well as various other disciplines, in order to establish a foundation of ethical truth and social dependability that may contribute to shape guidelines for establishing such life changing technological developments within digitized healthcare in general and more specifically, digitized accompanying measures for chronic illness. Hopefully it has become clear at this point that the cooperation and symbiotic relationship between ethics and engineering developments related to AI need to be better tuned, and that co-development of ethical and algorithmic measures is desirable in order to ensure that the underlying algorithms and data structures defining virtualized behaviors in AI will enforce moral values that reflect

what is considered ‘good’, described by Conitzer (2016) as the moral apex. ¹This moral apex is considered the ultimate good, and is what we should strive for, but it proves to be a challenge because the moral apex is dynamic and what is considered ‘morally good’ today might change in a 100 years from now as it is now exemplified by the case of slavery being a less stigmatized and more acceptable practice 100 years ago, but generally considered to be morally reprehensible in society today (Conitzer, 2016). This a statement following the interview that Creighton (2016) highlights.

“If we did the same ethical tests a hundred years ago, the decisions that we would get from people would be much more racist, sexist, and all kinds of other things that we wouldn’t see as ‘good’ now. Similarly, right now, maybe our moral development hasn’t come to its apex, and a hundred years from now people might feel that some of the things we do right now, like how we treat animals, is completely immoral.”
(Conitzer, 2016)

The goal for what is considered the ‘moral apex’ is therefore always shifting, and this should be taken into consideration when dealing with ethical aspects linked with digitized accompanying measures.

In our culture the emergence of machinery possibly capable of human level intelligence has in the latest years been booming on the agenda of political parties, academic scholars, researchers and scientists alike, as attraction to the unknown is a common denominator in society. One could deem such a fascination for artificial intelligence (or what is believed to be such), as a strange attraction to the unavoidable dystopian nature of AI, rooted in the psychological trait of humans being ‘morbidly curious’ and thus wanting to explore the ‘unknown’ at the risk of perishing. However, this is a mere hypothesis and a personal attempt at justifying the attraction to AI. It is also understandable that the field of artificial intelligence has gotten increased attention because of its already achieved and expected future capabilities. While this thesis will not specialize in recent ‘bleeding-edge’ developments of A.I, but rather will address a more general endeavor towards offering chronic patients ‘intelligent’ digitized accommodation, the debate about the implication of

¹ The Moral Apex (Conitzer, 2016) is terminology of a moral peak that can never be reach due to morality being dynamic in nature and changing depending on current values reflected in society.

Artificial Intelligence will have bearings on follow-up systems with no or very rudimentary aspects of ‘machine learning’.

However, it is safe to say that if our goal is to accommodate patients suffering chronic diseases with ethics in mind, it requires a collaboration of different academic fields coming together, as the emergence of advanced artificial intelligence in the health sector requires the collective attention of different perspectives, in order to ensure the well-being and safety of our people, especially when AI concerns itself with the health sector, as this has direct correlation to our health and well-being. If mistakes based on misinformation or lack of inquiry are made in the ethics department of an AI designed to accommodate a patient, one might end up with behavior that does not reflect good moral values.

2 Background

2.1 Looking Back: Gaining Perspective

In my life I have always been drawn to the technological dimension, mostly through the use of computers. Reflecting upon the historic context and the causal connections leading up to events in my life has always been important to me, as I find that it brings clarity in how events have unfolded in relation to digital technologies. That is why I am going to first go through the events that have led to my interest in digital technologies, cultures and AI's potential to achieve enter a state of symbiosis with human nature, which is in essence what this thesis is about; finding the ethical dilemmas of a world in which technological tools has become more than mere tools, but rather an extension of our image.

My basic approach is that we find ourselves in our use of technological devices, as these reflect and expand our behavior and help us adapt to the surrounding world. Additionally, one could point out that technological devices, including digital technologies, have an agenda of their own, which indeed would constitute a specific ethical issue. However, problems are likely to ensue when technological apparatuses encourage or provoke patterns of behavior that are not considered morally sound by current standards. One can therefore say that the irruption of digital technologies in modelling, e.g., the behavior of chronic patients, actualizes more deep-rooted issues linked with what is *actually* considered to be morally sound and reprehensible in the current health care context in advanced welfare societies. A key challenge when dealing with ethical issues, e.g., in health care, is whether there exists objective guidelines, standards, norms and procedures as to what should be implemented into the artificial, when morality relies on the subjective nature of human thought process. These thoughts, most particularly the embeddability of ethical systems in digitized accompanying measures in healthcare, have occupied my mind for a little over five years now, and I find them important for numerous reasons, which will be discussed in these pages.

2.2 Medicine: My Affiliation with the Health Sector

I would consider myself fairly familiar with the health sector and how it operates due to my extensive private involvement with the health sector, being someone who suffers from a chronic disease myself. In fact, for the past 15 years I have suffered from Crohn's disease, a Inflammatory Bowel Disease (IBD) that affects the bowels through irritation or inflammatory symptoms. Numerous doctor visits for treatment and care for my Crohn's disease has led me into occasionally questioning some actual procedures and findings of physicians. However timid in the past years, the disease has been followed up through frequent doctor appointments and it led me into being intrigued by the extensive institutional, clinical and technical apparatus addressing the needs of chronically ill patients.

Through consultations for treatment of IBD, and frequent conversations with physicians treating IBD, I have accumulated several experiences and reflected over how the process of treating and accompanying IBD works for individual patients. I have tried to apply my current knowledge of digital culture and my general interest in what I often refer to as abstract topics, e.g., critical approach to questions pertaining to ethics and morality, and endeavored to integrate these interests with my experience of being an IBD patient in the Norwegian health sector.

More concretely, and of particular importance to accommodating patients suffering chronic disease, a hypothesis that has entered my mind when receiving consultation for my IBD has been that patients suffering of this disease are all quite different in terms of how aggressive their disease is, and that, as a consequence, the required action from physicians in accommodating patients suffering IBD should vary depending on each person's symptoms - ultimately rendering the clinical aspects in treating IBD rather difficult to carry out. I consider myself lucky to not have the worst symptoms of IBD, but during consultations in which myself and other IBD patients are administered medicine through intravenous treatment during a whole hour it is not uncommon to have conversations with fellow patients of IBD regarding their symptoms and disease. It is noticeable then that the notion of 'patient' covers a wide spectrum of clinical and subjective situations, e.g., there are patients suffering far worse inflammatory symptoms than myself, leading such patients to struggle a lot, both mentally and physically, as a result of this. It is at this point, that more adapted, possibly

intensive, and hopefully cost-efficient (e.g., achieving more coverage) methods of approaching the problem of accommodating patients suffering from IBD enter my mind, and it is ultimately the reason as to why this topic was chosen. The numerous consultations, and the experience I have myself with IBD and accompanying measures to treat IBD in the Norwegian health sector, coupled with my interesting in digital culture, and a penchant towards reflecting over the abstract and therefore intriguing nature of morality and ethics – all these areas of interest and concern are reflecting in the various sections of this thesis.

2.3 Ethics: Questioning the Origin of Morality

Linking knowledge of the past with prospects for the future appear to me to be more thought-provoking than merely describing the present state of things, which is where the philosophy of ethics comes into question. Ethics is not a static discipline but is dynamic in every sense of the word, as it relates to a rich variety of situations and applications and contexts, and in its contemporary academic form incorporates key insights about socio-economic change, psychology and anthropology. In a historical perspective, the religious roots of ethics still may surface when discussing ethics, as there are different perspectives on where morality originates from, e.g. in the debate between theological or principled ethics vs. situational ethics. E.g., one may discuss, whether altruism may be viewed as a trait originating in a religious universe, or, by contrast, as an evolutionary trait, or more basically as a brain function that can be explained cognitively using objective arguments. These are thoughts that have prompted me to address the issue of morality and combine it with my affiliation and interest in the assumed growing potential of and reference to artificial intelligence (hereinafter: AI) in the health sector.

One may refer to a person's stance on issues of morality by addressing their 'moral compass', which will vary depending on the person, his/her culture, surroundings, upbringing and virtually every single occurrence that has happened in the person's life. There are so many factors that will determine an individual's moral compass. Such insight leads us to assume that notions about morality indeed are quite abstract, contextual, and adaptable, and the possible gaps between acceptable behaviors and abstract norms are numerous and varied. The subjectivity of moral appreciations, decisions and evaluations needs to be dealt with in

practical situations, as well as in academic ethics. This fruitful tension between context, situation and abstract norms is the reason that I am attracted to the ethics of healthcare and have incorporated this dimension in the scope of my thesis. Followingly, I will discuss such ethical issues one can find in the digitized accompanying measures that are developed and proposed to accommodate patients suffering chronic diseases. Such findings will be outlined in the chapter for ‘Understanding the Historical Perspective’, which discusses Gillon’s (1994) four principles which, according to the author, can constitute a framework for medical ethics in the health sector.

2.4 Technology: an extension of humanity or vice versa?

Thirdly, the next piece of the puzzle added to my analysis will be motivated by my interest in the consequences of digital technologies and digital culture. Such interest traces back to the fact that I find anything that is considered abstract, open, and ‘unsolved’ to be of interest, e.g., digital culture spans across vast research fields while involving us on a daily basis. A basic underpinning for this thesis is that most individuals around the world are, knowingly or unknowingly, surrounded by and using, directly or indirectly, digital technologies and incorporating elements of digital culture individually or collectively, be it voluntarily by participating in social media websites like Facebook, Instagram, Twitter, Snapchat and the likes, or unwillingly by appearing on surveillance cameras all over the world. We all partake in digital culture and it is a vast, extensive field. I do not only associate strongly with digital culture because it is my field of study and research, but also because I am an avid user of the computer and the Internet. I have adopted the culture that has emerged around digital technologies, I have become, to use simplified characteristics, a technological determinist who believes technology shapes us. However, I find it crucial to examine critically the *use* of digital technologies and explore ethical implications of digitized measures in the health sector. Technology has always been an extension of humanity, but I fear that, without intervention and careful examination, humanity might become an extension of technology. It might not be evident right now, but even more terrifying are the small changes and seemingly unnoticeable changes, because these are changes that fly under the radar. Much like looking at yourself in the mirror every day and not noticing that you’re gaining weight because it happens so gradually, technology acting upon us like it has its own conscious agenda.

3 Method

This chapter intends to outline the methods used in this thesis to acquire and combine information and explain in which aspects the information inquiry process could be defined as a multi-method qualitative research process. Additionally, this section will assess the credibility and possible disadvantages of the primary source material referenced in this thesis, e.g., determining if there are benefits or disadvantages in using each respective source. Another part of this section will consist of a presentation of the four ethical principles in medicine (Gillon, 1994) which will be the framework for ethical evaluation of the three cases in this thesis.

3.1 Qualitative Research

The method describing the information inquiry in this thesis is reflective of the basic philosophy of qualitative research, e.g., emphasizing contextual aspects, multi-perspective approaches, and ethical concerns. I have gathered case material from various sources using widely used search engines, such as Google Scholar, ensuring that I may collect potentially reliable peer-reviewed contributions, e.g., in scholarly journals and academic theses. In this thesis the premise involves an ethical *evaluation* and requires discussing and individual reflection, adding a fully assumed reflective dimension to the enquiry process, and is different from quantitative research focusing on detached and objectivizing statistical analysis. Consequently, the approach followed in this thesis more argumentative, e.g., regarding the ethical implications of the studied cases. This approach is in line with the general approach within academic moral philosophy, which is a dynamic and less ‘clinical’ domain of knowledge, emphasizing various contextual aspects and dilemmas.

3.2 Information Inquiry

In this section I will explain how I acquired information leading to my findings, ranging from the mixed use of search engines to interviews and collaborations. The main purpose of this section is to allow the reader to formulate an opinion on how the information that was acquired and systematized is relevant.

3.2.1 Use of search engines

Most of the resources acquired in the research of relevant literature was through Google Scholar, allowing me to find reliable and, where possible, peer-reviewed articles, journals and doctoral theses. Previous knowledge of the reliability and credibility of Google Scholar led me to do most of my inquiry in terms of gathering credible and relevant resources in Google Scholar, as the scope of the thesis is based on modern research, rather than research dating back to research that are only available on paper. To expand on this point, Google Scholar was launched in 2004 and covers most journals and academic articles published online, making it an ideal candidate in the methodological approach of information inquiry of this thesis. Using Google Scholar, I was able to find newfound knowledge and up-to-date information to support my thesis. I was assisted by my thesis supervisor as well in finding and discussing relevant resources that could potentially be of use. When reviewing resources related to the scope of my thesis, I concentrated on contributions which addressed the fields of healthcare ethics, medicine (chronic illness) and digital technologies. A key challenge was to find freely accessible articles, as most relevant peer-reviewed articles were published in journals that require a commercial subscription or purchase of the article. I ended up purchasing several articles related to the topic, as free articles were seemingly scarce.

3.2.2 Interviews and collaborations

I initiated my project, in the pilot phase, conducting an informal interview with Hilde Løland Volkmann, PhD/MD at Haukeland University Hospital, specialist in chronic disease, to address the potential challenges posed by a research project which ambition to implement an AI based artificial agent to accommodate patients suffering from chronic diseases.

The purpose behind this inquiry was going to be to gather contextual knowledge of the potential behind this research project, but also gather useful knowledge that could potentially lead me to other references or be a direct source within my thesis. Following this meeting, I got positive confirmation that the research project was interesting being that it affected Volkmann's field of research directly. It also served as motivation because an outside party could confirm in person that the research project scope was, quote, "an interesting field that

could definitely benefit from ethical analysis” (Volkman, 2018). Though it did not serve as a direct source of reference in my work, e.g., through transcripts of the discussions, I was grateful to have the opportunity to meet Volkman and be able to share some of my findings with her, as it ultimately prompted motivation and insightfulness from my perspective.

Another line of inquiry related to providing information on the historical context of how medical ethics have evolved from the Hippocratic era to a more autonomous model for patients in the health sector was provided by PhD fellow Henning Åge Skarbø, UiB. In an email exchange I was given a two-part article published in the CHEST Journal, namely “A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making - Part I: The Beneficence Model” (Will, 2011) and the following article “A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making - Part II: The Autonomy Model” (Will, 2011). Skarbø is conducting at Helse Vest and at the University of Bergen to develop a chatbot with the purpose of following up patients suffering from chronic disease. I met Skarbø through my supervisor, and I am grateful that I had the opportunity to share insights and discuss the thesis with Skarbø. I am also grateful that Skarbø led me to the CHEST Journal referenced in my thesis related to the historical context of ethics in the medical field, as this became a central part of my thesis. In the above-mentioned CHEST Journal (Will, 2011), I was able to identify the historical context as to how the patient-physician relationship has evolved over the years, dating back to the Hippocratic tradition. The CHEST Journal (Will, 2011) appointed to me by Skarbø interestingly had the consensus pointing towards an incremental introduction of ethical principles in the health sector, which highlights the importance of medical ethics and technology evolving in a symbiotic relationship.

