DATENHERRSCHAFT
– AN ETHICALLY JUSTIFIED SOLUTION TO THE PROBLEM OF OWNERSHIP OF PATIENT INFORMATION

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ABSTRACT

Patient information systems are crucial components for the modern healthcare and medicine. It is obvious that without them the healthcare cannot function properly – one can try to imagine how brain surgery could be done without using information systems to gather and show information needed for an operation. Thus, it can be stated that digital information is irremovable part of modern healthcare. However, the legal ownership of patient information lacks a coherent and justified basis. The whole issue itself is actually bypassed by controlling patient information with different laws and regulations how patient information can be used and by whom. Nonetheless, the issue itself – who owns the patient information – is commonly missed or bypassed.

This dissertation show the problems if the legislation of patient information ownership is not clear. Without clear legislation, the outcome can be unexpected like it seems to be in Finland, Sweden and United Kingdom: the lack of clear regulation has come up with unwanted consequences because of problematic European Union database directive implementation in those countries. The legal ownership is actually granted to the creators of databases which contains the patient information, and this is not a desirable situation.

In healthcare and medicine, we are dealing with issues such as life, health and information which are very sensitive and in many cases very personal. Thus, this dissertation leans on four philosophical theories form Locke, Kant, Heidegger and Rawls to have an ethically justified basis for regulating the patient information in a proper way. Because of the problems of property and ownership in the context of information, a new concept is needed and presented to replace the concept of owning, that concept being *Datenherrschaft* (eng. mastery over information). Datenherrschaft seems to be suitable for regulating patient information because its core is the protection of one's right over information and this aligns with the work of the philosophers whose theories are used in the work.

The philosophical argumentation of this study shows that Datenherrschaft granted to the patients is ethically acceptable. It supports the view that patient should be controlling the patient information about themselves unless there are such specific circumstance that justifies the authorities to use patient information to protect other people's basic rights. Thus, if the patients would be legally granted Datenherrschaft over patient information we would endorse patients as individuals who have their own and personal experience of their own life and have a strong stance against any unjustified paternalism in healthcare.

Keywords: patient information, ownership, Datenherrschaft, ethics, Locke, Kant, Heidegger, Rawls

TIIVISTELMÄ

Potilastietojärjestelmät ovat kriittinen osa nykyaikaista terveydenhuoltoa ja lääketiedettä. On selvää, että nykyinen terveydenhuolto ei voi toimia tehokkaasti ilman niitä. Voi kuvitella, kuinka aivoleikkaus voitaisiin suorittaa ilman tietojärjestelmiä joihin kerätään ja joiden avulla käytetään tarvittavaa tietoa tuon vaativan leikkauksen suorittamiseksi. Voidaan todeta, että digitaalinen informaatio on erottamaton osa modernia terveydenhuoltoa. Kuitenkin, potilastiedon omistajuutta ei ole laissa selkeästi määritelty, saati perusteltu. Koko aihe itsessään on ohitettu kontrolloimalla lailla vain sitä, kuka saa käyttää potilastietoa ja miten sen tulee tapahtua. Mutta itse kysymys – kuka omistaa potilastiedon – on unohdettu tai ohitettu.

Tämä väitöskirja osoittaa ongelmia, jotka johtuvat siitä, että potilastiedon omistajuutta ei ole yksiselitteisesti määritelty. Ilman selkeää laillista omistajuutta seuraukset saattavat olla yllättäviä, kuten näyttää olevan tilanne Suomessa, Ruotsissa ja Yhdistyneissä kuningaskunnissa. Ilman selkeää lainsäädäntöä Euroopan Unionin tietokantadirektiivin ongelmallinen implementaatio on tuonut mukanaan odottamattoman seurauksen. Edellä mainituissa maissa laillinen omistajuus potilastietoon on annettu potilastietokannan luojalle tietokantadirektiivin nojalla, mikä ei ole toivottu tilanne.

Terveydenhuollossa ja lääketieteessä ollaan tekemisissä potilaiden elämän, terveyden ja hyvin henkilökohtaisen informaation kanssa. Tämä väitöskirja nojautuu neljään filosofiseen näkökulmaan Lockelta, Kantilta, Heideggeriltä ja Rawlsilta, muodostaen eettisesti oikeutetun perustan määriteltäessä potilastiedon omistajuutta. . Koska itse omistajuus on ongelmallinen käsite informaation kohdalla, tarvitaan uusi konsepti, joka huomioi informaation luonteen. Väitöskirjassa esitellään termi Datenherrschaft (herruus yli datan), joka soveltuu potilastiedon kontekstiin hyvin, koska termin ydin on yksilön oikeuksien suojaamisessa. Lisäksi termi on linjassa väitöskirjassa käytettyjen filosofien teorioiden kanssa.

Tämän työn filosofinen argumentointi osoittaa sen, että herruus yli potilastiedon annettuna potilaalle on eettisesti oikeutettua. Potilaan tulisi saada kontrolloida potilastietoa itsestään, ellei jokin erityinen syy anna viranomaisille oikeutta? käyttää sitä suojatakseen muiden ihmisten perusoikeuksia. Jos potilaille myönnettäisiin herruus yli omien potilastietojen, tukisi se heidän asemaansa vapaina yksilöinä, joilla on oma näkemys ja suunnitelma elämälleen.

Lisäksi se olisi selkeä viesti epäoikeutettua paternalismia vastaan terveydenhuollossa.

Avainsanat: Potilastieto, omistajuus, Datenherrschaft, etiikka, Locke, Kant, Heidegger, Rawls

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Since this journey is almost over, it is time to acknowledge the people who have contributed to this adventure. I call it an adventure, because an adventure is a journey to unknown territory, as this process has been for me. Likewise, an adventure is an outcome that one does not always see come to fruition. However, my life has mercifully led to this point, and this world of philosophy has become a crucial part of my life and my being in this world, and I am fortunate to have had this wonderful possibility.

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1 INTRODUCTION

This chapter presents the background to the present study as well as the different research directions that stem from it. The chapter begins by explaining the motivation behind the study, namely the problems related to the issue of ownership of patient information. The aim is to demonstrate the complexity of the issue and the associated need for a transdisciplinary approach to the thesis. After the motivation for the study has been established, legislative examples are presented to illustrate the need for clear regulation of the ownership of patient information. This chapter closes by focusing on the complexity of the terms ‘health’ and ‘health information’ in order to ensure that the basic background and the use of those terms in this thesis is clearly established.

1.1 Motivation

Questions concerning the ownership of patient information as well as how such information is stored, used and regulated (or not) are more important than ever now that patient information is no longer stored in paper-based records. Recent improvements in information technology have made it possible to collect, use and transfer information at a different level than was possible in the era of paper-based patient records. The difference is clear when we think back to the time when only paper-based records were available. The control of use was far easier and more straightforward because of the physical limitations of paper records. Electronic patient records have no such limitations and thus new problems arise. Nowadays, patient information can be used and accessed far more easily, and it can be more unpredictable than in the time before the arrival modern information technology. We could almost say that it will soon be possible to access patient information without the limitations of time and space.

The traditional elements of ownership are often insufficient for intangible property because such property is often simply an assortment of contractual and other legal rights rather than something that could easily be qualified as property. It is important to note that multiple actors or parties, such as doctors, nurses, patients, companies and others, may have an interest in patient information and that those interests may overlap. Thus, the property laws that were designed to meet economical needs are insufficient to address the issues that emerge concerning electrical patient records (Hall & Schulman, 2009).

However, information technology (and the patient information stored in it) is a major factor in modern healthcare and medicine even though it has not yet been able to not meet all the expectations placed on it (Himmelstein, Wright, & Woolhandler, 2010; Kellermann & Jones, 2013). Legal, ethical and financial problems can be found that prevent the proper use and adoption of electronic health records (Sittig & Singh, 2011). Nevertheless, it must be acknowledged that information technology has made it possible to use and share vital patient information that enables the different actors in healthcare to deliver care – not forgetting the potential to analyse medical information produced by healthcare professionals – but not without problems and only limited success when compared to the exceptions put on technology. Thus, it is reasonable to say that the possibilities that information technology has brought to the field of healthcare are hugely valuable, although the legislation is badly lagging behind practice, which will be shown later in this chapter.

One reason for the lack of legislation could be the digitalisation of patient records, which radically changed the possibilities for the use of patient information. In addition to this rapid digitalisation, the focus behind developing patient information systems has mainly been on improving the work of healthcare professionals and intensifying healthcare from the healthcare professional’s point of view. Regulations have generally focused on solving emerging problems rather than on trying to create a clear regulative basis for patient information in this digital era. This can be seen as a consequence of the Moorian policy vacuum (Moor, 1985).

A policy vacuum is a situation where there are no policies (or where the existent policies are unclear) regarding how information technology should be used (Moor, 1985). Thus, the situation in which legislation is lagging behind the development of technology is an example of a Moorian policy vacuum, and it can become a very concrete vacuum in a number of very different ways (e.g. Boulton, 2013). Kainu and Koskinen (2014) considered the Moorian policy vacuum and how it interconnects with IT ethics and different legal interpretations (see Figure 1 (Kainu & Koskinen, 2014)). The term ‘techne’ in Figure 1 refers to the knowledge necessary to make certain objects in order to meet certain goals.[1] However, in the figure, ‘possible acts’ (use) with technology passes over the possibilities of laws (‘formalistic’ or ‘end-oriented’) and ‘ICT ethics’ to reach or fully demark. The formalistic case relies on legal interpretation wherein the law uses the core meanings of words that change slowly over time (see Hart, 1958).

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[1] The Aristotelian notion of *techne* will be discussed in chapter 2.

Thus, formalistic law is badly lagging behind technological developments. End-oriented legal interpretation is an approach wherein the development of ICT ethics and technology are closer because, under that mode of interpretation, the ends (i.e. intentions) of the law are considered more important than the actual words used (Tamanaha, 2007).

If the technology and the legislation (legal interpretation) have so clearly diverged, it is obvious that the situation concerning the ownership of patient information is similarly diverged because it involves a combination of regulating healthcare and ICT. Therefore, it is not surprising that we have not yet be able to enact legislation to overcome the problems of poorly defined ownership of patient information. As a society, we are always trying to overcome the problems that technology is bringing to us faster and faster.

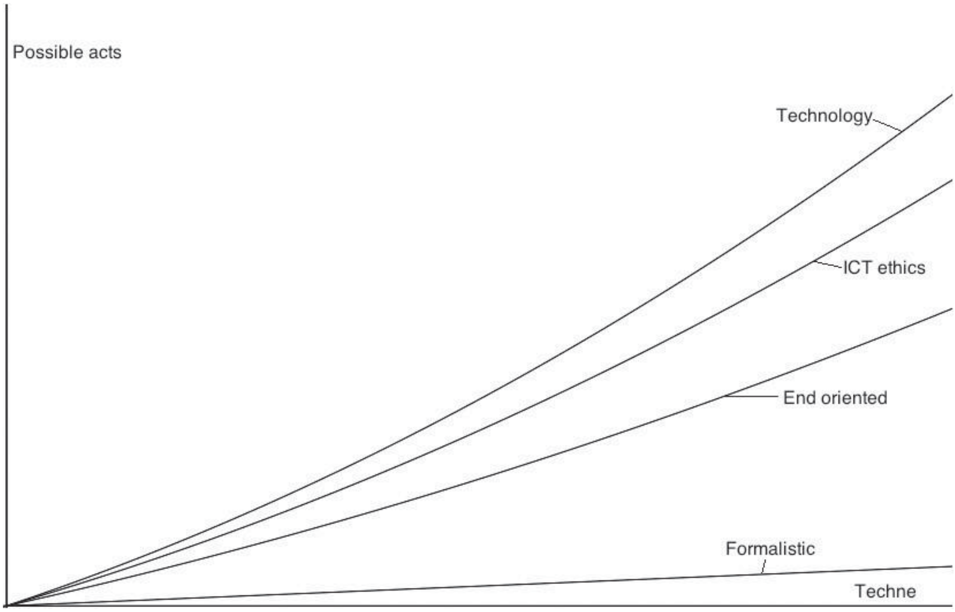

Figure 1. Moorian policy vacuum.

It seems that the most promising and fruitful way to approach this issue is to come up with a solid and ethically justified solution to controlling (owning) patient information, rather than just to try and catch up with the technological possibilities and then ethically fit them into the patient information system. It seems rational to clarify the ethical demands beforehand, which allows us the possibility to create a legal definition for the ownership of patient information and to define who can use it and how before the actual definition or implementation of a patient information system. Based on that, we can determine what kind of system should be implemented, instead of simply trying to ethically cope with almost unlimited technological possibilities. From this ethics first approach, it can be recognised that the ethical demands for the ownership of patient information are taken into account and thus are more likely to be implemented.

Using this approach – even though technological development is clearly fast in area of information technology – we can control the use of technology in some specific area (patient information systems in the healthcare field in this case) so that it rests on only trustworthy technical solutions and there is no attempt to be a pioneer of a new technology with risks attached to it. However, this does not mean that the development and use of technology should cease. Instead, it means that we do not use technology if it does not meet the ethical values of healthcare (see Koskinen, Heimo, & Kimppa, 2012). In that way, we can narrow the gap between ethics and legislation. Likewise, a gap between technological development and ethics can also be delimited. However, in order to achieve this, we must start to approach these kinds of problems from an ethical perspective, rather than from a legal or technical perspective.

Computer ethics – as Moor (1985) refers to it – is a relevant grounding point for the topic of this thesis. However, this thesis is not focused on information systems (technology). Rather, it is the background force or source that has brought up the problem of ownership of patient information. The problem has arisen with and due to technology. In the era of paper-based patient records, access to patient information was more or less restricted, and patient information was usually only accessed by healthcare professionals when they were working to care for a patient. Of course, there was still the possibility that the information would be used unethically and without permission. Nevertheless, information technology has had a huge impact if we consider how access to and use of patient information has changed (Cimino, 2013). Overall, that change has improved the outcomes of care, although there have been problems and despite the fact that the use or implementation of technology varies from country to country (see Buntin, Burke, Hoaglin, & Blumenthal, 2011; Currie & Seddon, 2014; Lluch, 2011). Thus, the fact that information technology is changing healthcare so radically, and that not all promises or expectations are fulfilled, is a strong indication that we need research – especially ethical research – and regulation to avoid negative outcomes in future and to correct the ones that have already occurred.

The effects of a patient information system on everyday practise are significant – even if not always positive – and it is hard to see how the modern healthcare sector could manage without using patient information systems. However, it is disconcerting that even as we understand the importance of information systems to healthcare, we still lack some fundamental legislation and understanding about the patient information itself. Hence, the use of that information is based on unclear justifications, despite that use appearing to have good outcomes in most cases. One reason for this could be that information technology has spread so far in our societies that it has become so established that we accept it as given, which is problematic and so one of the reasons why this thesis is needed.

1.2 The legislative problem and examples from Finland, Sweden and the United Kingdom

The issue that inspired this thesis is the finding that current legislation in many countries does not clearly state who owns patient information (Hall & Schulman, 2009; Koskinen & Kainu, 2013; Koskinen, Kainu, & Kimppa, in press; Rodwin, 2009, 2010). Only a few other medico-legal questions are more critical, contested or poorly understood than that concerning the ownership of medical information (Hall & Schulman, 2009). Sometimes, changes in technology bring about policy choices and require that we both clarify our key values and re-examine our legal concepts. The development of electronic medical records is that kind of change (Rodwin, 2010). However, there currently seems to be only limited academic discourse about the ownership of patient information (Koskinen, Kainu, & Kimppa, in press). Koskinen and Kimppa (forthcoming) found that those few academics who do contribute to the discourse seem to hold one of three different views about ownership. First, there is the view that such information should be publicly owned (e.g. Rodwin, 2010). The second view is that patients themselves should be the owners (e.g. Koskinen, Kainu, & Kimppa, in press). The third and final view is that ownership is not a problem and that it can be arranged with other regulations rather than property rights laws (e.g. Evans, 2011, 2012). It is notable that even though these three different views regarding the ownership of patient information exist, all of the authors have expressed that the issue is not straightforward and that there are concessions or overlaps between the different solutions (see Hall & Schulman, 2009).

In Finland, the patient or citizen is not the owner patient information by the law. This is due to the inadequate implementation of Directive 96/9/EC (Database protection) and hence the provider of healthcare – private or public – has the right to patient information (Koskinen, Kainu & Kimppa, in press). This was hardly the idea of the database directive or Finnish government. Especially when in Finland it is at the same time giving citizens more access to patient information in the national archive (see Kanta-palvelut, 2015). Likewise, in Sweden, the lack of clearly articulated legislation affects that the ownership seem to be granted by database right, even if it is not clearly stated (Koskinen, Kainu & Kimppa, in press). This seems to be contradictory with the fact that all Swedish people now have the right to access the information by the Patient Data Act introduced 2008 and there is an aim to make electronic medical records fully available for all citizens who want those (Hägglund & Koch, 2015). The problem is that European Union directive overrides national legislation in this particular case and thus national law cannot bypass the directive. United Kingdom is following the same path as Finland and Sweden, which means that the holder of the database is the owner of the data within. This situation is a result from the wrong implementation of the database directive, which is hardly a good legislative solution and legislative revision is needed without delay (Koskinen, Kainu & Kimppa, in press). These examples show that the clear and explicit regulation of who is the owner of patient information is needed to avoid situations of this kind. Likewise, the content of that ownership must be stated carefully to avoid new problems.

1.3 What is meant by ‘health’ and ‘health information’?

To understand what kind of relation exists between health and patient (or health) information, we need to first clarify those two terms. It is evident that every rational human being has an intuitive and personal understanding what health means (see Heidegger, 1927; Koskinen, forthcoming), but that is insufficient if the goal is to establish a strong basis for discourse about the ownership of patient information. The terms are used somewhat confusingly in literature, as ‘patient information’ is used along with ‘health information’ to refer to management information as well as to information that is directed to patients (Dixon-Woods, 2001). Thus, to ensure a common understanding of the meaning, key terms must be explained in the context of this research, which will also guarantee the meaningfulness of discourse.

‘Health’ is a term that may be impossible to define in such a way as to be entirely unambiguous. Still, we need a deeper and more explanatory definition to form the basis and framework for discourse about healthcare (Koskinen, 2010). The World Health Organization (WHO) (2014) has defined health as ‘a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’ and that definition is arguably one of the dominant ones. The WHO (2014) definition is almost 70-years-old and still it appears that we are failing to achieve the ‘spirit’ of that definition, which is to see and respect human beings as complete individuals and not to only concentrate on the biomedical state of human beings. Thus, in this thesis the term health is taken to refer to a *homelike-being-in-the-world* (Svenaeus, 2001), which emphasises that the personal experience of life and health is adopted. This definition is presented in more detailed later on in Chapter Three.

However, modern medicine is disease-oriented and it has become a field that is built on increasing specialisation, which actually causes the fragmentation of the field (e.g. Nolte et al., 2012; Stange, 2009; Starfield, 2011; Tinetti & Fried, 2004) and thus the human behind the body is easily lost. It is understandable that with medicine and healthcare being so specialised nowadays, healthcare professionals cannot have an understanding of all medical issues since the specialisation situation leads towards a more narrow view. It is just as reasonable that a doctor specialising in cardiology cannot be expected to have knowledge about all skin symptoms. However, the problem is that people in this situation easily became an object of the treatment or action that the highly specialised healthcare professional is performing. The real risk in the fragmented healthcare field is that the professionals are losing the opportunity to understand the complete picture about the individual human beings they are encountering.

In order to prevent such alienation, a new approach to healthcare must be brought forward and it is important that patients are seen as human beings rather than objects. Therefore, it is not surprising that patients' involvement in healthcare has become an important issue for both healthcare professionals and policy makers (Callaghan & Wistow, 2006). In addition, the growing financial pressure on healthcare is driving the actors involved to find new ways to deliver care, as well as emphasising the need for individuals to have the opportunity to affect their own health and wellbeing, and thus to reduce the growing burden of healthcare (e.g. Coulter & Ellins, 2007; Kennedy et al., 2013). Patient-centred healthcare and patient empowerment are seen as critical factors in improving the outcomes of healthcare (Rathert, Wyrwich, & Boren, 2013), without forgetting the impact of improvements made in medicine. Patient-centredness is a practise of organising healthcare in such a way that people are respected, so they can be more active and better informed in matters concerning their own healthcare and information (Epstein & Street, 2011).

The term 'patient information' is used in this thesis to refer to information about citizens – information that is stored by different healthcare organisations and healthcare professionals. There are two main reasons for this limitation. First, most of the current information about citizens' health is collected and stored by healthcare professionals and organisations, and it is thus the meaningful premise for analysing the ownership of patient information. It is meaningful to use the term patient information because the role for individuals in healthcare is seen as that of a patient, even if it has paternalistic[2] baggage and it is acknowledged that people should be seen as individuals with rights and lives outside the role of patient (Hogg, 1999; Koskinen & Knaapi-Junnila, 2014; Lahtiranta & Koskinen, 2013). Nevertheless, the term ‘patient information’ emphasises the relation between the information and healthcare, and so the use of the term is seen as a reasonable basis for starting discourse. Secondly, it is wise to separate the term ‘health information’ from ‘patient information’ in order to clarify the field where the information is used. Hence, in this thesis, health information is seen as a term with a larger range that covers all information related to the health of an individual, whereas patient information is seen as a subcategory of that health-related information. The key difference between health and patient information is the way that the information is managed and stored. Patient information is official information from the *patient*, which is stored by a healthcare organisation (either private or public). Patient information is hence the information that is imported to the information system by healthcare professionals, patients or (medical) devices. Health information includes all health-related information – such as diet diaries, sport logs from GPS, etc. – about an *individual citizen*. Due to this, health information can be more variable, harder to describe, and almost impossible to legislate. Usually, patient information is more controlled than health information and it is subject to legal regulation because the system is governed by legally obligated actors (i.e. healthcare organisations or professionals).

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[2] ‘Paternalism is the interference of a state or an individual with another person, against their will, and defended or motivated by a claim that the person interfered with will be better off or protected from harm. The issue of paternalism arises with respect to restrictions by the law such as anti-drug legislation, the compulsory wearing of seatbelts, and in medical contexts by the withholding of relevant information concerning a patient's condition by physicians’ (Dworkin, 2014).

2 RESEARCH DESIGN

This thesis can be positioned within the discipline of information systems science and, more specifically, in the field of computer ethics. Computer ethics is a field rather than a discipline like Stahl et al. (2014) stated. It is the reference discourse which points out the ethical issues of information systems and the use of those. The dominant approach to computer ethics is philosophical argumentation (Stahl et al., 2014), which is the chosen approach for this thesis too.

The main purpose of this thesis is to evaluate the nature of patient information and to identify an ethically justifiable way to regulate the ownership of, or should we say mastery over, patient information. More precisely, the aim is to demonstrate why the patient is the most ethically justified 'owner' of patient information, as well as to determine who the other possible ownership candidates are and why they should not have the right to own patient information in the place of the patient.

However, term 'ownership' is problematic because of the baggage associated with 'to own'. Therefore, the new term that is preferred instead of 'ownership' will be presented after the problems of term 'own' have been pointed out. However, before we can truly portray the problems, we have to gain a deeper understanding of patient information and the ownership of it, and so this thesis will offer a critical analysis of current legislation (or the lack there of).

Nowadays, in many countries patient information is usually stored in and used with information systems, and overall it seems that the use of patient information systems that are accessible to different parties is a dominant trend. One example of this trend is the Finnish national patient information archive, the so-called Patient Data Repository, where (almost) all patient information must be entered.[3] It is likely that, in the next decade, we will see the rapid development of patient information systems that open new possibilities and raise new issues. It will also be interesting to see what 'Big Data' will lead to.

However, before imaging all the vast possibilities of new technology and all information we have in our hands, there is an urgent need to examine what kind of issues must be taken into account when creating patient information systems

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[3] The Act on the Electronic Processing of Client Data in Social and Health Care Services (Finland).

or changing the existent ones. Thus, a philosophical entrance to the topic is needed and it opens on an interesting transdisciplinary world of research. Of course, ethical guidelines for healthcare information systems would be the work of life times and so this thesis is focused on the ownership of patient information. The thesis shows the urgent need for changes to patient information regulation – and thus for current and future patient information systems – in order to achieve the requirements revealed by the ethical analysis in the following pages. To get there, we must start the journey from the world of philosophy to find a solution to the problem of the ownership of patient information ownership before we can start to craft decent patient information systems that have the sufficient – though not necessarily inclusive – ethical legitimacy.

The one answer to the question of why ethics is chosen as the core viewpoint can be found by looking at the field of healthcare/medicine, especially the history of it. Philosophy and especially ethics have always been an important part of healthcare and medicine. Medicine and philosophy have followed a common path – or at least they have encountered each other along that path – from time of Plato, Aristotle, and Hippocrates to the present day, and it is likely that their companionship will carry on in the future. Svenaeus (2001) described the 19th century as a time when medicine left philosophy behind by focusing on empirical studies and shunning ‘speculative’ philosophies. The former situation where philosophy brought new ideas and theories to the field of medicine has changed to the contemporary situation where medicine has come to be a significant influencer of philosophical disciplines, especially the philosophy of mind and ethics (Svenaeus, 2001). Of course, ethics is not forgotten in healthcare and there are ethical codes, norms, regulations and declarations even in this millennium.

However, it can also be seen that medicine involves mainly practise, not theory (Svenaeus, 2001). Medicine has made huge breakthroughs during the last two centuries and the impact of scientific (empirical) research is undeniable. Yet, the principal situations where the benefits of medicine have been realised are in medical practise between the medical professionals and the patient. Likewise, patient actions as a source of actual impact by themselves should not be forgotten or overlooked if the goal is to achieve improvements in healthcare (Koskinen & Knaapi-Junnila, 2014). Hence, if practise is so central to the outcome then it is important to emphasise it so that it is not bypassed due to focusing only on medical theories or biomedical worldviews. This is an important issue and it is the driving force behind this thesis too. Even though this is a theoretical thesis, it must be remembered that the findings have implications for practise.

Studies made in the field of medical philosophy led to Aristotle’s (see Aristotle, Thomson, & Tredennick, 1976) classical distinctions between *episteme*, *tech-*

ne and *phronesis* in the *Nicomachean Ethics*, which detail the different aspects of knowledge (Svenaeus, 2001). These different forms of knowledge (presented in more detail below) are good examples when thinking about the kind of knowledge that is needed in healthcare and why.

Episteme means permanent, eternal and theoretical scientific knowledge. It is notable that, according to Aristotle, science is tied to knowledge of eternal things – which do not change and so are permanent – in such a way that it does not fit with many modern sciences. Modern sciences such as medicine are usually based on experimentation nowadays and thus *episteme* does not cover them. It only applies to disciplines such as mathematics. *Techne* is derived from *episteme* in such a way that while *episteme* was knowledge a priori, *techne* is knowledge involved in aiming for some goal or making an object. Thus, *techne* can be seen as knowledge of applied sciences in present times, such as the disciplines of information systems, ethics and medicine (see Svenaeus, 2001). *Phronesis*, from the Aristotelian perspective, is the practical wisdom that is executed in different situations in life. Having *phronesis* means that one must know how to deliberate in difficult situations and this must be learned through experience. *Phronesis* is not knowledge as it is understood in the sciences, as it is more like knowledge based on experience, which suggests what the outcome would or could be (see Svenaeus, 2001). *Phronesis* of healthcare professionals and patients can be seen as understanding what is in the patient’s best interests in a particular situation, and *phronesis* would emphasise the mutual understanding through dialogue between the patient and the healthcare professional (Lahtiranta et al., 2015).

The relevance of Aristotle’s ‘forms’ of knowledge to this thesis stems from the positioning of this research, which aims to bring together aspects from disciplines such as information system science, philosophy (ethics), medical sciences (medicine and nursing science), and jurisprudence. These disciplines can be seen as *techne* that are used for identifying the solution to a problem. In this thesis, the problem is the lack of a clear **definition of the ownership of patient information**. To achieve a solution, there is a need for *techne* from all of mentioned disciplines. Nevertheless, there is a need for *phronesis* too. How patient information is used and what the meaning of patient information is for patients and other involved parties (healthcare professionals, other individuals and organisations like the state, healthcare organisation, insurance companies, etc.) must be determined. The *phronesis* in this thesis is bound up with the phenomenological (in this thesis that means Heideggerian hermeneutic phenomenology, which will be discussed further later on) investigation, which gives the viewpoint of individual understanding and experience. The phenomenological approach is open to thoughts about what it means to be a human being, as well as what aspects form that viewpoint when considering patient information, and how they both should be taken into account. However, there is no aim to catch patient's inner sights with empiria. This is a justified choice because by empiric research we could only catch the bystanders' view which is different from the real inner sight of the patient. The situation is like Stalh (2014) has stated against empirical bias in interpretive IS research in his article – by empiria we only can reconstruct other people's constructions which is obviously problematic. Thus, this thesis only rests on phenomenological view of Heidegger to grasp the idea what patient information can mean to a patient. There is this dilemma with this understanding of what patient information means for patients. Reason for this dilemma is that it is something what anyone (*das Man*) could illustrate but only patient can have authentic understanding (*Dasein*) about meaning of patient information for oneself. See more in section 3.1. Hopefully, this thesis can at least bring closer together both sides of knowledge – *phronesis and techne*.

