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The state of the art of the blockchain ethics in healthcare: A systematic literature review

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Abstract

Blockchain is a software innovation which is based on a cryptographically secured, decentralised, and distributed storage of data. The technological breakthrough was done as a part of and became familiar through cryptocurrencies, where it is used to openly store currency transactions among its users. Blockchain technology has been since proposed and used in various domains ranging from open contracts to electronic voting—as well as in various purposes in eHealth, medical and well-being applications. However, its usage in these sectors possesses several ethical questions as these environments are full of personal and private patient information. To study the state-of-the-art of the *blockchain ethics* in healthcare, this study presents a systematic literature study (SLR) on this phenomenon. By collecting the relevant primary studies from Scopus, the results show that the utilisation of blockchain is swiftly maturing with new research and applications published constantly in this domain. However, the ethical discussion related to the use of blockchain technologies is still taking its baby steps in healthcare. Despite a few openings, ethical research is practically non-existing when compared against the full extant literature on the topic. Therefore, remarkable amount of further work is needed to cover the potential ethical questions related to the adoption and use of the technology.

Keywords: blockchain, ethics, systematic literature review, ehealth, well-being, medical ethics

Introduction

The conceptual idea of the blockchain technology—blocks that are linked using cryptography—was presented 2008 in a white paper written by an anonymous person or persons under the pen name Satoshi Nakamoto [1]. In that white paper, Nakamoto conceptualised the idea of cryptographically secured chain of blocks, which was presented already in 1991 [2].

Cryptography is a key element of any strong information security system as it allows protection for sensitive information as decentralised and distributed storage of data. Therefore, cryptography has become a critical element of international

trade, investments, and e-commerce. [3] The core concept of blockchain is that it uses public-key cryptography, and these public keys are never tied to a real-world identity. In this kind of a crypto-economy transaction, digital tokens, usually referred to as coins, are transferred using the digital signature of a hash function. [4]

The most common example of blockchain is Bitcoin, a digital cash and decentralised peer-to-peer digital currency, which was already presented to the world in Nakamoto's white paper and created after the publication of the paper [1]. Bitcoin is the most used example of blockchain technologies and that has led to that the terminology of blockchain, and Bitcoin can sometimes be confusing—this can be interpreted as a sign that the industry is still trying to shape and establish itself and find new paths to grow [5].

Since the conception of blockchain as a method to implement a digital cryptocurrency a decade ago, the underlying innovation has been accepted and adapted into various different fields [cf. 6,7]. New product and service ideas involving implementation of blockchain technology has been proposed from e-voting to logistics management, and from e-commerce solutions to the digitalisation of agriculture—as well as in medical imaging [8], electronic and personal health records [9], in identity verification [10] or for storing insurance information among many other solutions [11].

It has been seen that blockchain offers a wide selection of future opportunities and the revolution of this system, which will create distributed consensus for the digital world, has just begun. Although Bitcoin is the most common example of blockchain, both financial and non-financial areas are finding blockchain technology and concepts useful. The adaptation of blockchain has been rapid and even big companies such as Nasdaq and Microsoft are already using blockchain technologies in their daily operations. [12] It has been stated that now is the time to look at blockchain beyond Bitcoin, because blockchain capabilities are almost unlimited [13].

However, when technology is designed, it always has inbuilt values [14]. Most of those values are not necessarily ethical values [15], but rather other values, such as communication which is inbuilt in our mobile devices. But quite often, if not always, some of those values either are directly moral values or at least have moral consequences [14]. Technologies are not neutral—often they are not meant to be either good or evil [16], but can have such consequences none-the-less [14]. This is especially relevant in healthcare (including eHealth, medical and well-being sectors).

Please consider the following small example on this. Nuclear energy is not an "evil" technology, but nuclear weapons were created through it. It is hard to claim that nuclear weapons have other than two purposes: fear and destruction—fear of retribution with them, and if retribution (or, in extreme situations a first strike) is enacted, massive amounts of death and suffering results. The example is of course quite drastic, but we hope it illustrates the point clearly. (See e.g. [17]).

Technologies such as mobile technologies are more subtle; but for example, currently in the COVID-19 crisis, it has both been suggested, and also implemented that mobile devices are used for purposes they were not specifically designed for: for tracking our travel to presumably only track the spread of the virus. Suddenly it is "ok", according to various governments, for us to lose what little of our privacy we still have for "security". [18] Fortunately a lively civil society discussion, led by ethicists and privacy experts arose. Thus, it is of utmost importance to look at the various values in

technology and analyse which of them are ethically relevant and which are not, and see to it that those values which are, are taken into account in the design when possible, and either strengthened if they are positive values—or eliminated if they are morally negative.