3.3 Evaluation of the Credibility of Sources: Strengths and Weaknesses

In determining the reliability and usefulness of my sources, I find it important to state that the use of a reliable search engine (Google Scholar) that provides peer reviewed articles, journals and thesis has been a deciding factor in making my thesis strong in terms of its credibility. I draw this conclusion based on recommendations I have gathered, e.g., in conversations with my peers and professors in Digital Culture, about the credibility and reliability of Google

Scholar. Case One and Case Two in this thesis are both published in medical journals and peer-reviewed. Case One exhibits a high degree of credibility (but may be nonetheless subject to criticism) as it been published in on PubMed Central, which is a widely cited archive for biomedical and life science.²

As the results from Case One are expected to be available at the end of 2019, the above-mentioned research article has been uploaded to an archive at PubMed named JMIR Protocols, which deals with ongoing trials, grant proposals, methods and early results. Another strength to this source has is that it is peer-reviewed by two independent experts on the scope of the topic in Case One.

A possible critique against using this case might however be that the results of the case will not be ready before end of 2019, as patient enrolment began in 2016. However, Case One currently is being reviewed by a monitoring editor (Gunther Eysenbach). Additionally, Case One appears strong even though the applied research is not focusing on the *ethical* implications of accommodating chronic diseases through digitized measures in general, but more soberly, on the actual accompanying measures, e.g. procedures, and their observable effect on patients undergoing the trials. While the already observed and expected results themselves will indeed benefit the researchers of Case One in terms of creating similar functioning digital procedures to accommodate patients suffering diseases, the discussion in the ethical evaluation section of this thesis will deal more with the findings *during* the trials and procedural work.

Case Two shares many of the strengths of Case Two, being described in a publication that is peer-reviewed by multiple individuals. A benefit associated by Case Two resides in the fact that this research article also is authored by John D. Piette (same as Case One), which means the approaches chosen in Case One and Case Two, may be more easily compared. Case One focuses on the description of an actual medical procedure using technological devices such as

² “PubMed Central® (PMC) is a free full-text archive of biomedical and life sciences journal literature at the U.S. National Institutes of Health's National Library of Medicine (NIH/NLM). (PubMed Central, 2018)

mobile health tools, pedometers to track patients and reinforcement learning to adapt to patient needs, while Case Two is essentially a review of peer-reviewed contributions and grey literature that adopts the same premise as Case One. This is an interesting dynamic, as one may explore ethical implications in each of the cases, regardless of one being an actual procedure and the other case being a review of literature. Exploiting this distinction is potentially productive, because Case Two reviews not just one specific case of accommodating patients suffering chronic disease through digitized measures, but multiple instances of this, which makes it an ideal candidate to draw ethical implications from, and even information helpful determine the results of Case One.

Case Three (Takeda), regardless of it being the case with the least amount of currently available information, is relevant in that it offers an original and creative attempt, using a dedicated mobile app, to learn more about how to better accommodate patients suffering from Inflammatory Bowel Syndrome (IBD) including the use of additional technological apparatuses such as a device around the hips of the app users to track movement, and communicating through direct smart phone messages. I did not select this source because it was the most readily applicable, but because I was more impressed by such an original attempt at learning more about a disease, as originality can be effective contra the rather common methods and procedures one can find in other cases attempting to better accommodate patients suffering chronic diseases. One weakness however will be the fact that Case Three has not been published in an article yet and is not a peer-reviewed source as Case One and Case Two is. Attempts at contacting Takeda for more details regarding their findings in the research project and perhaps even getting access to the technology used to simulate what it's like to live with IBD was made, but unfortunately this did not result in any additional data or further resources to benefit this thesis.

3.4 Framework for Ethical Evaluation

The approach chosen to address the ethical implications in each respective case in the Evaluation Section will exploit the framework for ethical principles in medicine proposed by Gillon (1994). Gillon's framework addresses, in my opinion, the most central ethical demands which digitized accompanying measures may be expected to fulfill if they are to be

made public or may be authorized as legal medical procedures in Western countries. In short, Gillon (1994) states that the four ethical principles are beneficence and nonmaleficence, autonomy and justice. A thorough description of these principles will be given in chapter 5 of this thesis, hopefully leading to inscribe the evolution of these ethical principles in a more fluent approach. That said, the most important part of conveying this information is to state that the framework for ethical evaluation will be Gillon's (1994) four ethical principles of medicine as he describes them in his work.

4 Cross-disciplinary Contributions to the Ethics of A.I

In this section the intent will be to shed light on the complexity and difficult nature of researching ethics, medicine and technology, being that these are fields that requires a tightly knit symbiotic relationship between the different research fields. It is important to highlight this complexity because it paves way for some of the ethical implications to enter the domain of this thesis, as we shall see in the following section.

4.1 Perspectives from Cognitive Sciences

Through research and development in the cognitive sciences, such as neuroscience and psychology, we have gained more insights into how the conscious and subconscious brain functions, as proposed by Glaser et. al (2017). Such understanding constitutes a crucial step if we are to reproduce aspects of the human brain, (e.g. cognition or elementary consciousness) within a ‘computerized brain’ build upon advanced AI algorithm. While ambitious, and even utopian versions of AI, e.g., mind algorithm consciousness, may belong to science fiction, there are more pragmatic approaches to AI, e.g., Machine Learning (essentially algorithmic pattern learning classification and feature identification) which may be implementable in a real-life situation and offer short-term benefits. E.g., tasks in the health sector that are meant to improve, e.g., self-management of chronic patients are frequently of a repetitive nature and call for recurrent actions, such as giving medicine or mapping and following up a patient’s mental state. Piette (2016) proves that machine learning processes like reinforcement learning is a sufficient alternative. Processes involved in a typical chronic patient follow-up are amenable to be supported and enhanced by current AI techniques. (Glaser et. al., 2017). AI, even in its current state of development, may offer significant improvements in chronic patient care as it offers opportunities to remove cognitive biases and erroneous behavior that human beings display in their work in the medical field. AI is purely technical – algorithmic – and does not require the same neurological symbiosis as the human brain does. For instance, suffering from a chronic mental illness or simple cognitive bias can be ruled out in AI created to solve certain tasks, as AI algorithms may acquire and exploit reliable knowledge about predictable behavior patterns which can be embedded in applied AI

systems. In medical care situations, AI's capability to adapt to certain given parameters and variables has, as displayed in all cases of this thesis, predictable and measurable results.

4.2 Philosophical Considerations

Optimally, the yet-to-come advanced AI would have to be assigned some kind of personhood and follow a set of moral codes reflecting ethical guidelines and social norms that are widely accepted in contemporary society today. Because, if we are to allow advanced AI to live side by side with us, we must ensure that AI systems are capable of taking moral decisions, something that ultimately would require advanced AI to incorporate some aspects of human subjectivity. This is a challenge as being subjective and able to make judgement calls involves being aware of the decisional context, the situations and having some "moral compass. As of writing, an algorithmic moral 'subject' is still a not currently achievable through code & algorithmic behavior, but aspects of ethical analysis complying with ethical standards may be integrated in decision-making systems. Consequently, the emergence of advanced AI calls for integrating central themes of moral philosophy. To do so, it is necessary to acquire an understanding of various approaches to the philosophical notion of morality. Such considerations may constitute a crucial and unavoidable step when attempting to model and implement ethical analysis as a core function of an AI-based support system to accommodate patients in the health sector. In doing so, we may re-actualize ancient questions already covered extensively by moral philosophers. The main problem is related to the argument that moral persons are subjective by nature and we cannot truly determine what should be a universally, objectively correct set of ethical guidelines that represent humanity as a whole. AI systems need therefore to clarify which ethical fundamentals are adopted.

4.3 Economical Aspects

Another academic field of research, which calls for ethical reasoning is the field of economics. One of the most predicted and perhaps most debated implications of advanced AI is the increasingly autonomous behavior of AI, which makes them e.g., optimal job candidates, as they potentially could replace human beings in the job market, and especially in key activities within health sector as human errors have a critically damaging effect,

ultimately rendering humans jobless. Hisieh (2017) addresses this concern in his Forbes article by describing the situation from a position of someone who covers health and economics from a free-market perspective.

“In particular, new “deep learning” artificial intelligence (AI) algorithms are showing promise in performing medical work which until recently was thought only capable of being done by human physicians.” (Hisieh, 2017)

This notion again highlights what is central to this thesis, that AI in the health sector (but also virtually every other sector that uses AI) must be in unison human values. The AI must correspond with what a society wish to achieve, which becomes a challenge when faced with the fact that different people want different outcomes, depending on variables that affect said person's life. In respect to the ethical discussion of this thesis, one can entertain the question, “Is it truly ethical to invent AI with the capability to replace human agents in their line of work if the implication of creating such advanced AI is that we might suffer from its emergence into the job market?”. Being a radiologist, Hisieh (2017) would argue that one should not worry about the future of the job market as new jobs will be created at the same rate that they disappear, which is a general belief that society also shares in discourse surrounding autonomous behavior. Hisieh, even though he is a radiologist, is more of an optimist as he argues the following:

“In time, AIs will likely displace many practitioners in many branches of medicine, including my own specialty of radiology. But for all of us, the potential benefits outweigh the short-term costs. I, for one, welcome our future AI medical experts.” (Hisieh, 2017)

To what extent do we have the right to invent AI and establish a power-relationship in which we are the “owner” of this AI, and do we have the right to predetermine the destiny that this AI would seek out? One could draw parallels to a most unjust, unrighteous and unethical time in history, for instance when it was legal to own slaves. To solve this ethical dilemma, one would have to assess the ethical dilemma of implementing personhood in advanced AI, which is a determining factor in terms of their right to ethical guidelines. Nevertheless, our sustainable future in the health sector rests upon a sufficient understanding of AI, as

advanced AI would undoubtedly be a fundamental change to the health sector that can revolutionize the way in which patients receive treatment.

4.4 Generational Implications of Adapting AI to Digitized Health

Methods

The next ethical question and field of research challenged by the implementation of AI in the health sector is related to generational aspects. This field of research involves generational studies and is generally concerned with the challenge to adapt AI to different age groups in the medical field. One challenge for developers in AI-based patient care systems is: how can one accommodate patients suffering chronic diseases when their perception of and abilities to interact with, e.g. with mobile technologies are widely different? The proposed theory is that

Knowing this, it is important to realize that one cannot truly know the outcome of the future, but rather build on the foundation of valuable and credible information that scholars, researchers, professors and scientists have uncovered regarding advanced AI. That said, I will refrain from making assumptions with no basis in sufficient evidence, as one could argue that the emergence of advanced AI has in fact moved from the domain of fantasy and fiction to the domain of highly plausible, or seemingly possible theories. Though appearing as practical, self-explanatory information, the need to confirm the credibility and academic guidelines of this thesis is prevalent because the thesis will be addressing something of the future, namely advanced AI, and the future is not written in stone. What we know today might change, be altered or simply not be correct, in regard to AI, as it concerns itself with multiple fields and is constantly in a dynamic state in terms of its establishment in the world.

5 The Historical Perspective: The Evolution of Medical Ethics

Before engaging in the in-depth discussion of the ethical implications regarding our three cases of digitized medical accommodation for patients suffering chronic diseases, it is important to be equipped with the correct knowledge and perspective of past and current endeavors in medical ethics, patient autonomy and medical decision making as these are dynamic fields that has changed dramatically over time, and is now still in its adaptation stage. In addressing the historical aspect of medical decision making and going from a beneficence model to a more autonomous model in the health sector, we will refer to Will (2011). We will then dive deeper into this in the following section of this thesis, discussing the beneficence model, the autonomy model and the four principles of medical ethics as described by Gillon (1994).

5.1 Patient Beneficence and Medical Decision Making: The Beneficence Model

In this section I would like to address Will (2011, 669-673), as this gives a brief overview in the Beneficence model and how medical decision making has been affected by a change in the ethical landscape over the course of 2400 years. This will be to contextualize the moral stance on patient-physician relations from the perspective of the Hippocratic tradition era to how patient-physician relations are handled in today's society, which marks an autonomous shift in patient-centric relations. In the background section of this thesis I claimed that understanding perspective was important, as this gives you meaningful context, acting as a precursor to guide humanity through the challenges that was presented by artificial intelligence not evolving in unison with other research fields, specifically the field of ethics. Following that line of thinking, context is the main reason I choose to include this section as well, so that we understand the vastly different landscape of the Hippocratic tradition era, dating back almost 2400 years.

We will first start by addressing the beneficence model, which was the dominant patient-physician model that ruled for over 2400 years (Will, 2011, 669-673). To understand why ethics play an important role in today's medical ethics, it is probably convenient to go through the history of ethics from a medical perspective. Patients suffering chronic disease and other illness in the long era of Hippocratic tradition until the end 19th century were not assigned a meaningful role in the medical (clinical or post-clinical) decision-making process. This was largely because the moral landscape in the Hippocratic tradition was reflective of the culture and values that was prominent at the time, evident by the fact that one could own slaves and that was morally acceptable (in contrast to the moral stance on this today), which is also confirmed by Conitzer (2016) in the article referenced earlier in the thesis. This is exactly why morality is a dynamic principle, forever changing and evolving into a more developed system of showing affection and being just towards other people, treating them as equals.

