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Article information:

To cite this document:
Jani Simo Sakari Koskinen Ville Matti Antero Kainu Kai Kristian Kimppa , (2016),"The concept of Datenherrschaft of patient information from a Lockean perspective", Journal of Information, Communication and Ethics in Society, Vol. 14 Iss 1 pp. 70 - 86

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Received 16 June 2014
Revised 2 December 2014
23 February 2015
Accepted 11 March 2015

The concept of Datenherrschaft of patient information from a Lockean perspective

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Abstract

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.

Design/methodology/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, UK 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, Locke, Ownership, Intellectual property, Datenherrschaft, Patient information

Paper type Conceptual paper

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

Journal of Information, Communication and Ethics in Society
Vol. 14 No. 1, 2016
pp. 70-86

1477-996X
DOI 10.1108/JICES-06-2014-0029

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 intellectual property (IP) as a whole. One, perhaps the most important, reason for this is that some of the fundamental demands and values in health care are not similar to those in general IPRs or common property rights outside of IP. The *raison d'être* of health care is not the promotion of economic activities or to secure individuals' compensation for their contribution, which are protected by IPRs. Health care's purpose is instead the delivery of care for people and the promotion of well-being.

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 Aristotelian 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, re-defined 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. (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 health care 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:

(1) *the state*, to which the citizen belongs;
(2) *the healthcare worker* whose intellectual product the data are;
(3) *the healthcare provider organisation* (public or private) who supplies the environment for the care;
(4) *the organisation that provides the database* (within the information system); and
(5) 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 emphasised, 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, IP, 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.

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. As 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 are 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:

1. 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.
2. 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.

As 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 well-being 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 IP 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 health care 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 (EU) 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 (1963).

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 [2012], 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 equivalent 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, as 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 Online Dictionary, 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, as 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* judgement 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, p. 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 15 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 health care (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 are 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 judgements 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, as 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. 3,032/1997). 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 data 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 health care 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 health care 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 makes 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

IP 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 IP – 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 as modern health care 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 (2003, 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 (2003) 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, 2003, 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) – as 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 (2003, 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 (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 populations 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 USA 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 practice towards 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, 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., in 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 or 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* well-being, 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 the 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.
- Second, 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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Notes

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.
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.
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.

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