2.1 Research questions

At this point, it is useful to present the research questions or rather to offer a description that illustrates the aims, contribution and meaning of this thesis:

First research question (*Phronesis*):

> **What is the meaning of patient information for the patients?**

Second research question (*Techne*):

> **Is the patient the ethically justified owner of his/her patient information?**

Third research question (*Techne*):

> **How should the use of patient information be regulated?**

It is possible that *episteme* may also be found in this thesis; however, it is only partially available and is not straightforward like a mathematical chain of conclusions. This thesis includes a deontological aspect in the form of Kant's categorical imperative, which is seen as a universal way (episteme) to categorise whether some act ethically right or wrong. Its use hopefully incorporates episteme into this thesis. However, the main contribution lies in involving the issue in meaningful discourse – which it both needs and deserves – by suggesting arguments for a solution that seems to be ethically defensible.

2.2 The nature of argumentation in computer ethics

Immaterial property rights fundamentally shape our society and they have such scope that the rights are not easily justified (Hettinger, 1989). Thus, the central issue of this thesis – the ownership of patient information – is by nature not solvable using an empirical approach. Another approach must therefore be chosen and so this thesis adopts ethics with philosophical argumentation as its method. The different philosophical theories that are used for argumentation are presented in more detail later on in this thesis. This choice of philosophical argumentation is reasonable because computer ethics constitutes a reference discourse for an IS research area (Stahl et al., 2014). Before the issues of the justified ownership of patient information can be properly analysed, the ethical basis and justification must be established. This is the main contribution of this thesis – to define an ethically justified and sufficiently solid proposal for legislating and controlling patient information (systems) and their use. The outcome of this solution, when put into practise, can be tested with empirical research and with different methodologies.

However, the question that needs to be answered in this chapter is what concerns the practise and mode of ethics, in the area of IS. We can begin the description of the ‘methodology’ with a collection of Moor’s (1985) observations about what computer ethics is. First, it is the analysis of the nature and social impact of information technology to identify justified policies for the ethical use of information technology. Secondly, Moor (1985) notes the importance of general ethics for computer ethics, since it provides categories and procedures of what is ethically relevant. This is the reason why this thesis is strongly based on established philosophers and their theories – Heidegger, Kant, Locke and Rawls. Thirdly, computer ethics has a right to existence because it provides conceptualisations and policies for using technology, and it also prompts us to rethink think our values and the nature of information technology (Moor, 1985), which is exactly the aim of this thesis.

While Moor (1985) described the aim of computer ethics, Floridi (2008, p. 189) beautifully described the difference between the scientist and the philosopher:[4] ‘Scientists build, whereas philosophers dig.’ Scientists build by establishing every step based on a lower step and thus science involves teamwork and getting things right in order to push forward. Philosophers are more like explorers and they can be more individual. Yet, the higher we want to build, the more deeply we need to explore. Thus, philosophy may help humanity to make sense of this changing reality (Floridi, 2008). The philosopher can be a scientist in the sense that philosophers do base their work on lowers steps (or should we say preceding research) provided by the work of other philosophers. So, this thesis is digging deeper into the subject, but it is based on other philosophers’ work and hence combines both philosophy and science.

However, it is still possible to question the scientific part of this kind of research. Yet, the idea of philosophy is that there is a claim and arguments for its. If the arguments are not plausible, then the counter arguments should be stated to point out the wrongness of a claim or the deficiency of an argument. Through this dialogue, we can find better answers to questions. As Stahl (2014) stated, the interpretative approach has been accepted as an important research approach in the field of IS. One influential paper to that acceptance was Geoff Walsham’s (1995) article about interpretive case studies in IS research.

The main point of Stahl’s (2014) article is the criticisms aimed at the domination of the empirical approach in interpretative research. Stahl (2014) shows that the philosophical roots do not provide justification for the empirical approach to be in such a position because interpretative research is based on personal perceptions (second order perception) of empirical data (first order perception). This is a combination of phenomenology and hermeneutics, which constitute the philosophical basis of interpretative research itself and thus empirical research is not required. Interpretative research is not heading towards truth claims in the same way positivism is. Rather, it is trying to reconstruct other people’s constructions and so it is fair to question why this particular — empirical — construction is preferred over alternative constructions (such as armchair philosophising). The reason for this could be the lack of straightforwardness and validity of the research is hence pursued with rigour, namely empirical methodologies. The principal contribution of Stahl’s (2014) article is described by himself as being to support a more rich and enlightening landscape of interpretative research. This aim of enriching research was agreed by Walsham (2014) in his article in reply to Stahl (2014).

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[4] Philosophy and ethics are part science, albeit not in such a way as natural sciences, but in a more human and thus more meaningful way.

From Stahl's (2014) recognition of the need for a new approach, we can jump to Habermas and his rational discourse. The Habermasian rational discourse is based on arguments which are evaluated as how convincing and plausible those are. Those arguments can vary depending on the issue at hand. Arguments can be based on natural sciences, social sciences, philosophy (e.g. logic and ethics) or other justified basis. However an argument does not necessarily require empirical evidence if the argument is strong and justified. Habermas (1992) presents the idea of rational discourse where all subjects of legislation are given the opportunity to take part in rational discourse and thus different ways of augmenting will occur. What is notable is that no strategic games are allowed in rational discourse. A strategic game is a way of influencing others where some participant is trying to bargain for some outcome by using something other than a better argument, and this is not allowed. This thesis is trying to find a new way to regulate the ownership of patient information and thus actually involves a set of arguments in Habermassian rational discourse. Hence, it is open to other arguments and critique. Therefore, I need to lean on ethical argumentation in this thesis. This thesis does not focus on empirical side, rather it is trying to form an ideal form of mastery with a strong ethical justification. However it is notable that there could – and should – be other arguments. Nevertheless, ethics possess characteristic that cannot be part of strategic games for winning's sake. Ethics is about augmenting your stance and cultivating it and thus is excellent example of rational discourse which should and could be basis for legislation of just society. Thus, in this thesis there is no aim to make compromises because it means usually strategic games which are forbidden by Habermasian discourse ethics if we want to achieve a just society and morally justified legislation for it.

A more wretched view is that the real implementation of ownership or mastery as law is always making compromises between different parties with economic, political and personal aims or strategies. If the solution for that process is already compromised possibility to drive the issue as legislation is weakened. However, the ethics is not about what is easy to implement and thus we should not be too pragmatic. Ethics is about good and evil, just and unjust. Even if some issue is hard to solve we still should strive for it if it is ethically right thing to do and compromising beforehand is not helping to change the laws which is the idea of Datenherrschaft.

The thesis follows the four stages of methodology presented by Bynum (2014) with comments that show how this thesis fits with the presented methodology:

> '1. Identify an ethical question or case regarding the integration of information technology into society. Typically this focuses upon technology-

generated possibilities that could affect (or are already affecting) life, health, security, happiness, freedom, knowledge, opportunities, or other key human values' (Bynum, 2014).

- The research questions and background to the study belong to this stage.

'2. Clarify any ambiguous or vague ideas or principles that may apply to the case or the issue in question' (Bynum, 2014).

- The presented complexity and transdisciplinary of the topic of this thesis fulfil this stage of the methodology.

'3. If possible, apply already existing, ethically acceptable principles, laws, rules, and practices (the "received policy cluster") that govern human behavior in the given society' (Bynum, 2014).

- The four chosen philosophical theories are the solution to this stage even though they are not all-encompassing because of the number of possible theories. However, a detailed description of the selection of theories is presented in Chapter 2.4.

'4. If ethically acceptable precedents, traditions and policies are insufficient to settle the question or deal with the case, use the purpose of a human life plus the great principles of justice to find a solution that fits as well as possible into the ethical traditions of the given society' (Bynum, 2014).

- Datenherrschaft and the analysis using the chosen theories is the solution for this stage.

It is notable that this thesis is completed without the collection of empirical data and that this is justified because there is no way to collect empirical data on the ethicality of patient information ownership as there is no other reality to observe from the outside.

2.3 Datenherrschaft as a proposal for regulating patient information

In this thesis, Datenherrschaft is presented as a proposal for the basis for regulating patient information. Datenherrschaft is a definition for this special case of ownership – ownership of private information about individuals (Kainu & Koskinen, 2012). However, before Datenherrschaft is presented, the challenging nature of the issue at hand needs to be clarified. It is easy to say and believe the statement that ‘this computer is mine.’ Yet, when going a little further in analysing what it means to own the computer problems start to arise. If I own my computer, can I do whatever I please with it? If internet crime pleases me, can I engage in that because the computer is mine? Do I own the software or do I only have the right to use it? Can I throw my computer into the sea because that is what I want to do with my computer? Actually, after just these few questions are considered, the question of whether this computer is mine or not starts to become more complex and hard to manage.

The thoughts above clarify that the problem of owning is difficult to articulate briefly. Defining the concepts of ‘owning’ and ‘property’ would be the work of an entire academic career and still the outcome would not be comprehensive or all-encompassing. However, in modern society we take the right to own for granted, even if most of us (or all) do not know what it really means. We just simply own things, and that is the extent to which we usually think about owning. To tackle this problem, the concept of owning something is discussed briefly to demonstrate why we need a new definition – an issue which will be addressed later in this chapter – of owning patient information.

Ownership is a complex, transdisciplinary issue that has been, is, and will be under debate for many reasons (Waldron, 2012). Ownership can be described and defined in different frameworks such as jurisprudence, philosophy, sociology, and politics etc., and usually the term reflects the discipline and personal interpretation that the describer favours. It does not make the problem any easier that the term ‘ownership’ is itself not clear and self-explanatory, even if we know the discipline where the term is used. Indeed, it is possible that a clear definition of ownership (of property) is missing because there has been debate on it over the centuries or even millennia, and thus the term itself has been eroded or fragmented depending on the position of the observer and the aim of the discourse at stake (e.g. McKeon, 1938; Waldron, 2012). Linguistics and the philosophers of language could have a long and deep discourse about this issue, but that would bypass the real issue, which is the question of how we should treat patient information in society. Nevertheless, to avoid pitfalls we must clearly define what it means and what it does not mean when we use the term ‘to own’ something in the context of this thesis.

Regardless of the aforementioned problems, one attribute of property and owning is generalisable: the need for a social environment that accepts the concept. The approach that tries to gasp the idea of generalisation is the Habermasian rational discourse (see Habermas, 1992). According to Habermas (1992), rational discourse demands that the subjects of legislation can take part of that discourse. Another critical demand of rational discourse is that strategic games are not allowed because of the lack of rationality in strategic discourse (Kainu & Koskinen, 2012). Strategic games are a way of conducting discourse without the real purpose of achieving a consensus between the participants through valid speech acts. This lack of willingness to find the truth via a cooperative search of the arguments that are the most plausible is contrary to the rational discourses envisioned by Habermas (see Habermas, 1992, p. 228 and passim). Kainu and Koskinen (2012) did note that IPR legislation has come about through strategic games and so it lacks rationality and ethicality in itself. Thus, the IPR legislation cannot be considered to be a rational argument.

However, Kainu and Koskinen (2012) proposed a way to make laws by following the idea of rational discourse (see also Rawls, 1999). Their proposal subscribes to a critical positivist, instrumentalist concept of law. The main idea is to correct law through an external and interdisciplinary review (see Tuori, 2000). This means that we must apply social sciences to gather an understanding about reality and to evaluate the current state of reality with an ethical analysis. By means of an ethical analysis, the prevailing law can be criticised and demands for a new legislative solution can be proposed. This thesis adopts the Datenherrschaft – offered by Kainu and Koskinen (2012) – as a means of regulating the ownership of patient information.

The background of Datenherrschaft is the following:

> ‘The German word die Herrschaft means ‘mastery over a thing’ in the sense of having absolute or at least overwhelming power over the thing, not necessarily in the sense of having any particular skill, unlike the English translation implies. It is used e.g. German criminal law in conjunction with täter, forming the compound word täterschaft (§ 25 Abs. 1 1-2. Alt Strafgeseztbuch). Täterschaft means perpetrator-ship of a criminal deed and tätherrschaft is the mastery over the actions (that is, the power to choose to act in this or that manner in the circumstances in which the act took place) taken that the täter has. Datenherrschaft is a term that is used the Swiss Landesrecht in SR 420.31 Art 8 and SR431.112 Art. 12 to mean mastery a

> public official has over the information in data protection regarding a public database.
>
> A literal translation of die Datenherrschaft would be “possession of and mastery over data (information).” As this expression seems imprecise, indeed, mastery over information is specifically used in other discourses to imply the ability to skilfully make use of data, this paper introduces datenherrschaft (sic) as an anglicisation of the German word’ (Kainu & Koskinen, 2012, pp. 53-54).

However there is a need to clarify what is meant by Datenherrschaft and what is not, to avoid wrong and unwanted interpretations. Herrschaft can be seen as meaning mastery over thing – like in this thesis – but also over servant or other people and can evoke wrong and unwanted connotations from history and current day. However that kind of negatively charged interpretation of Herrschaft – which means power over other people – is not the case in Datenherrschaft where the prefix “Daten” is an essential part of term. The personal information in digital form can be seen as an expansion of a person in the digital world (see Clarke, 1994; Compañó & Lusoli, 2010) even though it is notable that even the personhood or self are terms which are hard to deal with (see Olson, 2015). Thus, one should be putting effort to research respect for person, identity and information technology (Dillon, 2010). It seems to be obvious that the digital self is increasingly important and interwoven with the “genuine” self of individual’s living in the digital world. Thus, it is reasonable to presume that the digital self-image is part of the entire self of the individual.

Therefore, in the context of Datenherrschaft this Herrschaft means mastery over information and over the person themselves as source of that information. Likewise, the gendered nature of word “herr” could be avoided by using a different word (e.g. mastery or control). However, the term Datenherrschaft was chosen because it has been used in legislation with quite similar approach – see Swiss Landesrecht in SR 420.31 Art 8 and SR431.112 Art. 12 mentioned above – and lacks the already laid burden of different interpretations such words as property and ownership entails. Nonetheless, it is essential to remark that there is no intention to denote at all for any kind of subjugation of others. Datenherrschaft only refers to the individual rights for control of personal information about the patients themselves.

As is also done in this thesis, Kainu and Koskinen (2012) chose to use the term ‘Datenherrschaft’ because it was not previously widely used and it would be a good tool for discourse on issues concerning privacy, copyright and the ownership of private information since it does not have the aforementioned baggage of the word ‘own’. They defined Datenherrschaft – which is applied in this thesis – to mean:

> ‘the legal right to decide the uses of, and continuing existence of, in a database or another compilation, collection or other container or form of data, over a entry, data point or points or any other expression or form of information that an entity has, regardless of whether they possess said information, with the assumption that sufficient access to justice is implemented for a citizen to have this power upheld in a court of law’ (Kainu & Koskinen, 2012, p. 54).

In this thesis, Datenherrschaft is only analysed in the context of patient information. Thus, the analyses in this thesis are not straightforwardly transferable to evaluate the suitability of Datenherrschaft for other types of information. However, Datenherrschaft seems intuitively to be suitable for all kinds of private information because its core is the protection of one’s right over information. It would be absurd it private information did not deserve that right. The interesting and wider question concerns what kind of information should be seen as private within Datenherrschaft and what kind of information should be outside of it. Nevertheless, this question is outside of the scope of this thesis, although it will hopefully be addressed in a future study.

What is notable about Datenherrschaft is the finding – which will be considered in more detail later – that Datenherrschaft cannot be absolute over patient information as it is defined by Kainu and Koskinen (2012). Ethical arguments can be found for specific situations where Datenherrschaft could and should be overridden. Those situations are such that there is a danger toward others’ more fundamental rights than the right to privacy of an individual. Thus, they are exceptions that do not remove the justification for Datenherrschaft, but rather they only allow it to be limited when necessary for the sake of the greater good. However, it is notable that a strict definition of those restrictions is not reasonable or credible to be given at this point. This issue needs further research and some of those restrictions most probably would not emerge until Datenherrschaft is used in legislation. Therefore some of those restrictions would be included in enactment either by amendment or with other enactment which elaborates the original one. Nevertheless, this does not remove the need for this thesis but rather justifies it as it is seen as a part and a contribution to the aforementioned Habermasian rational discourse.

2.4 The selection of ethical theories

The brief analysis of health and patient information in the introduction was intended to show the need for deeper investigation, and thus we can continue the ethical analysis of the justified method of treating and regulating the ‘ownership’ of patient information. The previous chapter concentrated on creating an understanding of what ‘health’ means and what the impact of patient information or the lack of it is for people and for their *homelike being-in-the-world*. This chapter is transitional in the sense that it leads to an investigation of how the idea of Datenherrschaft – as granted to patients – matches the selected deontological, normative ethical theories of different philosophers presented in next chapter.

The four chosen ethical theories relied on in this thesis – or should we say the four major works – from Martin Heidegger (1927), John Locke (TTG II), Immanuel Kant (1785) and John Rawls (1999) are used for the evaluation of Datenherrschaft over patient information given to patients. The selection of these four ethical theories instead of some others is somewhat intuitive and so cannot be reasoned without gaps. However, comprehensive justification for the selection is almost impossible to give because the right selection – evaluation using all deontological and other theories – would be an impossible mission. Nevertheless, there is still a sense behind selecting these four theories.

First, it gives a temporal dimension to the analysis because we have three different centuries present in the evaluation. That gives perspective about the need for understanding over our period of time when trying to establish a just basis for the norms we are trying to develop. Understanding the history is key for understanding the present day and need for the changes. Our society is altering all the time and we must try to make it better not just drifting aimlessness. However, this does not mean that we have to or we should abandon the past. Rather, we must try to learn from it and take what is good in the past and try to nurture it for the sake of the future.

Secondly, all of the theories have different strengths. Heidegger’s work strongly emphases the individual’s experience in life. His work shows that we cannot override patients if we truly want healthcare to serve the needs of the people. In addition, Heidegger’s work has been used widely in research of healthcare especially in nursing sciences (see Mackey, 2005; Earle, 2010). Thus it has been established as a research approach and influence which should be taken into account when observing patient information ownership. However, in this thesis the original text is kept as main source to avoid such problems that are pointed towards phenomenological nursing research as it can misinterpret Heidegger (see e.g. Paley, 1998; Petrovskaya, 2014). Locke focuses on people’s rights, especially on the freedom of people, and tries to develop a social contract that would create a just society including property rights. Locke is commonly used as basis for justification when it comes to property rights (Tavani, 2005), as it does in this thesis. Thus it is almost mandatory to notice and use Lockean arguments because the issue is after all about ownership of patient information. Kant's strength is that he was able to develop a strong normative rule called the categorical imperative, which has stood the test of time. Kant's categorical imperative is crucial to the argumentation of this thesis because it places the focus on an individual's own ethical evaluation, which gains support from Heidegger's view of an individual's being here in this world with others. Even though Kant did not take a stand on medicine, his influence has been strong in the medical field, especially in relation to autonomy and human rights. Kantian tradition is seen as a stable anchor for humanity (Wiessing, 2008). Thus, it would not be wise to leave out the Kantian approach in matters of healthcare. Hereby, we have the individual viewpoint to counterbalance the more society level approaches of Locke's *Two Treaties of Government* and Rawls's *Theory of Justice*. The Rawlsian approach is included because even though Locke's Two Treaties of Government is a theory of social contract, Rawls's is however a contemporary approach. It is notable that society today is different than it was three hundred years ago and thus to increase the credibility of the analysis in the thesis Rawls's ideas of just society are included.

Thirdly, Locke, Kant and Rawls have all contributed to the model of a social contract that gives legitimacy and justification for society over individuals, just as occurs in most western states. Thus, we can see that our societies today are based on a social contract made by individuals and that within the contract they have given up some rights to society (government, state, etc.). As healthcare is part of society, it is part of the social contract. Healthcare, whether public or private, is still usually governed and regulated by the state, and professionals working in healthcare have to have qualifications and be licensed to act, which makes healthcare part (or an outcome) of a social contract where individuals give authority over healthcare to the government. As Cruess and Cruess (2008) state, society and healthcare evolve, and thus the social contract evolves too.

The ownership of patient information is part of that social contract, but in the current situation it is not clearly expressed. As the development of information technology has offered new possibilities to gather, store and use patient information, the social contract should be 're-negotiated' to respond to the current situation, and that negotiation should be performed with an analysis of the situation and with a proposal for a new 'part of the social contract' (the definition of ownership of patient information) that has a strong ethical justification. The new contract should be made visible and there should be a reasonable way for it to be put into practice, either as a law or other regulative solution.

3 RESULTS

In this chapter, the main results – the philosophical argumentation for patients to be most justified holders of Datenherrschaft – are presented based on publications included in this thesis. The presentation is not chronological, but it will serve as a story to be more clear and logical. It starts by dealing with the meaning of patient information to the patient. Next, it looks at the basic rights or liberties of the people and tries to find a place for patient information in that context. After that, an analysis is carried out to identify universal laws that would be good for the control of patient information. Lastly, a just societal arrangement for the ownership of patient information is presented.

3.1 Heidegger and the ownership of health information

This thesis is based on defining health in the Heideggerian way, which means that the issue is approached from the offset of hermeneutical phenomenology even though not all of the articles are tied up with that premise. One reason for presenting the background to hermeneutical phenomenology is that while qualitative research has been growing in popularity, there has been a lack of necessary understanding of the rigour of the methodologies used, especially as phenomenology and hermeneutic phenomenology have been referred to as the same, which is not the case (Laverty, 2003). To clarify the approach used in this thesis, the difference between the two and reason for the chosen approach is presented before the actual analysis is presented later on in this chapter.

Husserl's phenomenology is a study emphasising the lived experience of a person or life world. It focuses on a world as it is lived by a person and it is not separate from the person living it. Husserl (1980) was criticising psychology, which – according to him – had gone wrong by applying methods from the natural sciences in the field of human issues. Husserl (1980) claimed that the phenomenological methodology was a way to see the true meaning of the phenomenon or object under observation by going deeper and deeper in reality. With this intentional process, one could develop a description of particular realities. Husserl's (1980) goal was to see things 'as they are' through intuitive seeing.

Likewise, Heidegger's hermeneutic phenomenology (based on Husserl's (1980) phenomenology but reconstructed) focuses on the lived experience of humans and it has the same German philosophy as its background. Both Husserl and Heidegger shared the idea that the world scientists believe in – which was based on Cartesian dualism – is only one world amongst others and that there was a need for a fresh approach to it (Jones, 1975).

Regardless of the similarities between the phenomenological views of Husserl and Heidegger, there are considerable differences between the two. While Husserl was focused on beings and phenomenon, Heidegger was focused on '*Dasein*', which could translate as 'the individual human mode of being in the world.'[5] Heidegger did not accept Husserl's view that entities could be encountered in the way of being 'present-at-hand', merely as objects essentially unrelated to our practical interests (Boedeker, 2001).

Heidegger's (2004) *Being and Time* presents three primary modes of being: *Dasein*, *ready-to-hand*, and *present-at-hand*. The special character of *Dasein*, as compared to other two modes of being, is that *Dasein* is the only one that can have an understanding about its own being and that can investigate it. Thus, *Dasein* is also about understanding one's own being here, which is the mode of being that is associated with human beings (van der Hoorn & Whitty, 2015). This understanding of one's own existence is the key factor that separates *Dasein* from *ready-to-hand* and *present-at-hand. Ready-to-hand* is a situation where being appears as ready to accomplish some task or purpose (Heidegger, 1927, §15-18). When entities appear *ready-at-hand*, like a hammer appears ready for hammering the nails, it is not given much consideration, meaning that the hammer is not usually consciously used (Koskinen, forthcoming). An entity that is at *present-at-hand* involves an object that is consciously looked at and therefore begins to show more deeply and thoroughly (Koskinen, forthcoming). Heidegger used the example of a broken hammer, which through 'brokenness' catches one's attention because it cannot be used unconsciously anymore. By this brokenness *present-at-hand*, the entity is revealed and so cannot be seen anymore as only *ready-to-hand*. *Ready-to-hand* and *present-at-hand* are possible modes of being for all entities, while *Dasein* is possible only for those who are aware of their own existence.

The relevant difference and the main point for this thesis between Husserl's and Heidegger's view is, as Mendelson (1979) shows that Heidegger broke free from the objectivistic ideal on extinguishing the self of the knower in the process

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[5] This is the author's own translation, but there do exist other translations. The original term 'Dasein' is used to avoid the problems of translations that are not exactly like the original one.

of interpretation. This difference could be simplified to that while Husserl considered that we can see things ‘as they are’, Heidegger’s position was that only individuals can have an understanding about things within the pre-understanding – based on one’s background – of the world, and thus individuals’ seeing is always subjective. In this thesis, it is seen that, especially in the context of patient information, the Heideggerian view is more justified because health is an issue that is very personal and that originates in the life lived by the people themselves. Hence, Heidegger’s hermeneutic phenomenology is used instead of Husserl’s phenomenology.

3.1.1 Health as homelike being-in-the-world

Health is a term that may never be defined in such a way that it is unambiguous, but still we need a deeper and more explanatory definition as a framework for discourse about and for healthcare (Koskinen, 2010). The World Health Organization (2015) has defined health as ‘Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.’ This definition is almost 70-years-old and it still seems that we are failing to achieve the spirit of that definition, which is to see human beings as complete individuals and not to look at only the biomedical state of human beings.

The problem is that modern medicine is disease-oriented and that it has become a field that is built on increasing specialisation (e.g. Nolte et al., 2012; Stange, 2009; Starfield, 2011; Tinetti & Fried, 2004). It is obvious that when medicine and healthcare are so specialised, healthcare professionals cannot have an understanding of all medical issues. However, this situation leads towards the narrower view of health or instead changes the view to focus on disease or its absence in the field of the professional’s own specialisation. The problem in such a situation is that people easily became objects because of a lack of professional possibility or the need to understand the whole picture about the patient as a human being.

We need a definition that respects patients as individuals who have their own needs, desires, fears, and backgrounds. Svenaeus (2001) has presented the definition of health as *homelike being-in-the-world*. This means that we should not only see the biomedical state of people, but should instead shift focus towards patients’ experience of their own life and its meaningfulness. From that viewpoint, as a premise, the patient is healthy if she or he is homelike with her or his life and has the ability to pursue meaningful and personal goals. In the sense of health as *homelike being-in-the-world*, some diseases do not necessarily mean that the patient is not healthy – she or he may just have some medical condition, such as diabetes, to be taken care of. Thus, this definition of health is a good approach for promoting patients' role in healthcare in such a way that their needs are taken into account. Koskinen (2010) shows that health, when seen as homelike being-in-the-world, is compatible with patient-centeredness and patient empowerment, which are two of the key approaches in modern healthcare.

Mead and Bowen (2000) divided patient-centredness into five perspectives: biopsychological perspective, the 'patient-as-person', sharing power and responsibility, the therapeutic alliance, and the 'doctor-as-person'. Koskinen (2010) evaluates two of those – the 'patient-as-person' and 'sharing power and responsibility' – and claims that they are in-line with health as seen as *homelike-being-in-the-world*. Yet, this phenomenological view goes deeper and emphasises the patient as an active participant in healthcare more so than patient-centredness and empowerment do. Those two perspectives are chosen because they are the perspectives directly connected with this phenomenological aspect, the individual experience of the patient, which is the focus of the article. To become an active participant, the patient must be supported, and one way to do this is to give them information about their health and treatment. Although the patient may not seem willing to participate in decision making and may prefer to leave it for healthcare professionals, this does not mean that the patient has no need for that information (Manson, 2010).

It seems that the ownership of patient information is an important but not easy to solve issue. If patients have access to information, they could be better informed and could gain an understanding about their own health and treatment. The patient should be feeling that there is 'nothing about me, without me' and it is a moral imperative that information must be given to patients if some harm is done to them (Leape et al., 2009). However, in this thesis it is shown that, in the case of patient information, simply informing is not enough and that the ownership/control of the patient information must be given to patients (see Koskinen, 2010).

3.1.2 Ownership based on Heidegger's view

In this chapter, the focus is on arguments regarding the ownership of patient information that are derived from Heidegger. However, due to the nature of Heidegger's writings, we have to approach the issue by presenting the terms he uses. It is essential to understand the terms used, since otherwise the argumentation could easily be based on an incorrect interpretation of Heidegger's idea(s) (see Carel, 2007).

Heidegger's (1927) *Dasein* includes the idea of *thrownness* (*Geworfenheit*) or that we are thrown into this world to live on it with the others who are thrown with us. This means that we have come to this world in some situation that gives the background and basis for our *Dasein*. *Dasein* is situated in the midst of the world, in the midst of what is there by *thrownness*, which also incorporates the embodiment of *Dasein* (Overgaard, 2004). Thus, this *Dasein*'s *thrownness* can be seen as the position from where we can start to analyse ownership from a Heideggerian perspective: here we are and we need to live this life that is embodied within our body. The importance of *thrownness* is underlined if we look at it with a medical perspective. We are born in this world along with our biological and social background. We have our genes (*embodiment*), a specific premise that has a significant impact on our lives together, with the socio-economic environment in which we live.

Heidegger meant that we are thrown into something with something we have to start with and deal with. We are sense-making creatures because sense-making is what we are and we cannot stop sense-making even if we want to. Even if we decide to stop sense-making by dying, that would be performing sensemaking in a way. Sense-making is the most basic starting point and the most fundamental dimension of our *thrownness*. It is a burden laid upon us and we are bound to it. However, it is not a personal burden, although it is essential or existential in the way that we are stuck with it (Withy, 2014). We are here in this world and we have to make sense of it. We cannot choose what we are born with and *thrownness* portrays that quite well. Regardless, this life is mine and I have to live it until the day I die. Only I can find the meaningfulness in it. However, I can neglect or hide my awareness of my possibilities by agreeing to live as all others do – *das Man* (see Heidegger, 1927). *Das Man* is the situation where people consciously choose to hide or lose themselves by replacing their *Dasein* with the generally accepted and non-disturbing way of being (Koskinen, forthcoming).