In fact, the era marked as the 'Hippocratic tradition' was characterized by deliberate withholding of information from patients regarding their chronic conditions. Physicians did not feel it necessary to include patients in the decision-making process, because they considered patients to be unaware of what was going on with them. This line of thinking, from today's perspective, is considered misinformed and objectionable in many aspects. Being treated like e.g., a clinical 'object' or 'case' with no or minimal interest in the patient's subjective experience and knowledge of his/her illness, is increasingly less accepted in today's health sector, as we move from what is known as the Beneficence Model to a more autonomous worldview in which patients and physicians are equals. (Will, 2011, 669-673)

The beneficence model did not end before thinkers like Gillon (1994) started studying the seemingly unfair conditions in the medical field. In fact, we can thank the philosophers of ethics in the Hippocratic tradition era for being able to identify the inherent value in respecting patient self-determination, which has been a gradual shift, but enhanced by addressing the lack of a framework that include ethical principles one should follow in order to accommodate patients in a manner that is ethical, something Gillon (1994) speaks passionately about in his work. Patients were eventually allowed to be part of their prognosis and eventually information would flow more fluently from patient to physician (Will, 2011, 667-673). This moral evolution and culture change in the medical field that Will refers to in the Journal of Medical Ethics was the start of the beneficence model's opposition, namely the

autonomy model; the inclusion of ethics in the medical field and ultimately the inclusion of a patient's legal and moral right to be an individual, rather than being treated as a research object, and ultimately to be informed what is going on with their health.

In fact, looking back at the beneficence model, one could establish that it took 2400 years before anything changed (Will, 2011, 667-673). It was only because of moral philosophy and progressive change towards ethical values that anything ever changed, but interestingly the most dramatic change of all in creating a more patient-centric worldview has occurred in the last 100 years.

Patients were allowed with the autonomy model to give their legally informed consent including their right to refuse the recommended treatment. Such evolution could particularly be observed by the way treatment was given to patients who were about to pass of old age, as patients then exercise a high degree of self-determination, a right that is philosophically valued and legally recognized in the autonomy model.

Recognizing this change, one also acknowledges that the change is still going on today. In inventing technological devices that focuses specifically on the patient's well-being, such as mobile health tools in the form of health trackers, we see that the autonomy model is continued even further. We are going towards an even more autonomous lifestyle in which patients have responsibility, control and ultimately a more patient-centric life.

5.2 Patient Autonomy and Medical Decision Making: The Autonomy Model

In the last 100 years, the autonomy model continued to be evolved (Will, 2016, 1491-1497) and was eventually given even more credit in law. There are now laws against doing unlawful practices on patients, and most importantly, the patients must consent to physicians conducting medical experiments using patient data or use information about patient health.

These laws are available for anyone to affirm today, by visiting University Health's website that list numerous laws informing patients what they can do and not do, according to the law in most western countries (University Health).

In part two of the article published by Will (2016), it is evident that bioethics were changed drastically to fit a more changing world in which patients suffered various diseases that should not be kept confidential from the patient by the physician. Informed consent was one of the key parameters for confidentiality to slowly fade, and autonomy beings to evolve into being the morally superior practice in the health sector, as Will states,

“The shift from the beneficence model to the autonomy model is governed legally by the informed consent doctrine, which emphasizes disclosure to patients of information sufficient to permit them to make intelligent choices regarding treatment alternatives. As this legal doctrine became established, philosophers identified an inherent value in respecting patients as autonomous agents, even where patient choice seems to conflict with the physician's duty to act in the patient's best interests.” (Will, 2016, 669-670).

We are given new laws to live by, and ethics now play a vastly different role in medicine than what it previously did.

5.3 Historic Perspective of Medical Ethics: The Four Principles of Medical Ethics

In studying Will (2016), one starts to question what the actual principles of medical ethics *are* as of the 21th century. What governs physicians to conduct lawfully moral experiments on patients, and how does one regulate the field of medicine? Gillon (1994) refers to this problematic question by suggesting that there are principles that govern ethical values in the field of medicine, and we will discuss and take use of these principles in this thesis.

“Medical ethics: four principles plus scope” found that there were four principles of ethical evaluation that one must consider in medical studies. Gillon (1994) addresses these four ethical principles when doing my evaluation of the digitization process & follow-up process

of chronic disease management. In short, the article and numerous other sources, state that the four ethical principles are beneficence and nonmaleficence, autonomy and justice. I intend to describe these four principles in the following sections below and use them as a framework in the section that attempts to evaluate the ethical implications of Case One, Case Two and Case Three. That is why it is crucial to understand exactly what the four ethical principles of medical ethics are, according to Gillon (1994).

5.3.1 Beneficence and Nonmaleficence

Beneficence is an ethical principle that is focused towards producing a net-benefit in medical situations, meaning that the outcome of a medical procedure, experiment or trial must produce beneficial information or an improved health state for the patient. Thus, beneficence describes the ‘good’ that comes from medical work. Non-maleficence is not similar in orientation to beneficence (Gillon, 1994, 185), but still closely tied to beneficence as it describes the ethical principle of not harming the patient during medical procedures, trials and experiments. Therefore, in a ‘good moral setting’ the overall goal of medical workers will always be to produce net-benefit while at the same time not harming the patient. There is an important distinction, however, between what the ethical principle of beneficence *meant* and what it *means* in today’s medical context. As we learned previously by discussing Will (2016), the Hippocratic tradition involved the ethical principle of beneficence. The distinction between what beneficence meant in the Hippocratic era compared to what it means today would be that beneficence in the Hippocratic era was a goal regardless of non-maleficence. This meant withholding information from patients, excluding them from key decisions in their accommodation process or physically hurting patients, because these morally reprehensible approaches were believed to be the most effective way of inquiring information. However, in more recent times, the indulgence of patient consent, background checks in terms of previous medical conditions and medicaments, non-harmful medical approaches and similar beneficial values all require careful consideration. Gillon argues this point clearly in his article “Medical ethics: four principles plus attention to scope” by stating the following:

“Whenever we try to help others we inevitably risk harming them; health care workers, who are committed to helping others, must therefore consider the principles of beneficence and non-maleficence together and aim at producing net benefit over harm.” (Gillon, 1994, 185)

Consequentially, from the gradual increase of non-maleficence and concern for patient’s wellbeing and health, we see the symbiotic relationship between beneficence and non-maleficence coming together in digitized medical procedures. However, it can be argued that when the medical procedures are digitized, the ways of producing net benefit and at the same time not harming the patient are different than when the medical procedures are physical. This is a point of discussion that we will look at later in this section when using the four principles of medical ethics as a framework of evaluation in the three selected cases.

5.3.2 Autonomy

The autonomy model is important and closely related to ethics because it talks about the patient's right to choose, be involved and responsibility. If we have this ethical principle, we can make our own decisions based on deliberation. In Kantian terms, Gillon (1994, 186) describes this as treating patients as an end and never merely means. The autonomy model, especially related to digitized health, also emphasizes the patients right to self-rule and be in control of their own health, which is what this thesis argues. Through various digitized health services and procedures, we find that patients are more in control of their own health, which one can argue changes the way Gillon (1994) traditionally looked at autonomy in 1994 when the article “Medical ethics: four ethical principles plus attention to scope” was written. In 1994 the digital health market was not as prevalent as it is now, which meant that autonomy meant physicians respecting a patient’s right to choose, be involved and make their own decisions. However, when the responsibility and notion of autonomous self-rule is shifted more towards the patient, e.g., a patient could use health-related apps to monitor their own health, the ethical principle of autonomy applies more to ‘self-rule’ than ‘respecting a patient’s right to make their own decisions’. A patient’s right to make their own decisions is already implied when digitized health tools is in the hands of patients, as they literally rule over themselves, with no third-party included in the decision making.

A patient's right to choose was not taken for granted 100 years ago, when it could be argued that patients were mere experimental objects in the hands of an immoral physician. However, with time and moral philosophy this has changed drastically. One could argue this because the inclusion of non-maleficence as an ethical principle and moral right gradually became more important as philosophers of ethics published and argued for the individual's right to be informed. To be involved and being responsible is something that has also evolved heavily from the medical field becoming more autonomous. Patients now reserve the right to be involved in medical decisions that affects health, regardless of their social, economic or racial background. Gillon (1994, 185) consequentially describes the ethical principle of autonomy as a right to self-rule and self-management.

The level of autonomy can be argued to be increased when medical procedures are digitized, furthering the level of self-management (autonomy) in the use of medically inspired technological devices, apps, tools and equipment. An example of this would be mHealth tools on your own personal mobile phone, for instance an app to measure your blood sugar. This is where autonomy takes responsibility into the equation, as a truly patient-centric model of the autonomy model comes forth through the patient actually being responsible for their own health. Patients can effectively monitor their own health through various mHealth tools and programs designed to leave the patient in the physician role.

5.3.3 Justice

Gillon (1994, 185) also talks about the essentiality of justice. This principle is one of the most important in the four principles of medical ethics. In medicine, one shall experience justice as one does in the everyday life. Discrimination based on religion, color or other factors should not occur in the eyes of the law and in medical experiments, as we are all of equal value. Justice is therefore tied closely with autonomy, as it recognized the lawful right of citizens to be treated equally by physicians. Fair treatment shall be given, according to Gillon (1994, 185).

Gillon (1994) is quite specific and seemingly profound in the way he states his view on justice in the medical field:

“Justice is often regarded as being synonymous with fairness and can be summarised as the moral obligation to act on the basis of fair adjudication between competing claims. In health care ethics I have found it useful to subdivide obligations of justice into three categories: fair distribution of scarce resources (distributive justice), respect for people's rights (rights-based justice) and respect for morally acceptable laws (legal justice).” (Gillon 1994, 185).

The ethical principle of justice is divided into three sub-categories, according to Gillon (1994, 185). Since these sub-categories of justice will incapsulate many of the ethical implications in the three digitization measures (cases), we are going to spend some time contextualizing the sub-categories of justice to understand how they might function and operate in practice. Fairness distribution of scarce resources (distributive justice) can be explained as an ethical principle that governs people’s right to receive treatment and receive medical equipment to self-accommodate their chronic conditions. It is important to note that distributive justice must also occur independent of socio-economic backgrounds and geographical backgrounds, to avoid unfair treatment based on economic, social and racial motives. For instance, if person A works a higher paying job than person B, they should not receive any medical benefits sole based on that statistic alone. Rights-based justice is also described by Gillon (1994, 185), but the description in the article by Gillon is rather short, which is why we intend to spend some time contextualizing the issue of rights-based justice. In this ethical principle the importance of respecting an individual’s right to deny treatment, opt out of medical trials and freedom to voice their opinion related to their condition are all determining factors when considering rights-based justice. In medical trials, experiments and procedures, much like the three cases mentioned in this thesis, the method for gaining patient consent is also crucial when it comes to rights-based justice. Legal justice is also brought up by Gillon (1994, 185) as an important sub-category of justice. This ethical principle implies that one should not force a patient to break certain moral, social or legal laws when conducting in a medical experiment, procedure or trial.

6 Digital Platforms Targeting Patients with Chronic Disease: Three Cases

The intended aim of this thesis will be to analyze *three* measures of digitization in the health sector and evaluate these from an ethical perspective. Synonymous to all these three measures is that they have been taken in order to better accommodate patients suffering various chronic diseases and that they are all digitized accompanying measures. The objective then will be to address and discuss potentially problematic or productive ethical challenges emanating from the three respective digitized measures to better accommodate patients suffering chronic diseases.

I will first give a brief introduction to each of the three selected cases. The purpose of this exercise will be to offer the reader contextual knowledge pertaining to each of the three selected digitized measures, so that we may discuss the ethical dilemmas facing each case of digitization in the health sector later in the Chapter “Ethical Evaluation of the Cases Introduced: Finding the Ethical Implications in Each Respective Caseation”.

6.1 Case One: “Patient-Centered Pain Care Using Artificial Intelligence and Mobile Health Tools: Protocol for a Randomized Study Funded by the US Department of Veterans Affairs Health Services Research and Development Program”

Case One is initiated by the U.S. The Department of Veteran Affairs (DVA). The mandate of this U.S. government body is to care for war veterans through appropriate health measures, promotion of a social environment prone to rehabilitation, and organization of support groups. One of the health measures promoted by DVA are digitized health accommodating measures, which involve the development and testing of technological tools such as mobile health tools and, in several cases, solutions propose involve implementing aspects of artificial intelligence, more specifically described as “reinforcement learning” (RL). These support

programs are funded by the U.S. Department of Veteran Affairs Health Services Research and Development Program.

For the sake of simplicity, I will refer to DVA's research project of accommodating war veterans using artificial intelligence and mobile health tools as Case One throughout this thesis, as the title of this research project is quite lengthy.

In outlining the details of Case One I will attempt to give the reader context as to what specifically the case is about and what it intends to achieve. By doing this the reader will more easily understand why some aspects of the case may seem problematic, judging from an ethical standpoint on digitized health care systems, which is essentially what the thesis is about; figuring out what ethical implications there might be in digitized measures taken in order to accommodate patients suffering chronic disease. To clarify, this section will be used to address the actual findings and outlining details of the case, while the later section in regard to ethical implications and the discussion of these will address the ethical implications found in the case material. Thus, the focal point of this section will be more towards the actual case findings as presented by the researchers of Case One, and less towards ethical discourse.

6.1.1 Rationale and Needs Analysis Underlying for Case One

The very first details that are disclosed in Case One is that Cognitive Behavioral Therapy (CBT) is considered one of the most proficient ways of treating one of the most commonplace chronic pains war veterans experience, namely chronic low back pain. The problem, however, is that currently only half of Department of Veteran Affairs (DVA) are able to afford and therefore have access to trained CBT therapists. The standardized method for treating low back pain would typically consist of 10 weekly hour-long sessions, with some patients requiring more extensive contact and accommodation and others slightly less (Piette et. al., 2016).

Case One defends the view that these treatment requirements are inadequate in terms of reach, cost, and availability of therapists.

“A review of data for veterans receiving outpatient opioid prescriptions showed that less than half received any mental health treatment, and a survey by VA’s National Program for Pain Management found that half of VA facilities did not have any pain-focused psychological services such as CBT.” (Piette et.al, 2016, 15)

6.1.2 Cognitive Behavioral Therapy (CBT) supported by Artificial Intelligence (AI-CBT)

A fair critique to Case One would be that the case doesn’t necessarily explain and dive into the defining factors of what classifies as Cognitive Behavioral Therapy (CBT), even though accommodating war veterans with a more effective treatment through an alternative way of treating low back pain through CBT is the main premise of the Case One medical trial. Consequently, we may need spend some time explaining what generally defines CBT as a treatment method, and then compare and contrast CBT with the new proposed method of treating low back pain as suggested by Piette et.al (2016) in this research article on accommodating chronic low back pain in the DVA. In fairness to Case One, the general terms of what defines as CBT is quite broad being that it is a technique used to treat a wide spectrum of different psychotherapy-related problems, be they chronic or temporary or, physical or mentally oriented. Such spectrum could range from diagnoses like depression, anxiety, Post Traumatic Stress Disorder (PTSD) or, as Case One describes, chronic low back pain. Therefore, it is understandable that Case One refers to the specific parameters that define the standardized approach within the DVA in dealing with chronic low back pain. That said, for the purpose of understanding CBT properly as a psychotherapy treatment, the objective now will be to address the general defining factors that attain to the term CBT, to broaden our understanding of why this specific treatment was the deciding factor in treating war veterans suffering from chronic low back pain.

