

# “Life of mine” - Datenherrschaft as Heideggerian way to treat individual’s patient information

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**Abstract** The patient information ownership is not clearly regulated or defined in many countries. This is problematic because many quarters have interests towards patient information and without clear definition there is room for variable interpretations how information can be accessed or used and even more crucial by whom. In this paper, the patient information is approached from Heideggerian perspective aiming to gather understanding about the nature of the information. Two notion of patient information is derived from Heidegger’s work “being and time”: information as a tool and information as inseparable part of one’s being. Based on analysis of those perceptives, proposal for using the special definition of ownership – datenherrschaft (mastery over information) – given to a patient is brought up. From Heideggerian perspective it can be stated that patient has the strongest rights towards patient information because information is crucial for a patient to have understanding about one’s dasein(being-in-the-world). Nevertheless, for authorities there is justified right to access the information in cases where common good requires it. It is important that the right for authorities must be justified and it is an exception which only temporary gives those rights.

Floridi’s Four challenges for informational privacy theories are used to analyze how well given datenherrschaft avoids problems in privacy theories presented by Floridi. It seems that datenherrschaft has theoretical and practical strengths on it – Heidegger’s philosophy with definition suitable for implantation as a law.

## 1. Introduction

Patient information is a widely used term, but a clear definition for it is not easy to find. One of the problems is what actually is included in patient information, what are the limitations and requirements for it? Is patient information to be information collected by healthcare from a patient or is it all information considering patient health and wellbeing? In this paper patient information is seen as official information which is stored by healthcare (public or private). Thus, the patient information system is seen as an official system created and controlled by healthcare.

Patient information systems are usually designed from the perspective of the healthcare professional and thus systems fulfil the needs of professionals because in current situation they are the main users of the information. Therefore, the systems are not usually optimised to meet the needs of the citizens or in many cases are not even accessible for them. In this paper, patient information is observed from a different perspective; the meaning of information for the patients in a Heideggerian sense is used to outline the need for a different approach compared to nowadays professional-centric solutions.

The problem is that current legislation in many countries is not clearly enough stating who owns the patient information (Koskinen & Kainu, 2013; Rodwin, 2009, 2010). This lack of clear legislation leaves possibility to have different interpretations about the patient information and use of it. The target in this paper is to define a justified ownership of the patient information which could be implemented as a law and have a proper and philosophical basis for it.

Ownership is commonly seen as entitlement to some object, named as property which is the target of that ownership. Other complex issue is that the conception of owning itself is a troubled phenomenon. This is especially true when the object of owning is private information and for a reason there has been research and debate about the privacy and ownership of private information. (Cohen, 2008; Floridi, 2006; Smith, Dinev, & Xu, 2011; Warren & Brandeis, 1890). Even patient information has some special characters which separate it from private information possessed by an individual – patient information is usually created by medical professionals, not by patients and it is usually used for the best of patients by professionals – it still is sensitive information and hence can be seen as private information.

If we think about personal and private information, it is easy to claim that the rightful owner is the individual person. Nevertheless, when we are dealing with patient information – which is usually collected and stored with some other party – there is possibility to have different interpretations and reasons for ownership. For example, the state (democratic) and its public healthcare sees the information as a tool for taking care of citizens. Therefore, a state can claim and expect that they should own information because they can use it for securing the lives and health of citizens whom the state represents. Likewise, the private institutions and actors that are creating patient

information (private hospitals, doctors etc) most likely want to own information because of the economic value of it.

In chapter two, two notions for patient information is derived From Heidegger's work *Being and time*. First notation is that information can be seen as a tool which appears as like tool does – there is a task (caring people) for which the tool is made. Second notion is the view that information is inseparable part of one's being and cannot be seen merely as a tool. Moreover, patient information should be seen as part of one's person or at least issue which is valuable for understanding about being in this world.