The above discussed dilemma of a new technological innovation, with its underlying ethical questions, conquering the new domain areas drives this study. We are especially interested in ethical questions and discussion related to blockchain solutions in healthcare. This motivation is pragmatic – while blockchain could offer new technological innovations for this sector, also the ethical questions and consequences are more prevalent than in, e.g., financial technology sector. For example, while an individual's bank account number can be changed after an information security leak, an individual's genome or personal health records cannot be.

Therefore, the aim of this paper was to shed light on the ethical considerations relating to blockchain technology in healthcare. For this study, we focused purely on academic discourse concerning blockchain. Specifically, this study focuses on the following question:

RQ What is the state of the blockchain ethics research in healthcare?

For this study, we defined blockchain ethics as an ethical study of blockchain technology, its application or moral philosophy questions in organisations, or larger entities, caused by the usage of blockchain technologies and solutions.

The current state of blockchain research overall has been fascinating researchers and there are numerous systematic literature reviews to map and find new directions for the future research (for example, Scopus returns 366 results with the query of blockchain and "literature review" as of February 15th, 2021). A literature review found out that large amount of blockchain research is focusing on the topics of privacy and security issues [19]. The research focus has been focusing around Bitcoin, although researchers point out that to enable the large scale implementation of blockchain for other areas, such as life science or arts, requires more detailed research about the possibilities, challenges and learnings from blockchain technologies.

Ethics of blockchain has also interested researchers but the way they have been handling the topic of ethics has varied [20]. A recent study deducted a conceptual framework for blockchain ethics [21]. The model is a three-by-three matrix, where one axis refers to level of review (micro, meso or macro) and the other axis refers to development from technologies to applications, and finally to ethical impacts of the technical choices. While the study is a literature review, they do not report the numbers of primary studies found, handled or included. In addition, the study does not have a section discussing inclusion and exclusion criteria for the selection of the primary studies.

The number of blockchain research has grown rapidly past few years. A recent study points out that the ethical studies of blockchain were focusing more on legal dimensions of cryptocurrencies and blockchain [22]. The philosophical (and thus also ethical) and ontological dimensions of cryptocurrencies and blockchain technology were still underrepresented in the research, representing only 3% of all of the blockchain research. This indicates that more deeper understanding of philosophical ethics is needed around the research of blockchains—especially in the healthcare where ethical questions are inbuilt to the technology.

Material and methods

We used a systematic literature review (SLR) method to collect the primary articles. A systematic literature review is *"a form of secondary study that uses a well-defined methodology to identify, analyse and interpret all available evidence related to a specific research question in a way that is unbiased and (to a degree) repeatable"* [23, p. vi]. For this study, we followed the procedure of SLR proposed by Kitchenham and Charters [23] for the use in the computing discipline. It is followed by a review of ethical theories used in the analysis.

Selection of primary studies

For this study, we utilised a process that is described in Figure 1. We started with a preliminary study to verify whether there were recent existing systematic reviews and whether there was enough content for the review (Phase 1). In this phase, we also tested various different search terms and databases in order to retrieve maximum amount of relevant studies. In the end, we selected the simple combination of

ethic* AND ("block chain" OR blockchain)

as the search term. That is, we required that the study used both key concepts in some writing form. A more detailed analysis of the relation to the themes at hand was done manually in later phases. This selection was justified due to the multitude of key terms used in healthcare research.

Table 1. Inclusion and exclusion criteria for the third phase of the selection.

Inclusion criteria	Exclusion criteria
• Written in English • Peer-reviewed • Focuses on blockchain technologies in the context of healthcare	• Reporting language is not English • Not peer-reviewed (e.g., book reviews, editorials) • Blockchain is only mentioned • No discussion on ethics