Cognitive Behavioral Therapy (CBT) is described as a treatment that focuses on conversation and guidance through face-to-face conversations with a trained psychotherapist, or, alternatively, as described in Case One through automated messages that adapt to a patient's physical and/or mental condition. Most commonly it is used to treat mental disorders such as different stages of anxiety and depression, but also works for more physical health related issues. Setting aside Case One, CBT does not necessarily rely on artificial intelligence as is the case for Case One, but rather face-to-face conversations. According to Piette et al. (2016)

the traditional face-to-face therapy sessions were deemed more costly and time consuming as it requires the physical presence and expertise of individual trained physicians to give guidance, often in the context of therapy sessions, which is not necessary for Case One being that the chronic back pain is a *physical* health problem, rather than a *mentally* oriented one, so guidance did not have to include human contact. (Piette et al., 2016)

However, when the health problems are more *mentally* oriented, which is not the case for Case One, face-to-face conversations are important because patients with mental deficiencies frequently show reduced risk of depression and anxiety, according to Bergland (2016) who cites an October 2015 study (Teo et. al, 2015).

After carefully reviewing the 2015 study published in the Journal of the American Geriatrics Society, Bergland (2016) concludes with the following statement (Bergland, 2016).

“The researchers found that having limited face-to-face social contact nearly doubles someone's risk of having depression. Study participants who met in person regularly with ³family and friends were less likely to report symptoms of depression, compared with participants who emailed or spoke on the telephone.” (Bergland, 2016)

Additionally, the sentiment that mental deficiencies requires therapy sessions in a face-to-face format is supported in a press release (Bergland, 2016) as lead author and assistant professor of psychiatry at Oregon Health & Science University Alan Teo claims the following statement, underlying the contrast in face-to-face conversation therapy versus socialization through digital communication and phone calls - which is essentially what Case One describes as its premise.

"Research has long-supported the idea that strong social bonds strengthen people's mental health. But this is the first look at the role that the type of communication with loved ones and friends plays in safeguarding people from depression. We found that all forms of socialization aren't equal. Phone calls and digital communication, with

³ Bergland (2016) describes that the importance of face-to-face conversation is necessary due to its effect on *mental* health, unlike the Piette et.al. (2016) case that focus on treating *physical* health.

friends or family members, do not have the same power as face-to-face social interactions in helping to stave off depression." (Teo, Press Conference)

This ultimately supports the theory as suggested by Piette et.al (2016) that physical health problems do not necessarily require physical consultations with therapists, which contrasts with *mental* deficiencies as social contact is part of the treatment to cure mentally oriented issues.

6.1.3 Identifying the Problem and Consequences of Chronic Low Back Pain

Musculoskeletal disorders are highly prevalent among VA patients, with chronic back pain being the most reported type of health issue related to musculoskeletal disorders (Sinnott & Wagner, 2009, 1338–1339). VA data shows that there is an annual 4.8% increase per year in low back pain since war veterans are aging and therefore experiencing musculoskeletal disorders as bone density decreases, but also because of an increasing prevalence of obesity (Sinnott & Wagner, 2009, 1338–1339). The problem, which Case One highlights as one of the most prominent issues related to treating this, is that the cost of treating back pain in the VA is estimated to be about \$2.2 billion annually⁴, using the CBT approach for treatment that relies on costly therapy sessions with trained professionals, and not the AI-CBT approach as suggested by Case One. There are several reasons as to why one would want to tend to chronic low back pain, but the most prominent symptoms associated with chronic low back pain are work interruption, emotional distress and risky health behaviors such as substance use to ease the pain (Piette et al, 2016). Emerging evidence also ⁵suggest that chronic pain may hinder or compromise successful treatment and management of other chronic conditions (Krein et al, 2007, 61-68). The need for Case One's AI-CBT treatment is even more pronounced as the research article references research on opioid medications, which is a common way of treating chronic pain, but their use can lead to serious adverse effects (Piette et al., 2016).

⁴ VA data affirms that treating chronic back pain costs \$2.2 billion annually prior to the AI-CBT approach (Yu et al, 2003, 146-167)

⁵ VA data affirms that chronic low back pain is increased by 4.8% annually (Sinnott & Wagner, 2009)

6.1.4 Mobile Health (mHealth) as a Self-Management Platform for Chronic Patients

Case One affirms that mHealth services typically have low marginal costs, meaning they can reach out to many patients on a low budget. In fact, there has been more than 50 studies that confirm through a demonstrative process that patients are able to use mHealth tools sufficiently and provide information to physicians (Piette et. al, 2016). However, Piette (2016) states, the implications of using mHealth are that these types of tools often consist of simplistic series of messages based on predetermined “if-then” algorithms. Patients report that CBT therapy through mHealth Tools can often feel “robotic” to users, causing the benefits of standard CBT to diminish after patients end their therapy. (Piette et. al, 2016, 4).

By looking at this, one can argue that autonomous behavior is typically cost-efficient, but may feel robotic to some as it does not involve social contact with other human beings. It seems that predetermined algorithmic like behavior must be approached carefully, because users may disengage if the messages become simplistic in its ability to interact with and engage the user.

Case One takes this into consideration by stating that it attempts to test a model that will take advantage of the cost-efficiency of mHealth Tools, while at the same time ensuring that CBT therapists and trained professionals have integrated the treatment model with sufficient information, with the hopes of being more engaging as the quality of messages and guidance is increased.

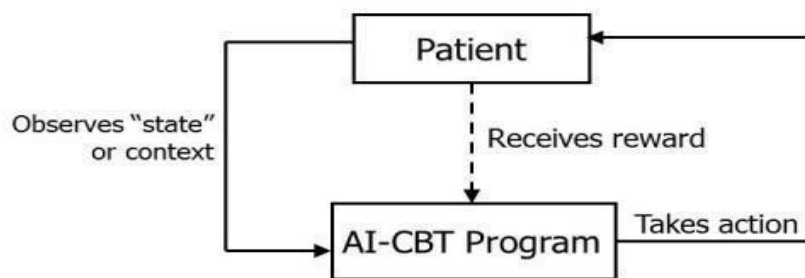
6.1.5 Outline of the Conceptual Approach Used to Analyze Case One

Lastly, in analyzing the background for Case One, we may need to address more directly its conceptual framework. Piette et. al (2016, 4) states that the intervention, which Case One will evaluate, is based on widely adopted evidence-based models of CBT, also referred to as traditional CBT, and is linked with a personalized care and-self management system using reinforcement learning (RL). This is the reason why the article refers to Case One’s CBT treatment process as AI-CBT, being that RL relies on artificial intelligence, meaning in this specific application case that it incorporates an “intelligent agent” designed to learn what treatment choices work best to optimize a measurable outcome (Piette et. al., 2016, 4). Case One stresses the fact that reinforcement learning in this case is used in order to attain

information about chronic low back pain through an adaptive system that collects patient data depending on physical movements through a pedometer, rather than the patient receiving guidance and learning self-care skills through the intervention of using the AI-CBT.

In fact, the algorithmic behavior displayed in the RL system has its basis in consumer targeting programs such as Netflix, Google and Amazon (Piette et. al., 2016) as it learns automatically what information is the most relevant for the target user.⁶

Figure 1: The Reinforcement Learning Feedback Loop. “The AI-CBT actions are the 3 CBT session types; the is IVR-reported pedometer step counts, and state data is IVR-collected information on patients CBT skill practice and pain-related functioning.” (Piette et. al., 2016)



6.1.6 Methods Used to Design and Implement Case One

The method used to successfully and sufficiently complete Case One relies on a comparison between standard pain CBT with an innovative strategy that uses mobile health technology and AI in conjunction with people that are trained professionals, Piette states. The trained professionals will deliver evidence-based and stepped therapy with the intent to cure chronic low back pain, and result in the research program being both cost effective and sufficient in terms of the information parameters inserted into the AI provided by trained therapists.

There will be a total of 320 patients participating in the study, all suffering from chronic low back pain. These patients will be recruited from 2 active VA health care systems and randomized to a standard of 10 sessions of telephone CBT and AI-CBT. Patients are split into

⁶ Reinforcement Learning (RL) is a field of artificial intelligence that uses adaptation as its model to reinforce its behavior and strengthen it through an individual, or “intelligent agent” (Piette et.al., 2016)

two camps, one which primarily focus on the results of standard CBT therapy sessions and one camp that result to AI-CBT as the treatment of choice to accommodate their chronic low back pain. (Piette et al., 2016, 1)

All of the 320 patients will begin with a weekly telephone counselling session, however the patients in the AI-CBT camp that report a significant response will be stepped down and put on a less resource intensive alternatives, which include (1) a 15 minute conversation with a therapist, and (2) CBT clinician feedback provided by interactive voice response calls⁷ to the patient, also referred to as IVR. (Piette et al., 2016, 1)

The AI engine will through the IVR calls and pedometer step counts that the patients provide, find out what works best in terms of a patients personally tailored treatment plans. These results and measurements take place at 3 and 6 months after recruitment. (Piette et.al., 2016)

Specifically, at 3- and 6-months post recruitment is when patients get to report on their current levels of pain and if the AI-CBT program has managed to tailor a more effective treatment plan for them, if the chronic low back pain patients are satisfied or if patients wish to drop out of the treatment program. (Piette et.al., 2016)

6.1.7 Results and Conclusions Drawn from the Pilot Test of Case One

Because the trial is currently in the start-up phase, the results will not be available before the winter of 2019, according to Piette. However, one can still draw thought worthy ethical⁸ discussion from the procedure and how Case One is currently planned out. These ethical implications will be looked at in the ethical evaluation section of this thesis, through the framework of Gillon's four principles of medical ethics (1994). The results in themselves, while interesting in terms of how sufficient AI-CBT actually will prove out to be for patients suffering chronic low back pain, will not play a determining role in discussing the ethical issues that one is able to identify in Case One.

⁷ Interactive Voice Response (IVR) is a therapy session between a trained therapist and a patient through the use of a telephone call, focusing on treatment through conversation filled with advice (Piette et al., 2016, 1)

⁸ In total, 320 patients will participate in "Case One". They will be divided into two groups, one for standardized CBT and one for AI-CBT. (Piette et al., 2016, 1)

That said, patient enrolment began in the fall of 2016 (Piette et al., 2016, 1) which means that the AI-CBT program has had sufficient time to take shape, but no findings or updated information has been added to Case One yet, being that this information will be readily available in Winter of 2019. However, these authors claim (Piette et al., 2016, 16) that if successful, the study will hopefully be able to establish a new approach for using AI in pain care treatments to treat similar chronic diseases. This may be a building block or stepping stone to new treatments if the same method of extracting data through adaptive AI is applied.

6.2 Case Two: Mobile Health Devices as Tools for Worldwide Cardiovascular Risk Reduction and Disease Management

Piette and al. (2015) describe an earlier measure taken to better accommodate patients with cardiovascular diseases in the form of preventive measures taken through a digitized procedure.

Case Two (Piette, et. al. 2015) exhibits quite different characteristics from Case One, as it is essentially a review of grey literature, as well as peer-reviewed literature, on cardiovascular disease prevention in mHealth Tools. However, Case Two stands out because it is essentially not a case that follows a procedure and shares its findings through said procedure, but rather a review of literature and findings.

The next generation mHealth programs should be based on evidence based on behavioral theories and incorporate advances in artificial intelligence for adapting systems (Piette et. al, 2015). This is interesting, because it points to an autonomy model that further points the responsibility on patients. Another interesting ethical challenge we are going to uncover and pay special attention to as we analyze Case Two would be that the study is worldwide, meaning it also focuses on assessing the situation of how mobile health devices as tools to accommodate cardiovascular disease reaches low to middle-income countries. This is interesting because it points to Gillon (1994) and the four principles of medical ethics, one of them being justice. How is cardiovascular disease management and risk reduction handled and treated in low to middle-income countries? To find out if there is just treatment and if the

ethical principles are upheld, we will start by analyzing the findings and details of Case Two now.

6.2.1 Challenges Posed by Cardiovascular Disease (CVD)

Cardiovascular disease (CVD) is a massive issue and is in fact the leading cause when it comes to global deaths, being that it is responsible for 30% of all deaths in the world. Treatment and risk reduction in CVD often depend heavily on how people manage their condition, and doctor visit at the local health care provider is a crucial factor in determining how well the patient is treated. When it comes to self-management there is a significant challenge to treat patients because such a thing requires that patients are disciplined in following a strict medication regime, understand their own condition and when it worsens and being in charge of their own lifestyle behavior changes such as physical activities and maintaining a healthy diet. Especially in low income countries, health care physicians and resources are scarce, meaning that it remains a challenge to provide sufficient interaction with patients suffering from CVD. The opportunity to take advantage of patient-centered health communication technology is therefore a promising evolution in the approach to provide patients suffering from cardiovascular disease a sufficient follow-up system that works both in terms of being cost-effective, and also provides a more extensive reach due to the cost-effectiveness of the treatment. (Piette et al., 2015, 1-2).

6.2.2 Claims to Address the Limitations of Health Systems in Low- and Middle-Income Countries

Giving patients an option to receive proper health care to treat CVD is even more important in low- and middle-income countries (LMICs). Patients in LMICs often face costs that are not regulated in a sufficient manner, and thus being too costly for patients in LMICs to afford. Another crucial reason is that patients suffering CVD in LMICs often work jobs that cannot provide financially in terms of their health care budget. Piette et. al provide relevant statistics of patients in LMICs suffering from having limited resources to spend on health care:

⁹ *A World Health Organization survey of >256 000 respondents in 70 countries found that health care accounted for 13% to 32% of household expenditures, and cost barriers were a frequently cited reason for inadequate chronic illness care.*” (Piette et. al, 2015, 2)

In some situations, the patients of health services in LMIC may afford the treatment, but it is often the case that the treatment is insufficient in terms of quality or just unavailable (ibid, 2015, 2). Judging by the statistics of the World Health Organization, the deficit in health care providers are beyond 4 billion, and 57 countries experience significant shortages. There has been a number of healthcare professionals leaving LMICs to find jobs in countries because LMICs have poor training in preventing and managing cardiovascular disease. (ibid, 2015, 2)

This opens up mHealth as this is a far more cost-effective and less physically-demanding tool that could potentially revolutionize the way cardiovascular disease is accommodate through expensive and often misinformed consultation with trained professionals.