Heidegger, however, did not emphasise a selfish way of being, even if the life is ours. Rather, he was using the term *being-with* (*Mitsein*) to describe how *Dasein* is always being with others and thus there is a constitutive part to *Dasein*. Heidegger also introduced the term *being-with-others* (*Mitdasein*), although its presentation is not as full when compared with his explanations of the main terms such as *Dasein* (Nancy, 2008). However, Heidegger did note the difference between how others are encountered or cared for, either negatively by a dominating and disregarding approach or positively by a liberating and considerate way (see Heidegger, 1927, §26). Thus, it seems plausible to argue that Heidegger did not mean that people should be encountered selfishly, even though he did see the danger when we are acting as we are expected to. This authentic living is more concerned with understanding one's own possibility to live and find one's own – the *Dasein* – meaningful being in this world, rather than to be hostile or careless toward others.

Patient information gains new meaning if we think about it together with sense-making. Koskinen (forthcoming) presented two different notions, patient information as a tool and patient information as an inseparable part of one's being, which he developed from *Being and Time* when analysing (making sense of) patient information.

First is the notion of patient information as a tool. Patient information can be seen as a tool for healthcare professionals for their work, with the aim being to cure and/or help people when they need medical intervention (Koskinen, forthcoming). From a healthcare professional's viewpoint, patient information is a tool for making proper diagnoses and evaluating what would be a good treatment plan for the patient. What is notable is that patient information is a kind of temporal tool that is not usually used outside of the doctor-patient relationship, which is itself limited to making a diagnosis, medical intervention, and follow-up after some period for recovery. This commonly accepted way of using patient information is actually a commonly created rule. Haugeland (1982) noted that we have commonly created rules for things seen as having as 'true purposes'. However, an entity's significance is only revealed in its full context; for example a knife is different in a kitchen or in the operating theatre than it is in the hand of a criminal (Harman, 2010). Thus, we must understand the whole context of patient information and we must also understand that a healthcare professional's need for information is only one side of the coin, with the other side being the meaning of information for the patient.

Hence, the second notion is that patient information has a deeper, more fundamental meaning and place in an individual's life (Koskinen, forthcoming). The information is the medical description of the individual, although it cannot fully describe the medical condition of the individual or be totally comprehensive. Despite the incompleteness of patient information, it can have a tremendous impact on an individual's understanding about her or his *being-in-this-world*. Patient information can thus reveal the possibilities that an individual has or does not have anymore. Information can be crucial for an individual's *Dasein*. This follows from the nature of *Dasein*, which is that it involves generating meaning through its interaction with objects like patient information (see Dreyfus, 1991).

By revealing a medical situation where an individual is seen as a *thrown projection* (see Figure 2 (van der Hoorn & Whitty, 2015, p 726)) tied up with the embodiment, the meaning of patient information is easily understandable. The past is something that we cannot alter, but it gives meaning to this present time by giving the circumstances and restrictions that we are facing (*thrownness*) and that we are coping with while projecting the future. If we have the information concerning our medical situation and background, we can understand the possibilities for the future as well as what may be closed to us because of our medical condition. Of course, we can neglect the past and just live as everyone else does (*das Man*). However, it would be better in the Heideggerian sense to be aware of our own situation and thus to be able to confront our own true possibilities to be here in the world in which we are living. Some might claim that the knowledge of our own potentially dangerous health condition would be better not known. Yet, that should be freely chosen and not chosen by *das Man*. Otherwise, we must accept that false living is acceptable or a good situation. *Dasein* cries out for the plain truth to be available and thus the ability for one to truly confront one's own being here. Everything else is paternalism or giving in to *das Man*.

Paternalism can be defined as overriding of one person's known preferences or actions by another, where the person who overrides justifies paternalism by the benefiting or avoiding harm to the person whose preferences or actions are overridden (Beauchamp & Childress 2013). The problem is that paternalism is in contravention of autonomy which Gillon (2003, p. 310) described as

> 'autonomy— by which in summary I simply mean deliberated self rule; the ability and tendency to think for oneself, to make decisions for oneself about the way one wishes to lead one's life based on that thinking, and then to enact those decisions—is what makes morality—any sort of morality—possible.'

Paternalism is justified if the actor does not have the capacity of acting autonomously – they are not able to act as a rational actor – for example in cases of patients with serious dementia, some definite mental illness, or emergency situations where the patient does not have the possibility to communicate and thus express their will.

However, paternalism towards an individual who has the capacity and possibility to be autonomous – despite any good intentions – overrides the individual's control of his/her own life, which is very problematic in the Heideggerian sense because no one else can have a real understanding of another's *Dasein*. Hence, paternalism is always acting as *das Man* and so cannot form the basis of healthcare.

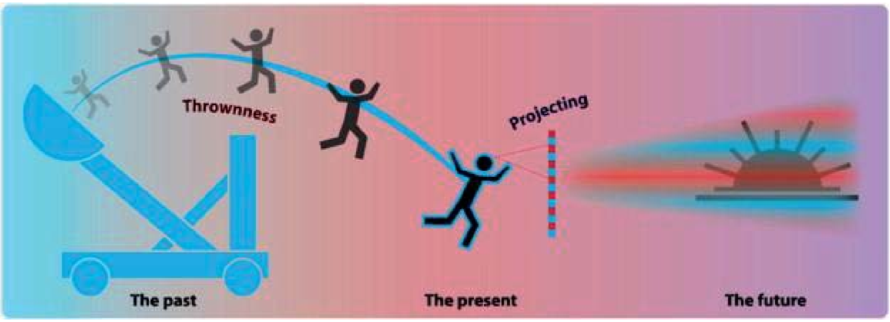

Figure 2. Thrownness and projection.

Furthermore, death is an event that cannot be faced by *das Man*. Rather, it is an event or concept that comes with a great possibility for the individual. Heidegger used the concept of death in a particular way that differs from ordinary concepts. He does not use death (*Tod*) for an event that ends *Dasein's* life – the term for that is demise (*Ableden*). All living things perish (*Verenden*), but *Dasein* perishes in a particular way that differs from demise, which is only the event of passing away. Death should been seen as containing *Dasein*'s temporal finitude and the finitude of possibility (Carel, 2007). Yet, there is pressure from *das Man* for us to only die like *das Man* does, without facing it before hand, because *das Man* sees it as the proper way to die. This Heideggerian view of death as a great possibility that highlights the pricelessness and uniqueness of our lives is deeply liberating. We can have a more individual and deeper understanding of the possibilities with which we are thrown here even though we can feel sadness when we think about leaving our life behind (Koskinen, forthcoming).

However there can be different interpretations on how information is revealing and what. Using patient information can be seen as enfraiming (*Gestell*) mode of thinking and doing and thus it cannot be a part of authentic being. Looking at patient information from that viewpoint can create an impression of focusing on a medical way of being and thus turning the patient to be as "standing reserve" of patient information. However, this is more relevant to the first notion of patient information as tool which is abandoned as its entails diminishing *Dasein* to *das Man*. Even though technology itself has this enfraiming nature (Heidegger 1977) it seems justified to claim that the view by Koskinen (forthcoming) is less enfraiming than the situation where others would possess Datenherrschaft. Even with the enfraiming nature of technology we could see that with using that technology – patient accessing and using patient information – patient can be awakened to see the limitedness of their life. Thus, patient information can support a deeper investigation of possibilities as we are thrown here in the sense of *Dasein*.

Thus, it is justified to claim that patients should possess the Datenherrschaft of patient information because they have a deeper meaning for that information than it has for others who only find instrumental value in it. To understand their own possibilities in this life, patients need information to be able to meet the deepest essence of being here in this world: *Dasein*.

3.2 Locke and the ownership of health information

The Lockean argument can be used to justify public healthcare or to be against it, and some claims in this area are the middle way between both ends (Hausman, 2011). Likewise, it has been used as an argument for the property rights discussion (see Tully, 1980) and for the right to privacy (see Volkman, 2003). The ownership of patient information falls somewhere in the middle of these discourses because it has aspects from all three: individuals' rights to property, privacy, and access to healthcare.

The problem with using Locke to justify the ownership of patient information arises from the time when Locke's work was created**.** The current situation is different to how it was over three hundred years ago. As Hausman (2011) argued, Locke did not defend industrial or post-industrial capitalism because he could not have seen it beforehand. Locke was a defender of property, but the context in which his argumentation was made was a society based on agriculture rather than the capitalistic, industrial and post-industrial world we live in today. It is justified to claim that this era of human society is a more complex and multidimensional world than existed in 17th century Europe. Thus, the argumentation must be carried out carefully to avoid conclusions that are arrived at without an understanding of the influence of the time and society Locke lived in. This is especially important for an issue like property, which is more multiform in this digitalised era than it was in the 17th century.

Immaterial property (i.e. the nature of information) needs its own approach because Locke did not focus on immaterial things, but rather on the land and on cultivating the fruits of the land, which is not the case with immaterial property nowadays (Kimppa, 2005). Thus, the argumentation must be derived through keeping this picture of the times in mind when analysing Locke's work. The main point in the *Second Treatise of Government* is the 'social contract', which is intended to organise a just society. In this regard, Locke describes the end of government as 'the good of mankind' (TTG II, 229.)

Healthcare is part of that aforementioned social contract, which is made in society. This becomes visible though different manifestations such as laws, regulations and codes of healthcare, which are formal parts of the social contract that Locke describes in the *Two Treatises of Government* (TTG II). It is obvious that the social contract of healthcare (a part of the social contract of society) is evolving and changing, just as Cruess and Cruess (2008) point out.

When the target of ownership is patient information, which is a description of the medical- or health-related issues of some individual person, the rights of that individual are at the core of that context. This emphasises the importance of understanding the rights of the individual and especially their rights to themselves as persons. The ownership of patient information is an issue that involves the consideration of people's self-ownership and that is tied up with it. Self-ownership is a commonly used term for the justification to own the property and person of one's self (e.g. TTG II). The term self-ownership has been used as a synonym of property in the person used to describe an individual as the owner of their abilities and attributes as it they were alienable property (Pateman, 2002).

Pateman (2002) analysed the concepts of self-ownership and property in the person and gave new insight into the discourse of self-ownership. She is critical of the libertarian view of self-ownership and she focuses on property in the person in her analysis. She evaluates the differences between the terms *property in the person* and *self-ownership*, and claims that *property in the person* is central to understanding contemporary institutions and practices. The idea of self-ownership seems to be attractive because it gives the idea of owning one's own life, pursuing one's own goals, and having freedom from interference. Pateman (2002) claims that there has been only limited attention paid to ownership and what follows from that. There seems to be no discussion as to why *self-ownership* should be preferred to *property in the person*, but it seems that it can be derived from the Lockean concept of property in the person. Locke (TTG II, 27) states 'Though the Earth, and all inferior Creatures be common to all Men, yet every Man has a Property in his own Person. This no Body has any Right to but himself.' Pateman (2002) finds no reason why the terminology has been changed from Locke's version of *property in the person* to *self-ownership* and states that it has its own implications. Pateman (2002) goes through the deed description of the outcome of using terms and shows that using terms can change the outcome when it is deeper analysed. It seems that understanding the terms is crucial for establishing a solid ground for argumentation. This is particularly relevant for discourse that aims to offer a philosophical justification for some societal structure – which is obviously the aim of this thesis – such as the position and regulation of patient information and patient information systems.

Due to the aforementioned problems that arise from using terms such as ownership and property, they are not seen as a suitable ground for patient information or as a proposal for the regulation for it. In this thesis, patient information is not seen as property in the sense used in the context of physical property or immaterial property. We instead need a stricter and clearly defined description of the rights and duties regarding patient information in our society.

Nevertheless, Locke's *Two Treatises of Government* is one of the works most commonly used to justify property rights, even immaterial property rights. Hence, Locke's work is a reasonable basis for the analysis of the 'ownership' of patient information even when a critical view is adopted toward owning and property because of the aforementioned problems that stem from the pre-industrial worldview or society in which Locke was living.

Koskinen, Kainu and Kimppa (in press) offer four arguments based on Locke to illustrate how the patient has the strongest claim to Datenherrschaft of patient information. Those arguments are:

1. Paternalistic argument

With paternalistic arguments, Koskinen, Kainu and Kimppa (in press) point out Locke's strong opposition to slavery and his commitment to the liberty of individuals. Koskinen et al. (in press) state that paternalism is as form of slavery where one falls under another's power in the context of healthcare. Even this paternalism is strong the Locke's statement (TTG II, VI) about paternalism is supporting it. Just paternalism is not arbitrary power over another person and so it should not be used like that. Justified paternalism is a tool for parents to raise their children to take their place as equal individuals of society, and this is the point where paternalism must end. If paternalism is limited to parents raising their children, it seems implausible that equal members of society can be treated in a paternalistic fashion simply because one does not have a medical education.

Thus, Koskinen, Kainu and Kimppa's (in press) claim that patients should be the possessor of the Datenherrschaft of patient information is justified in light of Locke's view of paternalism and slavery.

2. Argument of liberty and autonomy

Locke strongly emphasises the liberty of people and that only people with autonomy can have liberty. By using the terms 'property' and 'ownership' when describing the governance, regulation and control of patient information, we are embracing the property right-based worldview at the expense of basic liberties. By treating patient information as property, it is seen as the object of transactions, which contradicts the view of people's inherent liberty. Liberty and autonomy must be respected and nurtured if we want to follow Locke's view (TTG II, 87):

> 'Man being born, as has been proved, with a title to perfect freedom, and an uncontrolled enjoyment of all the rights and privileges of the law of nature, equally with any other man, or number of men in the world, hath by nature a power, not only to preserve his property, that is, his life, liberty and estate, against the injuries and attempts of other men.'

3. Argument that labour as a source for the ownership of patient information is problematic and unacceptable

Koskinen et al. (in press) criticise the common view of IPRs. The interpretation that labour is itself sufficient to justify the ownership of immaterial issues and especially patient information is criticised. The creation of patient information differs from the intellectual processes that create artistic compositions and so the commonly used arguments do not apply. The labour of healthcare professionals is based on medicine rather than on an artistic process, and thus the true source of that information is the patient not the labour. Moreover, a healthcare professional's salary is compensation for their work and so gaining immaterial property rights over patient information is not valid, and fortunately this seems to be the *status quo* in modern medicine. Likewise, if mixing labour with patient body is not plausible to make that medical information about patient could become property of other because it is hardly what Locke meant by labour argument. That would be in conflict with people rights towards their body, person and life which are investigated in next argument Thus, the labour argument for the ownership of patient information is not plausible and so cannot be accepted.

4. Argument that individuals have the right to their own body, person and life

This argument is mainly based on the view that patient information is a part of what a person is and that personal information is part of one's personal identity. Patient information can be crucial for one to gain an understanding of one's life, body and person and for defining those. Locke's statement that '…*No one ought to harm another in his life, health, liberty, or possessions…*' (TTG II, 6) strongly supports the view that Koskinen, Kainu and Kimppa (in press) are emphasising.

It is important to note that Locke is using a lexical order, which endorses life over one's other possessions, for example 'life, health, liberty, or possessions' (TTG II, 6) or 'life, liberty, or estate' (TTG II, 59). Thus, based on Locke, the only justified owner of patient information is the patient, since for others the ownership of patient information concerning someone else would be a mere possession and not part of their life and person.

Koskinen, Kainu and Kimppa (in press) show that by Datenherrschaft over patient information being given to patients, the basic liberties of Locke – life, health, liberty and possession (TTG II, 6) – are secured and a paternalistic situation is avoided. Likewise, the lexicality of the basic liberties is taken into account by the notion that this Datenherrschaft is not absolute. This means that if someone's life of health is in direct danger, and that if accessing other people's information could avoid that danger, then access is granted, and thus the higher basic liberty of life or health overrides the liberty to control one's own patient information.

Datenherrschaft seems to be a justified way to regulate patient information from a Lockean point of view. It highlights the basic liberties of people and avoids the problems of how traditional Lockean arguments are used to justify immaterial property rights, and hence it is a promising concept for the regulation of patient information.

3.3 Kant and the ownership of health information

Kant contributed directly to many subjects, although his direct writings on medicine are of only minor importance (Wiesing, 2008). Despite the lack of direct writings, Kant has been and is influential within the field of medicine and healthcare, especially in context of medical ethics (see Beauchamp & Childress, 2013; Gillon, 1985; Heubel & Biller-Andorno, 2005; Paley, 2002; Rothhaar, 2010). Some of the literature is critical towards the Kantian approach and claims that it is not suitable for healthcare (e.g. Le Morvan & Stock, 2005). Le Morvan and Stock (2005) stated that the Kantian ideal that all patients should be treated as ends in themselves conflicts with medical reality. They claim that patients are treated as only a means when medical practitioners are trying to learn some new medical practise because the patient 'is not treated as an end if she receives needed treatment in a way that unnecessarily exposes her to risk of harm' *(*Le Morvan

& Stock, 2005, p. 515). However, the patient is not only used as a means if the aim is to cure and if the risks are understood and accepted by the patient. People usually understand that less experienced doctors can make some mistakes, but if the risks are known then it can be acceptable to the patient. It is important to note here whether the doctor is using the patient solely as la earning object or if the doctor is encountering patient as an invaluable human being.

Moreover, Wiesing (2008) claims that the core content of the Kantian tradition regarding medicine is that it can be seen, to a certain degree, as a stabilising anchor in a time of rapid change. This seems to be true in two ways. First, by keeping human dignity present in the law, in philosophy, and in everyday language. Secondly, it underlines the non-negotiable character of human dignity in this time when there is so much demand for things to be negotiable (Wiesing, 2008).

Koskinen and Kimppa (forthcoming) approach the Datenherrschaft and the ownership of patient information from a Kantian tradition. They offer two main arguments that support the idea of the patient being the possessor of Datenherrschaft over patient information. The first is based on Kant’s (1785) view of rational agents and autonomy, whereas second argument is based on the categorical imperative and the interpretation of it.

Kantian rational agents and autonomy are preconditions for whether an actor’s acts can be held to be moral or not. People need to have free will and the possibility to choose their actions, otherwise no moral action exists because forced actions are not the moral will of people. However, the will is not enough in itself, since people can have the will to do good, but because of a lack of understand of their duties, their act can be morally wrong (Koskinen & Kimppa, forthcoming).

This need for autonomy and free will on the part of rational agents is compatible with views of medical ethics. The four principles of medical ethics (Beauchamp, 2003; Beauchamp & Childress, 2013; Gillon, 1994) originally developed by Thomas Beauchamp and James Childress support the autonomy of patients as one key principle.[6] Gillon (2003) even states that the principle of autonomy should be ‘first among equals’. It is clear that in order to achieve patient empowerment and patient-centredness, there must be autonomy and information available to patients (Koskinen & Kimppa, forthcoming; Koskinen, Heimo, & Kimppa 2012). Empowerment is a construct wherein people and communities gain mastery in matters that concern them by having the necessary resources and rights (Rappaport, 1981, 1987; Zimmerman, 1995). Thus, if healthcare is intended to be patient-centric and if it is seen to support patient empowerment, then autonomy must be respected. However, only truly informed patients can have real autono-

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[6] The other principles are beneficence, non-maleficence and justice.

my and thus we cannot accept a situation where people do not possess full access to patient information.

The second argument of Koskinen and Kimppa (forthcoming) is based on the categorical imperative and especially on first and second formulation of it (third formulation is handled through the other two). These formulations can be translated into English (Feldman, 1978) as:

CI1: Act as if the maxim of your action were to become through your will a universal law of nature.

CI2: Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end.

CI3: An act is morally right if and only if the agent, in performing it, follows the law autonomously.

Koskinen and Kimppa (forthcoming) argued that paternalism cannot be held as a universal law and so it must be rejected. As Taylor (2004) showed, paternalism results in people not having true self-control. It is indisputable that medical paternalism converts patients from being rational agents to being less autonomous beings, and that it leaves them subject to the control of medical professionals in a healthcare context. The situation is such that patients cannot be truly rational agents in the sense that they could will – rationally – theirs actions considering their health and this conflicts with the whole idea of the categorical imperative and the preconditions for it. Koskinen and Kimppa (forthcoming) suggested that the universal CI1 should be:

> ‘The patient should have mastery over their information, thus granting them as widely inalienable mastery of their patient information as possible, but not exclusive control of use, thus granting the possibility of using the data in exceptional situations such as in cases of pandemic or when information is crucial to save other people’s life or secure their health from serious danger. Likewise, the access is permitted for research purposes when properly anonymised.’

Datenherrschaft avoids paternalism and so fulfils the first formulation of the categorical imperative if the restrictions mentioned above are taken into account (Koskinen & Kimppa, forthcoming). It also needs to be noted, that inalienable does not mean the only access – it just means that the control itself cannot be removed, it can be superseded, though in some cases. This actually aligns with rights to life and liberty as presented by Locke (see TTG II).

The second formulation of the categorical imperative demands that people are treated as ends in themselves and not only as means. Even though doctors in a paternalistic position can act in such way that patients are treated as ends, it is not certain that all will act like that. As there is a possibility of not treating patients as ends, we must at least design systems that support treating patients as ends. If patients have mastery of information, they have the potential to access information when they need or want it and so we do not need to rely on professionals to decide what information patients need. We should respect patients' own will and understand that consequences (from a medical viewpoint) can conflict with the opinion of patients. However, a patient's will and opinion must be respected if we want to treat them as ends in themselves (Koskinen & Kimppa, forthcoming.)

However, Sjöstrand et al. (2013) pointed out that there is a form of paternalism that can be seen as justified if it protects the autonomy of patients. Sjöstrand et al. (2013, p. 711) first stated that to be autonomous is to be 'The descriptive meaning of autonomy concerns self-governance, ruling over one's own life.' But, as they stated, autonomy concerns capacities and exercise. Without basic abilities, there cannot be autonomy. There are at least three elements of autonomy that play key roles in the discussion on autonomy. First, there must be sufficient competence to be autonomous in the situation where the individual is exercising it. Secondly, there should be the ability to carry on the decisions necessary for realising the desires, goals, plans, etc.[7] Thirdly, there are arguments according to which desires can be more or less autonomous (i.e. authenticity of desires). Authentic desires are desires that are not based, for example, on brainwashing, self-deception, manipulation or coercion. It is notable that the authenticity of desires varies, with some desires being more authentic than others (Sjöstrand et al., 2013).

Autonomy can also be seen in a normative sense as both a negative and a positive right. The negative right means that patients cannot be forced or manipulated into treatment or practices they do not accept. The positive right is rather the right to receive information about one's own health and the available treatments (Sjöstrand et al., 2013). These views are in line with the spirit of Datenherrschaft, since patients should have the right to choose how their information is used (neg-

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[7] The connection between the Heideggerian view of 'being' and Rawl's notion of self-respect will be discussed later in this thesis.

ative) and since the information should be presented in such a way that they can understand its meaning themselves or after consultation with a healthcare professional (positive right).

Sjöstrand et al. (2013) identified situations where paternalism could be acceptable in the name of autonomy, for example when protecting a non-competent patient or imposing information for patient. Despite there being situations where paternalism is acceptable, paternalism itself cannot be held as a universal law. Only in those situations where paternalism is accepted can it be seen as a universal law and thus paternalism itself is not actually accepted at all, since only those specific actions fulfil the categorical imperative. Hence, it seems justified from the Kantian position to claim that patients should have Datenherrschaft over patient information if the aforementioned restrictions suggested by Koskinen and Kimppa (forthcoming) are added.

3.4 Rawls and the ownership of health information

Koskinen, Heimo and Kimppa (2014) analysed the five potential owners of patient information introduced by Koskinen and Kainu (2013) from the perspective of *Theory of Justice* by Rawls. The five potential owners are:

1. The state.
2. The healthcare professional.
3. The healthcare provider organisation.
4. The provider of the database or the health information system.
5. The citizen.

Of course, there could be other candidates who are not listed above, such as insurance companies or other companies, but they seem even less likely from a moral stand point. Thus, they are left out of the analysis.

The Rawlsian analysis is composed of three different parts. The first part involves using Rawls' concept of the 'veil of ignorance' to analyse who would be the most justified owner candidate. The second part of the analysis is based on the two principles of justice. The third step involves confirming that the candidate (i.e. the citizen as the only candidate who fulfilled the preceding parts of the analysis) is compatible with self-respect, which is the most important primary good according to Rawls (Koskinen, Heimo, & Kimppa, 2014).

Veil of Ignorance

Rawls (1999) started his investigation of a just (as in fairness) society by creating a hypothetical situation known as the *original position*. The original position is a point of view where we imagine ourselves, together with others, to be in the position of aiming to create a just society. Since we know that individuals have their own plans for life and that their capabilities affect how they act, there are limitations on the original position. All members of the original position have a similar weight of authority and the same level of capacities (i.e. physical and mental powers). The veil of ignorance takes centre stage in the original position to ensure that the background (as in social prestige) of people does not affect the outcome of the original position. The veil of ignorance is a practice whereby the participants in the original position are placed behind a veil so that they are not aware of their own position in society and so are able to evaluate the principles of society on the basis of general considerations. The participants cannot know which position and which generation of society they will end up in, and thus they will establish just and equal principles of justice.

Rawls himself also noted that the veil of ignorance raises several difficulties, which he defined widely as the whole process of creating a fair society and giving meaning to the original position and the veil of ignorance for that process (see Rawls, 1999, p.119, passim). Despite this criticism, the Rawlsian approach still has a major strength: the potential to try and settle oneself in a situation – behind the veil of ignorance – where one can try to identify a proposal that would be just for anyone regardless of their background. Of course, this would necessitate that people be eager to achieve that justness rather than only being driven or/and motivated by self-interests.

Hence, the veil of ignorance can be used in the manner applied by Koskinen, Heimo and Kimppa (2014), as a tool that works as the basis for discussion and analysing justifiable candidates for the Datenherrschaft over patient information. Their analysis resulted in a solution where the state (if society is well-ordered) and citizens (patients) are both good choices of just owners of patient information. The state, if it is a well-ordered society, seems to be a fair owner behind the veil of ignorance because a well-ordered society seeks the advancement of all citizens to the greatest extent possible. The citizen is also a good candidate for possessing Datenherrschaft. Granting Datenherrschaft to patients defends their privacy, as well as allowing them the possibility to use and decide who can use information about them, and so seems to be a good choice behind the veil of ignorance (Koskinen, Heimo, & Kimppa, 2014).

The three other candidates (i.e. the healthcare professional, the healthcare provider organisation, and the provider of the database or health information system) all have major problems behind the veil of ignorance. They all have interests in patient information, but their intention is to gain some good from doing their task and this is usually an economic profit. This highlights the benefit of determining the owner to be the state or the citizen when the good of the people is the main motivation. The economic claims and reasons for the other three candidates therefore all seem to be unjustified according to the Rawlsian sense of justice that demands we should seek fair principles for the whole population of society (Koskinen, Heimo, & Kimppa, 2014.).

Thus, from behind the veil of ignorance, the citizen and the state seem to be the only promising candidates for having Datenherrschaft. However, Koskinen, Heimo and Kimppa (2014) are aware of the need for stronger arguments that are derived from the *two principles of justice* and *self-respect.*

Two Principles of justice

The theory of justice is founded on the idea that there are two principles of justice that would be agreed on from the original position (Rawls, 1999, p. 52). Those principles serve as the basis of a fair and well-ordered society by securing the liberties of citizens and guaranteeing that wealth and income distribution are arranged in such a way that they benefit all members of society, not only the fortunate ones (Koskinen, Heimo, & Kimppa, 2014). The full statements of the two principles of justice are:

> ‘FIRST PRINCIPLE:
>
> Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.
>
> SECOND PRINCIPLE:
>
> Social and economic inequalities are to be arranged so that they are both:
>
> a) to the greatest benefit of the least advantaged, consistent with the just savings principle, and
> b) attached to offices and positions open to all under conditions of fair equality of opportunity.
>
> FIRST PRIORITY RULE (THE PRIORITY OF LIBERTY)

> The principles of justice are to be ranked in lexical order and therefore the basic liberties can be restricted only for the sake of the liberty. There are two cases:
>
> a) less extensive liberty must strengthen the total system of liberties shared by all;
> b) less than equal liberty must be acceptable to those with lesser liberty.
>
> SECOND PRIORITY RULE (THE PRIORITY OF JUSTICE OVER EFFICIENCY AND WELFARE)
>
> The second principle of justice is lexically prior to the principles of efficiency and to that of maximizing the sum of advantages; and fair opportunity is principle to the difference principle. There are two cases:
>
> a) an inequality of opportunity much enhance the opportunities of those with the lesser opportunity;
> b) an excessive rate of saving must on balance mitigate the burden of those bearing this hardship' (Rawls, 1999, p. 266-267).

For Rawls, autonomy is necessary for possibility to make free choices (Koskinen, Heimo, & Kimppa, 2014). Thus, autonomy is an essential and inseparable part of one's basic liberties (see Rawls, 1999, p. 53). The citizen as the potential possessor of Datenherrschaft gains strong support from the principles of justice. If autonomy is part of one's basic liberty, then it can only be limited for the sake of liberty. When considering patient information, it is hard to see how economic claims or healthcare or societies' aim for good health and well-being could override a citizen's basic liberty to control patient information. To clarify, even if it is designed (nowadays) for the purposes of healthcare, patient information is still an essential part of an individual's private and personal dimension, as well as a description of that individual's mental and physical condition. A counter argument here could be that by giving Datenherrschaft for state or the healthcare organisation, we could actually enhance the people's other liberties by securing their health. However, that argument fails for three reasons. First, people's interests can differ from the perspective of healthcare (and society), for example one may act in a way that is not healthy but that is part of what one wants to be (Koskinen, Heimo, & Kimppa, 2014). This contravenes Rawls' ideas about free persons:

> 'Rather, free persons conceive themselves as beings who can revise and alter their final ends and who give first priority to preserving their liberty in these matters. Hence, they not only have final ends that they are in principle to free to pursue or to reject, but their original allegiance and continued devotion to these ends are to be formed and affirmed under conditions that are free. Since the two principles secure a social form that maintains these conditions, they would be agreed to rather than the principle of utility. Only by this agreement can the parties be sure that their highest-order interest as free persons is guaranteed' (Rawls, 1999, pp. 131-132).