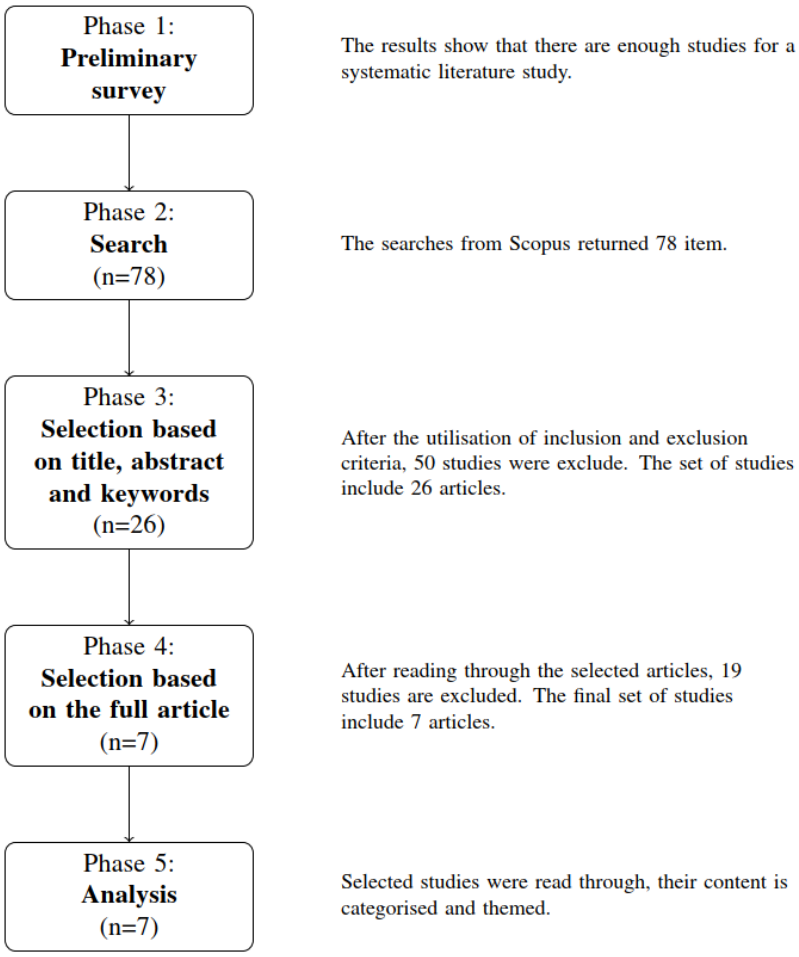

Figure 1. The process model of this research.

In addition, we decided to focus on Scopus publication database. It was selected as it incorporates a large amount of different databases from various fields and organisations. Involving more databases did not yield better results in the testing phase.

The actual selection of the relevant primary studies was done in three steps. In Phase 2, we queried all relevant articles with the search term and stored their metadata for later phases. The search was done in March 2020. This returned 78 peer reviewed articles. In Phase 3, two authors went through all 78 articles and decided based on the exclusion and inclusion criteria (see Table 1) whether an article should be included or not. For the analysis, the authors used the title, abstract and keywords. In this phase, we did not require an article to discuss healthcare explicitly in order to collect all relevant articles discussion blockchain ethics as many of the discussed approaches could be used in eHealth sector also. In cases of disagreement, an article was included for the next phase. A total of 26 articles were selected in this phase.

In Phase 4, all of the articles were read by the authors to study whether an article discusses any aspects related to healthcare research or development. We required that an article explicitly stated in the main text the connection to these

themes, but such a statement did not require to be in the abstract, title or in keywords. Finally, we selected 7 peer-reviewed original articles to be included into this literature review.

In the last phase, Phase 5, of the research process of this study, the final set of the selected papers were analysed. Specifically, we focused on their ethical discussions through the lenses of the major moral philosophical theories. Due to the small number of the primary studies involved, we utilised straightforward content analysis approach. The primary studies were read through by the authors and their ethical aspects were then identified according the selected major ethical theories. In the reporting, we will report ethical aspects related to the question at hand.

Analysis model

We analysed the papers based on three well established ethical theories; namely, utilitarian [see e.g. 24], deontological [see e.g. 25] and contractarian [see e.g. 26] approaches. These three theories were chosen because they are classical theories, widely used and accepted as well as they were suitable for this kind of analysis. Virtue-ethics [see e.g. 27] was discarded as a suitable theory, as the topic area did not fit well with it, and since virtue-ethics is oriented more towards personal moral growth rather than analysing the ethical impact of systems. Due to the limited length of this report, interested readers are referred to the original sources for more thorough description of these theories.

In utilitarian ethical theory [24], the consequences of the target of analysis are paramount; does the system create good or bad results for those impacted by it. We looked at whether the consequences related to the issue are mentioned in each article or not, and are the results ethically significant. Although the theory was originally about specific acts, it has since been extended to any actions, including those done by systems used by humans. In the analysis of the papers looked at this is visible in whether the authors have taken the ethical consequences of blockchain technology into account, and how—and whether—that is visible in the paper under analysis. Consequences are the most typical ethically meaningful concerns when analysing system usage. They are easier to notice, and are independent of the intentions of the system designers. In the papers below where ethics have been analysed, we attempt to find the ethical consequences mentioned, if any.