In chapter three, the datenherrschaft – as seen as Heideggerian approach for the patient information ownership – is presented. Datenherrschaft seems to be promising when analysing it with Floridi's ontological theory of informational privacy in the fourth chapter - or to be more precisely, four challenges for privacy theories which are presented in the Floridi's (2006) article. In the conclusion, the needed future work for the developing of the datenherrschaft and its implementation is briefly presented.

## 2. Two notions of patient information

Heidegger's view on modern technology has been receiving a lot of attention but the influence has been lacking in the field biomedical ethics. This may be the outcome of misinterpretations that Heidegger is generally hostile towards technology. Nevertheless, Heidegger was not seeing the medical technology as scrutiny but was worried about the industrial and information technology. He brought out the difference between scientific and phenomenological method in medicine as way to gain understanding of human body as biological organism and as lived body. (Svenaeus, 2013.) Svenaeus offers insight why Heidegger's view of the modern technology is relevant and important for the field of medicine and healthcare. People are not only organism and that point should be noticed and kept in mind when thinking about the meaning of patient information or ownership of it.

From intuitive perspective, the two different notions of patient information can be derived from Heidegger's(1927) *Magnus 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 usually used by healthcare or other medical professionals. Patient information can be used to make proper diagnosis and/or outline the medical treatment plan. In some cases, the information can be used for research purposes to develop new treatments or medications. Of course, the patients themselves can use the information for their own purposes if the information is available and understandable for them – which always is not the case because of the used medical language and way the information is presented. Other notion is that patient information has some deeper meaning apart from being a mere medical tool. Patient information can be seen as information which is very personal and inseparable from individual form it is derived. From that point of view the information begins to appear in a different way compared towards the first notion. The meaning of the patient information is tied up to individual and his or her experience and way of life and thus have more complex and more meaningful aspects.

## 2.1. Patient information as a tool

Heidegger focused on bringing the question of being under deep and permanent investigation. Heidegger was not giving a strict and explicit answer of being in *Sein und Zeit* especially because the project was not entirely completed. Rather, he was trying to clarify the question from different perspectives and emphasising the individual understanding about being – only the person themselves can have an understanding of their *Dasein* (being-in-the-world). Other important aspect while thinking of patient information is how Heidegger describes things like hammer is making appearance. This gives us some insight how to start to approach patient information with the description of ready-to-hand (*zuhandenheit*). Heidegger describes that something is ready-to-hand for some purpose to accomplish – like a hammer is used for some purpose (Heidegger 1927, §18).

Patient information can be seen as a tool for health or instrument for curing the diseases or least giving the patient some relief. This is understandable if we encounter information granted as an item for everyday use – like the healthcare professionals obviously does. Heidegger (1927, §18) shows that objects at ready-to-hand appear to the observer in the context of the world and referring with other things of the world for some purpose. Entities have significance only in their full context, like knife is different thing in kitchen, theatre or in the hand of the criminal (Harman, 2009).

Patient information together with the medical equipment, drugs and etc. are referring to curing the patient and hence it is reasonable to see the patient information as a medical tool for the healthcare professional – for example doctor it is like in his everyday being as professional. It is interesting, that the broke of object is something which is revealing the object as *present-at-hand*(see Heidegger 1927). If the patient information is not usable for the aforementioned curing of the patient, it starts to seem for the healthcare professional as mere facts with no use. However, the information can be meaningful to the patient as information about one's life in this world and this important issue which is pointed later on.

Thus, patient information could be seen as a tool for healthcare professionals to bring some "good" for the patient and they should have control over it and this view is based on how. This tool notion has similarity to the notion that Heidegger(1977) was describing: "The current conception of technology, according to which it is a means and a human activity, can therefore be called instrumental and anthropological definition of technology." Nevertheless, the meaning of patient information is something different that mere instrument which is mastered by some for some goal to achieve. This claims draws support from Heidegger(1977) when he brought out the problem of thinking too lightly about technology and its essence.