Thus, by giving control over information, we are endorsing paternalism over autonomy. Autonomy is part of an individual's basic liberty, while paternalism hardly endorses Rawls' idea of free people. Secondly, it can still be insisted that a citizen's liberty to live or be healthy is stronger than the right to control patient information, and thus healthcare or the state could have control. However, it is only a possibility that the information could be used to help citizens, even in the case where people have the right to decline treatment or to avoid healthcare. Yet again, we are left to face only untenable, paternalistic claims against the basic liberties. Thirdly, there can be a situation where patient information is not usable for any treatment, but where it can constitute an important part of patients' self-understanding and thus impact their plans for life (Koskinen, forthcoming). It therefore seems that the citizen has the strongest claim to be the possessor of Datenherrschaft over patient information based on the two principles of justice.

Self-respect

Self-respect may, according to Rawls (1999, pp. 79-80, 390), be the most important primary good. Self-respect or self-esteem may be defined as having two aspects:[8]

> 'First of all, as we noted earlier (§29), it includes a person's sense of his own value, his secure conviction that his conception of his good, his plan of life, is worth carrying out. And second, self-respect implies a confidence in one's abil-

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[8] Notice the similarity to Heidegger's view of individual experience and being-in-the-world.

> ity, so far as it is within one’s power, to fulfil one’s intentions’ (Rawls, 1999, p. 386).

Self-respect is a relevant aspect for individuals from whom the patient information is collected. Patient information can contain information that is relevant to their understanding of their potential to fulfil their own intentions in life and can hence constitute a partial component of their plan for life. For the other candidates, the information has only an instrumental value, even though it can be important for them too. However, the crucial difference is that the other candidates, even if they intend to use the information in the best interests of the patient, cannot decide what the concept of good is for the individual. In the Rawlsian view, it is assumed that all members of society – as rational persons – are able to adjust their conceptions of good. If other candidates than the citizens themselves are guaranteed the Datenherrschaft, then their self-respect and their positions as the definer of what is good for their life would be jeopardised by others’ control (paternalism) over them (Koskinen, Heimo, & Kimppa, 2014). Patient data – as well as any data about one – is a part of what defines oneself. Not the whole, but a significant part. Thus, by granting Datenherrschaft for the patient we can let them decide how patient information is serving their plan of life. Were it to be use of information by themselves, ignoring it or letting others (e.g. healthcare professionals) use it to gain some goal – like treating or other way helping them – they wish to pursue.

Datenherrschaft and support from the Rawlsian viewpoint

Koskinen, Heimo and Kimppa (2014) stated that Rawls’s idea of a just and fair society directs the view of patient information towards a description of individuals’ health and body or a tool for their plan for life. Datenherrschaft granted to individuals seems to be a plausible way to arrange the ownership of patient information in such a manner that it would be acceptable from behind the veil of ignorance. Likewise, it directly secures the basic liberties and by doing so it takes account of other people too, since if an individual’s information is crucial for securing the life or health of others then it can be accessed by the appropriate authorities (Koskinen, Heimo, & Kimppa, 2014).

4 CONCLUSION AND DISCUSSION

As this thesis has shown, the ownership of patient information is not clearly stated or legislated, at least not in many western countries. This can lead to undesired situations such as the legislative outcomes that occurred in Finland, Sweden and the United Kingdom (Koskinen, Kainu, & Kimppa, in press). The straightforward reason behind the current legislation in those countries is the improper implementation of the EU database directive. However, the real reason behind it is the Moorian (1985) policy vacuum, which shows that legislation is always lagging behind technology because it cannot predict technological possibilities. The shift from paper-based patient information systems to electronic ones did indeed change how information can and is used.

There seems to be a lack of academic literature seeking a solution or proposal for ending this unclear regulatory situation. The proposal suggested by this thesis to remedy such unclear regulation is a new legislative solution, namely Datenherrschaft (mastery over information), that is granted to patients. This thesis shows the importance of the issue, since the information is about the patients but they are not in the position to access or use it in a decent way. Patient information is currently mainly designed for the use of healthcare professionals. This is hardly empowering for patients, nor can it be seen as a patient-centric approach, both of which are issues that have already been the focus of healthcare research for decades. Likewise, the biomedical worldview dominates despite bypassing the individual needs of patients.

To overcome this biomedical worldview, a fresh definition for health is necessary. Health as *homelike-being-in-the-world* (Svenaeus, 2001) is an approach for identifying the needs of patients rather that concentrating only on diseases. To form a deeper idea of why patients should have control of the information, two notions of patient information were derived from the Heideggerian viewpoint of *Being and Time* (Heidegger, 1927). The first was the notion that information can be seen as a tool for healthcare professionals to perform their work. The other notion was that information is an inseparable part of one’s being and that it is crucial for one’s self-understanding and the possibility to see one’s life plan (and the impact that health might have on it). The current situation where information is seen as a tool is not justified when the needs of patients are overlooked and thus their being is limited in the Heideggerian sense. The Datenherrschaft given to patients is a solution to that problem.

The Datenherrschaft is seen as a plausible solution to the problem of the ownership of patient information based on ethical theories from Locke, Kant and Rawls. The Lockean lexicality of basic liberties together with his emphasise on liberty offers strong justification for patients to gain the Datenherrschaft. Arguments based on the categorical imperative of Kant end in same the conclusion. Treating people in a paternalistic fashion cannot be held as a universal law because by doing so we are limiting their capability to be rational agents, which is basis for Kantian – and pretty much any other – morality. To ensure that people are treated as ends in themselves, it is better to give ownership to the patients rather than relying on the hope that healthcare professionals will act as such and use the information accordingly. Likewise, Rawls' *Theory of Justice* supports the same conclusion that the patient is the most justified owner of patient information and that Datenherrschaft is a legitimate definition for that ownership. The analysis based on the veil of ignorance makes it visible that only a well-ordered state and patients themselves could be seen as justified holders of Datenherrschaft. However, by looking at Rawls' notion of free people, the two principles of justice, and the idea of self-respect, it became clear that only patients could be the justified holders of Datenherrschaft, since only through choose can we respect the basic liberties of citizens.

The relevance of this thesis is clarified when we start to look at the consequences of Datenherrschaft granted to patients. The results of this justified mastery over information are diverse. Indeed, there are regulative needs for jurisprudence to take care of. First, the failed implementation of the database directive in Finland, Sweden and the UK must be corrected. Secondly, a wider legal review should be undertaken to see if there have been any other failed implementations of the database directive. Thirdly, Datenherrschaft should be defined in more detail in the legal terms, such as what is included within patient information and what the possible needs for exceptions are. However, this is an area that is best left for legal professionals. From an IS perspective, there is an urgent need to start defining and developing patient information systems that can fulfil the needs of patients. This means that information must be shown in such a way that laymen can understand it, rather than pure medical jargon being shown unnecessarily to the patients.[9] The paternalistic control over patient information – meaning

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[9] There can be medical jargon as well, since it is necessary for the information to function as a tool for health care professionals; however, the medical jargon needs to be available in as understandable a format as possible for the patient, who is the owner of the information.

over the patient – is not a real or justified solution when information is not understandable for the patient. Instead, the current situation is like that of the role of an advisor or a consultant, which is what is needed from the doctor if the patient needs support.

Likewise, control mechanisms concerning how information is accessed and by whom must be designed in such a way that patients have the possibility to see who has seen their information and of what basis. For healthcare organisations and healthcare professionals, there is a need to truly act in empowering and patient-centric ways. This has fortunately been the target and direction of research over the few last decades, although it still needs to be focused on. Thus, even though this thesis is a theoretical one, it still has practical and critical implications that must be taken into account.

Realities of technology, laws, policies and lobbying will unavoidably affect for that Datenherrschaft would not be implemented or used in its strict and fundamental sense. However, this is not an issue which takes away the theoretical and philosophical offerings of Datenherrschaft over patient information given in this thesis. Hopefully, strict and insistent search – hence avoiding strategic games – for what is ethical may show us the way how laws and mores of our society can be altered for the better.

The ownership of patient information is an issue that must be taken care of and Datenherrschaft is a justified means for doing so. To ensure that healthcare has a strong ethical basis, the solution offered here – fulfilling its part for the Habermasian rational discourse about patient information ownership – should be noted and put into action unless there exists an ethically more appropriate solution, which is not in sight at the moment.

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ORIGINAL ARTICLES

Paper I

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Phenomenological view of health and patient empowerment with Personal Health Record

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Abstract

Background — Healthcare is going through a time of changes. New technologies and changes in society are altering the healthcare and the way it functions. People can find and access information about health in larger quantities and in new ways. There are digital libraries where users can seek health-related information. Discussion boards can be found on the Internet where users share their experiences within peer-groups. Acquiring the information is likely to have a diverse effect in patients' demand for treatments. In addition to the patients' varying demands, in healthcare different standards, laws, declarations and codes of good care or treatment are implemented and must be obeyed. Healthcare regulations define what good, satisfactory and right care of patients means. Healthcare personnel should have the professional skills and a very strong ethical background. Thus a solid basis is necessary to meet the high standards of healthcare [1]. Reconciling people's demands and the limiting factors of healthcare system or society is a challenging task. Research has sought ways to meet the challenges of healthcare with different theories and models and in this paper a few of those are discussed.

This paper has three main goals. The first is to examine how the term health is defined phenomenologically by Fredrik Svenaeus [2]. Svenaeus' health, seen as homelike being-in-the-world is a promising viewpoint when evaluating healthcare and its challenges. Thereby health as such is chosen as the philosophical grounding and framework of this paper. The second goal is to evaluate how patient-centeredness and patient empowerment correspond to Svenaeus' concept of health. The third is to evaluate how personal health records (PHRs) could be used to improve a patient's status or position in present day healthcare. Thus, the way PHRs support the patient's health through patient-centeredness and empowerment of patients is examined in this paper.

Approach/methodology — The goal of this paper is to construct a theoretical synthesis of the phenomenological view, empowerment, and patient-centeredness. This is achieved by a review of Svenaeus' work and by a bibliographical search of databases of medicine, nursing science, and information technology. In addition, a manual search has been made for articles based on references in previously searched articles.

Findings — Svenaeus’ [2] definition of health gives a strong basis for evaluating healthcare. Health as homelike being-in-the-world supports patient empowerment and patient-centered care. PHRs are a concrete way to empower the patient to gain mastery of their own health. PHRs are also powerful tools for establishing patients as the core actors of healthcare instead of being objectified.

Keywords — Phenomenology, Ethics, Health, Healthcare, Patient-centerness, Empowerment, Personal health records.

Paper type — Theoretical framework.

1. Introduction

In this paper we make the assumption that the purpose of healthcare is to enhance the health of people. But what is health? What does it mean to be healthy? Is it an absence of diseases, feeling good or something totally different? World Health Organization [3] defines health as being "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". But even that definition is too broad and leaves possibilities for interpretations. The purpose of this paper is to go deeper in the definition of health and make it understandable. The intention is to describe the term health so that it caters the human subjective way of experiencing existence and feelings. Thus, in this paper the term health is understood as a kind of well-being, rather than a lack of diseases or injuries. We probably cannot ever establish unambiguously what health means. There are and there will be different views and definitions of health for different purposes. Nevertheless, different views do not make the discourse meaningless; actually those views make discourse necessary for gaining a deeper understanding of health. By labeling and defining things people make sense of our world [4]. But at some point there has to be a working definition of health for a certain purpose. If we are going to develop our understanding about health, we have to define its meaning in our framework. A well-grounded definition of health is essential for evaluating changes when we are developing or transforming our healthcare and healthcare information systems. We have to find what is needed for achieving good care while respecting people's dignity and their experiences.

2. Health

Fredrik Svenaeus defines health to be as "homelike being-in-the-world" [2]. This definition is inspirited mostly by Martin Heidegger's Phenomenological view. Stanford Encyclopedia of Philosophy [5] describes phenomenology as

> *"the study of structures of consciousness as experienced from the first-person point of view. The central structure of an experience is its intentionality, its being directed toward something, as it is an experience of or about some object. An experience is directed toward an object by virtue of its content or meaning (which represents the object) together with appropriate enabling conditions."*

Svenaeus' phenomenological view of health is a basis in our concept of good patient-centred healthcare and empowerment of patients.

Homelike being-in-the-world is to be whole, to being able to have an attuned understanding, ability to act and having a meaning in being in this world with self and with the others [2]. This paper looks briefly through this Svenaeus' definition of health.

The main focus is to make sense on how this definition could be applied, especially when thinking of patient information in a PHR.

An understanding based on Heidegger's phenomenology is seen by Svenaeus as *"to find one's place in the meaning-structure of the world and project oneself towards possible goals"* [2]. To have an understanding of oneself one has to understand ones place in world, have comprehensible meaning of being in the world [2]. And to understand ones part in the meaning-structure there is a need for discourse [2]. Because language is what makes the world meaningful and understandable for us, we cannot bypass it [2]. So to be healthy one needs an understanding in larger context.

Health seen as attuned is to be in balancing mood that support our *homelikeness* [2]. But health by Sveaneus [2] is not mood like happiness or sorrow, those are feelings, not moods in this context. The healthy mood (attuned understanding) is seen as a balanced mood. E.g. when one is bicycling one does not think of ones own balance, but when bicycler loses balance, it will be noticed very clearly and soon. Attunement is alike bicycling but covering ones whole *being-in-the-world.* Balancing is also seen as *dynamis* rather than *stasis*; balancing is not something that stays static forever. Balancing in the case of older people embodies different aspects than in the case of younger people. This feeling of being balanced can be altered by time and at the same time one is balanced all the time.

Homelikeness of being-in-the-world is also very personal [2]. There are situations where different people have different experiences of their being-in-the-world even when they seem to be in a similar kinds of situations [2]. Having a broken leg is a totally different experience for an office worker than for a professional athlete, although the injury and the treatment could be similar; the athletes whole career could be in danger, whereas the office worker would be capable of working fairly soon [6]. Another different experience introduced by Svenaeus [2], is a handicapped person's being-in-the-world, which can actually be very homelike and at the same time very different than other people's being-in-the-world is. A visually impaired person who has a way of living using senses differently can live very homelikely. But for a person who loses ability to see, being-in-the-world is not very homelike. When someone becomes handicapped it usually makes ones homelikeness to be very un-homelike. But after a time this can return to homelikeness again. Of course there can be injuries or illnesses which prevent gaining homelikeness ever again. E.g. becoming quadriplegic probably prevents restoring homelikeness after an accident which caused the disability.

3. Meaning of healthcare; Seekers of lost health

Nowadays western medicine has made almost everyone constantly ill. There is a danger of finding diseases from everyone if people are examined carefully enough. Thus, even illnesses which are found are actually insignificant for person health as *homelike being-*

in-the-world. For an example high blood pressure, depression, high cholesterol or similar ‘illnesses’ could be found from practically anyone. The biomedical model of medicine is trying to solve what is wrong with us, guided by signs and symptoms [6-7]. The users of the biomedical model are looking at the world through a microscope. Medical science, chemistry, biology etc. are advancing in countless fields finding new diseases, risks and treatments. Doctors, biologists and other scientists are apt at finding what is wrong with us. And, if we are carefully looked at, it is easy enough to find a lot of things which are not in ‘perfect shape’.

But what is healthcare actually trying to do? And more importantly what should be the aim of healthcare? Eliminating diseases and infirmities is an ‘easy answer’ for that question. But does that answer cover the purpose of what essentially healthcare is? Let us ask a question: is depression a disease or is it a state of mind? If we are expanding our view of the diseases to cover a phenomenon outside of the physical or biological boundaries, where can we draw the line of what is the actual area of medicine. If we claim that there are no clear boundaries for healthcare, we still need somehow try to understand the meaning of healthcare. The meaning is not understandable by causality or the scientific measurement; it depends on the experience of the subject [2]. So we have healthcare, which has to have some meaning to justify its own existence. We also have a patient whom healthcare is trying to affect or influence somehow. Hence it’s obvious, I claim, that we have to understand healthcare through the patient’s subjective view.

Whereas health is seen as *homelike being-in-the-world*, illness by the Svenaeus is seen as the alienating from the *homelike being-in-the-world* [2]. Thus, the purpose of medicine is to try to retrieve the lost *homelike being-in-the-world* experience of the patient [2]. Svenaeus uses word medicine, like many researchers do. But the term medicine lacks aspects which the term healthcare again contains. Thus, the term healthcare should be used in place of the term medicine. The term medicine is a physician/doctor centered word, while healthcare includes different aspects as the medicine, nursing, rehabilitation and etc. Hence, in this paper the term healthcare is used because of its wider scope when compared to medicine. When we see the inseparability of health, healthcare, and patient we can better understand the people’s needs. When we have deeper understanding, we can justify our demands on healthcare and how to develop it. People need healthcare when something is unbalancing their lives from *homelike being-in-the-world*. Obviously there is no need for the medicine without patients, they should always be in the focus of the medical worldview [7]. Thus, medicine should always be seen as part of the healthcare, which contains different aspects and actors. People need healthcare to become homelike again. For and because of that, patients have to be central to healthcare.

4. Patient centerness and empowerment

The patient-centered care, which is replacing the disease-centered care, has lately been receiving wide attention in the academic research [8-9]. Mead and Bowen [6] divide the patient-centerness into five perspectives, though they note that the term itself lacks an universally agreed definition. The key dimensions of the patient-centerness are; *Biopsychological perspective, The 'patient-as-person', Sharing power and responsibility, The therapeutic alliance and The 'doctor-as-person'*. This paper evaluates the patient-centerness in the healthcare from two of those viewpoints; *The 'patient-as-person' and Sharing power and responsibility*. These two are chosen because they correspond with the way health is viewed in this paper and its context.

The patient as *person* is the human who has personal lived experience of illness [6]. Falling to ill is divided to the five states by Svenaeus:(1) pre-reflective of discomfort, (2) lived bodily discomfort, (3) suffering illness, (4) disease pondering, and (5) disease state, where patient is experiencing growing alienation with each step [10]. It is important to understand that the patient is experiencing something beyond being an object with diseases and symptoms [6]. The patient is experiencing illness and seeking help [6]. The physician should see beyond of those symptoms and signs [6]. The physician should see the entire living person behind the medical framework [6]. Even though there are different kinds of people, and they are experiencing their existence differently, the healthcare personnel should try to achieve an understanding of the patient's experience. It is important to understand that when person has some minor lived bodily discomfort, it is possible that the experience actually does not unbalance the person's health. In the meantime another person can suffer in the same kind of situation in such way that he is not healthy anymore. Hence we have to understand that the patient is a person and this understandin should be taken into account when the patients are treated. The treatment is not only dependent on the healthcare professional's knowledge, it is also dependent on the patient's needs and opinions. The patient is not merely the object of medicine. Thus it should always be remembered that patients are the legitimacy of healthcare. The patient-centerness is one indicator of how we can measure the quality of care [11].

Sharing power and responsibility means that the paternalistic view of patient-doctor relationship are being replaced with the egalitarian patient-doctor relationship [6]. We have to allocate the money, time, coordination, communication and guiding in the organizational level for strengthening the patient's position [12]. It's essential to have the whole organization paying attention to the patient-centerness to achieve it [13]. Empowerment of patients is a way to strengthen the patients and to keep them in the key role of healthcare. Empowerment is a multilevel construct where people, organizations and communities gain mastery in matters which concern them by having rights and needed resources [14-16]. Empowerment incorporates the personal control of one's own life and mediating structures, to which a person is connected. Empowerment includes the social influence, political power and legal rights [15]. In this paper we are focusing on the individual patient and his empowering. Empowerment analyzed on the individual level doesn't mean that other aspects are overlooked, they still have a role in empowerment of individuals [16]. We have to understand that the patient's empowerment also affects the healthcare organizations and the healthcare staff. People are more and more looking information on health and illnesses from the Internet [17-18]. For an example think about a patient with diabetes. The patient seeks information about the diabetes from the internet. The patient's purpose is to manage with the diabetes and to find peer groups to communicate with the people in similar kinds of situations [17]. Patients with chronic conditions are in many occasions experts on their own condition [12]. We can say that people are partly empowered by the information they have access to, because they have gained the possibility of understanding and even influencing their own condition. When patients are empowered they can have a reasonable discussion with their care providers. This requires a change in how patients are considered in the healthcare, as the care providers should be responsible to their patients, not *for* their patients [19]. Understanding the meaning of information for patient's empowerment raises issues of patient information and control of the patient records.

5. Patient information and its ownership

Many countries have been developing processes and systems for transfering patient information between healthcare providers, but there are less known how to engage patients in the process [20]. It is essential that patients are not bypassed when the matter is up to the patient information. If we do not take into account the patients' rights to the their own patient information we are taking a very suspicious position ethically. Why should the information covering the patient, be owned by someone else? The patient is the origin of the information, even if healthcare staff are recording the data.

The ownership of patient information is important to solve, because it might affect the patient's health, especially if health is understood as *homelike being-in-the-world*. An idea for developing the patient centered care: it requires understanding of patient's experience and possible needs. Information about the health and the state are essential for patients to achieve *attuned understanding* and discourse which both are a part of being healthy. Let's think of a situation where one has a disease. The healthcare personnel are not giving information to the patient about what is happening to him. Instead different operations and tests are performed. I claim that this kind of action would break down the homelikeness of the patient. But if the patient had free access to his patient information, and in addition someone would talk through the information with the patient, the patient would be more relaxed or at least would understand the meaning of the treatment or other actions concerning him.

Patients should have the experience and the feeling that there is "*Nothing about me, without me*" [21]. There is a moral imperative to not to withhold information from the patient, if some harm is done to him [21]. But there is need and justification for the wider access for patients, concerning the patient information of their own. The information which is related to the patient should been seen as the property of the patient, not the property of doctors, healthcare organizations or governments. Of course there will be situations when the information is related to some other people or objects. In those situations information can be the property of those other entities, too, but those situations can be regulated as well.

In the United States there are organizations which buy patient records from different organizations and sell them forward to the end users [22]. Many states treat patient records as physical property owned by hospitals and physicians [22]. But at the same time patients have rights for their patient data [22]. Thus, there is a situation where the ownership is not clear. Neither the United States or European Union have a precedent for copyrighting patient data [22]. There is no clear legislation for courts to use, and this situation could lead courts to enforce organizations to gain an ownership to the patient data [22]. This proves that we have to ensure that patients posses the ownership of their own patient information and the healthcare system has only the right to store and access it with some restrictions. Ownership of patient information should also be understood in a similar manner as the citizenship is in Finland. Finnish citizen has the citizenship and it cannot be taken away, and furthermore, the citizen cannot give it to someone else, either. That way it would be ensured that patients could not sell their rights to patient information to third parties. Without the restrictions there could be situations where people would be tempted to sell the information, for an example when in a problematic financial situation.

6. What kind of Systems should be implemented?

Implementing information systems in the patient centered organization have to be taken in consideration as well when developing the patient centered healthcare organization. Information system develpoment on healthcare has been focused on informing healthcare staff and improving their use of systems [23]. Traditionally information systems and electronic patient records have been maintained by healthcare providers [24-25]. But because of pressure and limited financial resources there has been need for shifting the care policy away from the traditional medical organizations [26]. The next step is to develop services and applications for patients [23]. Medical information is critical to both patients and physicians [24]. We have to empower patients to be active actors in healthcare. So it is important to understand that information systems affect the work of healthcare professionals. Furthermore patient’s possibilities and interests in accessing their own patient information has to be taken into account. If the patient-centered healthcare is to become reality, it requires the use of patient-centered medical records [8].

One way to empower patients in healthcare is to provide access to their own patient information, which is created by the doctors, other staff of healthcare and possibly by themselves. One solution for empowering patients with information is the use of Personal Health Records (PHRs). Whetstone and Goldsmith describes well what PHRs are: “*electronic record that you can store medical and health information for yourself, a child, or other in your care, but it is also a health management tool that encourages active participation in your health*”. PHRs can be implemented in many ways, as there are different forms of PHRs; Web-based, smart cards etc. [27]. These PHRs can be divided in the two categories; the stand-alone PHR solution using an IT-artifact, or the networked PHRs, with which the patient has access to information, but does not possess the artifact itself [28].

The stand-alone type PHRs has some ethical advantages, when compared to networked PHRs. Firstly, if PHR is maintained and physically stored in a healthcare organization or by some third party, the patient depends on that service provider. But if patient had a stand-alone PHR, for an example a physical devise which would contain the patient's whole medical data, the data is literally in the patient's hands. This is also a matter of ownership of data. Of course there will be records which are held by organizations, but the idea is that patient has all of the data in his own hands. Secondly if data is stored and maintained by some other party than patient, there is always a risk that the systems have been designed and developed for the purposes of that other party. At least there will be compromises between the needs of patient and provider. Thirdly, when a patient has a physical artifact which contains their medical data, they are better informed of what is being done to them. For instance, covering up malpractices would be much more difficult, if all data and it's modifications were in patient's hands. Fourthly, there is a possibility of gaining a better understanding of one's own health if the PHR structure and features support the representationof the needed information. For an example; diagnosis of patient could be expressed more comprehensibly. This means translating the medical terms and linking the diagnosis to defitions. One possible idea would be to create a Wikipedia-like structure or an other kind of a user-friendly structure for patient records and diagnoses. The patient could find the information needed, and the system would show this information in a clear and approachable form. What kind of systems PHR technically or even logically should be, it is question of it's own paper and is not discussed further here.

If such easily accessed PHR's were implemented, patients could get the needed information when and where it is necessary. The patient would not need to contact anyone to access his own health information. Part of being healthy or becoming healthy is having *attuned understanding* of one's own being in the world. PHR is a tool for achieving that healthy state. PHR itself cannot make people healthy, but it is a powerful artifact for those who want to understand their own health, or need information for influencing their own health. So the PHR is empowering people to achieve *homelike being-in-the world* by coordinating with healthcare systems and healthcare professionals when needed. Thus, people have gained the possibility of being active actors in healthcare because of patient centered, empowering effect of information delivered by the PHR.

7. Conclusions

Svenaeus' definition of health is a good ethical base when developing or dissecting our healthcare or its future directions. It keeps focus on people and their personal needs. Healthcare needs new ways to improve the people's health. Furthermore, there is an ethical need for the patient to become an equal actor in healthcare. In future people are probably going to be more interested their health and will not accept a paternalistic relationship with healthcare professionals anymore. PHR is one solution for empowering the people and binding them as active actors when maintaining their own health. Thus, PHR is one way to implement health as understood by Svenaeus, hence fulfilling the ethical demands on future healthcare development.

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Paper II

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THE CONCEPT OF DATENHERRSCHAFT OF PATIENT INFORMATION FROM A HEIDEGGERIAN PERSPECTIVE

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Abstract: Patient information ownership is not clearly regulated or defined in many countries. This situation is problematic because many actors have interests in patient information. In this paper, patient information is approached from a Heideggerian perspective with the intention to gather an understanding about the personal nature of the information. Two notions of patient information are derived from Heidegger’s work “being and time”: information as a tool and information as an inseparable part of one’s being. Based on an analysis of these perspectives, a proposal for using the special definition of ownership of patient information – Datenherrschaft (mastery over information) – given to a patient is suggested. From a Heideggerian perspective, it can be stated that the patient has the strongest rights towards patient information because this information is crucial for a patient to have an understanding about his or her Dasein (being-in-the-world).

Keywords: Datenherrschaft; Heidegger; Information privacy; Ownership; Patient information

1 Introduction

This paper shows that the ownership of patient information is lacking in the jurisprudences of different countries. This is a problematic phenomenon because the lack of a clearly articulated regulation has led to the emergence of different laws and other regulations considering patient information use (see e.g. Koskinen, Kainu and Kimppa 2016 In print). In this paper, the situation of undefined ownership is critisised, and a justified alternative solution is offered.

Patient information ‘ownership’ is the main issue of this paper, but one question inevitably arises before we go deeper into the issue: what actually is patient information, and what are the roles of patient information systems? Currently, variable names exist for records that contain information about patients: electronic health records (EHRs): electronic medical records (EMRs): electronic patient records (EPRs): personal health records (PHRs): healthcare information systems (HISs): etc. (see e.g. Hayrinen, Saranto and Nykanen 2008 or Rantanen and Heimo 2014). One fact that all these systems have in common is that the information is stored in the systems for some medical, health and/or wellbeing-related purpose.

However, there still is no standard or universal definition for those systems despite international standards like Health Level 7 (HL7) for healthcare information systems which contain standards regarding how the systems can communicate with each other but do not focus on the use of the systems (Health Level Seven International 2015). Thus we have different systems for different purposes that contain different health-related information, and this is one aspect that certainly affects how these systems are used and by whom.

The component of the aforementioned problem that is in question when analysing the ownership of patient information is what is actually included in patient information? Other questions also exist: How is patient information defined? What are the limitations and requirements for patient information? How is that information regulated? We must make a decision about what we classify as patient information. We cannot leave room for unclear definitions if we want to regulate it properly. For example, is patient information seen as a compilation of information collected from a patient and stored by a healthcare provider, or does it instead include all information concerning an individual’s health and wellbeing?