In deontological analysis [25], the main target is the intention of the system. Is the aim of the system to impact the life of those it affects positively or not, and whether the design of the system shows that its designers felt a duty towards those affected. In deontological ethics, each person (or rational being) is considered to be an end in themselves, i.e., a morally meaningful entity, towards which we have duties, such as not lying to them, or valuing their wellbeing. Intentions are harder, but often in design not impossible to show. Although traditionally, and Kant [25] indeed claimed this himself, it has been thought that intentions of individual people are extremely difficult to verify (people lie, after all, and their internal states are typically impossible to fathom), in system design this is often possible. Typical example where it is possible are certain types of games, such as casino games and many freemium computer games where the whole intention is to keep the player playing as long as possible, with the knowledge, that on average, they cannot win, but will instead use more and more money on the game. [28] Again, as with the consequences in the papers analysed below, we will look into whether intentions are mentioned when ethical aspects of

blockchain use in health applications is gone through in them.

Finally, the contractarian approach looks at stakeholder groups and whether they can negotiate a social contract from a position of rationality that benefits everyone [26]. This is often, even typically, not the case, as various parties to the development and use of the application wield different amounts of power, and thus can affect the design and use of the application in different amounts. Some also play organisation internal, or even inter-organisational power games, which result in skewed end results for the stakeholder groups. (See e.g. [29] or [30]) However, as a theoretical tool, a contractarian approach can be used to analyse whether the kind of balance that benefits all, and especially those in the weakest position have been achieved. This is again something we will look whether it has been used when analysing the individual papers in this review.

All three of these theories were visible in at least one of the analysed papers in one form or another. It is good to notice that we are looking at two different kinds of ethical questions: practical ethical questions, i.e. how to avoid a known ethical dilemma, and true ethical questions to which we do not know an answer, and thus the issue has to be resolved also from an ethical perspective, not just as an action taken to ensure an ethically valid solution.

Results

The papers found to contain blockchain and ethics, and which were in the healthcare area are shown in Table 2. In the following, we will analyse them one by one individually due to the low number of relevant articles found.

Table 2. The papers containing blockchain and ethic in the healthcare area.

#	Authors	Year	Title
1.	Calvaresi et al. [31]	2019	*”The good, the bad, and the ethical implications of bridging blockchain and multi-agent systems.”*
2.	Duong-Trung et al. [32]	2020	*”Smart care: Integrating blockchain technology into the design of patient-centered healthcare systems.”*
3.	Fernando et al. [33]	2020	*”Blockchain technology for pharmaceutical drug distribution in Indonesia: A proposed model.”*
4.	Kendzierskyj et al. [34]	2019	*”The transparency of big data, data harvesting and digital twins.”*
5.	Kuo et al. [35]	2019	*”Fair compute loads enabled by blockchain: Sharing models by alternating client and server roles.”*
6.	Rasmussen et al. [36]	2018	*”Gap analysis for information security in interoperable solutions at a systemic level: The KONFIDO approach.”*
7.	Shabani [37]	2019	*“Blockchain-based platforms for genomic data sharing: A decentralized approach in response to the governance problems?”*

While transparency and safety are clearly ethical questions, only transparency is something not legally required and can be considered a real ethical question. Answer to it seems obvious from the article by Fernando et al. [33]: blockchain can ensure traceability of pharmaceutical drugs, and thus increases transparency, and through it verifiability of the validity of the drugs supplied, thus increasing safety in drug use. Thus the consequences of using blockchain are clearly visible, and a utilitarian approach is used in the paper to analyse the situation. We were left to wonder however, whether the solution actually is ecologically sound as is claimed [33], as blockchain tends to need high processing power to function.

The issue in Duong-Trung et al. [32], protection of patients' clinical data, is more a legal question than an ethical one. The ethical question has been underlying the legal requirement, of course, but the topic itself has basically been solved: we need to use safeguards to see to it, that the clinical data does not fall in wrong hands. What is needed, are effective measures to actually see to it that the measures are put in place and followed. [32] All three approaches have likely been used when the laws have been passed, but in the paper, they are not visible when ethics are discussed.

Even though Kuo et al. [35] do address healthcare, they also basically just acknowledge that there are limitations regarding ethical, legal, and social implications. Unfortunately, they do not go into any detail regarding the ethical implications. Thus, looking at the paper through an ethical lens is not really fruitful.