6.2.3 Mobile Health as a Partial Solution

Through innovative thinking and through the use of mobile health technology, researchers of Case Two have found that mobiles may be a central tool in addressing the barriers to CVD prevention and management. Currently there are about 6 billion mobile phones users worldwide (Clark et al., 2007, 942-950) and with about $\frac{3}{4}$ out of those currently residing in LMICs. Going by these statistics, one can determine that the frequent use of cell phones present an opportunity to use this as a resource for behavior change in managing CVD, which is supported by evidence that demonstrates how telephone therapy sessions will improve a patient's current health situation (Piette et al., 2015, 2).

There are more than 6 billion mobile phone users worldwide with almost three-quarters living in LMICs. The explosion in cell phone use represents an important resource for lifestyle change and disease management, because abundant evidence has demonstrated that telephone follow-up improves the quality and outcomes of care. Piette et. al. (2015, 2) states in Case Two that most of the research done so far in the effectiveness of using mobile phones in

⁹ A World Health Organization survey of >256 000 respondents in 70 countries found that health care accounted for 13% to 32% of household expenditures. (Piette et al., 2015, 2)

accommodating health problems have been done in high income countries (HIC), but one can find promising health related results in accommodating chronic diseases such as controlling glycemic control and telephone therapy for patients with heart failure.

“Although most trials of telephone care have been conducted in high-income countries (HICs), investigators in Chile reported that low-income diabetic patients randomly assigned to telephone nurse counseling had better glycemic control than patients receiving usual care, and postdischarge telephone support for patients with heart failure in Argentina significantly reduced readmission rates relative to randomly assigned controls.” (Piette et al., 2015, 2)

Unfortunately, however, in the case of telephone related health management, it is difficult sometimes to demonstrate the actual cost savings that companies look for if they are to invest human capital in telephone related health tools such as mobile health tools. Piette et. al (2015, 2) describes this in Case Two as he refers to a review of 15 randomized trials with the intent of managing chronic disease through mobile health tools. The trials with a total of 18 000 patients suffering chronic disease concluded that only a total of 2 studies provided evidence for sufficiently lower costs. (Peikes, 2009, 603-618).

In discussing Case One (Piette et al, 2016), we might find the partial solution to the difficulty in maintaining a low budget in telephone follow-up for accommodating chronic disease, as we have already discussed the potential of mHealth tools and how using adaptive algorithms will save a health care provider a significant amount of work and be a better financial decision than therapy consultations. Hence, in order to meet the two-sided goal of both having a low-cost option to follow up patients suffering from CVD and also provide sufficient and quality treatment, Case Two (Piette et al., 2015, 2) argues the same as Case One argues. mHealth is superior in the fact that it is able to provide positive impacts on patient well-being, although significant implications and barriers remain if were to introduce this technology in LMICs.

mHealth interventions take a variety of forms, each with its own benefits and limitations in terms of the specific modalities reach and the richness of the information exchange. Interactive voice response (IVR) calls allow patients to receive information and communicate with others asynchronously using their mobile or landline telephone. Using IVR, patients

interact with a structured series of recorded message components and respond to queries using their touch-tone keypad or voice-recognition technology. Based on their responses, patients can receive recorded messages tailored to their individual needs. Clinicians can receive automated updates based on patients' responses during IVR calls, along with structured feedback about how to improve disease management. Patient-directed short message service (SMS) or text messaging interventions are designed to improve disease management primarily through reminders that improve adherence to behavioral goals such as medication taking, and through educational or supportive messages that increase motivation for changes in lifestyle behaviors or self-care. SMS messages can be triggered automatically or by clinicians, and some services use bidirectional communication with patients to increase program engagement and service impact. More recent advances in mHealth include smartphones and other mobile communication tools enabled with graphical screens, video, audio, and Internet access. An advantage of smartphones is that structured information from patients can be collected through a touchscreen or voice recognition system, thereby allowing more accurate and extensive patient reporting than is possible with SMS. Global positioning systems and physiological sensors can be added to further tailor health communication and monitor patients' status. The widespread and growing use of social media such as social network sites, blogs, wikis, Twitter chats, photo/video sharing services, and virtual worlds represent additional opportunities for engaging patients via their smartphone. In particular, new social media can extend the reach and impact of social networks, enable sharing of knowledge and information, and integrate real-time personal health data to leverage peer support.

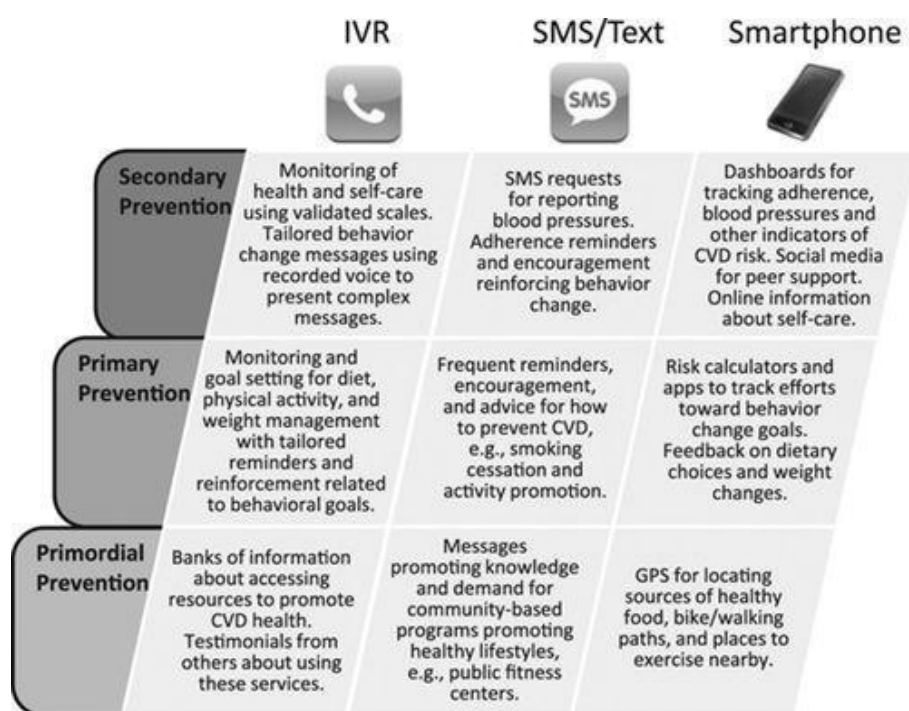


Figure 2: Illustration of Three mHealth Services Targeting CVD. “Examples of mHealth services targeting 3 levels of cardiovascular disease prevention and management. CVD indicates cardiovascular disease; IVR, interactive voice response/automated calls; SMS, short message service/text messaging”. (Piette et al., 2015, 3)

6.2.4 Interactive Voice Response

Trials conducted in HICs have shown that IVR-based interventions can be effective in promoting physical activity, improved dietary behavior, and smoking cessation. A trial of 337 blacks with hypertension found that 32 weekly IVR calls improved overall dietary quality and energy expenditures relative to controls who also received a resource manual and a 20-minute in-person health education session focused on lifestyle behaviors. A study of an IVR-delivered intervention focused on family goal setting and changes in the home environment showed improvements in obese children’s level of physical activity, dietary behaviors, and body mass index. In a diverse low-income sample of patients with diabetes mellitus, investigators found that an IVR service coupled with nurse care management achieved physical activity objectives at modest cost.

6.2.5 SMS or Text Messaging

With 5800 participants, the SMS smoking cessation program (txt2stop) trial sought to improve smoking cessation rates in the United Kingdom through a series of motivational messages. Patients were randomly assigned to receive motivational SMS messages or messages unrelated to smoking. Txt2stop more than doubled biochemically confirmed quit rates at 6 months relative to controls. Studies of SMS interventions focused on promoting a healthier diet, weight loss, and physical activity in HICs have shown mixed results. One US trial using daily SMS messages focused on tailored dietary goal setting and showed significant improvements at 4 months in eating behavior and body weight. However, an SMS intervention incorporating pedometer step-count feedback among adolescents with diabetes mellitus did not increase physical activity. A trial focusing on promoting weight maintenance after a 3-month behavioral weight loss program through bidirectional and tailored SMS messages found no overall benefit over the subsequent 9 months in weight, eating behavior, or psychological mediators of behavior change. Despite relatively high adherence among adult participants in an interactive and personalized weight management program, investigators found no between-group difference at 6 and 12 months in weight when comparing groups receiving SMS messages versus a monthly e-newsletter. However, SMS-group participation did increase users' pedometer-measured physical activity levels, and greater activity and text messaging adherence were associated with greater weight loss. Research currently underway may further elucidate the potential of SMS for promoting meaningful lifestyle behavior changes that are important for cardiovascular risk reduction. Studies including SMS interventions have been conducted in more than 30 countries, including several LMICs. A trial conducted in Hong Kong found that SMS messages focused on diabetes mellitus-related lifestyle modification reduced rates of progression from prediabetes to diabetes mellitus over 12 months. Many mHealth studies in LMICs have focused on human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS); 2 large randomized trials in Kenya found that SMS reminders improved adherence to antiretroviral therapy, and 1 trial also reported reductions in viral load among patients receiving SMS adherence reminders relative to randomly assigned controls.

6.2.6 Case Two: Summary and findings

Although not all studies have had positive outcomes, several randomized controlled trials, including 2 studies from LMICs, have shown that IVR interventions can improve lifestyle risk factors for cardiovascular disease and disease management, as well. An advantage of IVR self-management support programs is that they can be used with any standard cell or landline phone. Because no reading or writing is required, IVR interactions are accessible to low-literacy populations, and to those with vision problems. Patients can use IVR to report detailed information about their status and receive tailored feedback about their health and self-care. However, IVR interactions typically require patients to participate when the call is placed or to call in to the system. Although patients sometimes can specify when they are likely to be available, changes in their schedule may be difficult to accommodate. Unlike texts, images, or website links sent to patients via a smartphone, patients using IVR cannot review information after the fact. Unfortunately, because of the diversity of study populations, outcomes, and IVR system designs, we still cannot identify the characteristics of interventions that are associated with greater behavioral change and health improvements. Evidence also is growing about the effectiveness of SMS interventions in improving behavioral risk factors and cardiovascular disease management, especially interventions enabling real-time feedback, exchange, and support. Most randomized trials of SMS interventions for chronic disease behavioral change have been conducted in HICs, however, and little work to date has examined different behavioral approaches to intervention design or content development. Also, there is little known about the optimal dosing, frequency, and content of text messages, the duration of interventions, or the individual and group characteristics that may identify patients most likely to benefit. An advantage of SMS interventions is that they can be used with almost all mobile phones, and they take advantage of the widespread use of texting both in HICs and LMICs. However, SMS services are difficult for individuals with limited vision, dexterity, or literacy, all of which are more common in poor communities. SMS self-care supports tend to be less interactive than counselling by a clinician, but when patients are asked to confirm receipt of texts, interventions may have increased engagement and impact. More complex 2-way SMS messages may boost engagement and effectiveness, but this may require a clinician or other live person to be in the loop, because computers are challenged by the nonstandard spelling and grammar from patients' texts.

Newer mHealth interventions hold considerable promise, but the research base on interventions delivered via smartphones or social media is still small. In the next few years, results from ongoing trials will help to develop the evidence in this important area. The advantages and disadvantages are varied depending on where the treatment is funded, as LMICs often display implications in funding treatments SMS, IVR or mHealth while HICs is often more adaptable in terms of budgeting and can afford to manage chronic diseases using SMS, IVR or mHealth. While the important variable if a digital health accommodating system is sufficient is often funding, there are overall conclusions to be made in terms of the actual effectiveness of the tools themselves as well. In conclusion, perhaps the most lacking digital accommodation system is Smartphones and Online Tools, as it is both expensive and requires more from the patients in terms of literacy and the complexity of the interaction.

6.3 Case Three: “In Their Shoes” by Takeda

Case Three is an app developed by Takeda, a pharmaceutical company based in Japan, Tokyo. The intended purpose of the business is to innovate the health market by serving the needs of patients and physicians worldwide. In a recent project the pharmaceutical company has attempted to simulate what it’s like to be an Irritable Bowel Disease (IBD) patient through the use of a mobile app with the purpose of getting insight into the everyday life of an IBD patient. Employees of the company have participated in the experiment by taking use of the app in everyday situations, while Takeda has also shipped the tools needed to participate in the simulation project to volunteers contacting Takeda in order to assess the experience.

The strategy underlying Case Three is original and potentially disruptive as it does not only portray information and accumulate findings about IBD itself but simulates the difficulties IBD patients may experience in a real-life situation. By presenting real life scenarios using tailored messages suggesting what the app-user must do next in order to accommodate for their IBD symptoms, the app-user, in this case employees at Takeda, have challenged themselves in order to gain true insight into the everyday life of an IBD patient. The participants in the experiment reported their encounter with “In Their Shoes” as a quite

stressful experience, as they would have to respond accurately to messages they would receive through the app they were given, e.g. messages about when to go to the bathroom and such were received frequently, and the participants would need to take precautionary measures that they otherwise would ignore in their day-to-day activities, such as always being close to a nearby bathroom in case they would get a message saying they have to go to the bathroom. For an IBD patient, symptoms such as spontaneous bathroom visits are quite frequent. In fact, it is quite commonplace for IBD patients to research locales for bathroom opportunities prior to events or meetings, so that they can fluently find a nearby bathroom if a situation causing stomach upset might occur. The constraints and annoyances experienced by real-life IBD patients are imposed on “In Their Shoes” participants, who have agreed to follow the instructions of the app.

This study analyses the ethical dilemma and the stress put on IBD patients who need to be excused in various social settings, which can, depending on the situation and individuals involved, appear as inappropriate, in contrast to social norms, or psychologically diminishing. Interestingly, the participants in the “In their Shoes” experiment were quick to realize that the social pressure felt in situations like those described above are ethically questionable. This app-based experiment gave ordinary people the ability to experience and appraise the pressure of a situation which a typical IBD patient frequently experiences, opening for the discussion about social norms and how one should deal with situations were IBD patients experience social distress because they must leave social gatherings or meetings due to emergent issues related to their IBD.