To avoid problems that can arise from a poor definition of patient information, the degree of abstraction must be kept at a higher level rather than trying to be too detailed or having a narrow and technical definition. This can upon first look appear to be a contradiction: a clear definition vs. a high abstraction level. However, this approach can avoid the pitfalls of attempting to describe and categorise different information systems (systems that contain patient information) used in healthcare or other health-relevant areas of society. By keeping the analysis at a high level, we can ensure that the main issue, the ownership of information, is the focus, not the systems that store that information. Thus, in this paper, patient information is seen as official information about the patient that is stored and usually entered by (public or private) healthcare organisations. By that definition, the patient information system is an ‘official’ system used to gather and store patient information, created and maintained by healthcare organisations. Personal records held and collected by individuals are not considered because there is no problem with the ownership as long as these records are kept by the patients themselves. Above mentioned definition for patient information is not inclusive but should be sufficient for analysing the ownership of patient information from a Heideggerian perspective. The definition concentrates on the issue itself – information and the nature of it – and still contains an understanding regarding the complexity of the world where patient information systems are used but focuses instead on the information, not the systems, which can be and will be changed over time.

In Chapter 2, the problem of patient information ownership is presented, and some special characters of the problem are brought forth. The issue has already been analysed from a Lockean perspective (see Koskinen, Kainu and Kimppa, in press): but the Heideggerian approach offers deeper insight for the personal meaning of that information for an individual and underlines the individual’s own inner and inseparable experience in one’s life. Thus, in Chapter 3, two notions for patient information are derived from Heidegger’s work Being and Time (1927). The first notion is that information can be seen as a tool because it appears as a tool does. For every tool, there is a task (here: caring for people) for which it is made and used. The second notion involves the view that information is an inseparable part of one’s being and cannot be seen merely as a tool. Moreover, patient information should be considered as a part of one’s person or at least an issue that is valuable to understand one’s being in this world. In Chapter 4, a solution for the question of what kind of ownership would be justified – and still retains the possibility to be implemented as a law – is presented. Ownership should be seen as Datenherrschaft (mastery over data/information) that is given to the patients. In the conclusion the main claim of this paper – that the patient should have Datenherrschaft over all patient information – is presented.

2 **The background of patient information ownership**

Patient information systems are usually designed from the perspective of the healthcare professional rather than the patient. Thus, the systems fulfil the needs of professionals because professionals are the main users of patient information in current situations (Menachemi and Collum, 2011). The systems are not usually optimised to meet the needs of the citizens; in many cases, the system or the patient information in them is not accessible to them even as patient-centred care and empowerment have lately been emphasised in healthcare (see e.g. Donnelly 2005; Hiscock and Shuldham 2008; Holmström and Röing 2010; Mead and Bower 2000)

Epstein et al. (2010) have stated that three factors are necessary for patient-centred care: First, an informed patient and an involved family. Secondly, healthcare professionals need to focus on the illness and on knowing the patient. Thirdly, there must be a healthcare environment that supports the efforts of patients, families and clinicians. In addition, they noted that information technology should help the clinician provide care instead of distracting him or her away from the patient for administrative and billing purposes. However, for the patients, the authors only noted that information technology should help them to be more active by helping them ask questions or – if they are minorities with low literacy levels or limited local language proficiency – to help them with web navigation and finding relevant information. This lack of consideration of patient needs is a representative example of disregarding patients' various needs.

A review of the outcomes of patient access to medical records found no substantiated evidence regarding negative patient outcomes due to access of health information (Davis Giardina, Menon, Parrish, Sittig and Singh 2014). This finding is notable because some still believe that healthcare professionals should function as gatekeepers to avoid the negative outcomes of patients gaining too much information about their health and treatments (see Wells and Kaptchuk 2012). However, the results of Davis Giardina et al. (2014) indicate that a paternalistic claim is not medically justified.

Hence, it seems that there is no relevant medical reason for denying patients' access to their own health information. Moreover, this paper shows that there is strong philosophical justification based on Heidegger for patients to have more control over their own patient information than any other party. The meaning of this information for the patients in a Heideggerian sense is used to outline the need for a different approach for patient information compared to the current professional-centric and dominating medical worldview in healthcare.

The problem is that current legislation in many countries does not state who owns the patient information clearly enough (Koskinen, Kainu and Kimppa, in press; Rodwin 2009, 2010). The main reason for this omission seems to be that only a few academic contributions have directly addressed the issue of patient information ownership (e.g., Evans 2011, 2012; Hall and Schulman 2009; Rodwin 2009, 2010). This lack of investigations is surprising because academic discourse regarding privacy and security issues in healthcare and patient information systems seem to be very active even when the practical solutions appear somewhat incomplete (Fernández-Alemán, Señor, Lozoya and Toval 2013; Perera, Holbrook, Thabane, Foster and Willison 2011; Smith, Dinev and Xu 2011). This lack of research and clear legislation for patient information ownership leaves room for different interpretations about how patient information is used, and why. The aim of this paper is to define justified ownership of patient information, which could be implemented as a law (or other instance of regulation) and present proper and philosophical basis for it derived from the work of Heidegger.

What makes this problem nebulous is that ownership is commonly seen as an entitlement to some object – usually named as property – which is the target of that ownership. Complexity arises from the notion that the concept of ownership itself is a troubled phenomenon that needs to be clearly described to determine what it means in a specific context. This requirement is especially true when the object of ownership is private information; this is why there has been extensive research and debate about the privacy and ownership of private information (e.g Cohen 2008; Floridi 2006; Smith et al. 2011; Warren and Brandeis 1890). It should be remembered that patient information has some special characters that separate it from the typical private information possessed by an individual: patient information is typically created by medical professionals, not by patients, and it is usually used in the best interest of patients by professionals – although it still is sensitive information that is connected to individual patients.

The thoughts above show that the problem of owning is difficult to describe shortly. Defining the concept of "owning" and "property" could be a task for a whole academic career and still the outcome would likely not be comprehensive and all-encompassing. Nevertheless, in modern society we take as granted the right to own, even if most of us (or all) do not know what it really means, we just simply own things, and that is how far we usually think the issue at all. A reason for that could be that we are missing an agreed definition for ownership (of property) as there has been debate on it over centuries or even millennia and thus the term itself has been obscured depending on the position of the observer and the aim of the particular discourse (eg. McKeon 1938; Waldron 2012). To tackle this problem the concept of owning something is inspected briefly to demonstrate why we need a new definition – of which later in chapter four – for owning patient information.

Hence, patient information is private information, even though it can be seen as a subcategory of more general private information which helps direct the focus upon the special aspects of information in the right context. A more detailed definition of the special nature of patient information can be found in an article by Koskinen, Kainu and Kimppa (in press).

If we consider patient information to be personal and private information, it is easy to claim that the rightful owner is the individual. Nevertheless, when we are dealing with patient information – which is usually collected and stored by some other party – there is the possibility for different interpretations and reasons for ownership. For example, the state (at least if democratic) and its public healthcare system (should) view the information as a tool for taking care of the citizens. Therefore, the state can claim that the healthcare system owns the information because it can be used to secure the lives and health of the citizens. On the other hand, the private institutions and actors that create patient information (private hospitals, doctors, etc.) most likely want to own this information because of the economic value of it (see more Koskinen, Kainu and Kimppa, in press). This conflict of interest is a bridge to the next chapter, which discusses the meaning of the information for the patient and why the patient should have the right to own[1] patient information from a Heideggerian viewpoint.

3 Two notions of patient information from Heidegger

Heidegger's view on modern technology has received a lot of attention and also critique (especially now after the publication of the Black Notebooks). Nevertheless, its influence, and in this paper it is argued deserved influence has been lacking in the field of biomedical ethics. This may be the outcome of the interpretation that Heidegger is generally hostile towards technology. However, Svenaeus (2013) argues that Heidegger did not view medical technology as a scrutiny but instead was worried about industrial and information technology. Heidegger noted the difference between the scientific and phenomenological method in medicine as a way to gain understanding about the human body as a biological organ-

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[1] Here, we use the term 'own,' which has just before been shown to be problematic; a better alternative method to regulate patient information is presented in Chapter 4: Datenherrschaft (mastery over information).

ism and also as a lived body. (Svenaeus 2013.) Brassington (2007) explained why medicine has been able to avoid the dangers of modern technology that were presented by Heidegger. He claims that as modern medicine has assimilated modern technology it uses it as the ethos of medicine demands. Modern technology can be enframing[2] and see people as a compound of cells or material – medicine has different paradigms, and the dangers are avoided by the ethos of medicine. As presented before, Svenaeus (2013) has offered insight regarding why Heidegger's view of modern technology is relevant, and Brassington (2007) has shown that medicine seemed to be able to avoid the dangers Heidegger saw in (other) technology. With these perspectives, we can understand the relevance and importance of ownership of patient information for the medicine and healthcare industries and also for the society at large. If we forget the people behind the physical body or behind the role of the patient, we are losing the ethos of medicine – and from that the following two different views of patient information emerge.

From an intuitive perspective, two different notions of patient information can be derived from Heidegger's (1927) magnum opus, Being and Time. First is the notion of information as a tool, which is used for some purpose or goal. In this context, the information is typically used by healthcare or other medical professionals as a medical tool. Patient information can be used to make a proper diagnosis or outline a patient's medical treatment plan, or both. In some cases, the information is used for research purposes, such as developing new treatments or medications. A patient's medical information can also be valuable for statistics gathered for governmental purposes. Of course, the patients themselves can use the information for their own reasons if the information is available to them and understandable – which is not always the case because of medical jargon and the way the information is organised. The other notion for patient information is that it has some deeper meaning apart from being a mere medical tool. Patient information can be seen as information that is very personal and inseparable from the individual about whom it is derived. From that point of view, the information begins to appear in a different way than the first notion of it simply being a medical tool. The meaning of patient information is tied to the individual and his or her experiences and way of life. Thus, patient information has more complex and more meaningful aspects rather than being seen as a mere tool for healthcare and healthcare professionals.

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[2] Enframing (Gestell) is a term used by Heidegger to describe the essence of modern technology where things are revealed as standing reserve — an issue that endangers things as things.

3.1 Patient information as a tool and problems with that view

Heidegger raised the question about the concept of being under deep and permanent investigation. Heidegger did not offer a strict and explicit answer of being in Being and Time because the project was never entirely completed. Instead, he attempted to clarify the question from different perspectives, emphasising the individual comprehension of the idea that only the people themselves can have an understanding of their Dasein (Heidegger 1927). Dasein (being-in-the-world) is a central term that Heidegger uses to describe human existence which is aware and confronts its own being in this world.

It is essential to understand that there are three primary modes of being and those are Dasein – which could also translates as 'the individual human mode of being in the world[3]' even it is just one translation of many which better or less try to grasp and present the meaning of the original German term – ready-to-hand (zuhandenheit) and present-at-hand(Vorhandenheit). Present-at-hand can be seen as a situation where we start to view the object consciously and therefore begin to see it more deeply. If you compare this approach to ready-to-hand, which focuses on the use of an object for some aim and not on the object itself, you can see the power of present-at-hand. It is about how we concentrate and challenge ourselves and thus start to see more. The special character of Dasein compared to other two modes of being is that Dasein is the only which can have understanding about ones' own being and hence can also investigate it. Thus, Dasein is also about understanding ones' own being here which is mode of being that is associated with human beings (only). (van der Hoorn and Whitty 2015) This understanding of ones' existence is the key factor which separate Dasein from present-at-hand and especially from ready-to-hand. Dasein can see the present-at-hand and ready-to-hand but Dasein cannot truly be reached as present-at-hand or as ready-to-hand.

One way to approach patient information is to examine how Heidegger describes things such as a hammer as making an appearance. This is a good way to understand Heidegger's view about how we see things. There is a natural difference between concrete objects like a hammer and immaterial things, such as information. Patient information has more obvious immaterial and material features or properties than a hammer does, but even the hammer has both these qual-

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[3] This is the authors own translation, but there are various translations used. Thus the original term Dasein is used to avoid the problems of translations.

ities. The hammer example gives us some insight into how to approach patient information with the description of ready-to-hand. Heidegger explained that something is ready-to-hand if it has some purpose to accomplish – like a hammer is used for some purpose (Heidegger 1927, §15–18). Usually, we do not give much consideration to the objects we use, we just use them like we always have and accept that they are there, ready for us to use to accomplish some goal but without active reflection towards the object we are using. For example, when you are reading this article, the tool (paper or screen) that allows you to read it is not used consciously. You just use it and hopefully concentrate on the content of the article and get some sense out of it (goal or purpose). Thus, it can be noted that we use such objects in the way they are meant to be used or should we say; those are proper to use.

Haugeland (1982) notes that humans have 'true purposes' for things that are the commonly created and accepted rules for their use. Thus, these things play some certain role in our everyday world. Heidegger (1927, §18) defines the character of the thing or nature quite simply: an object's structure exists in relation to other things. This net of references towards other things (as a hammer refers to a nail, a piece of wood, a wall, etc.) conveys the meaning of the thing – a meaning that is commonly seen as the proper use for some aim – and thus creates the everyday world where we understand the meanings of different things. From this perspective of commonly accepted proper use, patient information can be seen as a tool for health, an instrument for curing illnesses, or at the very least a method to bring the patient some relief. This concept is understandable if we encounter information being granted as an item for everyday use – as healthcare professionals do.

Heidegger (1927, §18) shows that objects that are ready-to-hand appear to the observer in the context of the world and are referred to along with other things in the world for some purpose. Entities have significance only in their full context, as a knife is a different thing in the kitchen, theatre, or in the hand of a criminal (Harman 2010). To gain an understanding of patient information, we first must examine this type of information in the context of healthcare. Patient information along with medical treatment, equipment, drugs, etc., all contribute to curing the patient. Hence, it is reasonable to view patient information as a medical tool for the healthcare professional – for example, like it is a tool for doctor while making diagnosis about patients in his or her normal working day.

It is interesting that a broken object reveals the object as present-at-hand and exposes the nature of objects, which refers to some purpose the thing exists for (see Heidegger 1927, § 16). The referral indicates that we understand the meanings of objects by their reference, as a hammer is referring to nails and wood towards the wall under construction. When the hammer is broken, we see its nature consciously, and it is revealed for us. When the hammer is not broken, we do not give thought to it, and it is revealed as ready-to-hand.

If the patient information is not usable for the curing of the patient, it starts to appear as mere facts with no proper use for the healthcare professional. However, this is not the full context for patient information, and this is also the result if the information is only viewed as healthcare professionals rationally do – the information is referring to the problem, which must be remedied with medicine or other treatments. If a cure or improvement is not possible, it is a useless piece of information and represents time misspent; for example, time spent away from other patients. However, the same information can be meaningful to the patient because it is information that can reveal – if viewed as present-at-hand – something about one's life in this world and an important issue that is mentioned later on, as seen in the earlier example by Harman (2010): which emphasises the meaning of full context.

Thus, patient information could be seen as a tool for healthcare professionals to bring some 'good' for their patients; and thus the healthcare professionals'' can be seen from first sight to have control over it, and this view is based on how control can be obtained. This tool notion is similar to the idea that Heidegger (1977) described as follows: 'The current conception of technology, according to which it is a means and a human activity, can therefore be called instrumental and an anthropological definition of technology.' Nevertheless, patient information has a more distinct meaning than being a mere instrument which is mastered by some to achieve a goal. This claim had support from Heidegger (1977) when he addressed the problem of thinking too lightly about technology and its essence. We should be aware that things are not always what they appear to be at first glance. We can reveal a deeper meaning if we concentrate on those things that are more present-at-hand rather than ready-to-hand, which just takes things like they 'are' in an everyday sense.

Nevertheless, it is essential that the perception of patient information as a mere tool is inconsistent with the individual dimension of Dasein and Heidegger's drive for world disclosure, which is to reveal the world and all the possibilities to be in it (1927, passim). When the doctor uses information in the patient's best interest without the patient's understanding – which sadly is often the situation – the patient's Dasein is not always revealed to the patient. Revealing in this context is seen as an act that opens the world for the patient in a medical sense and thus is eventually related to death – or life – and all its associated possibilities.

Like Heidegger (1927, §51–53) shows us – even at the risk of being nebulous and thus offering possibilities for different interpretations, which seem to be the nature of his writings – death is something that Dasein must face, and it should not be lived like the ordinary man (das Man) does. Das Man is a term that Heidegger (1927) uses to describe a situation where people consciously choose to hide or lose themselves and replace themselves with commonly given ways of being or acting, whereas Dasein is living a life consciously and make sense of it. Thus, das Man could be described as a generally accepted and non-disturbing way of living or being. However, death is an issue which cannot be outsourced to das Man, because common shared way of living cannot reach or face the death. Actually, das Man gives justification and adds temptation to cover up oneself from one's own most possibility as being-towards-death (Sein-zum-Tode) (Heidegger 1927, p. 297).

Nonetheless, it is important to remember that Heidegger had different meanings for death and we must be careful when we are using term death. He is not using death (Tod) for an event that ends Dasein's life – the term for that is demise (Ableden). All living things perish (Verenden) but Dasein perishes in a particular way which differs from demise which is only the event of passing away. Death should been seen as containing Dasein's temporal finitude and finitude of possibility. Failing to recognise this difference has led to criticism towards Heidegger's concept of death but is shown to be no longer plausible by pointing out the different use of words for death in different contexts. (Carel, 2007.) Dasein is exepriencing finitudesness of it own by taking account and anticipating its own deathness. By this being-towards-death mode of death Dasein can be in this place of thrown projection and independently act with that throwness it has fallen to. This authentic being-towards-death is like Heidegger summarises as he has projected it existentially:

> "anticipation reveals to Dasein its lostness in the they-self, and brings it face to face with the possibility of being itself, primarily unsupported by concernful solicitude, but being itself, rather, in an impassioned freedom towards death – a freedom which has been released from the Illusions of "they", and which is factial, certain of itself, and anxious." (Heidegger 1927, p 311).

Option for being-towards-death is to hide this possibility acting like das Man does. Problem in that is that people will lose the possibility Heideger described but are still going to face death eventually.

Hence, das Man cannot ever know what death is for others – death is our private domain and a possibility that we all face alone. Other people cannot approach death like das Man does because das Man cannot tell us anything about it. However, death is an important phenomenon that offers great possibility – like

Heidegger calls it – to reflect upon our life towards something imperturbable, which can help us understand our possibilities and limitations in our own life. Death is an entity that cannot be evaluated or experienced; it is mine and I will face it when my time is done.

Being-towards-death can reveal the understanding – making it present-at-hand that a person's life, as is his or her death, is his or hers alone. This revealing can help people see the meaningfulness of their lives in a new light. But, by outsourcing healthcare and confining unavoidable deaths to an area that is absent from our sight, we are erasing that aforementioned great possibility of death; the end of our being, which makes our lives priceless and thus unique. Instead, if we consciously look towards our death, it can reveal the meaning of our being in this world where we are thrown (Geworfenheit: see Heidegger 1927, §29, 31, 38, 68).

This throwness together with projection (Entwurf) makes possible a sense-making as a thrown projection (Withy 2014). By sense-making we are in this present time – limited by our past – and can look towards possibilities of future and make sense out of it. However if we are not allowed to have knowledge of our medical condition (patient information) we are not aware of our past and present and our projection towards future possibilities is more incomplete than it would be if we would have the information. One great possibility of patient information could be that it could help us be-towards-death by making us focus towards our health condition and thus be aware of our finite lives and help make sense out of it.

Thus, the sense-making can release us from das Man and replace it with a more individual and deeper understanding of being here in the world: understanding the possibilities by which we are thrown here and the sadness that we feel when we think about leaving it.

3.2 Patient information as an inseparable part of one's being

Heidegger (1927) emphasises the need for understanding what the meaning of being is. The necessity of the question of being is relevant for patient information ownership because patient information can offer great insight about one's body and life that may alter one's possible plans or life goals. Fernando (1998) has used both information technology and the institute of identity to reflect upon Heidegger's thinking. One core component for Fernando's article (1998) is the notion that information technology and the internet are entities that are used to communicate and are places where our identities are forged.

It is notable that Fernando's (1998) article is almost two decades old but is still relevant and timely – maybe even more than it was at the time of its publication. The use of computers and the internet is a way to communicate; at the same time, both are changing our structure of life and social institutions and altering our narrow perspective. Instead, we should view things as catalysts for changing our social structure and thus altering our commitments towards others (Fernando 1998). It seems plausible to say that information technology has radically changed our world, particularly our social lives. They are much more hectic, and the market-oriented world has directed us towards the way to find the best offer available, as Fernando (1998, p. 355) reflected: we are witnessing the transformation of western political leadership towards economic management. It is time to ask what the meaning of the individual in that picture is, and we must recover the value of human dignity once again. In regards to the issue of patient information 'ownership', we must approach it from a perspective that emphasises the patient side rather than the organizational side to find the humanity which Fernando is emphasising.

People and their experiences in the viewpoint of Heidegger's (1927) approach are a promising basis for research when the meaning of patient information for individuals is the issue. Heidegger (1927) brings forth the meaning of a person's unique experiences and studies what it is to be or to exist. A good example of a personal experience of existence is the significance of emotions for the disclosure of information. Negatively experienced health, altruism, and trust propensity indicate a willingness to provide access to patient information (Anderson and Agarwal 2011). Likewise, research has found that the intention to disclose health information is not only related to circumstances but also depends on the individual's disposition and experiences (Bansal, Zahedi and Gefen 2010). Existence and how people experience it are relevant because healthcare should be dedicated to securing and improving the health and life of people, but only with their approval. Hence, we should try to understand our being in this world and the meaning of it.

Hermeneutic and phenomenological views are tied together in Heidegger's work. To understand what it means to be in the world – where we are thrown – and the meaning of our lives we must also understand the nature of being. Heidegger (1927) described the need for that question to be asked over and over again to reveal the nature of being – phenomenology is giving the starting point of understanding about one's being, which must be fed with the hermeneutic circle.

Dasein is the main term of Heidegger, which literally translates as being there, but Heidegger uses Dasein more as 'we are in our average everydayness' (1927). Dasein is thus actually more a question of 'who' than 'how' because people's experiences are how they live their lives, and as a result, only they can have the knowledge of their Dasein. Heidegger's essential point is that people's experiences of their existence are very personal and their own. People have their own lives, and those lives are lived by the people themselves, not by any other. This concept endorses the idea of people as the prime actors of their own lives – or at least, they should be the prime actors. Thereby, the people themselves should have the closest connection to their health information. Other actors are outsiders when the experiences of one’s health and life are viewed in the sense of Dasein.

The definition of health by Svenaeus (2001) as homelike being-in-the-world is a promising and fruitful concept of how we should define health to avoid situations where the biomedical view of health controlled by healthcare professionals overrides the individuals’ or patients’ experience of their lives (Koskinen 2010; Svenaeus 2001). If health is seen as a homelike being-in-the-world, which foreshadows the individual experience of one’s life, it positions the biomedical worldview of healthcare in a curious light. Patient-centeredness and empowerment of patients are often absent if the individuals are mainly treated as medical objects that must be cured by healthcare (see Koskinen 2010).

Thus, patient information – as it describes one’s existence in a medical sense – should be viewed as an inseparable part of our being that may provide an understanding of our lives, our health as a homelike being-in-the-world, and finally our inevitable death if the information is to be accessed and comprehended by us. Thus, by giving too much power to healthcare organisations and professionals regarding patient information (and patient information systems) at the cost of the patients, we are concealing death, our lives, and our possibilities for living in this world and are left with the possibility do as everyone is expected to do (das Man) instead of what we should and want to do (Dasein). This paper suggests that the reason behind that concealment is that death in our modern world is almost solely a negative and avoidable thing. It is not surprising that people tend to engage in more risk-seeking behaviour when they face a life-or-death choice than when they face other problems in life, such as financial ones (Druckman and McDermott 2008). Perhaps something is unveiled when one faces the possibility of death, and it begins to be revealed through improper actions, such as elevated risk taking. Still, we are expected to keep death away from our consciousness because das Man cannot truly face our temporal existence in this world and thus takes the power from our hands. If people choose to do so, it is their choice and must be respected, but it also cannot be premised that das Man is the only way.

The problem is that the healthcare system is designed in such a way that people in many cases are not able to obtain the needed information to understand their situation, which is viewed as an important aspect for patients based on the presented interpretations of Heidegger. Technology knowledge is a factor that affects how citizens are engaged in using information systems and thus promotes their participation (Cegarra-Navarro, Garcia-Perez and Moreno-Cegarra 2014). Hence, healthcare (information) systems should be created in such way that people are given the actual ability to achieve a needed understanding about their lives, health, and death so that they can reasonably choose their actions and ways of being in this world – whatever those ways then may be. This aspect is important and also is a good philosophical ground for healthcare, especially if we take a liberal position when defining a good society (for a more thorough handling of the liberal position, see Koskinen, Kainu and Kimppa 2016 In print). Patients should be the "owners" of their patient information because it is information about their lives and is description of their medical existence (even if less than a full one). For other parties, there is only instrumental value for patient information, which is secondary compared the patient's rights.

4. The new way of defining patient information ownership: Datenherrschaft and its implications

As seen above, Heideggerian phenomenological and hermeneutic view in the context of health seems to support the view that the patient is the justified owner of any patient information because people have the right to information regarding their own life experiences, including their illnesses and health. Thus, it would be absurd to think that someone else would have more rights to information about one's health than oneself. Of course, healthcare professionals and organizations need information to provide proper and accurate treatments, but it is the patient who should own the information and thereby be able to decide who can use the information and when and how the information will be used. The problem that arises when dealing with ownership is in regards to what it actually means to own patient information. Koskinen, Kainu and Kimppa (2016 In print) show that ownership must be defined so that it considers the nature of patient information and the ethical consequences of that definition. Without proper and accurate definition of ownership, it is problematic to further explore the phenomenon of the justified use of patient information. In this paper, ownership is seen as Datenherrschaft: which seems to be the mode of ownership that could fulfil the tone of Dasein if given to the patient. The background of Datenherrschaft is following:

> "The German word die Herrschaft means 'mastery over a thing' in the sense of having absolute or at least overwhelming power over the thing, not necessarily in the sense of having any particular skill, unlike the English translation implies. It is used e.g. German criminal law in conjunction

> with täter, forming the compound word täterschaft. (§ 25 Abs. 1 1-2. Alt Strafgeseztbuch) Täterschaft means perpetrator-ship of a criminal deed and tätherrschaft is the mastery over the actions (that is, the power to choose to act in this or that manner in the circumstances in which the act took place) taken that the täter has. Datenherrschaft is a term that is used the t Swiss Landesrecht in SR 420.31 Art 8 and SR431.112 Art. 12 to mean mastery a public official has over the information in data protection regarding a public database.
>
> A literal translation of die Datenherrschaft would be 'possession of and mastery over data (information).' As this expression seems imprecise, indeed, mastery over information is specifically used in other discourses to imply the ability to skilfully make use of data, this paper introduces Datenherrschaft (sic) as an anglisation of the German word." (Kainu and Koskinen 2012).

Thus, Kainu and Koskinen (2012) presented the definition of Datenherrschaft as follows:

> 'The legal right to decide the uses of, in a database or another compilation, collection or other container or form of data, over an entry, data point or points, or any other expression or form of information that an entity has, regardless of whether they possess said information, with the assumption that sufficient access to justice is implemented for a citizen to have this power upheld in a court of law."

The Datenherrschaft differs substantially from property rights in four specific ways. First, when ownership of property can be moved from one party to another one that is not case with Datenherrschaft. Datenherrschaft is irremovable from the individual who has it. It is the individuals choice of to make or not to make the criminal act, and is not removable form what the actor then is – even the driving forces behind the act can be interpreted. Datenherrschaft can be only be given to the person from whom the information is. It is notable that the person cannot give up the Datenherrschaft even they want to. This makes Datenherrschaft so unique. Even if there is some contract which limits one's Datenherrschaft the contract does not have power to be upheld in a court of law as Datenherrschaft is intimately tied to the person and not transferable.

Secondly, the work done is seen as justification for individual to gain an immaterial property right. However, the context of healthcare differs substantially from common creation of immaterial works. Immaterial property rights are seen to be a compensation for an individual for work done. But in healthcare the income is based on a salary and thus there is no need for this kind of compensation (see Koskinen, Kainu and Kimppa 2016 In print)

Thirdly, the immaterial property rights are commonly passed on to other parties who have not done the intellectual work in question. This alone is very problematic because in many cases there has not been true possibility to keep the right by the individual doing the actual intellectual work due to a weak negotiating position. But Datenherrschaft is non-transferable – it is part of the patient in the sense Kainu and Koskinen (2012) showed.

The last and maybe the most fundamental difference is that whilst immaterial property rights are based on creative or artistic process done by an individual, the healthcare situation is not like that at all. Healthcare is based on evidence based medicine – or at least it should be, lest we are talking about selling snake oil or performing art. The healthcare professionals need to rely on science and knowledge of medicine – there is a reason for the phrase “evidence based medicine” – not on their artistic or creative ideas and thus the property right cannot be justified due to it being art or creative work.

