Exploration of Health Data Management Systems; a Scandinavian Point of View

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Abstract. In the era of digitalization, healthcare has become highly dependent on data management. As a result, health data management systems have become increasingly important in cost reduction, treatment improvement, and healthcare procedures enhancement. This study explores blockchain-based health data management systems and their development factors in the context of smart city assets. The features and challenges of blockchain-based development solutions are explored based on the General Data Protection Regulation act and Regulations for the Directorate for e-Health of Norway. Latent Semantic Analysis correlation examination and word cloud analysis were conducted on scholarly documents and Tweets and a conceptual smart asset development framework for health data management systems has been proposed from a Scandinavian point of view. Moreover, based on the findings, this paper proposes a conceptual patient-centered blockchain-based architecture for the development of current health data management systems in Scandinavia.

Keywords: Health Data Management, Scandinavia, Blockchain.

1 Introduction

In the era of digitalization, healthcare has become highly dependent on data management. As a result, health data management systems (DMS) have become increasingly important in cost reduction and treatment improvement of healthcare procedures [1]. This digital transformation of healthcare has empowered healthcare with diverse digital services like electronic health records, patient monitoring, family-rooted disease diagnosis, treatment enhancement, integrated health datasets, etc. However, challenges like big data, reliability and security have also risen simultaneously [1]. Plus, the International Institute for Management Development (IMD) reports that, due to digitalization, concerns have been raised regarding personal freedom limitations and potential misuse of the personal data collected during the digitalization process [2].

In addition, recently, data subject-centricity has been added to the criteria of any eligible health data management system. Korea, as a developed country, has changed its governmental attitude towards its DMS in the medical, financial, public, logistic,

cultural, communicational, educational, and energy field [3]. This global movement toward data subject-centricity in healthcare has been named differently across the world. Nonetheless, all of them share the same content, which is the rightfulness of data subjects in making proactive decisions regarding sharing and transferring their data [3].

According to the most recent patient-centric approach in the health sector, especially the health data management sector, it is believed that blockchain (BC) technology can enhance the security and reliability of patients' data. The combination of BC and the transformation of healthcare to a patient-centered approach helps consolidate and exchange patient data across interoperable health systems [4]. While thinking of BC as a solution for health data management, it is important to notify challenges like cost, data size, and privacy [5]. The benefits and challenges of BC applications in the health sector indicates that the issues of traditionalism of the current systems and immaturity of BC solutions may lead to problems such as lack of interest in self-managing health data, interoperability of complex health systems, cyber-attacks, and resource consumption [6].

This study aims to explore health data management, BC, and regulatory matters from the point of view of the scholars and users in Scandinavia with the help of text and social media mining to extract the common beliefs around BC-based health DMS and user-centricity. Considering the significant role of a patient-centered health data management system in a Scandinavian context and the rich infrastructure and technological approach toward implementation of innovative solutions [2, 7], this study investigates the possibilities of conceptualizing a BC-based data subject-centered health data management system that is compliant with the GDPR and Directorate for eHealth regulations. Accordingly, the research question is:

What is the common belief around blockchain-based data subject-centered health data management systems, and what blockchain capabilities can resolve related challenges?

To find answers to the above research question, this study used the smart asset development framework to explore possible BC-based developmental solutions for current health DMS. The common scientific belief regarding such a solution was extracted from prominent scholarly publications and the common user-centered belief will be extracted from Twitter users in Scandinavia. A complementary BC-based patient-centered literature investigation was conducted based on the requirements of the GDPR and the Regulations of the Directorate for e-Health to propose possible conceptual development models from a Scandinavian point of view.

2 Related Literature

2.1 Health Data Management System: A Smart Asset

Smart City Index (SCI) reports the perception of those who live and work in the cities and defines a smart city as "an urban setting that applies technology to enhance

the benefits and diminish the shortcomings of urbanization for its citizens" [2]. These indexes assess the perception of residents on factors related to structures and technology applications implemented in their city. Nordic countries are in an increasingly ongoing collaboration with information technology companies for the enhancement of data analytic products or smart assets in favor of cost-saving and cost-efficiency in services, and health services are one of five public services that work in the framework of smart cities [8, 9]. Smart assets include the dimensions that help their strategizing, evaluation, and development the most [9]. Consequently, any health DMS as a smart asset that delivers digital public health services must consider the drivers and related dimensions of smartness in their designs. In a health DMS context, policies refer to GDPR and Directorate of eHealth regulations, technology refers to the infrastructure, and community refers to the users of health DMS.