It can be argued that what Case Three lacks in terms of academic credibility, it makes up for in the unorthodox approach it makes in its method to inquiry information about IBD. Case Three simulates a disease and the stakeholders of Takeda are the ones undergoing medical procedure that Takeda initiates. This is the reason why the choice to include Case Three, despite its shortcomings in amount of information displayed in the outlining, was made. Because Case Three is a simulation to acquire information, it completely revolutionizes the ethical principle of autonomy in the way information circulates, being the participants (stakeholders of Takeda) are also the recipients of the information, making the medical experiment fully autonomous in the way information is acquired.

7 Analysis of Ethical Implications in Each of the Three Reviewed Cases

In this chapter of the thesis the intention is to address certain ethical implications central to the three cases and use the four principles of ethics in medicine (Gillon, 1994) as a framework in the analysis of each given ethical implication. The four principles of medical ethics will be used as a basis in this section because the intention will be to evaluate the cases based on justice, non-maleficence, level of beneficence and the level of autonomy, focusing mostly on the one principle that applies to the ethical implication in each respective section.

7.1 Case One: “Patient-Centered Pain Care Using Artificial Intelligence and Mobile Health Tools: Protocol for a Randomized Study Funded by the US Department of Veterans Affairs Health Services Research and Development Program”

Case One, as we refer to it in this thesis, brings forth numerous ethical implications that will be address in this section, using the information described in the presentation of cases - section of this thesis and the four principles of medical ethics applied to each ethical implication in order to see if the case has complied with the four principles of medical ethics or not.

Because the results of Case One will not be concluded before the winter of 2019, the ethical implications derived from the case might change as patient enrolment and results take shape. However, the abstract of the measure and the actual procedure of how the measure is going to be conducted is interesting, as it is the act of conducting such research that is interesting, and not necessarily the results of the research. The reason why one does not necessarily need the actual results of Case One is because the procedure, method, objective and general way of handling patients *during* the research project is what's interesting in terms of deriving ethical issues.

7.1.1 Justice

In identifying and discussing justice which is one of the ethical principles of medicine according to Gillon (1994) to see if it is upheld or not in Case One, reference is made to an article originally published in *The Technology Source* and authored by Timothy VanSlyke, “Digital Natives, Digital Immigrants: Some Thoughts from the Generation Gap” as VanSlyke (2003) shares some much needed knowledge regarding the generation gap in his review of literature such as the contribution of Prensky (2001) regarding the ‘digital natives’ which describe the younger, more adaptable generation and the ‘digital immigrants’ describing the generation that was not born with the same amount of information and instant gratification as the digital natives, typically born in the 1990s (VanSlyke, 2003).

It appears what VanSlyke (2003) describes is especially relevant in Case One, as the average age of U.S veterans is a strong factor of adoption/rejection of assistive technologies, e.g., how various U.S veterans relate to procedures involving digital solutions, may depend strongly on age variables. Understandability of technology is often highly dependent on developing a personal relationship to digital tools and on the frequency of use. Such an age-dependent key factor would put U.S. war veterans, whose average age are between 65 and 74 years old¹⁰, at a disadvantage, as they are more likely to experience difficulties in complying to and adjusting to the use of digital tools than the younger generations. In general, the younger generations would have a closer and more personal relationship to technology and therefore would be able to relate to such measures more easily, than those who grew up without the Internet. The Internet more and more reflects humanity and becomes increasingly individualized, as reflected by thoughts from Prensky (2001) in his description of youth - described as digital natives - and how they relate to information.

“Digital Natives are used to receiving information really fast. They like to parallel process and multitask. They prefer their graphics before their text rather than the opposite. They prefer random access (like hypertext). They function best when networked. They thrive on instant gratification and frequent rewards. They prefer games to "serious" work. (2001, 1). In contrast, those not born in the digital world

¹⁰ The average age of war veterans partaking in the Veteran Affairs (VA) according to The Department of Veterans Affairs and The United States Census Bureau is between ages 65 and 74.

reveal their non-native status through a "digital immigrant accent" that manifests itself in a number of ways—printing out a digital document to edit it rather than editing it online, for example” (Prensky, 2001, 4).

Having affirmed that there might be an implication in war veterans adapting to the AI-CBT approach described in Case One due to it being quite technically complex and possibly not very suited for war veterans who average an approximate age of 65 to 74, we can invoke the four principles of medical ethics as described by (Gillon, 1994) to address this issue.

In terms of information provided by a healthcare provider being understandable and approachable by the patients involved in the study, the most central principle in medical ethics to invoke would be the ethical principle of justice in medicine. For the sake of the thesis, we are going to revise this principle and repeat that the ethical principle of Justice in medical ethics is dependent on fair treatment for all the participants of a new treatment. (Gillon, 1994) It also states that the treatment must be according to the law that constitutes the health regulations in each country. Having said that, the question remains for Case One if fair treatment according to the principle of Justice found place in how war veterans were treated - as described by the case.

The hypothesis in this thesis is that fair treatment did take place, as a priori information regarding the scope of the medical experiment was provided to the patients, and patients could report back with feedback or decide to drop out voluntarily in month 3 and 6 of the study (Piette et al., 2016, 1). However, the implication of the generation gap was not mentioned or given consideration in the description of Case One, and as evidence by Prensky (2001) and the literature on the generation gap implication, the ethical principle of justice was not upheld in Case One. In fact, there was little mention of the average age of war veterans and how this could impact the study in Case One, with little to no consideration that age may be a determining factor in how patients respond to the treatment.

In terms of the other ethical principles surrounding medicine, namely non-maleficence, beneficence and autonomy, the overall consensus based on analysis of the AI-CBT approach in Case One is that Case One took these principles into consideration and represented the patients' rights sufficiently. For the sake of this thesis and its scope, it is more important to determine if there was insufficient representation in any of the ethical principles (justice),

being that evaluation of ethical implications in accommodating patients suffering chronic diseases is the scope of the thesis.

However, it is worth explaining just how the other principles apart from justice was taken into consideration through some examples from Case One.

7.1.2 Non-maleficence

To uphold the four ethical principles in medicine one must first of all consider non-maleficence, which is saying that a medical procedure must be provided with the intent of not doing harm to the individual partaking in the procedure (Gillon, 1994, 185). The level of non-maleficence in the study can be considered to be sufficient, being that in the feedback period in which patients were allowed to provide feedback, no patients reported worsening of their chronic low back pain condition as a result of partaking in the study. In fact, interviews were done in order to ensure that the patients were satisfied with their current level of pain management, making the level of non-maleficence in Case One satisfactory regarding the four principles of medical ethics (Gillon, 1994). In Case One, the authors state the following to affirm this statement:

“The focus of patient interviews will be on satisfaction with pain care, barriers and facilitators of pain management, and motivation for making behavior changes using automated systems. AI-CBT patient interviews will focus on patients’ satisfaction with the adaptive intervention and the extent to which patients felt that it was able to provide them with the care they needed while using their time effectively. “ (Piette et al., 2016, 16)

That said, it would be fair to delay judging Case One by the level of non-maleficence as the final results will be available towards the end of 2019, which means it is an ongoing research project, and results in patient satisfaction with the treatment may change during this time.

7.1.3 Beneficence

In terms of beneficence being upheld in Case One, and for the reader to ease more into the context of what that is about, there will be a quick recitation of what it means to uphold beneficence as one of the ethical principles in medicine when conducting a study.

Beneficence, in this context, describes that the procedure must be done in order to benefit the patient and provide good results for the patient, rather than, e.g. a net benefit for the healthcare provider that issuing the procedure. It claims that the procedure must be for the better good and provide net benefits. A patient's rights and individual situations must be considered in the start-up process of the procedure and during the procedure and adapted if deemed necessary. When discussing if this ethical principle of medicine was taken into consideration, we can look to how patients were carefully and respectfully invited to join the research project through giving their consent over mail as described by Piette et al.:

“After obtaining agreement from patients’ primary care providers, a letter will be sent to veterans informing them about the study and inviting participation. Veterans who do not opt-out by postage-paid response card will be called by research staff to explain the study, conduct screening, and solicit their involvement. If the veteran is willing, s/he will be sent the consent form by mail along with a postage-paid return envelope.” (Piette et al., 2016, 7)

Another way the principle of nonmaleficence was upheld was through a long list of requirements veterans had to meet to be included in the study, taking precautions regarding health issues that may have been a problem in affecting the trials and procedures of the AI-CBT program. (Piette et al., 2016, 7)

7.1.4 Autonomy

In this section the intent will be to speak on the level autonomy that is practiced in Case One. The notion of autonomy is relevantly described by Gillon:

“Respect for autonomy is the moral obligation to respect the autonomy of others in so far as such respect is compatible with equal respect for the autonomy of all

potentially affected. Respect for autonomy is also sometimes described, in Kantian terms, as treating others as ends in themselves and never merely as means-one of Kant's formulations of his "categorical imperative." (Gillon, 1994, 185)

Autonomy, following this author, describes the fact that one must respect individuals as individuals, and not mere objects, or e.g., “clinical cases”. This approach was adopted convincingly in Case One, for numerous reasons. First and foremost, patients were given respect and treated as individuals by allowing them to decline the treatment and overall project and essentially giving the patients, also described as consent and the right to choose to be involved or not, by Gillon (1994, 185). Gillon (1994) describes this relevantly in his description of autonomy with regards to patients consent.

“In health care respecting people's autonomy has many prima facie implications. It requires us to consult people and obtain their agreement before we do things to them-hence the obligation to obtain informed consent from patients before we do things to try to help them. “(Gillon, 1994, 185)

7.2 Case Two: Mobile Health Devices as Tools for Worldwide Cardiovascular Risk Reduction and Disease Management

In this part of the thesis I will discuss the ethical implications found in Case Two through the same framework described in unveiling of ethical implications in Case One, namely the ethical principles of medicine by Gillon (1994). We will find that Case Two share many of the characteristics as Case One but is different because it analyses peer reviewed literature and grey literature. Interestingly, the review of literature opens for even more ethical implications to discuss as there are a multitude of cases described in Case Two.

7.2.1 Justice

Following the four principles of medical ethics by Gillon (1994), it is evident that Case Two especially builds on the ethical issue related to justice. The reason to include the ethical principle of justice is because it is evident from the case material that this was a study done in

30-50 low to middle income countries (Piette et. al., 2015, 5). Because the ethical principle of justice in medicine describes sufficiently reaching out to all patients in medical procedures, regardless of an individual's traits, e.g., wealth, sex, orientation, race and other describing characteristics, and because Case One indeed raises the issue of how LMICs can receive sufficient and justifiable medical coverage through various technological tools, e.g., mHealth, IVR and SMS (Piette et. al., 2015, 1-21), it can be argued that Case One takes justice as governing medical principle into consideration.

In Case Two, telephone care management programs were the main way of being innovative in regard to treating patients through mobile health (Piette et. al., 2015, 2), but this turned out to be a problem in LMICs because reporting back to the program initiatives regarding the cost of the procedure and contrasting it with other methods was found to be problematic or at times impossible, as the technology of telephone care management programs typically did not support this action of tracking cost-efficiency (Piette et. al., 2015, 2).

Due to this, a solution was mHealth tools using reinforcement learning (Piette et. al., 2015, 3). In light of this, one could argue that justice is carefully considered as Case Two appears to be problem oriented in its approach to find literature and cases that pertains to all patients suffering cardiovascular diseases, regardless of it being a HIC or a LMIC.

An ethical implication directly linked to the defining variables of justice as an ethical principle in medicine can be found as Case Two addresses issues of language barriers, e.g., stating that the “development of mobile health services for language minority patients, e.g., the many indigenous communities in Latin America, is an important priority.” (Piette et. al., 2015, 12). As evident by the description of Case Two previously in this thesis, the authors argue that it was indeed a challenge to find literature that consulted this issue of making language-friendly technology that could be applied and understood globally, and not just in the English-speaking countries. Case Two cannot provide a sufficient solution in its review of literature to solve the ethical implication of justice, stating that “more evidence is needed on the impacts of mHealth in LMICs.” (Piette et. al., 2015, 12).

7.2.2 Non-Maleficence

After careful review of the content of Case Two, a logical conclusion would be that there is little to no reasons to believe that Case Two has any maleficent intent. The fact that the premise of the thesis is to find and review literature with the intention to highlight the current research and potential of digitized medical approaches for CVD patients should lead to the logical conclusion that it is not maleficent in its scope, method or findings. When it comes to the approaches that were reviewed within the article to accommodate patients suffering cardiovascular diseases in a digitized manner, one could, however, argue differently.

If one is to argue differently, and state that there might be a level of maleficence displayed in the procedures that was reviewed in Case Two to accommodate patients suffering from CVD, it is essential to highlight that it is only a possibility, and not a matter of fact. However, as it relates to the scope of this thesis, it is worth explaining and highlighting how such maleficent intent could occur in procedures attempting to better accommodate patients suffering from CVD.

Lupton (2015) is one of those who would probably look at the medical procedures and trials reviewed in Case Two and question their intention with respect to the ethical principle of non-maleficence, as Lupton (2015) believes that there are several socio-economic and political implications of digitized health tools attempting to accommodate patients suffering chronic disease (Lupton, 2015, 174-183).

Lupton (2015) states her mis contempt with the idea of self-monitoring digitized health tools, which more or less describes every initiative described in Case Two, by stating that we draw attention away from the actual symptoms of disease and thus our well-being through the use of self-monitoring devices that are increasingly autonomous in their nature.

“What is particularly noticeable about the ways in which digitized health promotion is employed in the majority of current programs is that most strategies render health states even more individualized, and draw attention away from the social determinants of health to a greater degree than ever before” (Lupton, 2015, 174-183)

Another possible critique that applies to Case Two in terms of the ethical principle of justice in medicine, could, as argued by Lupton, 2015, 174-183), be that digitized medical programs portray public groups or individuals as incapable of taking care of their own health. Lupton (2015, 174-183) argues this point by stating that research critical to the emerging digitized approaches of accommodating disease points to a general consensus that these initiatives try to pain individuals or social groups as inept in dealing with their own disease.

“They have contended that this focus tends to represent individuals or social groups as ignorant, morally deficient and lacking self-control and the capacity to take appropriate responsibility for their health if they fail to take up health promotion imperatives” (Lupton, 2015, 174-183).