The consent approach is a view which can be argued to be more plausible than Datenherrschaft and it is true that the consent view has one major advantage – it is a part of the prevailing legislation in many countries. However, Datenherrschaft reaches further than the consent approach – it changes the paradigm between the patient and healthcare – the patient is no more the object for healthcare[4]. Rather, the patient is more a person who has control over the information and she or he is interacting with healthcare for some purpose of her or his own. The consent regime aims to provide enough information to the patient for her or him to make a decision on any specific medical issue at hand. Datenherrschaft approach focuses in serving the need of the patient when she or he is observing her or himself in a medical sense and more broadly in her or his whole life. Only the patients can judge what are the relevant issues for her or him even if she or he may – and most probably do – need medical professionals to help her or him to gain an understanding of patient information. Deber et al. (2007) also suggest that autonomous patients could be seen to mean people who wish to understand their diseases and their possibilities although they usually do

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[4] Author notes that in healthcare patients are not treated as objects in a sense that they do not have rights but this means instead that they are “objects” for healthcare in the sense that healthcare has information designed for healthcare professionals about a patient and by mixing this information and professional work the healthcare is executing medical tasks appointed to it.

not want to have a provider role in healthcare. The self-judging approach and the patient view of one's own life-plan is critical when we think of the problem of controlling patient information. Lee and Lin (2010) have shown that the impact of patient centeredness – which should include the patients desires and goals – to health outcome is elusive. However, even if we can find no indisputable evidence for a positive health outcome for the patient from patient centeredness, it is not a reason to diminish the value of patient centeredness. The health outcome is not only relevant for the patient – maybe not even the most important for the patient. The knowledge of one's own situation is a core factor for having an understanding of one's own situation and the possibilities of one's life. If we must rely on a judgement of healthcare professionals on what information is needed by us we end up in the position of das Man in this specific situation – we are expected to accept the doctors' viewpoint like everyone should do. This is hardly what Dasein is all about and thus it cannot be acceptable because our individual and unique experience of existence. To have a proper understanding of patient information for the patients there would need to be new patient information systems which should also be serving the layman's needs, not only the professionals – or the aim Datenherrschaft is missed because the information may not be understandable or even accessible for the patients.

The main practical contribution of Datenherrschaft can be summed up to be this paradigm shift – which is also supported from the legislative direction – which gives strong support for the patient's sense making of health and life (Lahtiranta et al 2015). This is crucial in healthcare where the healthcare professionals and especially medical doctors have traditionally possessed the control of the medical path and information rather than the patient (Koskinen and Knaapi-Junnila 2014)

Thus Datenherrschaft (mastery over information) is an ethically acceptable solution to improve an individual's privacy, control over one's private life, and position in our information-driven society ([names deleted to maintain the integrity of the review process]). Patient information is a sub-segment of the broader private information area; therefore, Datenherrschaft should be applicable to patient information, too. Based upon the second notion derived from Heidegger as presented in Chapter 3, it is obvious that there is strong reason with phenomenological justification to grant Datenherrschaft for the patient.

Even the term itself is based on the discipline of jurisprudence; Datenherrschaft is more detailed than the common view of information ownership and thus is fit to be used in philosophical discussions by nature. Datenherrschaft – if granted to individuals as proposed by Koskinen, Kainu and Kimppa (2016 In print) – is fruitful when the aim is to understand the meaning of patient information for one’s life in the sense of Dasein. It reinforces patients’ rights and their position towards other actors or stakeholders in healthcare. This is an important factor because healthcare professionals have the opportunity to exercise power over the patient due to their social capital – knowledge and position in society they possess (Callaghan and Wistow 2006). If implemented as a law, Datenherrschaft would provide a strong basis and a balancing force for the medical world currently controlled somewhat patronizingly by healthcare professionals. Datenherrschaft would also offer a possibility for the patient to choose how her or his personal information is used and by whom. There would still of course be a need for professionals because of their knowledge and experience, and this is also as it should be – at least until the patient can be the professional (if that ever happens). Nevertheless, by shifting the power balance in the direction of the patients, they will have a better possibility to take control of their lives or wellbeing and thus a better possibility to have a deeper understanding about their being in-the-world.

Of course, people cannot expect that personal information is only for the person it concerns and that no one can have rights over it in any circumstance ([name withheld to maintain the integrity of the review process]). Patient information can be relevant and in some cases even necessary for others. People live and interact with other people and thus should consider their part in the world as well. People are all thrown (Geworfenheit) into this world with others, and they must somehow live with that (Heidegger, 1927). As Koskinen, Kainu and Kimppa (2016 In print) point out, Datenherrschaft cannot be absolute because there are circumstances where one’s patient information can be crucial for others. In cases of epidemics and when information about one’s health is needed for securing the safety of others, authorities must be allowed to access patient information. However, this need should be described as an emergency provision, and any individuals whose information is accessed must be informed; the justification of the action must also be clearly expressed. An individual’s right to patient information is strong, and any violation of it must be justifiably explicated to ensure that practices and professionals will respect the individual’s Datenherrschaft over her or his own patient information. However, there has been concern regarding the problems that could arise for medical research development if privacy rules allow patients to decline the use of their information for research or public health purposes (see e.g. Wartenberg and Thompson 2010). If patient information is anonymised, it actually is no longer the same information; it has now become information about populations, and a patient’s Datenherrschaft would not cover that, and this would satisfy the requirements for Datenherrschaft in patient information. However, it must be ensured that the information cannot be traced back to specific individuals – deanonymised. The question of how these exceptions should be regulated is an issue that falls in an area of jurisprudence and within technical solutions that are outside of the scope of this paper.

If Datenherrschaft was implemented, it would have a significant impact on current information systems used in healthcare. The necessary changes regarding how information systems are used in healthcare and how patient information should be delivered to the patient in an accessible and understandable form is a challenging task. The 'Point to consider' query tool document could be used for developing electronic health records (Meslin et al. 2013). The purpose of that tool is to determine the issues that should be ethically considered when developing a system where the patient is given granular control over patient information. It is a valuable tool that information experts, clinicians, administrators, patient groups, and healthcare teams can use to have a discussion about this emerging topic. The issues that must be solved as presented by Meslin et al. (2013) illustrate that much work remains before Datenherrschaft can be internalised as part of the healthcare information infrastructure. However, Datenherrschaft seems to be an ethically promising basis for regulating patient information in the Heideggerian sense as it also was from a Lockean (Koskinen, Kainu and Kimppa 2016 In print), and Rawlsian (Koskinen, Heimo and Kimppa 2014) positions and thus should indeed be considered as the foundation for patient information legislation. However, before actual implementation in law should be started, further research will need to be conducted on the specifics of how to enact the ethical requirements into legal provisions.

5. Conclusions

The primary aim of this paper has been to describe the problem of absent regulations regarding patient information ownership and to offer a solution which seems to be a potential basis for just regulation for patient information. In the current situation, healthcare professionals are the main users of patient information and patients are treated as bystanders who are not given the opportunity to control, or in the some cases even see their patient information. The Heideggerian approach is used to identify problems that follow from the current situation. Patient information can have a crucial impact on how people see and understand their own lives, especially in a health context. Thus, it seems bizarre that the patient has not been granted proper access to her or his own health-related information. As a solution for the problems presented in this paper, Datenherrschaft (mastery over information) is offered to the patients. By giving this mastery to patients, we endorse the patient's position and capacity in healthcare and therefore give them the chance to gain an understanding about their own health and lives if they are interested, a possibility for dasein rather than das Man. From a Heideggerian perspective – which underlines the lived experience of the individual – an understanding is crucial for finding one's place in this world where we live and thus has a strong justification for Datenherrschaft for the patients.

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Paper III

Koskinen, J., Kainu, V., & Kimppa, K. (in press). The concept of Datenherrschaft of patient information from a Lockean perspective. *Journal of Information, Communication and Ethics in Society*, *14*(1).

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The Concept of Datenherrschaft of Patient Information from a Lockean Perspective

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Purpose

The purpose of this paper is to analyse the current status of ownership of patient information from a Lockean perspective and then present Datenherrschaft (German for "mastery over information") as a new model for patient ownership of patient information.

Approach

This paper is theoretical in approach. It is based on arguments derived from Locke's *Two Treatises of Government*. Legal examples of the current situation are derived from Finnish, United Kingdom, and Swedish legislation.

Findings

Current legislation concerning patient information is not clearly formulated and so recognising a new right on the part of the patient, Datenherrschaft, would be an ethically justifiable way of remedying the issue.

Research limitations/implications

The legal analysis was limited to Finland, the UK, and Sweden, and so other legislation should be looked at in future research. Datenherrschaft is used as an example of an ethically justified way of regulating patient information ownership and should be analysed further.

Originality/value

Patient information ownership is an issue that is not unambiguously solved in many countries nor has it, in our view, been ethically justified. The potential solution presented in this paper is clear and has strong ethical justifications.

Keywords

Ethics, Patient Information, Datenherrschaft, Locke, Ownership, Paternalism, Database right, IPRs

1. Introduction

Hettinger (1989) states that "Property institutions fundamentally shape a society. These legal relations between individuals, different sorts of objects, and the state are not easy to justify. This is especially true of intellectual property." The aim of intellectual property rights (IPRs) is not just to promote arts and sciences or secure the livelihood of authors, but also to enable individuals and organisations to buy and sell rights over works and inventions. The main aspect of debate concerns justifying financial issues and how economic compensation is implemented and regulated. Even though there have been different approaches, such as the social functions of IPRs (Geiger, 2013), the financial issues are still at the core of the discourse.

Justifying the property rights status of patient information ownership is a different undertaking to that of justifying traditional IPRs and thus needs its own discourse when compared to IP as a whole. One, perhaps the most important, reason for this is that some of the fundamental demands and values in healthcare are not similar to those in general intellectual property rights or common property rights outside of IP. The *raison d'être* of healthcare is not the promotion of economic activities or to secure individuals' compensation for their contribution, which are protected by IPRs. Healthcare's purpose is instead the delivery of care for people and the promotion of wellbeing.

Alexander and Penalver (2012) have found that property rights are usually justified based on the following theories: utilitarian-based, person-based, Lockean-based, Kantian-based or based on the Aristotelean concept of human flourishing. In this paper, the argument is based on Locke because it has been widely used in justifying property rights (including IPs) and many of Locke's arguments are seen as part of the basis for the justification of liberal democratic societies – which seems to be a relevant model of society in this context.

This paper argues that ethical demands would be better served by clearly defined regulation governing patient information and patient information databases. A clearer, redefined concept of ownership than that which currently prevails is needed to overcome the problems of regulating patient information. In the current situation, unclear regulation leads to the dismissal of the special aspects of the ownership of patient information in many countries. (See Rodwin, 2009; 2010; Koskinen and Kainu, 2013).

The analysis starts by using the IPR sense of the word "ownership". It is obvious that the concept of ownership is complex and allows room for different interpretations. Our response to this problem is a new definition of ownership of patient information via *Datenherrschaft* (mastery over information). Datenherrschaft, as we define it, is proposed as a viable and ethically justified solution to the problem of patient information ownership.

The aim of the present paper is to analyse the problem of ownership of patient information and offer a solution that endorses moral legitimacy in healthcare and avoids problems that arise from unclearly defined ownership. To achieve this, a comparison between five alternatives for ownership of patient information is offered. These alternatives owners are: **the state**, to which the citizen belongs; **the healthcare worker** who's intellectual product the data is; **the healthcare provider organisation** (public or private) who supplies the environment for the care; **the organisation that provides the database** (within the information system); and, finally, **the citizen** whom the information concerns. This paper argues that each citizen has the strongest ethical claim to ownership of information about themselves. We argue that the ownership – or rather Datenherrschaft – of patient data should be granted to the citizen because this solution is ethically superior (based on Locke) to the other alternatives presented.

2. Owning Patient Information

One example of the difficulty when ownership is not clear is the case of Milwaukee Health Services, which was cut off from its electronic patient record system when the contract with the provider ended. The provider of the electronic health record[1] and Milwaukee Health Services had a disagreement about the fee required to transfer the information to a new system, which eventually led to a court case (Boulton, 2013). The patient is not an equal negotiator for the contract when compared to the health services or the system provider, thus contract law alone will not satisfy the rights of the patient. The patient has typically very little choice on the system the health services use. The rights of the patient must be emphasized, and Datenherrschaft attempts to answer this. Under these kinds of circumstances, it is clear that whoever controls the patient information can govern the uses to which it will be put or at least impact how the information can be used. The situation where the patient does not control the information is therefore extremely problematic. Who has access to the information? What is the extent of the privacy of the patients? Why should someone other than the patients themselves benefit from patient information? Even though the patient could sign an agreement for distributing the rights to their information to a third party, due to the negotiation situation being unequal the law should protect the citizen from unfair treaties being required for receiving treatment.

The first difficulty when analysing ownership is that the term *ownership* itself is multidimensional. It has historic aspects; even ancient philosophers Plato and Aristotle gave the concept consideration and so have, of course, countless other philosophers from that time to the present day. Ownership also incorporates different manifestations, which are dependent on the nature of the object that is seen to be owned. Property can be physical objects, land, intellectual property, money (real or credit on an account), etc. Likewise, the rights that are implemented by ownership can vary. The rights can either be exclusive or just give some degree of control to the owner. To minimise the problems concerning what kind of ownership would be justified, the kind of "ownership" used in this discourse must be clearly defined. In this paper, we focus on patient information and analyse what kind of ownership would be reasonable, acknowledging both the immaterial and personal nature of patient information.

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[1] In this paper we generally use the term "patient information system" but if the reference uses some other form – e.g. electronic health record (ERH) or electronic medical record (EMR) – we use that instead. What is important is that the system, whatever it is referred to as, stores information about the patient.

In order to achieve a reasonable understanding concerning ownership, we must look for what we actually want to say when we *own* something. In the context of patient information, which is usually actualised as a patient information system, this clarification is taken into account so as to prevent misunderstandings. Having ownership is closely tied to the term property and reckless use of either ownership or property could cause problems. Since the focus of this paper is the ownership of the patient information of individuals, we are limiting our analysis to immaterial ownership or, as is commonly used, IPRs and so exclude the ownership of physical objects.

As the terms should not be used loosely or without caution in this paper, we use the term “Datenherrschaft” free from previous baggage introduced by Kainu and Koskinen (2012). A good example for this concern regarding using terms loosely can be found in Pateman’s (2002) analysis of the difference between and outcomes of the terms *self-ownership* and *property in the person* in the contexts of labour, democratisation and employment. She shows that different terms like “self-ownership” and “property in the person” have different outcomes – when analysed deeply enough – even though they seem *prima facie* to be synonymous. The difference between self-ownership and property in the person is important as different interpretations of Locke have been used; it is not distributable – as in selling oneself to slavery – but rather a form of control over oneself. Even if the target of Pateman’s (2002) analysis differs from the focus of this paper, the argument and understanding of the terms used is still valuable in the context of patient information ownership, which will be considered later in this paper.

In this paper, the premise and focus is on immaterial property, namely patient information, but the direction of the approach is critical. We have made this choice for two main reasons: First, due to the inherently immaterial nature of patient information, even though it can be stored and can become concrete through physical objects such as when printed on paper or shown on screen from different information systems. Second, it is commonly understood that medical information cannot be solely seen as property – patient information has deeper meanings for both the patient and wider society. However, we claim that the prevailing view of property rights is not suitable for patient information and so a new way to deal with it is presented: Datenherrschaft (mastery over information; in this case patient information). Also, as Collste (2008) argues, fundamental rights, such as the right to health in the case of HIV/AIDS medicine, or the right to sustenance can override rights to IPRs. In this paper, we argue similarly that our right to selfhood is more important than the database right of the organisation that keeps or produces the database containing our health information.

Since patient information is here subject to evaluation, it is critical to elucidate the specific nature of the situation:

- First, patient information is immaterial, but it is still bound to the individual persons from whom it is created. However, this is not how it is understood in the current legal framework as immaterial property. People are the actual source of the information even if creating it can include different actors and organisations.

- Second, health information is not created in the same way as artistic creation is made. Thus, the arguments for incentives for creative work, which are widely used to justify ownership of immaterial property, are not at all relevant because of the different nature of both the work and the content.

- Third, patient information is produced by employees or entrepreneurs, to whom income should result from their labour, which here means the medical actions that they exercise in their position not through the property rights of patient information. Similarly, the patient information database producer should receive income from producing the database, not from owning the data in the database.

- Fourth, the information can be crucial for a person’s life and wellbeing and, hence, must not be evaluated without understanding how patient information is used and what kinds of meanings it has for the patient and also for society at large.

- Finally, the idea of property itself – which refers to some transferrable object or value – is problematic in this context.

Thus, defining patient information as intellectual property is not acceptable as it is commonly used in standard IPR legislation. In this paper, such a definition is seen as problematic based on the Lockean arguments to be presented later. An alternative way of defining patient information and regulating it – in such a way that the ethical basis of healthcare is fulfilled and the Lockean basic liberties of the people are secured – is given after the current legal situation is presented in the following section.

2.1. *De jure* Ownership of Patient Information in Finland and Directive 96/9/EC

Traditionally, the essential element necessary for granting copyright protection has been that there is a “work” to protect. With Directive 96/9/EC (hereafter the Database Directive), the European Union directed that member states implement a *sui generis* protection, sometimes called the “database right”, for all databases (96/6/EC Chapter I Article 1(1–3)) and, additionally, copyright protection for databases that “by reason of the selection or arrangement of their contents, constitute the author's own intellectual creation shall be protected as such by copyright. No other criteria shall be applied to determine their eligibility for that protection.” (96/6/EC Chapter II Article 3(1))

For the reader’s benefit, we must mention that EU directives are not in force in member states *ab initio*; indeed, only after the implementation period has expired can a directive have a so-called *direct effect*, as found by the European Court of Justice (hereafter the ECJ) in the *NV Algemene Transporten Expeditie Onderneming van Gend en Loos v Nederlandse Administratie der Belastingen* Reference for a preliminary ruling: Tariefcommissie - Netherlands Case 26-62 judgement.

There are two kinds of harmonisation: *minimum* harmonisation and *maximum* harmonisation. The kind of harmonisation mandated by the Database Directive is maximum harmonisation. This means that member states are not allowed to deviate to either a more permissive or a more restrictive form of regulation in implementation. Thus, after the implementation period has expired, in the eyes of the ECJ, the law in force in every member state is exactly the contents of the Database Directive and nothing else. This is the meaning and significance of direct effect. However, national courts may not always agree with the ECJ and, in such a case, an individual is forced to appeal to the ECJ.

Finland implemented the Directive via the Finnish Copyright Act (404/1961) (hereafter FCA) 40 b §.

> "Jos tietokoneohjelma ja siihen välittömästi liittyvä teos on luotu täytettäessä työsuhteesta johtuvia työtehtäviä, tekijänoikeus tietokoneohjelmaan ja teokseen siirtyy työnantajalle. Sama koskee vastaavasti myös virkasuhteessa luotua tietokoneohjelmaa ja siihen välittömästi liittyvää teosta.
>
> – –
>
> Mitä 1 ja 2 momentissa säädetään tietokoneohjelmasta, sovelletaan vastaavasti työ- ja virkasuhteesta johtuvia tehtäviä täytettäessä luotuun tietokantaan." (3.4.1998/250)[2]

Essentially, the FCA 40 b § grants ownership of the copyright over the database containing, for example, patient information to the employer or the creator of the database. The ECJ has given several decisions regarding this directive. In case C-444/02 Fixtures Marketing [2004] ECR I-10549, paragraphs 33 to 36, the ECJ states that a database listing basic information enjoys the *sui generis* protection. However, in case C-604/10 Football Dataco and Others (not yet published), paragraph 27, the ECJ states that copyright and the *sui generis* right are two separate rights. In paragraphs 36 to 40, the ECJ states that, in order to enjoy *copyright* protection, the author must express his *creative ability* in setting up the database by making free and creative choices.

While it could be claimed that the patient has ownership over his or her personal information, such an assertion is not supported by the existing regulation. Merely having the right to access one's own information and the necessity of patient assent for sharing of patient information between two health care providers do not, in fact, constitute ownership or property right, when the explicit wording of the relevant statute confers ownership to a different party. The rights of the patient are limits on the property rights of the health care provider, not a basis to postulate an ownership of the patient. That claim is directly refuted by the wording of FCA 40 b §.

The implementation in FCA 40 b § is not the implementation that Directive 96/9/EC obligated, and still obligates, Finland to implement. The Database Directive reserves copyright for a subsection of databases, whereas the inadequate Finnish implementation grants copyright to all databases that are created in a circumstance this paper will, for reasons of simplicity, consider "employment" or "work". The word 'all' is not equiva-

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[2] "If a computer program … is created in carrying out the employees work duties, the copyright passes to the employer … this provision shall apply to databases created in carrying out work duties or official duties" This translation lacks the force of law. NB: in Finland, only the Finnish and Swedish expressions are law, any translation into other languages lacks the force of law.

lent to the word ‘some.’ As the thrust of this paper is to argue for better regulation of patient information, in the framework of this paper the only case where FCA 40 b § would not apply is the case of a sole proprietor’s patients, as there is no employee-employer relation.

Intuitively, it seems highly questionable that a patient record could be set up following a set of free and creative choices, or allowing a medical professional great freedom of creativity, since the law typically requires a certain form within which creativity and freedom are discouraged. Rather, it seems that, due to the legal requirements, there is very little room for creative choices. The Merriam-Webster online dictionary defines “medical record” as “a record of a patient's medical information (as medical history, care or treatments received, test results, diagnoses, and medications taken)” (Merriam-Webster, 2014). It seems that rather than being the creative work of an author, a medical record is a recording of facts using the practices of the medical profession. As an aside, the skill and labour necessary to create the data are irrelevant to the question of the database’s copyright (ECJ C-604/10 Football Dataco and Others paragraph 46).

An electronic patient record would hardly seem to qualify for copyright protection under the ECJ’s interpretation of the Database Directive. In paragraph 52 of Football Dataco and Others, the ECJ explicitly states that member states may not grant copyright protection to databases under any other conditions than those established in Article 3(1) of the Database Directive. Thus, the Finnish implementation of the Database Directive is inadequate since it contains no differentiation between the *sui generis* right and copyright. In contravention of the directive it seems to extend copyright protection to all databases created in an employee-employer relationship. However, this failure in implementation does not mean that this failed implementation actually grants this right as the *Van Gend en Loos* judgment shows. There is, as of writing, no pending revision of the FCA 40 b §.

The ECJ can only give decisions in cases actually brought before it. Currently, there are no relevant, pending cases that the authors are aware of. This, however, does not mean that the situation will be fine as it is. The question of the correct implementation of the Database Directive has been conclusively decided by the ECJ in Football Dataco and Others. A Finnish court would be free to seek a further preliminary ruling on the implementation of the Database Directive in the case of patient records, but the language of the ruling is clear: ‘Directive 96/9 must be interpreted as meaning that, subject to the transitional provision contained in Article 14(2) of that directive, it precludes national legislation which grants databases, as defined in Article 1(2) of the directive, copyright protection under conditions which are different to those set out in Article 3(1) of the directive.’ (ECJ C-604/10 Football Dataco and Others, ruling, paragraph 2)

In judicial interpretation, the apparent conflict between a Finnish statute and a European Directive can be resolved. In case KKO 2005:145, the Finnish Supreme Court decided that the word “no” can be interpreted to mean “yes” if this interpretation removes the conflict between a national statute and an EU statute. Thus, if a case were brought before a Finnish court, it would have the fairly clear precedent to interpret FCA 40 b § to mean that the creator of a database does not have copyright over the database, but instead has a *sui generis* right, even though the wording of the statute is explicit in granting a copyright.

Legislation by interpretation is somewhat problematic for the citizen, as it becomes a very time-consuming task to ascertain to any reasonable degree whether the words of a statute mean what they have previously meant in the legal context or if they are to be interpreted to mean something else instead. Whether or not the right granted is a copyright or another form of IPR matters. A somewhat facile example of why it matters is the duration of the protection: in 96/6/EC Article 10(1) the duration of the protection of the database right is set at fifteen years from the January following the year of the database's completion. Thus, the difference between copyright and this *sui generis* right is not inconsequential even to the creators of databases.

This paper cannot, for reasons of space, go deeper into the many problems arising from a conflict between member state legislation and EU regulations.

2.2. De jure Ownership of Patient Information in the UK and Sweden

So, under Finnish law, a patient is not the owner of his or her own patient information. The information is compiled into a database and the provider of healthcare (regardless of whether this provider is a public authority or a private healthcare provider) gains the right to this information. Even though there are of course restrictions on what the database provider can do with the data, the data is not controlled by the patient as it should be.

Finland is not alone in implementing Directive 96/9/EC inadequately. One of the two ECJ judgments referred to in Football Dataco and Others, involved the UK implementation of the Database Directive. The ECJ ruled that no other criteria than those listed in Directive 96/9 are allowed to create a copyright over a database.

In the UK, NHS medical records have long been considered the property of the Secretary of State (HC Deb 30 November 1976 Vol. 921 c91W). Thus, it is no surprise that there is no provision granting the ownership of electronic medical records to the patient. The juridical conclusion is that, since there is no special provision for the ownership of medical records, they must follow the principal rule of the Copyright, Designs and Patents Act of 1988, amended by the Copyright and Rights in Databases Regulations 1997 (S.I. 3032/1997). Thus, medical records are under copyright or database right, with the right being owned by the healthcare provider.

The Swedish implementation of the database right in 49 § upphovsrättslagen (1960:729) requires that an investment be made in the making of the database in order for a database right to be created. The plans for the development of Swedish national health records (which exclude all primary healthcare records) do not mention IPR at all. It appears that the issue of ownership remains unexamined in healthcare, but the fact that setting up an electronic health record does usually require an investment of (at the very least) effort points strongly in favour of considering the criteria for database right having been fulfilled.

The patient's ownership of their own information is not mentioned at all; thus, it can be concluded that the patient is not the owner of their information, as someone else is allocated ownership via the database right, and the patient is not mentioned at all.

For reasons of space, a more thorough comparison of the legal status of patient information is not possible in this paper. It therefore appears that further research in this area is necessary.

2.3. The Right to Verify Personal Information in a Database and the Exercise of this Right

Despite the lack of ownership, on basis of the Finnish Personal Data Act (523/1999) (hereafter the PDA), citizens have an unwaivable right to know about their personal data being stored in a registry (PDA 24 §), to check its accuracy (PDA 26 §) and to correct (PDA 29 §) any data concerning themselves.

However, there is no law guaranteeing that the exercise of this right should be free of charge. Accessing the different databases that are maintained by public authorities incurs a cost. The Finnish Electronic Handling and Manipulation of Client Data in Social and Health Services Act (159/2007) 18 § states that, if the client of a social or health service wishes to access the log files documenting accessing of their client data, the service provider has a right to charge an access fee equal to the direct costs incurred by providing access to the log files. By way of analogy, the same applies to the health records themselves.

Finland's inadequate implementation of the Database Directive does not alter the locus of ownership. If it should be found that the current locus of ownership is unjustifiable, granting IPR over patient information in the form of copyright rather than a database right is more problematic, as copyright lasts longer than database rights.

Having shown that the patient is not the locus of patient information ownership in any of the three EU member countries discussed, this paper will now argue that, from a Lockean perspective, it is more justified to conclude that the locus of patient information ownership ought to be the person of whom the information is a description.

3. Arguments Offered by Locke for the Patient to be the Owner

3.1. Paternalism

One does not have the right to enslave oneself as one cannot give to another more than one has power over and one has no power to take one's life away when pleased to do so (TTG II, IV, 22-24). This argument is valid and applicable here because health information can be crucial for people to gain an understanding about possible limitations or options that they have in their life. If this understanding is cut off from them, they fall under the power of another in this matter, which can be seen as a form of slavery (paternalism) and Locke was strongly in opposition of slavery.

As Locke states, paternalism is a tool for parents to raise their children to the point that they can take government of their own will (TTG II, VI). Still, it is not an absolute or arbitrary power, it is more a duty to use the paternal relationship in the best interests of the child and it is meant to stop after the child has the power to be an equal individual of society. Thus, if paternalism is so restricted between the parent and the child, paternalism between two equal members of society must be even more restricted and thus is not justified.

This is specifically relevant as traditionally healthcare has been seen as a paternalistic relationship where the patient unable to cure themselves seeks help from the knowledgeable healthcare provider. However, in this paper we are looking for a more equal solution. Thus we turn to a social contract theory to find a better alternative for the relationship between the patient and the healthcare professional due to the patients being more and more capable and willing to be an active partner in caring for their health.

While healthcare and society evolve, the social contract also evolves. The literature shows that professionalism changes in response to societal needs. The social contract consists of implicit and explicit, written and unwritten, rules. The explicit part is based on the laws, regulations and different contracts made in the society (Cruess and Cruess, 2008.)

This part of the social contract between the healthcare organisation and the patients can be cancelled if the healthcare organisation treats the patients paternalistically instead of equally (cf. Locke (TTG II, XIII, 149) on the relation between the state and the citizen). Thus the patients (i.e., the citizens) have a duty to renegotiate the contract between themselves and the system.

Excluding people from something rivalrous is acceptable only if there is enough of the same left for others (TTG II, V, 32). It seems that people can have a mandate for property, but only if others have the possibility to have their own equal share. In the case of patient information, if information is taken away from the patient, there is nothing left for the patient anymore. Even if we presume (as Locke in TTG II, V, 50 seems to) that money changes the equation, there is not enough patient information ownership to be shared with others. But, if the patient is the owner of their own patient information, there is still enough left for others – each has their own patient information – which make the patient’s ownership of information more justified than its ownership by someone else. That is, if one’s patient information is one’s own and one will not allow others to use or see it, others still have their own information – which can even be similar in some cases – and their freedom is not unjustly restricted, while the paternalistic situation is avoided.