Security and data privacy, as pointed out by Rasmussen et al. [36] are of course ethically meaningful. However, there are both national and international laws in place to ensure these. Even if the data is exchanged across borders, actual ethical questions do not figure strongly, except maybe in declining the transaction. Declining the transaction needs to be considered in relation to the laws of the potential receiving country however, and whether they guarantee same level of security and privacy as is required in the sending country. Also, there is really no ethical analysis of the situation in the paper. [36] The paper does not, when handling ethical issues, refer to any of the above mentioned theories or their occurrences: intentions, consequences or stakeholder negotiations are not visible.

Shabani [37] points out the same privacy and sharing issues as were true in the previous article by Rasmussen et al. [36]. The paper introduces basically only one new interesting technological issue from an ethical perspective, namely genomic data—but most of the issues pointed to in this paper are already handled by Rasmussen et al. [36] in a more generic context. On other fronts the paper of course has plenty to add to previous research, but alas, not from an ethics perspective, although we found it positive that the author had pondered these questions.

Tracking malicious actions [see e.g. 31, p. 13], per se, is not an ethical issue, as it is clearly unethical to conduct malicious actions, and that needs to be stopped. This is, in and of itself, both an intention and consequence related. It is good that this has been noted, and that solutions to avoid it are put in place. In this paper, blockchain technology is more clearly considered a negotiating form, which reminds us of a Rawlsian approach to ethics, although not done in the same form, and thus does not fulfil a contractarian ethical approach. Also, since blockchain technology is in some ways equal to the participants (although it is pointed out in the paper that this is actually not always the case), this impression is strengthened. In the paper posi-

tive consequences of the technology are clearly spelled out, although the health connection is, at best, tangential, visible mainly through a couple examples [31].

In the article by Kendzierskyj et al. [34] there are true ethical questions relating to internet of mobile things (IoMT) devices. The consequences of how these devices and the applications analysing the data they gather can be very important to large amounts of people, and we do not have clear answers on how to solve the issues they raise. Even the intentions of those creating these applications can be suspect in some environments, such as insurance or governments, which are not necessarily designed for the benefit of the users of the systems, but for the benefit of the organisations. Discrimination and especially segmentation can be intentional, and thus harm the target. The use of IoMT devices can be appropriated to causes for which the systems have not originally been intended — or have been intended, for that matter, such as following ”the enemies of the state”. Also, as pointed out in the paper, privacy issues either through reverse engineering or just plain following the data, if relevant safeguards are not in place, are present. Once blockchain is used, the data is permanently pinned, and if it can be identified to a person once, then it can be done again and again, and the ethical consequences of that can be horrifying for the person. As pointed out above, both the design and use of such systems can be intentionally harmful to the user. Thus, both deontological and utilitarian considerations are very visible in this paper.

For the other topics handled in the paper by Kendzierskyj et al. [34] blockchain is not used at all. The paper does not tie blockchain to the potential ethical problems presented, e.g. digital twin use in eHealth or potential targeted terrorist uses of health data.

Thus, of the seven papers analysed very few combine eHealth and blockchain in a meaningful manner—and unfortunately, the other papers which handled ethics and blockchain do not handle healthcare related topics at all. The area demonstrably needs more research before much on the topic can be said.

Discussion

Key findings

We summarise our key findings into following points:

1. There is an ever-increasing number of studies published in blockchain and health, well-being and medicine. While there are already over 300 literature reviews on blockchain, only a handful of articles related to healthcare touch ethical questions of the innovation. Practically, the research on these issues is non-existing.

2. Overall, a number of designs, frameworks and architectures have been published on blockchain and motivated by claiming an ethical approach towards the subject. However, a closer look on these studies reveal that while the intention certainly might have been good, there are no actual analyses or discussion on ethical consequences on blockchain utilisation in healthcare.

On the one hand, this reveals a commonly shared concern regarding the pitfalls of blockchain technologies and solutions. That is, several scholars have defined an ethically justifiable solution to be one of the key characteristics for their system and they have

shared this in report of their study. On the other hand, the lack of further analysis of actual ethicality of the proposed artefact further pinpoints the lack of common methods, tools and ethical analysis framework for blockchain ethics.

3. Blockchain technology has touched these different areas broadly. For example, there are studies devoted from various areas, ranging from digitalisation of agriculture to supply chain logistics, smart contracts, sustainable development and governmental services—as well as various use cases for blockchain in healthcare solutions. In addition, a number of scientific disciplines have been involved in the research. This observation emphasises the need for ethical analysis of the proposed solutions as the technology's adaption is spreading.