Nevertheless, the notion as patient information as a mere tool is inconsistent within the individual dimension of *dasein* and Heidegger's drive for world disclosure (revealing the world and possibilities to be in it). When the doctor is using information for the patient's best without the patient's understanding – which sadly is the situation in many cases – the patient's *dasein* is not always revealed for the patient. Revealing in this context is seen as something which is opening the world for the patient in a medical sense and thus is eventually related to death – or life – and the possibilities of those.

Like Heidegger assert, death is something which everyone must face and it cannot be lived like everyone else does (this means concealing the world behind act which everyone else does in their everyday life and is commonly accepted – *das Man*). The *das Man* is a term which Heidegger(1927) uses to describe the situation where people are hiding or losing being as they can consciously choose to and replacing it with the commonly given ways of being or acting. With outsourcing the healthcare and concealing the unavoidable death to be an area which is taken from our sight we are erasing the great possibility of death; the end of our being which makes our life so beyond a price 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 and release us from *das Man* and replace it with more individual and deeper understanding of being here in the world.

## **2.2. Patient information as inseparable part of one's being.**

Heidegger empathises the need for understanding what is the meaning of being(Heidegger, 1927). The necessity of the question of being is relevant for patient information ownership because patient information can give such insight about one's body and life which may alter one's possible plans or life goals.

People and their experience in the context of Heidegger's approach in his book "*Being and Time*", originally "*Sein und Zeit*" (Heidegger, 1927) is a promising basis for research when the meaning of patient information for individuals is the issue. Heidegger brings forth the meaning of a person's personal experience and studies what it is to be or to exist. Existence and how people experience it is relevant because healthcare is securing and improving the health and life of people – or at least it should be. Hence, we should try to understand one's being in this world and the meaning of it. Hermeneutic and phenomenological views are tied together in Heidegger's work. To have an understanding about being in the world and meaning of our life – where we are thrown – we must understand the nature of being. Heidegger emphasized the need for that question to be asked over and over again for revealing 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 like as "we are in our average everydayness". *Dasein* is thus actually more a question of "who" than "how", because people's experience is how they live through their lives and thereby only they can have the knowledge of their *Dasein*. Heidegger's essential point is that people's experience of their existence is very personal and their own. People have their own lives and those are lived by the people themselves, not by any other. This endorses the idea of people as the prime actors of their own life – or at least they should be the prime actors. Thereby the people themselves have the closest connection to their health information – or at least they should have. Other actors are outsiders when thinking about the experience of one's health and life in the sense of *Dasein*.

Thus, patient information – as it is describing one's existence in medical sense –can be seen as an unseparable part of our being which may provide understanding about our lives and our inevitable death if understood. Thus, by giving too much weight to

healthcare and professionals in it, we are concealing the death and our life and living as everyone is excepted to do (*das Man*). *Das man* cannot face our temporal existence in this world and thus gives the power out of our hands. If people choose to do so, it is their choice and must be respected. The problem is that the healthcare system is designed in such a way that we in many cases are not able to achieve the needed information for informed consent which is seen as an important aspect of ethically acceptable healthcare. We should create such healthcare (information) systems where people are given possibilities to achieve needed understanding about their life and death so that they can choose reasonably their actions and ways of being in this world – whatever it may be. This is an important aspect and a good philosophical ground for healthcare especially if we accept the liberal position when defining a good society. This means that we must start to develop the patient information systems such way that they are accessible for the patients and that the information is understandable for a layman but is out of the scope (and space) of this paper.

### 3. The new way of defining patient information ownership - Datenherrschaft

Thus, the Heideggerian phenomenological and hermeneutic view in context of health seems to support a view that the patient is the justified owner of the patient information, because then people have the right to information when they are experiencing their own life with their illness 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 healthcare organizations need information for 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 is used. The uprising problem is – which comes forth when dealing with ownership – what it actually means to own patient information? Koskinen and Kainu(2013) show that ownership must be defined so that it is taking into account the nature of patient information and the ethical consequences of that definition. Without the proper and accurate definition of ownership it is problematic to further consider the phenomenon of justified use of patient information. In this paper, ownership is seen as *datenherrschaft* (see Kainu & Koskinen, 2012; Koskinen & Kainu, 2013) which seems to be the mode of ownership which could fulfil the tone of *Dasein* if given to the patient. Kainu and Koskinen(2012) presented the definition of Datenherrschaft, which is presented below:

*"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."*

The datenherrschaft (mastery over information) is an ethically acceptable solution to improve individual's privacy, control of their private life and position in information society(Kainu & Koskinen, 2012). Patient information is the sub segment of broader private information area and hence the datenherrschaft should be applicable for patient information, too. If we are thanking the second notion presented in Chapter 2, it is

obvious that there is strong reason with phenomenological justification to grant datenherrschaft for the patient.

Even the term is based on the discipline of law, or jurisprudence; datenherrschaft is very sophisticated, more detailed than common view of information ownership and thus fits to be used in philosophical discussion by nature. Datenherrschaft – if given to individual like Kainu and Koskinen (2012) are proposing – is a fruitful basis when the aim is to understand the meaning of patient information for one's life in a sense of *dasein*. It is reinforcing patients' rights and position towards other actors or stakeholders in healthcare. This is an important factor because the professionals have possibility to exercise power over the patient because of social capital –as knowledge and position in society - they possess (Callaghan & Wistow, 2006). Datenherrschaft implemented as a law would be strong basis and balancing force for healthcare's very professional based worldview. Datenherrschaft would provide possibility for the patient to choose how their personal information is used and by whom. Still, there would be a need for professionals because of their knowledge and experience and that must be recognised. Nevertheless, by shifting power balance in the direction of patient, they have better possibility to take control of their life or wellbeing and have a deeper understanding about being (in-the-world).

Of course, we cannot think and claim that personal information is only for the person themselves and no one can have rights over it in any circumstances. The patient information can be relevant and in some cases even necessary for others. We are living and acting with other people and thus we should consider their part in the world as well. We are all being thrown (*Geworfenheit*) in the world with others and we must live with them (Heidegger, 1927). Like Koskinen and Kainu (2013) stated the 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 others life and health there must possibility for authorities to access the patient information. However, this need should be described as emergency provision and individual whom information is accessed must be informed and the justification of that action must be clearly expressed. Individual's right to patient information is strong and violation of it must be justifiably explicated for ensuring that practice will respect the individual's datenherrschaft over one's own patient information. The question about how these exceptional situations are regulated is issue which falls in the area of jurisprudence and is also out of scope (and space) of this paper, but before actual implementation as law the detailed research within Heideggerian framework must be conducted.

#### 4. Floridi's Four challenges for a theory of informational privacy and datenherrschaft

Floridi was presenting four challenges for informational privacy theories (Floridi, 2006) which his ontological interpretation would cope with (Floridi, 2005, 2006). Even this paper is not literally focusing on the "privacy" the outcome is the privacy and control of patient information. Thus, the use of Floridi's Four challenges is justified. Those four challenges are used for analysing *datenherrshaft* – in Heideggerian sense – as solution

for patient information ownership and like Floridi(2006) states “ ...to cast a better light on why theory is particularly valuable.” Those four challenges presented by Floridi are:

- I. Parochial ontologies and non-western approaches to informational privacy
- II. Individualism and the anthropology of informational privacy
- III. The scope and limits of informational privacy
- IV. Public, passive and active informational privacy

### *Parochial ontologies and non-western approaches to informational privacy*

Like Floridi(Floridi, 2006) shows, the privacy is a term and a concept which is issue which has western baggage on it. Likewise, term ownership was shown in introduction to be problematic and even confusing term. To avoid that ontological problem, the new term datenherrschaft was presented. With using the term which has given more detailed definition than an ownership the problems has been limited and the cultural background is reduced even there is a background(ontological and cultural) of individual who defined the term. Paradoxally, the use of Heidegger's philosophy in analysis is issue which shows that there is always aforementioned baggage. Nevertheless, it is better to have more neutral ontology than try to have” view from nowhere” which is never achievable(Floridi, 2006). It seems that datenherrschaft fulfils the first challenge of Floridi even there still a need or possibility for a deeper ontological research.