3.2. Problem of Labour as Source of Ownership

Intellectual property is commonly justified by Locke’s notions about property gained through labour (Hughes, 1988; Spinello, 2003). Locke’s (TTG II, V, 27) argument

"Though the earth, and all inferior creatures, be common to all men, yet every man has a property in his own person: this nobody has any right to but himself. The labour of his body, and the work of his hands, we may say, are properly his" seems *prima facie* plausible but, upon further evaluation, it can be seen that it only fits physical property – not intellectual property – and still needs limitations in the case of physical property.

Kimppa (2005) has argued that Locke's argument is valid only if the ownership is exclusionary; meaning that Locke's argument is valid only for things from which we can be excluded, such as food, drink or cars. But information is not removed from anyone else. Thereby, Locke's argument about creating ownership through work is not valid when considering immaterial property because of the limiting factors of property over peoples' life and liberty. As argued in this paper, one needs to also take into account that patient information is fundamentally different from other immaterial (intellectual) property. Even though the creator of patient information can be, and usually is, a healthcare professional, the mechanism for the creation of patient information is atypical and is not sufficient for gaining IPRs.

An important aspect is that, while traditional intellectual processes like artistic composition can be made solely by the creator of the art, the situation is not equivalent when creating patient information even though there is some work (labour) done. *The fundamental source of information about the patient is the patient themselves, not the healthcare professional.* The healthcare professional is actually not providing more than diagnosis, especially since modern healthcare rests on medicine. The diagnosis cannot be conducted without the patient and the patient is, ultimately, the source of the information – even though the healthcare professionals work to retrieve that information. The patient, as shown in the next section, is a sum of parts, one of which is information about who or what they are. Hence, it seems that the common justification for ownership – labour – is not suitable for patient information and that a different solution must be identified. Thus, copyright could not be used as a justification for the ownership of the patient information belonging to the healthcare professionals or the healthcare organisation.

3.3. My Body, My Person, My Life

It is important to note that Locke stated that people, through labour, have a right over things they change from the state of nature, and that this idea conflicts with the situation in which patient information is created. People are not in the state of nature because people are actors capable of removing things from the state of nature and so are subjects, not objects of nature. Thus, Locke specifically did not mean that through mixing labour with other people or persons, those people or persons would be turned into the property of the labourer. As Bergelson (2013, pp.420-421) points out:

> "Using modern terms, Locke defines a person through the individual's personal identity, which, among other things, should include the individual's personal information – the unique collection of facts that makes the individual who she is. If that is the case, then everyone has an original property right in her personal information, i.e., personal information does not exist in the state of nature, it is already owned."

This is important because personal information – in this case health information – can be seen to be a manifestation of the person like Bergelson (2013) claims. The property rights of the collector of personal information should not be allowed to be superior to the rights of the individual who is the subject matter of the information collected (Bergelson, 2013, p. 421). Thus, we claim that health information – as a subcategory of personal information – is a manifestation of one's person and therefore cannot be treated as separate from the person without acting against Locke's view of personhood, although this seems to be the *de facto* situation on many occasions

To underline the problem of labour as justification, we highlight the idea of labour itself: if the labour of the healthcare professional is mixed with that of the patient, this would be problematic as it would change the patient into the property – namely a slave – of the healthcare person performing the act, which obviously is not what Locke meant while talking about his labour theory of property. If we see especially valuable personal information (such as patient health information) as a manifestation of the person, then the case of health information is crucial for people's wholeness as a person and so it cannot be acceptable for it to be overlooked, particularly when considering Locke's views about slavery. Other especially valuable information could be this kind of information, however in this paper we do not take that into consideration as the focus of this paper is on health information. There is a reason Locke lists liberty as more important than possessions[3] ("life, health, liberty or possessions" TTG II, II, 6) – since the work is mixed with the person (patient), it cannot be owned, as persons cannot be owned, at least through labour alone (for a more thorough discussion on liberalism and slavery, see Palm, 2009).

It is also worth noting that if one owns one's body, it cannot be that another party has rights over information about the body while the person themselves does not. Yet, even more crucial is how someone can have rights over my person, which nowadays could be defined as an individual person with different manifestations, including the aforementioned personal patient information. If there is an individual person, the health information about that person is private by nature when thinking about Locke's view of personhood (TTG II, V, 27) which Bergelson (2013, p. 420) also notes. Therefore, the idea of someone other than the patient as the owner conflicts with Locke's idea about personhood and thus cannot be justified because the health/patient information can be crucial for one's understanding about their life, body and eventually (see also Koskinen, 2014).

Nevertheless, in some cases we can claim that information about some individual is not personal. An example could be where information from every citizen is collected and subsequently anonymised in such a way that the information is not (at least not easily) traceable back to individuals. This kind of information is (and can be, even according to our interpretation) used for medical research. In cases like this, the information is not connected to the identity of the person anymore, it is instead information about popula-

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[3] Note that when Locke mentions property (e.g. TTG II, VII, 87), what he means is that property consists of life, liberty and estate, not property as we currently understand it.

tions and thus its use does not violate anyone's right to their person. Specifically, because of the order of importance of "life, health, liberty or possessions"(TTG II, II, 6) being as it is, we can assume that if research is saving lives or improving the health of people, the freedom to deny the use of anonymised information is not justified. This seems intentional (although a different interpretation has often been drawn looking at the sixth and seventh chapters, in which property is over-emphasised) in Locke. After all, the order of value was so instinctively understood by his contemporaries that some quite casually even replaced possessions with, for example, the "pursuit of happiness", as in the US Declaration of Independence (1776). Even though Locke (TTG II, V, 27) justifies the ownership of property through ownership of ourselves, it is not used as a justification for life, health or liberty, but merely for the least important of the four, namely property.

A further point that endorses the collection of anonymised patient information can be derived from Locke's work. Coleman (2005) states that we have an obligation to keep ourselves alive and a duty to all mankind to preserve their life, health and liberty. If we can do this by collecting anonymised patient information, we are fulfilling that given duty to preserve all mankind. This offers a strong justification and thus a mandate for the collection of such data. In that case, there actually is an obligation to allow the use of our anonymised patient information for the good of humanity.

Still, we want to underline that, even though life is higher than liberty, we cannot have patient information accessed freely when used in medical research, even though there seems to be a justification for it to be used in some cases. If healthcare personnel are given full, free access to a patient's health data, it does not directly guarantee that others' lives are saved or that their health is improved, and yet liberty is still abridged. In that case, we may violate the right to liberty for nothing, which is neither justified nor a desirable situation.

An important point is that in Locke life and health are rights that override liberty (TTG II, II, 6). Securing the estate or other possessions at the cost of liberty is not justified by Locke as liberty is a weightier right than estate in Locke's order of basic rights (TTG II, VI, 59). Thus, we cannot grant the right to use identity forming information concerning ourselves through purely economic reasoning; it must always be justified through health and life or through liberty, and thus the selling of the information is not justified unless these higher rights are satisfied. Thus, the provider or compiler of the patient information database should be rejected as the owner of health information, even though they could have some pecuniary claims towards the information. A monetary argument cannot override the interest that everyone has in their own life and health (inspired by Himma, 2008). The aforementioned arguments are valid when considering healthcare workers or healthcare organisations as owners based on labour alone because of the lexicality of life, health, liberty and possessions (TTG II, II, 6), as the next section will discuss.

If information about ourselves that is critical to self-understanding needs to be procured at a cost, then effectively we are not free to know ourselves unless we pay someone else for a fuller self-knowledge. If, as we argue, self-knowledge is an essential element of being free, we cannot be free unless we pay for our freedom, reminiscent of the manumission of slaves.

3.4. Autonomy and Liberty

Another problem is that if some party external to the citizen owns (controls) the patient information, what are the actual rights of the citizen in regards to that information? If someone other than the citizens themselves has ownership of their patient information, people's rights to information concerning themselves are restricted and thus their liberty and autonomy are likewise restricted. This idea of someone other than the citizens themselves controlling patient information is also problematic in light of Locke's (TTG II, VII, 87) argument that:

> "Man being born, as has been proved, with a title to perfect freedom, and an uncontrolled enjoyment of all the rights and privileges of the law of nature, equally with any other man, or number of men in the world, hath by nature a power, not only to preserve his property, that is, his life, liberty and estate, against the injuries and attempts of other men…"

Even though the previous points are true in the state of nature, these are the values which Locke defines in the social contract to be the things to be guarded by the state. This argument points out that we ought not to abridge people's liberty or autonomy. On the other hand, when the citizens own their patient information, the liberty and autonomy of the people are actually expanded because they have more control and thereby wider possibilities to use that information as they wish. Furthermore, one can have a deeper understanding of one's own person – or a manifestation of it – and so can evaluate encountered medical events and understand the meaning of one's life.

As Pateman (2002) suggests, if one's person (and personal information is part of a person) is seen as property and people are able to treat their property as they wish, we are taking steps towards slavery. This is particularly so in libertarianism, which Pateman (2002) criticises. If we want to secure the basic liberties that Locke underlines, we must abandon the terms "ownership" and "property" when describing the governance, regulation, and control of patient information. The concepts of "property" and "ownership" are used in current language in such a property rights-oriented way that it directs politics and practise toward where the pecuniary aspects are strengthened at the cost of basic liberties. The conception of patient information as property, where it can be the object of transaction, is contrary to the aims of Locke, and thus life and liberty cannot be seen as property as it is currently understood – it is hard to see that is what Locke means when using the word property in this context (TTG II, VII, 87). Thus, these terms must be replaced with a term that emphasises the basic liberties of the people and is free from economic emphasis.

In the healthcare context, patients can accept that healthcare professionals have control over patient information because there is no alternative solution available for them. This does not mean that it is ethically acceptable or desirable. Rather, we must deliver a solution which provides new ways for the patient to control their information and thus gives them the possibility to be empowered – Datenherrschaft over patient information.

4. Datenherrschaft as a Solution of Ownership

Patients – or, more generally, individuals – should be the owners of patient information as the previous arguments based on Locke show. Nevertheless, as discussed above, a clear definition of ownership is necessary, especially in cases like patient information, in order to avoid mistakes in future interpretations, which could lead to undesired outcomes. To avoid this, ownership should be implemented as Datenherrschaft, which would emphasise the personal bond between the person and their patient information.

The German word *Herrschaft* means "mastery over a thing" in the sense of having absolute or at least overwhelming power over a thing. It does not necessarily mean having any particular skill, contrary to what the English translation implies: "I have mastery over my breathing" (and no one else does), although this requires no specific skill. Herrschaft is used e.g. German criminal law in conjunction with *Täter*, forming the compound word Täterschaft. (§ 25 Abs. 1 1-2. Alt Strafgeseztbuch) Täterschaft means being the perpetrator of a criminal deed and Tätherrschaft is mastery over the actions (that is, the power to choose to act in this or that manner in the circumstances in which the act took place). Datenherrschaft is a legal term that is used in the Swiss Landesrecht (SR 420.31 Art 8 and SR431.112 Art. 12) to mean the mastery that a public official has over the information in data protection regarding a public database.

A literal translation of Datenherrschaft would be "possession of and mastery over data" (information). As this expression seems imprecise, mastery over information is specifically used in other discourses to imply the ability to skilfully make use of information. This term is defined in this paper to mean (Kainu and Koskinen, 2012, p. 54):

> "the legal right to decide the uses of, in a database or another compilation, collection or other container or form of data, over a entry, data point or points or any other expression or form of information that an entity has, regardless of whether they possess said information, with the assumption that sufficient access to justice is implemented for a citizen to have this power upheld in a court of law."

Datenherrschaft as a legal term is not widely used. Out of the three major European states that have legally binding legislation in German (Germany, Austria, and Switzerland), only the Swiss regulation uses it. It is used in a single article in SR 431.112, Bundesgesetz über die eidgenössische Volkszählung, vom 22. Juni 2007. Here it is the term for the power that a public authority has over information. Thus, the general thrust of the term is similar to what is proposed in this paper, but not identical, as SR 431.112 Art. 12 provides no legal powers for natural persons over their own data.

Thus the word is relatively free of baggage, and can be used without confusion of terms. Such a legal right does not yet exist, so it seems practical to adopt a new term. The right of publicity is similar, but not exactly the same, as it only concerns the public use of certain information (International Trademark Association, 1998). Using "information ownership" or "right to privacy" or "copyright over one's private information" would be either inaccurate, unclear, or would obfuscate the issues. It is also conceivable that a new term might enhance the discourse.

In this context of patient information, a restriction is added. As patient information in some cases can be critical for *another person's* wellbeing the citizen cannot be justified in having an absolute mandate over their own patient information like one could for example have over information concerning personal shopping habits collected by store chains. Legal ownership is only in an extremely few cases actually *absolute* and so there must be different regulations for those exceptions. One cannot, for example, choose to bury radioactive pollution on one's property without the proper permits, even though usually one has right to dispose of one's chattels as one sees fit.

The public healthcare system should, in carefully delineated and ethically justified circumstances, utilise information to safeguard the health of others. While this restricts Datenherrschaft, it is justified and necessary. The limitations of Datenherrschaft are judged a lesser evil compared to an absolute Datenherrschaft. Thus, for the purposes of this paper, Datenherrschaft is restricted as follows:

- First, the citizen may not destroy information in the patient information database because it can be crucial in some cases for other patients, for example when a citizen carries an epidemical disease or the information is needed to avoid direct harm to other citizens.

- Secondly, in specific cases, the liberty to choose how patient information is used violates or endangers other people's lives or health. Considering Locke's order of rights – life, liberty and estate (TTG II, VII, 87), or life, health, liberty, and possessions (TTG II, II, 6) prioritising life and health before liberty, and especially possessions – this justifies overriding the freedom to choose how one's information is used in some situations.

Nevertheless, even if healthcare authorities in some circumstances have a right to see and use the patient information without the consent of the citizen, it does not mean that they have been granted mastery over it. The right is only a limited right and must be used only to protect the life, health and liberty of others. Thus the use of the information must be controlled in such a way that the individual can know how and why their patient information is accessed or used – and, when necessary, limit that access to protect their basic liberties.

5. Conclusions

We have shown that the current legislation concerning patient information is lacking, at least in Finland, UK and Sweden, and that, based on our understanding of the EU Directive, we have no reason to believe this would not be the case in many other EU countries as well. As the property interest is financially quite small, there will very likely not be any cases of a citizen appealing to the ECJ and, therefore, it is extremely important to subject this matter to legislative revision without undue delay. The need for legislative revision is further underlined by the fact that the Database Directive has been inadequately implemented in the observed countries.

Moreover, critical arguments exist – based on Locke – which support the notion that citizens should be the owners of their patient information. Datenherrschaft as a legal basis fulfils the demands founded on the Lockean view of liberties and an individual’s rights over their own life and person, and thus is a more justified way to treat patient information than the current EU legislation, which lacks the necessary unambiguity.

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Regulations:

EU:
European Union Directive 96/9/EC

Finland:
Copyright Act (404/1961)

Personal Data Act (523/1999)

Electronic Handling and Manipulation of Client Data in Social and Health Services Act (159/2007)

The United Kingdoms:
Copyright, Designs and Patents Act 1988

The Copyright and Rights in Databases Regulations 1997 (S.I. 3032/1997)

Sweden:
Lag (1960:729) om upphovsrätt till litterära och konstnärliga verk

Switzerland:
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Paper IV

Koskinen, J., & Kimppa, K. (forthcoming). *An unclear question: Who owns patient information? - A Kantian take on the concept of Datenherrschaft*.

Unpublished manuscript

An unclear question: who owns patient information? A Kantian take on the concept of Datenherrschaft

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Abstract

Patient information systems[1] are critical instruments in modern healthcare; thus, modern healthcare systems cannot function properly without them. While there are countless varieties of information systems used in healthcare, there is one overarching commonality among them – they all contain information about patients. Different groups involved in healthcare have an interest in patients' information for different reasons. However, in many countries, it remains unclear who exactly owns the data. This issue thus needs to be resolved. As ethics is critical in determining the justifiable owner of patient information, any legislative solution to competing interests ought to be ethically well justified. In this paper, we argue that an ethically acceptable formulation of the ownership of patient data has already been suggested and that it can be further justified also through the Kantian tradition.

Keywords Patient information; Datenherrschaft; Kant; Ownership; Regulation

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[1] We use the term patient information (system) to avoid the problem of different terms being used, for example, electronic health record (ERH) or electronic medical record (EMR) etc. What is important is that the patient information system, or whichever term is used, stores information about the patient.

1 INTRODUCTION

Who owns patient information, and perhaps more importantly, who should own it? This is a question that the research literature has so far failed to conclusively answer. Furthermore, the potential answers offered have mainly been derived from the field of jurisprudence (although authors tackling the issue are typically also knowledgeable about ethics and healthcare) and from the United States (see e.g. Hall 2009; Rodwin 2009; Rodwin 2010; Evans 2012). The paucity of academic discourse is interesting because of the topicality of the issue, and there is a strong global drive towards developing healthcare information systems. Cognisant of the differences between the legal tradition of the US and that of (particularly continental) Europe,[2] we need to engage in further discourse from academics with different backgrounds in terms of traditions and fields.

It appears that the ownership of patient information is a target of regulation that seems to have either failed or has not been accurately or explicitly defined in many countries (Rodwin 2009; 2010; [Names withheld] 2016). Existing arguments or viewpoints arguably diverge in relation to how the issue of ownership should be solved or approached. The first view is that patient information should be publicly owned and regulated (Rodwin 2010). The second view is that the patient should have mastery over his/her information ([Names withheld] 2016). The third view holds that the propertisation of information is not a solution and actually leaves the problem unsolved (Evans 2011; 2012). Common among all these views is the recognition that ownership or property rights is not easily implemented when it comes to patient information.

There seems to exist contradictory scenarios when it comes to patient information. The (lack of) regulation of ownership mentioned above, when viewed against the protection of personal information found in European Union directives, seems to be inconsistent (Kierkegaard 2011; Di Lorio et al. 2014). [Names withheld] (2016) show that by approaching the issue from the perspective of ethics, rather than from that of jurisprudence, the problems of unclear regulation become visible.

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[2] There are of course other traditions, but the authors want to underline the differences between the United States and (particularly continental) Europe, which have been the main traditions of relevance to this topic.

[Names withheld] (2016) propose a different approach to how the ownership of patient information is viewed. They note that the traditional view of property, or current immaterial property rights, is not a plausible solution because of the nature of patient information. The solution they propose is the use of a different definition of ownership, namely Datenherrschaft (see Kainu and Koskinen 2012) – mastery over data – granted to patients to overcome the problem ([Names withheld] 2016). This definition seems more appropriate in serving the aim of controlling patient information because it takes greater account of the problems of property and ownership in this context.

This paper starts by analysing patient information from the viewpoint of ownership because there is an established practise as well as trends to propertise different kinds of information with immaterial property legislations. The academic discourse on what constitutes ownership has considered information about people in internet and company databases. This suggests that we are in an era in which the boundaries of our privacy and protection of personhood have been re-drawn. Patient information is at the core of this issue, or at least it should be – which is not currently the case. The legislative approach is essential because our societies are controlled through the use of legislation; thus, without clear legislation, rights become non-appealable, i.e. such rights can and will be ignored or deprecated. Of course, the approach could be other than ownership-based, for example, in Finnish legislation,[3][4][5] the aim has been to control and restrict the use of patient information with laws and regulations, not through ownership. However, with the ownership approach in focus, the issue can be clarified by analysing and stating who in the end should control and by ascertaining how patient information is used and by whom. Property rights do have a strong and fundamental position in Western countries, and this approach suggests that it is fruitful to have a strong offset for clarifying the patient's position as well as rights that protect the patient's information.

It is notable that in different countries there can be numerous ways of controlling patient information. However, it seems that a look at the Finnish legislation on the proper use and storage of patient information can lead to complex and case-specific legislation, which could be avoided with a focus on legislation based on ownership. In this way, the detailed practices – which must respect Datenherrschaft – could be regulated with soft law and could thus cope more easily with technological developments (see also Kainu and Koskinen 2014). With

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[3] Laki potilaan asemasta ja oikeuksista 785/1992

[4] Laki sosiaali- ja terveydenhuollon asiakastietojen sähköisestä käsittelystä 2007/159

[5] Sosiaali- ja terveysministeriön asetus potilasasiakirjoista 298/2009

this, patients can thus control how their information is used (with some limitations, which are shown later on).

It seems that Datenherrschaft is an ethically justified way to regulate patient information, at least according to the Lockean ([Names withheld] 2016) position. Nonetheless, we want to strengthen the ethical justification for Datenherrschaft with Kant's categorical imperative(s). The Kantian view is relevant here because, as Wiesing (2008, p.229) states, '*In a time of rapid change, the concept of human dignity and human rights from the Kantian tradition serves at a certain level as a stabilizing anchor*'. The Kantian tradition respects the value of humans differently than, for example, the utilitarian position. Utilitarianism seeks the most efficient outcome of good and can thus lose sight of humanity, an aspect of critical importance in the field of healthcare.

2 DATENHERRSCHAFT – MASTERY OVER DATA AND INFORMATION

This paper uses the concept of Datenherssaft – as per Kainu and Koskinen (2012) – as a way of regulating ownership of patient information.

The following presents a backround to Datenherrshaft:

> *The German word die Herrschaft means 'mastery over a thing' in the sense of having absolute or at least overwhelming power over the thing, not necessarily in the sense of having any particular skill, unlike the English translation implies. It is used e.g. German criminal law in conjunction with täter, forming the compound word täterschaft. (§ 25 Abs. 1 1-2. Alt Strafgeseztbuch) Täterschaft means perpetrator-ship of a criminal deed and tätherrschaft is the mastery over the actions (that is, the power to choose to act in this or that manner in the circumstances in which the act took place) taken that the täter has. Datenherrschaft is a term that is used the Swiss Landesrecht in SR 420.31 Art 8 and SR431.112 Art. 12 to mean mastery a public official has over the information in data protection regarding a public database.*
>
> *A literal translation of die Datenherrschaft would be 'possession of and mastery over data (information).' As this expression seems imprecise, indeed, mastery over information is specifically used in other discourses to imply the ability to skilfully make use of data, this paper introduces datenherrschaft (sic) as an anglisation of the German word.* (Kainu and Koskinen 2012).

Thus, Datenherrschaft is a word derived from German and can be concisely translated as 'mastery over data' (or information). As this expression appears to be overly interpretative, we use the term in this paper in the same way that Kainu and Koskinen defined it:

> [Datenherrschaft is] the legal right to decide the uses of, in a database or another compilation, collection or other container or form of data, over a entry, data point or points or any other expression or form of information that an entity has, regardless of whether they possess said information, with the assumption that sufficient access to justice is imple-

> mented for a citizen to have this power upheld in a court of law. (Kainu and Koskinen 2012).

Datenherrschaft differs substantially from property rights in four specific ways. First, when ownership of property can be moved from one party to another, it is not a case of Datenherrschaft. Datenherrschaft is irremovable from the individual who has it. This is similar to the aforementioned by Kainu and Koskinen (2012): an individual's choice to participate, or not, in a criminal act is not removable from the actor – even though the driving forces behind the act can be interpreted and argued. Datenherrschaft can only be given to the person about whom the information is. It is notable that someone cannot give up his/her Datenherrschaft, even though he/she may wish to do so, as it is an integral part of who and what he/she is. This is what makes Datenherrschaft so unique. Even if there is a contract that limits one's Datenherrschaft, it cannot be upheld in a court of law.

Second, the work done is seen as a justification for individuals to gain immaterial property rights. However, the context of healthcare differs substantially from the common creation of immaterial work. Immaterial property rights are seen as compensation to individuals for work done. However, in healthcare, income is salary based, and thus, there is no need for compensation (see [Names withheld] 2016).

Third, immaterial property rights are commonly passed on to other parties who have not done the actual intellectual work. This in itself is very problematic because, in many cases, there is no real possibility of possessing a right when another individual produces the intellectual work. This is so because of a weak negotiating position when rights are negotiated between parties. Instead, Datenherrschaft is non-transferable; it is a part of the patient in a similar sense as the criminal deed is bound to the person who commits the crime, as Kainu and Koskinen (2012) show.

The last and arguably most fundamental difference is that whilst immaterial property rights are based on creative or artistic processes, work done by an individual in a healthcare situation differs substantially. Healthcare is based on evidence-based medicine – or at least it should be, or we are talking about snake oil or the art of performance. Healthcare professionals rely on science and knowledge of medicine and not on their artistic or creative ideas; therefore, property rights cannot be justified here.

The consent approach is arguably more plausible than Datenherrschaft as it has one major advantage – it is part of the prevailing legislation in many countries. However, Datenherrschaft reaches further than the consent approach. It changes the paradigm between the patient and healthcare – the patient is no longer the object of healthcare;[6] rather, he/she has control over his/her information, and he/she interacts with healthcare for some purpose. The consent regime aims to provide sufficient information to patients to make decisions regarding the medical issue at hand. The Datenherrschaft approach focuses on serving the need of the patient when he/she observes him/herself in a medical sense and, more broadly, in his/her life as a whole. Only patients can judge what are the relevant issues for them even if they may – and most probably do – need medical professionals to help them to gain an understanding of their patient information. Deber et al. (2007) suggest that autonomous patients could be seen to mean people who wish to understand their disease and their possibilities even though they usually do not want to play the self-provider role in healthcare. The self-judging approach and the patient view of one’s own life plan is critical when we think of the problem of controlling patient information. Lee and Lin (2010) show that the impact of patient centeredness – which should include respect for the patient’s goals and desires – in health outcomes is elusive. However, even if we find no indisputable evidence for health outcomes for patients from patient centeredness, it is not a sufficient reason to disclaim it. The health outcome is not only a relevant issue for the patient and perhaps not even the most important. Knowledge of one’s own situation is a core factor in gaining an understanding not only of the situation but also of the possibilities for one’s life. If we must rely on the judgement of healthcare professionals regarding what information is needed by us, it is not clear that we would necessarily be treated as ends in ourselves; rather, we could end up as mere means in the system. After all, we would be expected to accept doctors’ viewpoint like everyone should. This cannot be accepted if we wanted to be ends in ourselves and not reducible to mere means. To have a proper understanding of patient information for patients, there is a need for new patient information systems that would serve primarily the layman’s needs and not only those of profes-

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[6] The author notes that in healthcare, patients are not treated as objects in the sense that they do not have rights; they are ‘objects’ for healthcare in the sense that healthcare contains information designed for healthcare professionals about patients, and by mixing this information and professional work, healthcare executes the medical tasks appointed to it.

sionals. Here, the aim of Datenherrschaft would be misplaced because the information may not be understandable or even accessible to patients.

The main practical contribution of Datenherrschaft is this paradigm shift – which it also supports from a legislative standpoint – and its strong support for patients' sense-making of their health and life (Lahtiranta et al. 2015). This is crucial in healthcare where healthcare professionals and especially doctors, rather than patients, have maintained control of the medical path and information (Koskinen and Knaapi-Junnila 2014).

Datenherrschaft would thus seem to be an appropriate solution by which to overcome the baggage associated with the term 'property' in general and especially with its economically weighted use in intellectual property rights. Datenherrschaft emphasises the right of the patient to be free from paternalistic control and speaks for the patient's right to choose how his/her information is used and by whom.

Understandably, this mastery cannot be absolute and can be overridden if it conflicts with the *fundamental* (which are not property rights of any sort) rights of others, such as the right to life or health. Situations in which the patient's rights are justifiably overruled would occur, for example, during lethal epidemics where others are in direct and grave danger ([Names withheld] 2016).

However, the patient's mastery can only be overruled temporarily and only with justifiable reason to protect the idea of Herrschaft. Information about overriding Datenherrschaft must be clearly reported to the patient ([Names withheld] 2016). Another critical issue to note is the use of patient information for research purposes. There are justified reasons – for example, the duty to preserve all of mankind – for collecting anonymised patient information for research purposes, but only that anonymised data can be accessed and not the original data ([Names withheld] 2016). However, this data should be collected within some common database(s) to which free access for research purposes would be available. This way, both the rights of individuals and their duty towards mankind would be served.

Health information technology is changing, and there is a need to analyse the idea of informed consent in the healthcare context (Goldstein 2010). Traditionally, paternalism has been justified due to the doctor knowing more than the patient about various medical conditions. This is no longer always the case, and patients are more capable of taking responsibility for their own condition/s. If, in this situation, the patient continues to be treated as a target for paternalistic handling, he/she is not considered an end but rather a means for the healthcare professional. Any use of power over another needs to be justified, and in the current situation, paternalism is no longer typically justifiable as in the traditional sense.

3 KANTIAN AUTONOMY AND RATIONAL AGENTS: PREREQUISITES FOR PATIENT CENTEREDNESS AND EMPOWERMENT

Patient centeredness and empowerment are seen as important factors in today's healthcare systems and thus need to be taken into account (Mead and Bower 2000; Donnely 2005; Hiscock and Shuldman 2008; Holmström and Röing 2010). Empowerment is a multilevel construct whereby people, organisations and communities gain mastery in matters that concern them by having rights and needed resources (Rappaport 1987; Zimmerman 1995). To be empowered, citizens require information while patient centeredness supports respect for patients and ensures that citizens' needs are fulfilled. Without information, one obviously cannot have credible mastery or gain an understanding of one's own health or treatment. This is where Datenherrschaft makes a difference in healthcare practice as it respects the autonomy of the patient and enforces the patient's right to decide how his/her information is used by granting him/her mastery (compare this to empowerment as defined above) over his/her own information, thus reducing the possibility of healthcare professionals exercising paternalism over him/her.