While Lupton (2015) does point to thought worthy critique that could be applied not only to Case Two and the literature it reviews, but also to Case One and Case Three being that they are both of the same context, it remains to be concluded that the ethical implications of justice in terms of socio-economic and political implications described by Lupton (2015) is true. However, it is still a relevant and thought worthy discussion, and can shed light on the possibility of maleficent intent in procedures that one would not normally consider to be maleficent in nature, being that a ‘digitized measure of accommodating patients suffering chronic disease’ does not necessarily provoke doubtful intentions.

7.2.3 Beneficence

Beneficence as described by Gillon (1994, 185) is closely tied to the notion of non-maleficence, and it is the balance of the two and applying them at the same time in a given medical approach, consultation or procedure that is the key to justify the ethical principle of beneficence. The overall goal of will always be to provide net-benefit (beneficence) while still practicing safe medical approaches and methods to ensure that patients are not hurt, mentally or physically, during encounters with health digitization processes or in non-digitized approaches (non-maleficence) (Gillon, 1994, 185).

In studying Case Two, one can find several examples of beneficence being approached and taken into consideration. A common denominator for Case Two is that virtually every

digitized measure to treat CVD is focused towards cost-efficiency, because this provides a net benefit in terms of how many patients can be reached with each specific digitized medical treatment. That said, however, not all the medical approaches to digitized healthcare were able to produce a net benefit in terms of cost. As previously learned in the description of Case Two, 256 000 respondents in over 70 countries found that health care accounted for 13-32% of the household budgets in LMICs (Piette et. al., 2015, 2). This is a significant blow to beneficence as 13-32% of a household budget is a rather large number, meaning that in terms of costly digitized treatment methods, beneficence as an ethical principle in conducting digitized medical approaches in LMICs was not sufficiently justified.

An essential defining factor of beneficence in medical research or in conducting medical approaches is that each patients individual needs are respected and incorporated into the thought process building on the research enquiry, which can be argued that Case One is mostly ignorant of, being that Case Two is more a review of literature about social groups and culture's applicability in terms of receiving medical care through innovative, digitized health approaches. In contrast to, e.g., Case One, which focus primarily on one specific type of age group and is confined within the DVA, focusing on primarily on treating war veterans suffering from chronic low back pain (Piette et. al., 2016, 1). Case Two has a much broader range than Case One, e.g., in terms of the review of apparatuses, digitized medical approaches, socio-economic factors and cultural factors. The digitized approaches in Case Two include SMS, IVR, telephone management consultations, social media information and RL, and one can imagine the difficult nature of considering individual patients needs in such a wide variety of digitized medical approaches.

7.2.4 Autonomy

In discussing to what degree Case Two has "respect for autonomy" (Gillon, 1994, 184), it is important to understand the defining factors of autonomy and in what degree it takes place the digitized practices we see in Case Two. In biomedical ethics, the principle of autonomy or as Gillon (1994, 184) describes it, 'self-rule', is important as it allows the patient to develop an understanding of their own medical condition. A key part of autonomous 'self-rule' is what McBain et.al (2015, 1) describes as 'self-management', using digitized tools or

hardware to monitor one's own health, often related to chronic illness where consistent monitoring of health-related factors is deemed necessary.

“Self-management has been defined as an individual’s ability to manage the clinical and psychosocial consequences, along with the lifestyle changes inherent in living with a chronic condition” (McBain et.al, 2015, 1)

Now that we have defined autonomy as self-management or self-rule, an interesting topic of discussion related Case Two would be the implication of storing personal data through an increasingly monitored and *autonomous* way of approaching healthcare for patients suffering chronic disease. The assistive and disruptive technologies mentioned in Case Two to better provide health care in LMICs, e.g., mHealth, SMS-texting motivational messages (txt2stop) and IVR are all approaches that can provide health care assistance through awareness and information about CVD, but these approaches require that the patients share personal data about their health.

This increasingly autonomous way of monitoring and acquiring information about patients through various digital health measures pinpoints the implications of misconstruing information for financial gain. The argument made against collecting patient health data (PHI) through a more autonomous digitized health market in LMICs could be that LMICs suffer from a lack of knowledge and understanding of medical conditions due to a lack of clinicians with an expertise in CVD-based treatment methods, leaving them vulnerable to be exploited and taken financial advantage of, as mHealth, SMS-texting and IVR all collect sensitive PHI that could be sold, used and misconstrued to financially benefit private companies, namely unregulated software companies that produce apps or pharmaceutical companies that sell prescriptions (Thielman, 2017).

Now that we have presented the argument against Case Two and how autonomous self-monitoring might lead to a misuse of PHI through selling data to unregulated companies, we can examine the conducted trials that were performed in Case Two to determine if Case Two has a respect for autonomy or not. To do this, one must understand the underlying principles of the Health Insurance Portability and Accountability Act (HIPAA).

“The Health Insurance Portability and Accountability Act (HIPAA) is a federal law which governs the use and disclosure of PHI by covered entities, defined as health plans, health care clearinghouses, and health care providers who electronically transmit PHI.” (Lacktman, 2018)

To address our concern, we must then examine of the trials conducted using digitized health measures to accommodate CVD patients (e.g., SMS-texting, mHealth and IVR), corresponds with HIPAA. In looking at HIPAA we find that there are different laws for sharing PHI depending on which entity is using the PHI, but the general rule for all entities using PHI is that all data extracted from a patient must be in correspondence with said patients consent to share that data. Because the “entity” we are referring to in Case Two is that of a “research trial”, we will examine if the criteria for respecting patient autonomy was met in the way Case Two dealt with PHI.

First, Lacktman et.al (2018) describes that if PHI is used in a research process, which is correct for Case Two, the providers must do *one* of the following: (1) receive approval from an institutional review board or a privacy board waiver of authorization, (2) receive approval from each individual featured in the research trials that were conducted, (3) use the PHI through a limited data set or (4) use the PHI and then de-identifying the information so that it cannot be reused. Being a review of peer-reviewed literature that addresses different methods of accommodating CVD through digitized measures, Case Two does not mention once how PHI was acquired and through which process it was affirmed that patients gave consent to the different research trials, which I regard as an oversight to ‘respect for autonomy’ as Gillon (1994, 184) describes it. A critique that I would assign to Case Two would be that the focus on patient autonomy (respect for self-rule) in terms of ‘applicability’ of each respective digitized method (e.g., SMS-texting, mHealth and IVR), was lacking, thus rendering PHI collected through the trials to be misplaced or sold to private companies - this being the initial implication argued earlier in this section.

7.3 Case Three: “In Their Shoes” by Takeda

The third case is a project by Takeda, a patient-focused, innovation-driven global pharmaceutical company that builds on a distinguished 236-year history, aspiring to bring better health and a brighter future for people worldwide.

Takeda is a pharmaceutical company based in Japan, Tokyo. The intended purpose of the business is to innovate the health market by serving the needs of patients and physicians worldwide. What the project lacks in peer-reviewed research supporting the data that has emerged from ‘In Their Shoes’, it makes up for in being an interesting and creative new way of looking at innovative strategies to accommodate patients suffering chronic disease, in this case Inflammatory Bowel Disease (IBD). The article Takeda posted on their official website depicts the following research trial process:

“The program utilized a mobile application to guide participants through some of the common struggles patients face. An “IBD kit” of materials was used to participate in “challenges” prompted by the app. These challenges were designed to simulate several physical and emotional aspects of the disease. Through role-play scenarios and interactions with actors playing managers, nurses, and healthcare professionals, employees gained unparalleled insight into the impact IBD can have across all aspects of someone’s life, including professional and personal relationships.”

(Takeda, 2017)

In a recent project the pharmaceutical company has attempted to simulate what it’s like to be an IBD patient using an app. The innovative move was a decision made with the purpose of getting insight into the everyday life of an IBD patient, and employees of the company participated in the experiment by taking use of the app in everyday situations. The creative strategy is an attempt that is considered ‘outside the box’ as it does not only portray information about IBD but simulates the difficulties one can experience in a real-life situation given you are suffering from IBD. It was reported by the participants of the experiment as a fully encompassing and quite stressful experience, as they would have to respond accurately to messages, they would receive through the app they were given. Messages for when to go to the bathroom and such were common, and the participants would have to take

precautionary measures that they otherwise would ignore in their day-to-day activities, such as always being close to a nearby bathroom in case they would get a message saying they have to go to the bathroom.

For an IBD patients, symptoms like spontaneous bathroom breaks are not irregular. In fact, it is quite commonplace for IBD patients to research locales for bathroom opportunities prior to events or meetings, so that they can fluently find a nearby bathroom if a situation causing stomach upset might occur.

7.3.1 Justice

Gillon (1994, 185) argues that one can look at the ethical principle of justice in medical ethics and divide it into three categories.

“In health care ethics I have found it useful to subdivide obligations of justice into three categories: fair distribution of scarce resources (distributive justice), respect for people’s rights (rights-based justice) and respect for morally acceptable laws (legal justice).” (Gillon, 1994, 185)

In discussing the degree in which justice has been thought of when conducting the experiment of ‘In Their Shoes’ we are going to apply the three categories as provided by Gillon (1994, 185) to see how each category relates to the conducting of the experiment, starting with how fairly the distribution of scarce resources (distributive justice) was in Case Three.

The resources that were distributed in Case Three would be the equipment required for the trial to be conducted, namely the In Their Shoes app, the Takeda box with equipment and instructions and the telephone calls to assign role playing situations for each participant of the research experiment. In this research experiment the resources needed for conducting the experiment were first and foremost distributed to 22 employees at Takeda in Zurich, December 2015. This was the intention, according to project leader Audrey Liechti. One could say that the respect for distributive justice, then, was sufficient in terms of how all resources were given out to the participants of the study in the pilot period of the experiment.

Although critique in terms of distributive justice might be assigned to Takeda for conducting the In Their Shoes experiment with such a minor sample pool, being that the pilot of the experiment was rather minor with only 22 employees at Takeda in Zurich being included, one can argue that it is justified because of the unorthodox and innovative move of including actual employees in an experiment to simulate the symptoms of IBD, to then further develop a better consumer product that would help IBD patients using real-world experience.

Once the pilot period of In Their Shoes was concluded, Takeda introduced the research project to several industries that assesses research on health-related issues, as evidenced by a Legemiddelindustrien (LMI) article assessing In Their Shoes and its benefits for patients suffering from IBD. To give some context, Legemiddelindustrien, which translates to “Pharmacy Industry”, is a company working to test and assess pharmaceutical products and research. Their website reads:

“The pharmaceutical industry (LMI) is the industry association for the pharmaceutical industry in Norway. Norwegian and foreign pharmaceutical companies that develop, produce, sell or market pharmaceuticals in Norway may be members of the association. LMI will be the natural industry association for both large multinational companies and small Norwegian founding companies that operate in the pharmaceutical / life science area.” (LMI, 2018)

In a short article published by LMI, LMI interviewed the communications director in charge for Takeda’s In Their Shoes project and did a short assessment of the research. LMI explains that the research project by Takeda has now expanded and several 100 employees at Takeda have been given the necessary resources and information to conduct the self-managing experiment in which they simulate what it’s like to suffer from IBD, which is a positive indication towards the ethical principle Gillon (1994, 184) refers to as distributive justice. In their article, LMI also explains that the research experiment has also been introduced to internal parties, namely individuals suffering from IBD, and not just Takeda companies, on an international scale. In light of this, we could argue that, in terms of ‘distribution justice’ as a category of justice, is sufficiently represented in Case Three.

Next, we’re going to look at how respect for people’s rights (rights-based justice) is conveyed in the Takeda experiment. In looking at this subcategory of the ethical principle of justice, it is important to understand that all medical experiments must show a significant level of

respect for people's rights (Gillon, 1994, 184). There is no evidence of unfair treatment conducted in the experiment, but the patients did suffer in their day-to-day life, being that they had to adjust their lifestyle in accordance with messages they would receive through telephone calls and through the app-system. Liechti explains that there were varied responses to the simulation experiment, but the overall opinion was that the experiment was "humbling and difficult". Several inconveniences were experienced in the experiment, such as missing out on daily activities because the "patients" had to adhere to messages through the app/phone telling them to e.g., find the nearest bathroom, go to the bathroom, schedule physician calls and more, which are all commonalities of a typical IBD patient. This begs the question, to what degree is rights based on justice sufficiently taken into account in the conducting in Case Three? One could argue that even though the patients did suffer inconveniences as a result of participating in the experiment, it would be unfair to conclude that the participant's rights were not looked after. In fact, suffering the inconveniences of the experiment was the entire goal of this medical experiment, which makes this medical experiment unorthodox in its approach, but the results according to the participants were positive as the information gathering potential through real-life simulation of IBD was immense. Due to there being no sign of not respecting the rights of the participants in Case Three (only the intended and minor day-to-day inconveniences), we can argue that In Their Shoes was sufficient in terms of adhering to the participants rights.

Next, we're going to discuss the last sub-category of justice, namely what Gillon (1994, 184) refers to as respect for morally acceptable laws (legal justice). The survey did not force the participants to break any legal laws, but there were certainly minor inconveniences in the day-to-day lives of the participants, which again was the intended purpose. The Takeda branch in Canada, represented by Edward Feijoo from Takeda Canada, had this to say about the medical experiment, "This experience really gave me a different sense of how disruptive the disease can be, and how strong you must be to still live a normal life". However, Takeda did not report any of the participants having to break any laws as a result of participating the experiment, arguing that the respect for legal justice was sufficiently met in Case Three.

7.3.2 Non-maleficence

Case Three pinpoints the ethical dilemma of stress put on IBD patients to be excused in social situations which can, depending on the situation and person, feel as if it's inappropriate

or in contrast to social norms. The participants in Takeda's "In their Shoes" experiment was quick to realize that social pressure in situations where they were forced to break their daily routines and adapt to a simulated response from either a phone-call or the app, were difficult and at times caused an uncomfortable social scene. This experiment gave ordinary people the ability to feel the pressure of a situation an IBD patient experience frequently, opening for the discussion of social norms and how one should deal with situations were IBD patients experience social distress because they must leave social gatherings or meetings due to emergent issues related to their IBD.