### *Individualism and the anthropology of informational privacy*

The second challenge is focusing on individualism and to the possessors of privacy which may also be some other than individual “me” (Floridi, 2006). Floridi presents the different holders and contrasts the difference between western individualism and other views or approaches which value community over the individual. Still, more communal cultures they know still personal responsibility and there is individual capable shouldering it. Thus, there must be understanding about individuality without forgetting the common good when developing theories about privacy or ownership (of patient information).

The datenherrschaft is giving strong support for individual to control their patient information. Nevertheless, the common good or background of community is noticed and for that there is proposal for exceptions for the datenherrschaft. What those exceptions are and how these are regulated can be solved in the cultural context of jurisprudence those are in. even the reasons for those exceptions must be strong and justified like aforementioned in this paper. Thus the datenherrschaft governs the needed balance between individualism and common good, thus fitting in many different cultural environments if implemented accurately.

### *The scope and limits of informational privacy*

The scope of informational privacy is issue where it is easy to lose one's way. What are the limitations of something to be held private and what is the target of that privacy? Floridi gives examples (not presented here, see detailed examples from Floridi's article)



where information violation start to seem senseless because of the given definition of privacy(Floridi, 2006). It seems that too broad and inaccurate definition of privacy seem to have unforeseen consequence and problems which reduce the usefulness of that privacy description.

The problem of scope and limit is solved by datenherrschaft of patient information with strict limitation. The scope is only in patient information and the information is such form that its use is easy to analyze and follow (at least access on it). This limitation – datenherrschaft of patient information compared with wider datenherrschaft of private information (Kainu & Koskinen, 2012) makes it easier to predict a possible outcome and hence strengthens it . Thus, the scope and limitation of this paper/issue fulfills the Floridi's third challenge.

#### *Public, passive and active informational privacy*

Fourth challenge, presented by Floridi(2006) is the issue of different types of privacy: public, passive and active. Whilst defining the *public privacy* Floridi is focusing on the dealing phenomenon of public informational privacy. Because Floridi(2006) is stating that individual's medical records are private not public the outcome is that we need no definition how patient information is handled in public because it is private and thus not should be seen public.

*Passive informational privacy* means the way of acting where we have duty or tacit agreement to be not noticing issues which we get to know but which are private as marital acts even if we know that they have been carried out. On the other passive information privacy means that we have right not to know which must be respected. Those two different sides are both which should be taking account on a theories of informational privacy(Floridi, 2006) The passive informational theory part is giving ideas how patient information should be used. Do not let outsiders hear or see patient information of other – for sake of individual privacy whom information is upon and for sake of outsiders because they have right not to hear it.

Floridi stated "*by "active informational privacy" in the public sphere I mean to refer to those practices that facilitate and foster the development of individuals, by guaranteeing relevant conditions of informational privacy construction"*(Floridi, 2006). We must have such construction which is supports individual privacy and datenherrschaft is legal construction which is emphasizing individual rights balanced with common good. It seems that the fourth challenge is also fulfilled.

## 5. Conclusions

We should have regulation for patient information for creating healthcare which would fulfil the needs of individuals and the needs of healthcare. Datenherrschaft is one promising option for that regulation because it gives the needed emphasis to the individual with the mastery of their own information instead of the current very healthcare centric system. It also fulfils the four challenges for theory of informational privacy presented by Floridi. The main contribution of this paper is that the ownership defined as datenherrschaft has the strong basis on Heideggerian view and it has both

theoretical and practical advantages. It respects the individual privacy and individualism which is the key component when thinking about ones understanding about life in light of Heidegger's work. At the same time, Datenherrschaft is practical in a sense that it gives clear and straight forwarded proposal for legislation even there is a urgent need for defining the aforementioned restriction for the datenherrschaft of patient information. Likewise, the use of the anonymized patient information for medical and pharmaceutical research is issue for future research.

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