Nevertheless, Sjöstrand et al. (2013) show that there can be an acceptable level of paternalism if it enhances patient autonomy. Autonomy is constructed from at least three parts. First, there must be competence held by the individual who is exercising autonomy. Second, there should be the ability to make decisions aimed at realising desires, goals etc. Third, desires should be authentic, meaning that they should not be based on, for example, self-deception or coercion. The level of authenticity in desires varies; some desires are more authentic than others (Sjöstrand et al. 2013). However, there can be situations in which paternalism is acceptable – for example, in cases of nervous breakdown and shock – but paternalism itself cannot be held as a universal law.

Although Kant did not take a stand on medicine, his influence has been strong in the medical field, especially in relation to autonomy and human rights (Wiessing 2008). Autonomy and the free will of actors are preconditions for duty, which is an essential part of Kant's moral philosophy. Duty is something that can only be performed by rational agents, and actions can only be moral when conducted by rational agents on the basis of free will (see Sjöstrand et al.

2013). Forced ‘good’ actions cannot be moral because morality comes from people’s will, and the actions they undertake are just consequences of that will. The outcome is secondary or even irrelevant to the will and its goodness. Nevertheless, the will is a necessary but not sufficient condition. If the actor has not understood his/her duty, he/she can still act wilfully, but that action can be a bad action. Therefore, the universality of moral acts and taking each person into account as an end are also preconditions for moral action and essential parts of Kant’s moral philosophy, which becomes concrete in the three categorical imperatives that are, according to Kant, all modifications of the same moral law, just presented differently (Kant 1785).

4 DATENHERRSCHAFT IN LIGHT OF THE CATEGORICAL IMPERATIVE(S)

There are three different forms of categorical imperatives identified in Kant's *Grounding for the Metaphysics of Morals*, and there are also different translations from German to English, not forgetting other languages. Nevertheless Kant's three categorical imperatives can be translated into English as (Feldman 1978):

CI1: Act as if the maxim of your action were to become through your will a universal law of nature.
CI2: Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end.
CI3: An act is morally right if and only if the agent, in performing it, follows the law autonomously.

In what follows, the third categorical imperative is examined through the first and second formulations; it is visible throughout the paper and is, as Kant points out, directly connected to the other two.

4.1 Categorical Imperative 1

The first categorical imperative, 'Act as if the maxim of your action were to become through your will a universal law of nature', demands that the Datenherrschaft of patient information be formulated and legislated in such a way that it satisfies the requirements of being a universal law. Taylor (2004) has analysed the paternalistic maxim and came to the conclusion that it is not acceptable for people to be treated in a paternalistic way. If a world in which the maxim of paternalism as a universal law is imagined, there would be situations in which people would not be able to truly exhibit self-control. The paternalistic maxim converts rational agents into less autonomous beings and diminishes their capacity for self-control, which is a precondition for the potential to effectively will any action. Thus, by willing the paternalistic maxim as a universal law, one takes away this capacity and leaves that will to face a collision with itself. Therefore, paternalism cannot be held as a universal law (Taylor 2004).

[Names withheld] (2016) argue that the patient should be held as the possessor of Datenherrschaft whereby the solution to the problem of paternalism is reached by giving the patient control over his/her information. However, the patient's Datenherrschaft cannot be absolute without violating the first formulation of the categorical imperatives. There are occasions when healthcare professionals or other authorities must have access to patient information, for example, in situations concerning disease epidemics or when access to patient information is crucial for some other individual. It appears likely that European Union legislation will increase the problem of using information for the purposes of healthcare if amendments to the Data Protection Directive (DPD) are implemented as written whereby privacy will have greater value over health (Di Lorio et al. 2014). In some situations, information is a premise for securing the lives of others, and so, withholding that information – as the DPD would – cannot be seen as an act of universal law. Likewise, the aforementioned anonymised patient information used for research purposes seems fitting as a universal law as it makes possible the curing or saving of people in the future. In addition, the literature (though limited) indicates that patients consider the use of their information for research and public health proposes to be legitimate (see e.g. Spriggs et al. 2012). Thus, our suggestion for a universal CI1 is:

> Patients should have mastery over their information, thus granting them as widely inalienable a mastery of their patient information as possible, but not exclusive control of use, thus granting the possibility of using the data in exceptional situations, such as in cases of pandemic or when information is crucial to save the lives of others or to secure their health from serious danger. Likewise, access is permitted for research purposes when properly anonymised.

The first categorical imperative clearly brings out the advantages of Datenherrschaft because it avoids the flaws inherent in paternalism compared to a situation in which citizens are without mastery of their own patient information. However, the limitations and use of anonymised information for research purposes seem to be exceptions that should be catered for. Thus, Datenherrschaft fulfils the first formulation of the categorical imperatives if those restrictions are added, as proposed in [Names withheld] (2016).

4.2 Categorical Imperative 2

The second formulation of Kant's categorical imperative states: 'Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end'. Thus, people should always be treated with respect by virtue of their humanity and not in an arbitrary manner. Each person should be honoured because he/she is a human being and not only because he/she is something that serves some personal end or goal (Kant 1785). Therefore, citizens cannot be bypassed in deliberations on patient information. The contrary suggests that people are treated only as means.

Kant places greater emphasis on the motivation – good will – behind actions than on the outcome. Thus, following Kant's deontological approach, a situation in which the outcome would be good is unacceptable if the moral codes are neglected or given less weight on utilitarian grounds. This makes a position in which people's liberty or other personal rights are limited by others very problematic. Thus, through the paternalistic actions of some other party, we can lose the autonomy of patients, which is seen as one of the core values of medical ethics (Gillon 2003; Beauchamp and Childress 2001). Hence, paternalism violates the second categorical imperative. It is obvious that solely restoring a citizen's health or curing his/her disease does not sufficiently fulfil the second Kantian formulation, thus nullifying it as a basis of how people are treated in a healthcare system. In that case, people would be treated merely as objects by the healthcare system as well as by healthcare professionals carrying out their care or medical treatments, and that would be unacceptable.

This point of objectification needs to be noted in situations where a holder of Datenherrschaft over patient information is proposed to be some party other than the patient. If some party other than the citizen is granted Datenherrschaft, the patient, as a human being, is not honoured as an end in him/herself. Accordingly, if the patient is set aside from other Datenherrschaft candidates – who have their own goals (even though these goals *can* be similar to those of citizens) – we do not respect people's autonomy and liberty when we choose how their information (which is an extension of themselves) is used or not used. Even though the goals might be similar to those of citizens, the outcome is not the point; the main point is the moral motive which satisfies respect for the patient as an end in him/herself.

Even though many (probably most) healthcare professionals *do* consider the patient as an end, not all of them necessarily do. Thus, as we cannot be sure of this, we must design systems that at least ensure that the *system* supports treating the patient as an end. Manson (2010) shows that even though patients seem in many cases to be unwilling to participate in decision-making, they can have different requirements for information. By according mastery to patients, we ensure that they have all the necessary information when they want or need it, and we do not rely on the hope that healthcare professionals will treat patients as ends in and of themselves.

For example, people are not necessarily treated as ends if healthcare professionals have mastery over their patient information and thus have a paternalistic hold over them. In a paternalistic relationship, healthcare professionals can decide how information is used and what is best for the citizen without knowing the personal needs of the patient (Manson 2010). The problem is that the biomedical worldview focuses on medical *consequences*; this collision of worldviews (deontological vs. consequentialist) is problematic and can generate conflicts if not taken into account. Thus, the citizen's humanity as a person with his/her own will and opinions about his/her life can be lost through someone else's power over this citizen. Even though the intentions are good, the paternalistic approach itself can easily lead to loss of a person's control over his/her own life. If the possessor of information is an institution (such as the state, a healthcare organisation or a company), the problem is actually worse since institutions can and usually do treat citizens as only part of a bureaucratic process, without a trace of humanity (see, e.g. Wiesing (2008) for the view that the Kantian tradition functions as a stable anchor for humanity).

5 CONCLUSIONS

The clear regulation of patient information seems to be missing in several legal systems or traditions of jurisprudence. While patient information obviously plays an essential part in modern healthcare, there must be a wider discourse on the issue than there is at present. The proposal that patient information should be regulated in such a way that it gives patients the strongest possible rights over their information is ethically justified from a Kantian perspective. Other viewpoints from different perspectives and traditions are needed to elaborate Datenherrschaft in such a way that it fulfils the ensuing transdisciplinary demands.

This proposal also has the advantage of being free from the baggage of previous legal solutions. It responds to the problems of current views on property and respects the privacy and autonomy of patients. Likewise, the proposals note the right of public healthcare authorities to access and use patient information in situations deemed necessary to protect the life and health of others, for example, in the case of epidemics. Future research should evaluate what kinds of changes are needed in information systems and healthcare practices if Datenherrschaft is implemented.

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Paper V

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Rawls's View in Context of Datenherrschaft over Personal Patient Information

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Abstract

The ownership of patient information is a topic which has great ethical impact on healthcare and especially in the life of individuals. Current legislation in many countries is not clear and thus there is different ways to interpret ownership. Therefore the use of patient information is based on poor justification and is promoting the needs of healthcare organisations and professionals on the cost of the citizens. In this paper five stakeholders, namely the state, the healthcare professional, the healthcare provider organisation (public or private), the provider of the information system and the citizen as possible owners are evaluated as the possible owner through Rawls's Theory of justice. Three arguments which are derived from Rawls, based on the Veil of Ignorance, Two Principles of Justice and two aspects of self-respects, all point towards the conclusion that only the citizen is a justified owner of their patient information. Thus, the ownership in a sense of datenherrschaft (mastery over information) should be given to citizens with some specific restrictions in cases where the public authorities' lack of information could be endangering other citizens' lives and basic liberties.

Keywords

Patient information, ownership, Rawls, Theory of Justice, datenherrschaft, citizen

1. INTRODUCTION

Datenherrschaft, s, f, -en. – Mastery over data or information.

Patients are seen to be in a more active role in healthcare and they are usually becoming more interested about their own health than they used to. Need for information for different actors and parties in healthcare systems at large is evident and a significant phenomenon. Already three decades ago Andre De Vries (1980) stated that the responsibility of one’s health lies within the individual (subject which is topical also today). Nevertheless, he also presents three issues to be fulfilled in order for people to be expected to possess that responsibility. First, there must be patient autonomy if responsibility is expected to be given to the person. Second, the individuals must have a right for care and treatment before they can be held responsible. Third, they must have information in order to possess that responsibility; without understanding there cannot be responsibility. (De Vries 1980.) Thus, the patient information is a crucial factor in modern healthcare and its meaning for the patient has become more important because of the individual’s possibility to affect their own health and well-being in modern society. At the same time use and possibilities of use have become more complex when information has been relieved from limitations of paper-based entry and use of patient information has been transferred to electronic patient records. In the current situation the problem is as Rodwin (2009 & 2010) proposes it: the ownership is not clearly defined, at least not in the United States or in European Union. This means that we have a wide range of possibilities to use patient information based on different needs which different stakeholders have and the regulations are not giving us unambiguous guidelines for the use of patient information. Hence, the matter of ownership (datenherrschaft) of the patient information must be solved – and justified.

Koskinen and Kainu (2013) presented five potential owners for the patient information, namely the state, the healthcare worker (professional), the healthcare provider organisation (public or private), the provider of the information system and the citizen. From these options as a justified owner for patient information only the patient as owner was seen as a promising possibility to be an ethically justified owner. Heimo, Koskinen and Kimppa (2013) analyse eGovernment systems’ interest groups and according to them they can be limited to the following four: the government office, whose task is to formulate the solutions to fulfil the needs of the society, the producer, who delivers the requested system, the end-user group consisting of people using the system and, the citizens, who are the targets of the system usage. They also state that any or all of the aforementioned groups can overlap. These interest groups can also be analysed to be the candidates to hold the mastery over the eHealth data. Like Hart (2002) presents, the ownership of information is not an unambiguous or easy issue to solve. The owner of the information can vary depending on the theory which is used to define the ownership (Hart 2002). In this paper, the focus is in analysing the datenherrschaft with A Theory of Justice (see Rawls 1999).

The term ”datenherrschaft” is based on a German word “die Herrschaft” which means “mastery over a thing” in a way where the possessor of mastery has an absolute or at least overwhelming power over the thing or matter. The term datenherrschaft is new in the sense that it is not used commonly and thus it is quite free from historical baggage. The contradiction with the English translation (mastery over) herrschaft is not referring to any specific skill or ability. It is used for example in German criminal law in conjunction with “täter” (Eng. perpetrator), forming the compound word ”täterschaft” which means perpetrator-ship of a criminal deed and tätherrschaft is the mastery over the actions (that is, the power to choose to act in this or that manner in the circumstances in which the act took place) taken that the täter has. The term Datenherrschaft is used in the Swiss Landesrecht in SR 420.31 Art 8 and SR431.112 Art. 12 to mean public officials' mastery over the information in public database protection. (Kainu & Koskinen 2012)

Kainu and Koskinen (2012, p. 8) propose that ownership of personal information should be defined as datenherrschaft:

> *'the legal right to decide the uses of, and continuing existence of, in a database or another compilation, collection or other container or form of data, over an entry, data point or points or any other expression or form of information that an entity has, regardless of whether they possess said information, with the assumption that sufficient access to justice is implemented for a citizen to have this power upheld in a court of law.'*

In this paper, Rawls is used for the argumentation of justification for ownership (datenherrschaft) of the patient information which can be seen as the subclass of the aforementioned ownership of the personal information. Datenherrschaft in the sense Kainu and Koskinen (2012) presented it, is securing the rights of the citizen, the individual who is the object of the information which is collected and stored of them. The primary goal of this paper is to evaluate the justified owner of patient information, in the sense of datenherrschaft, and evaluate that solution by shareholder analysis through Rawls's theory of justice.

2. ANALYSIS BASED ON RAWLS

In this paper, three main steps based on Rawls Theory of Justice (1999) are used for arguing why citizens from the aforementioned interest groups should be granted datenherrschaft over patient information, and which arguments support the justification for it. First, the Veil of Ignorance is used to analyse who could be a justified owner of the patient information. Second step is based on the Rawls's Principles of justice and what potential solutions it offers for issue. Third, the two aspects of self-respect are used as the verification of conclusions based in the two previous steps.

2.1 Veil of Ingorance

The *Veil of ignorance* is Rawls's thought experiment developed for determining the morality of an issue at hand. The participant of the thought experiment has to distinguish themselves from their current personal life and observe life from behind the 'veil of ignorance', a place where they do not know in what circumstance they will find themselves in the society. Rawls (1999) states that this forces the participants to allocate the available recourses more fairly.

As Rawls (1999) explains in Chapter 24, the Veil of Ignorance can be used to reflect the current situation with a different viewpoint with the aim of generating a just situation, a scenario, where society's welfare would be distributed fairly. Thus Rawls calls his theory "justice as fairness".

Because of the abstract nature of the Veil of Ignorance, other ethical theories and arguments, e.g.

Rawls's two principles, are required to complete the process, but the Veil of Ignorance seems to be a quite good tool for determining the basis where to start both the discussion and designing process. As it was mentioned before, the healthcare information system development and usage has numerous stakeholders who all are good candidates for the datenherrschaft over the patient information.

The State

In considering patient information and its use to benefit citizens, the state as a well-ordered society can be seen as justified owner of patient information. Well-ordered society is a society which is designed to advance the good of the citizens and is regulated by public conception of justice (see Rawls 1999, pp. 4-5). The state, if it is a well-ordered society should be using patient information to benefit citizens in such way that it could advance the good (i.e. in this health or wellbeing) as well as possible. From behind the veil of ignorance, the state seems *prima facie* to be a good choice to be the possible owners of the patient information.

The Healthcare Professional

To the healthcare professional (typically a doctor or a nurse) the patient information can be argued to be their intellectual property through the work they have put into the creation of it. Nevertheless, the healthcare professional is either working for the patient or for the society or (typically) both, and thus they can be argued to be one of the healthcare professionals' employers' by default. With the payment and other benefits the healthcare professional receives ownership of the data they produce of the patient seems to be an unfair compensation. Moreover, the healthcare professionals are usually required to use evidence based medicine and when recording patient information it could be hazardous if a healthcare professional would use too much creativity while writing down possibly life-dependant data (if threshold of originality is expected for copyrighted works, as is in many legal traditions). Like Koskinen and Kainu pointed out, if patient information is treated as intellectual property the problem is the following:

> *"Whilst traditional intellectual process like artistic composition can be made solely by creator, situation is not equivalent when creating patient information. The fundamental source of information about patient is the patient not healthcare professional. Healthcare professional is actually not doing no more than diagnosis, especially when the modern healthcare rests on evidence based medicine."* (Koskinen & Kainu 2013)

Behind the veil of ignorance this seems to be a worse solution than the state, mainly for the reasons in the latter paragraph. Thus, it must be put aside as a possible owner of patient information.

The Healthcare Provider Organisation

The healthcare provider organisation could be seen as the owner of the health information if as an employer of the healthcare professional they get the ownership of the intellectual property due to contracts or due to law by being their employer. The same argument as in the case of the healthcare professional is valid; the nature of the intellectual process does not justify the ownership. Another way to see a reason for the healthcare organisation to be the owner of patient heath information is that they use it for the good of the citizens. In case of public healthcare provider organisation the state would be a better candidate, however, as why give organisations power over the state who owns those organisations. The problem is more complex if the healthcare organisation is private. Its interests lie within the interest of the owners of the organisation. Private organisations usually have financial or other private interests which sometimes can be not so desirable in a sense of the fairness, by example providing care only for some group. Thus, behind the veil of ignorance the healthcare organisation is not as good owner as the state and thus not acceptable.

The Provider of the Database or the Health Information System

As the governmental levels of our society tend to think their data to be common property the healthcare information system providers tend to use their technological superiority (mainly in the procurement and development phases of healthcare information system lifecycle). Thus, it is not uncommon for the HIS providers to for example lock the data gathered with their systems to be only used by their systems – not any other systems – and thus indirectly claim partial mastery over the data. Behind the veil of ignorance this seems to be an unfair situation and is not advancing the situation for most of the population.

The Citizen

The patient is the stakeholder to whom patient information and its use is most influential and the effect most personal and thus is a promising owner candidate. If citizens have ownership over patient information, they can choose how it is used and who can access it. This solution is giving protection for people's privacy which seems to be a good alternative when considered from behind the Veil of ignorance. In this case everyone would get the possession of patient information considering themselves and this solution would most probably be such that one would be in a situation with stronger rights towards their own patient information. From behind the Veil of ignorance this also seems to be a suitable solution, where – no matter who the subjects are – they can benefit from and control their own information by their own will.

To summarise the usage and analysis with the veil of ignorance method it seems that the state and the citizen are most likely to be the owners of patient information when looking from the original position. Nevertheless, there is a need for stronger arguments and the Two principles of justice is used to confirm justified ownership from the perspective of basic liberties.

2.2 Two Principles of Justice

Rawls (1999) presents a philosophical view according to which there are two principles of justice: first, *the principle of liberty* and second, *the principle of fair equality of opportunity*. Those principles are as follows (Rawls 1999, p. 266):

First principle:

> *"Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all"*

Second principle:

> *"Social and economic inequalities are to be arranged so that they are both:*
>
> > *(a) to the greatest benefit of the least advantaged, consistent with the just savings principle, and*
> >
> > *(b) attached to offices and positions open to all under conditions of fair equality of opportunity."*

These two principles of justice serve as basic structure of society which is seen as fair and well-ordered. The Principles secure the liberties of citizens and ensure that distribution of wealth and income is done in socially responsible manner and economic inequalities are arranged in such a way that they benefit all members of society, not only the more fortunate ones. This means that people cannot have too much benefit from personal characteristics which they have because people with less useful characteristics are not responsible for their lack of luck.

In addition of the aforementioned principles, Rawls (1999) defined the priorities of these principles. The first principle is primary to the second one. Thus, basic liberties can be restricted only for the sake of liberty. Basic, and equal amongst, liberties, are (Rawls 1999, p. 53):

> *"political liberty (the right to vote and hold public office) and freedom of speech and assembly; liberty of conscience and freedom of thought; freedom of the person, which includes freedom from psychological oppression and physical assault and dismemberment (integrity of the person); the right to hold personal property and freedom from arbitrary arrest and seizure as defined by concept of the rule of law."*

Nevertheless, as pointed out by Taylor (2003) there exists a long list of articles which criticize the lexical Priority of Liberty. This is an issue which has to be given attention before those principles and lexical priority of the principles can be used as an argument. Taylor (2003) examines Rawls's three arguments of Priority of liberty in Theory of Justice and has found that two out of three of those arguments seem to be problematic. According to Taylor, Rawls's problem is the belief that instrumental value of basic liberties he has shown for some essential purpose automatically shows the reason of lexical priority of those liberties. According to Rawls (1999, pp.131-132):

> *"Rather, free persons conceive themselves as beings who can revise and alter their final ends and who give first priority to preserving their liberty in these matters."*

This clearly prioritises freedom higher than any other ends, as those other ends might change, but the need for the possibility of change does not. The same is true of other interests. The kinds of interests that enable other choices are always more important than 'final' interests – as these may always change. This creates the order of the interests from freedom, to primary interests to 'final' interests. (Taylor 2003, p. 254.)

For Rawls, as for Kant, autonomy is necessary to be able to make free choices (Taylor 2003, p. 256). Mastery over data about ourselves falls under autonomy in this sense, and thus is more important than the 'final' interest – promoting health and wellbeing. Even though health and wellbeing are clearly necessary for autonomy, the way we go about to get them may change, and if we do not have mastery over our health data, we cannot choose this, and thus are not free.

As an example of a 'final' interest changing could be used loosing (or gaining) faith. For an atheist, a good material life would be a 'final' interest, whereas for a Christian, having faith could be a 'final' interest. In the case of healthcare, this kind of life plans must be considered for the individual. From the perspective of the healthcare professional, drinking alcohol excessively on Fridays might seem not beneficial for the health of the individual, but it might be a central part of who that person sees themselves to be, and thus only the person can actually know this.

Rawls clearly understands intellectual property to be a right, but it is clearly secondary to people's basic rights and thereby it is not protected by the priority of the first principle (Gewertz & Amado 2004). As an example, a just society could allow some benefits (e.g. ownership of patient information) to some members (e.g. healthcare professionals) of the society (e.g. healthcare), if and only if that benefits the weakest member (e.g. patient) of the society. Research about a patient's improved health and commitment to care, when they are in an active role care, cannot thereby be bypassed (see e.g. Funnel & Anderson 2004 or Baars et al. 2010). To achieve commitment, and thus improved care, the patient needs to possess relevant knowledge and adequate resources. Without information one obviously cannot have credible mastery over anything or even have an understanding of one's own health or treatment. Thus, we can make a conclusion that Rawls's point is to secure people rights, and inequality is acceptable if and only if it improves the status of the weakest. If someone else than the patient owns the patient information, there is no clear improvement of the weakest in society which is mandatory for justifying the inequality of possessing patient information.

Another critical issue is that patient information is unique, by nature, to the patient. For the healthcare professional, healthcare organisation or the state, the patient information of a person is only a single file in a larger information collection, and thus has only instrumental value. For the patient the information is not only an instrument, it is personal, and is thus a meaningful part of their life as a manifestation of their health. Because there is so much variation in people's experiences of health it is obvious that they are typically the best experts of their own lives specifically, even if the healthcare professionals do possess greater amount of information about sicknesses and the human body and mind in general (see e.g. Svenaeus 2001 or Koskinen 2010). Healthcare professionals and healthcare overall should be serving the needs of the patients rather than only giving them paternalistic solutions from perspective of professional. Patients should have the experience and the feeling that there is "*Nothing about me, without me*" (Leape et. al. 2009, p. 426).

2.3 Self-Respect

Information for citizens has a major difference compared to other aforementioned parties. Information is crucial for the citizen because it is linked to the citizens life and understanding of their own existence or, in the worst case, the possibility of the end their existence.

It can be seen as a tool for self-respect which is, according to Rawls (1999, pp 79-80, 386), perhaps the most important primary good. Rawls (199 p. 386) states that:

> *"We may define self-respect (or self-esteem) as having two aspects. First of all, as we noted earlier (§29), it includes a person's sense of his own value, his secure conviction that his conception of his good, his plan of life, is worth carrying out. And second, self-respect implies a confidence in one's ability, so far as it is within one's power, to fulfill one's intentions."*

In the case of patient information self-respect stands out. Self-respect is important for a citizen who is the object (should citizen to be active subject is other interesting issue) of the patient information record (the collection of information stored in patient information database or other collection). For other parties the information has important, *but still only instrumental*, value. The information is crucial for the citizen because of its connection to self-respect and its two aspects. For citizens it is crucial to have the information because of its obvious relevance for their plan of life. If the citizens are bypassed, the conception of their good life is altered because they cannot be evaluating their plan with information which patient information contains. In other words, if the citizen does not possess relevant information their confidence of their ability to control their life can rest on fallacy. Of course it can be argued that even without citizen to be the owner of the information the needed information can be given and used for the best of the citizen.

But the fundamental problem lies in that even if the other parties use the information to serve good causes towards the citizens they do not to have the same understanding of the citizen's plan of life and how the patient information can be altering that plan. In that case the (potential) good deed of the other party can endanger the citizen's possibility to plan their life which is problematic because of the position of self-respects as perhaps the most important primary good. Like Rawls (1999 p 80-81) writes:

> *"...Justice as fairness, however, takes a different view. For it does not look behind the use*

> *which persons make of the rights and opportunities available to them in order to measure, much less to maximize, the satisfactions they receive. Nor does it try to evaluate the relative merits of different conceptions of the good. Instead, it is assumed that the members of society are rational persons able to adjust their conceptions of the good to their situation"*

It is not the other parties' duty or right to decide which is good for others, it is a matter for the citizen themself. Thus we must give citizens the right for patient information to use according to their own will as long as they do not violate what justice demands. In the current situation, where patient information is not under citizens' control we are giving power over the citizens to other actors who then decide which is best for patient – instead of the patients themselves. By granting ownership (with some limitations which can be derived from demands of justice) of patient information to the citizen it would ensure that the information is used as the citizen chooses, and therefore they would have more liberty than without owning the information.

3. PATIENT AS AN OWNER IN SENSE OF DATENHERRSCHAFT

Ownership held by someone else than the patients themselves seems to be an unjustified solution due to the aforementioned arguments based on Rawls's Theory of Justice. Veil of ignorance seems to be giving justification to either the citizen or the state of the five potential owners presented to possess the ownership of patient information. Nevertheless, if there would be some beneficence for the patient if the state (and healthcare provided by the state) would be the owner of patient information, the principle of liberty would be in conflict with the justification of Rawls's second principle. Thereby that solution should be rejected because of the priority of the first principle even if it would improve the status of the weakest. Also the effect of patient information towards citizens' plan of life is an aspect which justifies the citizens as the strongest candidate for the ownership of patient information.

Another issue is whether a patient can have absolute and unlimited datenherrschaft over patient information. Koskinen and Kainu (2013) pointed out occasions in which authorities should have access to patient information, for example in the case of a pandemic. Koskinen and Kainu (2013) also gave a definition for datenherrschaft which acknowledges the authorities' need and justification in some specific situation to access patient information. In this paper we agree that this definition is correct and that it emphasises the special need in the context of patient information, but in legislation it would be clearer to use datenherrschaft as Kainu and Koskinen (2012) presented it in the first time considering private information overall. The restriction which is needed in case of patient information can and should be handled with separate regulation. That solution is clearer and emphasizes the meaning of datenherrschaft as common protector of privacy, and thus also emphasizes the freedom of citizens.

There can be arguments which point out problems of power asymmetry between healthcare professionals and the citizen and thus attempt to point out that the logic presented in this paper is difficult to implement. But it is a worth to note that where asymmetry is a problem – which can be seen as paternalism – it can be lessened by informing the citizens and for that purpose datenherrschaft is a strong tool for the individual patients. Moreover, citizens datenherrschaft could serve as promoting informed consent (whether consent can be uninformed is a question we leave for others to ponder). It can do this through promoting individuals' information about their health and medical condition. To enable this, information should be arranged and put on patient records in such a way that it is understandable for citizens without professional skills.

Patient information is not easily understandable by the citizen, but in a well-ordered society information should be presented in such a way that the owner – the citizen – could understand and use the information as easily at it is possible. This of course means the information should be stored in a citizen understandable format, or at least we should be developing information systems which assist citizens to construe an overall picture of the information. Current patient information systems are designed to support the professional and healthcare, which is of course also important, but the citizen should not be bypassed as a justified owner of information.

4. DISCUSSION AND CONCLUSIONS

Rawls's idea of an improved society and his view of fair possibilities and liberty directs us towards thinking about the patients and their experience about health and patient information as a manifestation or description of one's health and body and plan of life. Datenherrschaft given to the individual person seems to be a plausible way to arrange the ownership of patient information.

Nevertheless, there is an argument that will rise, or at least should rise, about the rights to this information. The argument is that other parties, such as the state or the healthcare organisation has to have a right to get information about contagious diseases or information on matters which affect others than the patient only, such as mental illness of a close relative, or similar information. This is easy to understand and can be easily justified through Rawls because in this situation other basic liberties are endangered. If the lack of access to information reduces the freedom of others or endangers their lives, the information should not be considered private; although it still should be owned by the patients themselves. In these situations where other people's lives, or at least life plans are at stake it is justified for the healthcare professionals to access patient information to protect the life and liberty of other individuals or the society at large.

But these exempt rights should be restricted to these kinds of special cases and access should be allowed to relevant information only. To situations where information is necessary to be retrieved to other people from direct harm. Any information which affects the patients themselves only is obviously theirs and should only be accessed for the patients' sake. Thus, their ownership or mastery – datenherrschaft – of the information must be respected.

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