This brings us to the discussion of whether non-maleficence was practiced sufficiently and thought about in the conducting of this medical experiment. Case Three in terms of non-maleficence is quite special, because the entire goal of the experiment was for the participants to experience the maleficent side-effects of being an IBD patient, however the intention for doing so and the purpose behind In Their Shoes was to learn more about IBD. The answer would then have to be that there indeed was maleficent repercussions, e.g., participants having to sacrifice activities in their day-to-day lives to adhere to the simulated messages in the simulation program that the participants had to partake in, but because the participants *knew* this going into the medical experiment, consent was given, and because the intentions behind the medical experiment was to better accommodate patients suffering from IBD, the conclusion could be argued to weigh more towards that non-maleficence as an ethical principle was sufficiently represented. To sum up this, we could say that there indeed was minor maleficence as the participants experienced inconveniences, but the greater result was beneficence and the overall net-benefit prevails in this medical experiment.

7.3.3 Beneficence

The goal of beneficence is to produce net-benefit with no harm done to the participants of a medical experiment, and it is closely in symbiosis with non-maleficence (to not hurt the patients undergoing the medical experiments). In case three, one could argue that the beneficence was that Takeda was spreading awareness and information about a rather disclosed and taboo subject, opening it up to be assessed, discussed and experienced by medical workers (employees at Takeda) to better understand why IBD patients feel the way they feel. The reach of this program is evident by Takeda's article, pinpointing just how much of a wildfire-affect the innovative program has had.

“Beyond the initially focused internal audience of Takeda, the team has continued to expand the program across broader audiences (HCPs, journalists and institutions) in the Europe and Canada region. In each country where the program has been initiated, patient associations were involved.” (Takeda, 2017)

As evidence to this statement, the article that LMI published on In Their Shoes talks about how In Their Shoes had been featured on the popular Norwegian news site VGTV, which features a politician by the name of Bård Hoksrud talking about the importance of understanding the implications of IBD and opening up the conversation to the public, removing the stigma around some of the symptoms IBD patients may experience.

Another point to beneficence was made when an employee in Takeda came forward, according to Takeda’s article, and talked about her struggle with the symptoms of IBD combined with long-haul flying and traveling in general. This prompted another initiative that Takeda intends to work more on called #FlyWithIBD, calling on airlines to serve IBD-friendly food.

7.3.4 Autonomy

We have learned previously that autonomy is the respect for self-rule and letting patients in on information when medical trials are conducted. In the case of Case Three, it is evident by the Takeda article that autonomy is the driving factor of the medical experiment. We can argue this because the entire medical procedure is monitored and controlled by the participants themselves, and the information is relayed back to the participants, being that the participants are employees working on finding better solutions to accommodate patients suffering from IBD. Thus, in the case of autonomy and the respect for self-rule in Case Three, it’s a self-fulfilling prophecy. The experiment is conducted by participants and the participants are also the ones who will take use of the information that is acquired from the experiment. The respect for self-rule is therefore undoubtedly sufficiently represented in Case Three, as it is a medical experiment that is *based* on autonomy in the form of self-management.

8 Addressing the Characteristics and Heterogeneities of the Three Cases

In this next chapter the intent will be to describe the differences between the cases, namely what makes them strong or weak in terms of their applicability in the health industry, how they differ in terms of sufficiently representing the four ethical principles that Gillon (1994) outline for medical workers as ethical guidelines to uphold and also we're going to look at how the cases differ in terms of their approach to retrieving information or solving a particular medical problem, through the use of digitized accommodation methods.

The choice to include three digitized cases of accommodating patients suffering from chronic disease that were all different in their approaches, but at the same time all intended to achieve the same results in terms of retrieving valuable information about a chronic condition, was made to showcase the disparities in approaches that has been made in the field of digitizing accommodation approaches for chronic health patients, and consequently also show how the ethical implications also are different in each respective case, depending on its approach.

Starting off with Case One, we immediately identify that the case is focused towards one target group, namely war veterans in the U.S suffering from low back pain. This makes Case One stand out in contrast to Case Two, as Case Two is a review of literature on digitized accommodation measures to accommodate patients suffering chronic diseases and a displaying of the findings and applicability of said accommodation methods, thus focusing on quantity (in terms of information inquiry) rather than a single target group (war veterans). Case One is also different from Case Three, being that Case Three has an unorthodox approach to retrieving relevant information about IBD, namely a digitized *simulation* of a disease (IBD) rather than approaching the chronic disease through a clinical trial intending to *treat* the patient.

In Case One, we find that the case is ethically well represented in terms of it being focused on a smaller target group (war veterans), reflected by the fact that Piette et al (2016) describe the methodological approach to gain consent from patients in high detail. The represented ethical principle in this case would be one of the sub-categories under justice, as defined by Gillon (1994), namely respecting a patient's right to refuse treatment and forfeit their patient status in medical experiments and respecting the social and moral laws of conducting a medical

experiment. The statement below showcases how carefully Case One approaches the issue of obtaining patient-consent:

“After obtaining agreement from patients’ primary care providers, a letter will be sent to veterans informing them about the study and inviting participation. Veterans who do not opt-out by postage-paid response card will be called by research staff to explain the study, conduct screening, and solicit their involvement. If the veteran is willing, s/he will be sent the consent form by mail along with a postage-paid return envelope.” (Piette et. al., 2016)

There was also a list of requirements that patients needed to meet in order to participate in the medical experiment that Case One showcases, which especially highlights the ethical principle of beneficence in its symbiotic relationship with non-maleficence, as described by Gillon (1994). It is identifiable that the overall goal is to produce net-benefit in terms of information inquiry and helping war veterans treat their chronic low back pain, but at the same time Case One also has respect for the patient by stating numerous health requirements that each respective patient must meet in order to participate in the medical experiment. In contrast, this is very much lacking in both Case Two and Case Three, as they do not set forth specific medical requirements for each patient participating in the medical experiment.

It can be argued that Case Two is unique in the way it has a broader reach in terms of its wide methodological approach to information inquiry, including not just one digitized method of accommodating patients suffering from CVD, but several accommodation methods (e.g., IVR, Social Media, SMS-Texting and RL). It also targets not just one geographical area, in contrast to Case One which mainly focus on the U.S, but targets several geographical areas and the geographical, economical and ethical challenges of implementing the accommodation methods that Case Two reviews in these geographical areas. It can be argued that this is what makes Case Two such a prominent candidate in representing the sub-category of justice as described by (Gillon, 1994), namely distributive justice, in contrast to Case One which focus is primarily on U.S war veterans suffering from low back pain. Case Two also differs from Case Three in terms of distributive justice as Case Three was more oriented around the employees at Takeda, rather than focusing on LMICs and HICs and a wide range of medical approaches, which is the purpose of Case Two. That said, it should be mentioned that Case Three did expand gradually to include more patients suffering from IBD, but this process was gradual and Case Three was not intended to be a large-scale medical experiment, judging by

the Takeda article. Judging by this information, we find that the ethical principle of *justice* is more sufficiently represented in Case Three than in Case One and Two, as Case Three's main purpose is to display the results and statistics in digitized medical experiments. Because Case Three is more large-scale and data-driven (results oriented), it focuses heavily on one of the ethical principles that Gillon (1994) mentions as one of the three categories of justice, namely a focus on justly distributing scarce resources/information that patients of chronic conditions need in a given medical experiment through a focus on LMICs as well as HICs. However, in studying Case Two we find that its focus is quite derivative of the remaining two sub-categories of justice, namely rights-based justice and legal justice. Because of the quantity of cases reviewed in Case Two it can be argued that people's rights (rights-based justice) was not sufficiently represented in the method of approach in each given medical experiment, or at least this was not part of the focus in reviewing the literature surrounding digitized medical approaches to patients suffering from CVD in HIC and LMIC (Case Two). One could also play devil's advocate in favor of Case Two, pinpointing that it's important to understand that Case Two was indeed *based* on quantitative research, thus producing quantity in terms of a wider disparity in the results, rather than a focus on quality and thus a more patient-consensual approach to accommodate patients suffering chronic disease.

Beneficence in terms of producing a net-benefit is also something that one could argue Case Two has sufficiently represented. Gillon (1994, 184) describes this ethical principle as 'producing net-benefit' which is exactly the main goal of Case Two; displaying a vast array of different results in medical approaches to accommodate patients suffering from CVD. The net-benefit in Case Two would be the evaluation of different medical approaches and the information inquiry that comes from this, as this evaluated information could be used to help health investors decide upon which technologies they should invest in and produce more of when it comes to better accommodate patients suffering CVD in LMICs and HICs. The quantity over quality approach is therefore both negative in terms of respecting individual patients' rights and social/moral laws (rights justice, legal justice and nonmaleficence) and positive in terms of net-benefit and its global reach (beneficence and distributive justice).

In assessing Case Three we find a vastly different approach than both Case One and Two, being that its intention is to *simulate* a disease (IBD), which is the very opposite approach of Case One and also the approach in the literature reviewed in Case Two that both focus on digitized accommodation methods of *treating* a disease. This creative approach might be

lacking in terms of non-maleficence, being that the participants of the research project had to actually simulate a disease which has detrimental effects on health, causing the participants to suffer in their day-to-day planning of activities, but make up for it in how effective the medical experiment was in terms of autonomy. The information inquiry in Case Three did not follow the usual patient-producer-physician information chain, but rather did a full circle in terms of the intended recipient of the information coming out of the experiment was also the patient, namely the coworkers at Takeda who participated in the experiment during the trial period. This is a fully autonomous system, as the notion of 'self-rule' is completely encompassed in the conducting of the medical experiment. The reason we mention this is because, in contrast to Case One and Two, we cannot identify this level of 'self-rule', making Case Three a rather strong ethical candidate solely based on this fact.

9 Conclusion

In this chapter I will attempt to conclude the findings made in the thesis and summarize the most defining arguments that has been presented in this thesis. Lastly and to conclude this thesis, this section will include an educated prediction as to what will happen in the field of digitization of health-related approaches to accommodate chronic patients, and present further research in the field that I would hope to witness in the years to come.

9.1 Findings and summary

To conclude the findings that we have uncovered in this thesis, it is important to note the required relationship between ethics and technology, namely digital technologies in the health sector, and that this relationship always continues to evolve with the four ethical principles in mind. This must be a priority for ethics boards all around the globe in determining whether one should invest in digitized health accommodation systems for patients suffering chronic diseases, and I hope the information that I conveyed in this thesis will help guide that decision.

It can be argued that in discussing the collaboration of different fields in order to ensure that AI stays ethical we have found that it is required that the underlying factors of ethics are understood and considered when incorporating ethical values in health-related products and procedures. The complexity of writing on anything regarding ethics is quite difficult when it's isolated to ethics, but when you incorporate medicine, the layers and complexity become far more immense, again underlining the inherent need for seemingly different fields of science to communicate and work in a symbiotic relationship. For instance, one cannot consider the applicability of a digitized medical experiment without considering, consulting and inquiring information about the history of medical ethics.

We have found that there are ethical implications in digital technologies when they relate to the health sector, such as the generation gap, implications of storing personal data, the implication of adopting a deterministic view on technology and the importance of face-to-face conversation and lack thereof in digital services with the intent to accommodate patients suffering chronic disease. In addressing Gillon (1994) we have found that there are four

ethical principles that determine whether a medical experiment can be considered morally sufficient. These principles have been the result of an ongoing evolution of ethical discourse in the field of physician-patient relationship, as documented by Will (2016) in his article on the evolution from a beneficence-oriented health model to a more autonomous model. We have also found that there are disparities in the cases, each case having a different approach in terms of one being a medical experiment, one being a review of peer-reviewed literature and the last being a simulated medical experiment. Because of these different methodological approaches as to how one can accommodate patients suffering chronic diseases in a digitized manner, we find that each respective case is represented differently on the spectrum of medical ethics. What one case lacks, another makes up for in terms of sufficiently representing an ethical value, and vice versa. This leaves us with the overall interpretation that each case of accommodation patients suffering chronic disease has valuable information extracted from it, and the disparity in how the issue of accommodating patients suffering chronic disease was approached in each medical experiment, played a part on what kind of information the medical experiment produced, and also played a part in how well the medical experiment represented each respective ethical principle.

9.2 Further Research in the Field

In writing this thesis, I hope that the research continues to evolve in a symbiotic relationship with ethical guidelines, so that medical experiments intended on treating patients with chronic diseases don't have a perverse effect. Physicians and companies working in the health industry must not let their curiosity or financial needs given priority over the ethical principles in support of patients' rights, legal rights, distributive justice, nonmaleficence, beneficence and autonomy, in medical experiments, trials and products. Understanding the digital is crucial, not only in the present moment, but also for the future. Developing a strong relation and understanding of what it means to be in the Fourth Industrial Revolution with digital influence in almost every activity will hopefully highlight the digital implications of this digital era in a more preemptive manner, so we can deal with the ethical implications before they actually take place and cause distress to our wellbeing and way of life.

More specifically, it is my hope that Case One will uncover more revealing information about the applicability of the digitized approaches Case One introduces us to, to accommodate war veterans in the U.S suffering from low back pain. The results according to Piette et al (2016)

will be readily available in the Winter of 2019. Perhaps this will reveal more ethical implications in terms of the generation gap and how U.S war veterans of the elderly generation might've had trouble relating to a digitized accommodation method.

Another interesting development one could hope for would be to see if 'In Their Shoes' by Takeda is going to produce or inspire more academic articles or journal entries on the ethical issues surrounding IBD, as the Takeda article by itself did lack in credible and peer-reviewed information, which it made up for in its creative approach to accommodating patients suffering from IBD. Takeda did point out that other movements, such as #FlyWithIBD, were inspired by the digitized accommodation measure. This is hopefully a step in the direction of more academic funding and focus on IBD and the different digitized methods one can approach the treatment of this highly prevalent disease.

10 List of abbreviations

AI-CBT: Artificially Intelligent Cognitive Behavioral Therapy

CBT: Cognitive Behavioral Therapy

HIPAA: The Health Insurance Portability and Accountability Act

HIC: High Income Country

IVR: Interactive Voice Response

LMIC: Low to Middle Income Countries

mHealth: Mobile Health

PHI: Patient Health Information

RL: Reinforcement Learning

SMS: Short Message Service

11 List of frequent terms used

Reinforcement Learning: description of an adaptive algorithm with simulations.

Cognitive Behavioral Therapy: psychotherapy with the intent of treating a patient through conversational tactics and guidance.

Interactive Voice Response: telephone call between a physician and a patient with the intent to counsel a patient through guidance and therapeutic stimuli.

Mobile Health: a tool for communication regarding health between a patient and physician, oftentimes in an autonomous system to provide or give feedback regarding a health issue.

SMS: a short message service from a mobile phone that provides text in a mobile format, often in the context of sending information from A to B.

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