4. Whereas there has been an increasing interest towards blockchain—as well as, e.g., artificial intelligence—ethics in the recent years, the ethical approach remains superficial or even non-existing in many of the studied articles. However, most of these studies were devoted to discussing ethical challenges of blockchain. For example, often the studies did not refer to any ethics or computer ethics sources, but instead used, e.g., GDPR as a starting point for an ethical discussion; the problem with this is, that GDPR is a law, not an ethical framework. Also, in many of the papers there might be a mention of ethics only in the topic of the paper and then only in discussion—and even there only briefly.

The findings presented in this study emphasise the need for a concrete tool or tools, framework, or method to analyse the ethical aspects of healthcare blockchain solutions. As nearly half of the studies (being present still in the third phase of the research process used) aimed to present an ethically justifiable blockchain solution for a specific problem, there is a call for an easy-to-use method, tool or framework. In addition, as it is likely that the users of the method, tool of framework are not experts in computer and medical ethics, the tool should be usable and well-guided also for non-professional users.

Avenues for further work

First, further work would be required to developed an ethical apparatus for researchers and practitioners for helping to evaluate ethical considerations. A special concern should be paid to developing a concrete tool, with guidelines, which can be utilised also by practitioners without deep understanding on moral philosophical questions and schools of thought; a tool which first clarifies the questions the developers have, then the stakeholder groups and finally potential ethical answers which can solve the ethical issues in the design of blockchain solutions.

Second, the extant literature is lacking studies moving into higher abstraction levels from blockchain technologies. Currently, the focus has been on immediate effects generated by the technology and larger discussion on the implications is not quite non-existing but still remains marginal compared to the mainstream discussions on blockchain ethics. For example, there exists calls for privacy and transparency, but hardly any other issues are addressed.

Third, as research on ethics in different stages of software engineering and computer science is receiving growing interest, more attention has to paid to the real meaning of ethics. Thus, researchers should acknowledge what has been done in other fields of ICT and ethics and look for some solutions from there instead of trying to reinvent

the wheel. Of course, blockchain will bring its own questions as well, and these need novel solutions, but many of the more general issues have already been handled elsewhere, and these solutions can be used in relation to blockchain.

Limitations

This study has its limitations. First, all systematic reviews with electronic search strategy are limited by the representativeness of the search term. While we tested various different search terms before selecting the used one, it is still unlikely that we have been able to capture studies utilizing all of the different terms for the same phenomenon. Further work should aim to systematize the used terms and concepts.

Second, we used qualitative analysis on the selected primary studies, which is always limited to the observations and emphasis set by the researchers. Yet, this study can serve as a starting point for further literature studies in blockchain ethics.

We analysed the selected papers for common themes and research areas. The results show that there is an increasing attention to the theme whereas there seems to be a lack of usable ethical tools, methods and frameworks for blockchain ethics. In addition, the results show that the research domain is maturing fast and blockchain is spreading into various industrial domains. In addition, this study showed that blockchain ethics discussion remains often artificial and the study calls for further work to define and systematize the domain.

Conclusions

This paper presents a literature review on recent studies relating to the ethical aspects of blockchain technologies and solutions in the areas of eHealth, medicine and well-being. We used a systematic literature review method to collect the data from Scopus publication database and selected 7 primary studies to be included. Overall, the papers do not handle blockchain's ethical impact on the healthcare industry either very widely or deeply. This leaves a clear research gap in the field with the increasing importance of blockchain in the field and in IT development in general. This is of course, to a degree understandable, as the evolution of blockchain beyond cryptocurrencies—primarily, but not only Bitcoin—is still fairly new and mostly on research, rather than development stage. However, it is important that, especially due to healthcare sector's delicate nature this research is conducted along the development of any applications that may have issues with privacy or, on the other hand transparency; understandably from different directions of these issues. Especially when it comes to IoMT devices, specifically those tracking our health, the implications can be far reaching if the applications connected to these devices are not developed with great care. But other issues, such as cross-border data delivery that is based on unalterable blockchain information may prove problematic if the legal systems do not match, and protection guaranteed in one is not guaranteed in another, as all provided data is locked into the chain permanently. These questions amongst others raise a worry in the authors that is hopefully unwarranted, but which needs to be taken into account when moving forward with the use of blockchain technologies in healthcare.

Conflict of interest

The authors do not have any conflict of interest.

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