Data is the core of any DMS and is a symbolic representation of observable or non-observable properties. In other words, data are the givens of any kind that leads to information, knowledge, and wisdom [10]. DMS store, process, retrieve, and deliver structured, unstructured, semi-structured, and streaming data to support data organization [1]. The storing process can adopt different technologies based on the defined procedures of data storage. Also, data processing minimizes the data service costs by handling the volume and reduction of unwanted data, and data accessing is focusing on the retrieval of data from the data warehouse [1]. Utilization of personal health data has a direct relationship with the willingness or resistance to disclosure of personal medical data. This utilization must consider consent-based use of personal data as a vital fundamental element and requires a specific personalized service architecture for patient-centered health data management [3].

Most of the existing health DMS use centralized servers that are prone to single point of failure vulnerabilities, insider attacks, and loss of control over outsourced data while decentralized solutions can tackle such a flaw [11]. New technology may help overcome these challenges; however, they bring up other challenges as well.

2.2 Blockchain-Based Health Data Management System

Consortium BCs seem to fit the requirements of personal data management. For instance, the Gem Health Network uses Ethereum's BC technology to help all medical stakeholders access the same integrated health information. GHN provides real-time authorized access [12]. Switzerland has implemented a BC system using Hyperledger based on their standard of healthcare messaging format and a common consensus between the hospitals. This has resulted in integrated healthcare actors and provides secure health device tracking [13]. Any BC-based health DMS should consider the Health Insurance Portability and Accountability (HIPAA) act of 1996 and GDPR [5]. These privacy rules categorize any individually identifiable health information such as demographic and genetic information, that is transmitted or maintained in any form or medium, as Protected Health Information (PHI) [14].

One of the most recent published frameworks of health data management that have been proposed using BC and AI as complementary technologies to notify the strength and prerequisites of BC-based health DMS [15]. This BC-based framework has been

designed to tackle the current unagile and provider-centered health DMS. Key stakeholders are defined as patients, providers, payers, pharma, researchers, regulators, and government. Patients are put at the center of the system by being entitled to full access, control, and ownership over their health data. [15]. This patient-centered approach is required to acquire GDPR-compliancy by enabling privacy protection and incentivization. Moreover, it can elevate patient-centered health service provision. However, other stakeholders are also critical and vital [15]. After all, by exploring different methods of BC implementation for health data management, one can understand that BC has strengths and challenges, and implementation is highly dependent on the nature of regulations and healthcare procedures [13].

This study explores BC-based health DMS from a Scandinavian point of view through the theoretical framework of Smart Asset Development to explore possible BC-based developments for the current health data management from a Scandinavian point of view [2, 8, 16].

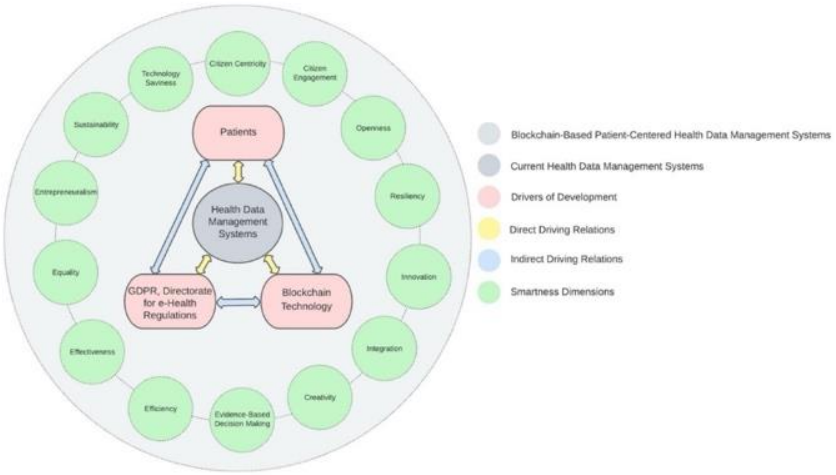

Fig. 1. Health Data Management Development Framework [Adapted From 9, 16].

Health DMS are considered smart assets of a smart city and technology, policy, and communities are the drivers of its development [16]. Not every smart asset entails all the dimensions shown in Fig.1 [17]. Accordingly, Fig. 1 depicts the framework for a BC-based development of the current health DMS in a Scandinavian context.

Since GDPR and regulations of the Directorate for e-health are the imposing rules for handling health data management in Scandinavia, they are put instead of policy [16, 18, 19]. Moreover, considering the importance of a patient-centered approach in handling health data management in Scandinavia, patients are put instead of communities [2, 7, 16]. Finally, due to the high-tech infrastructural richness in Scandinavia and considering the importance of creative solutions for smartness sustainability, BC technology, as a disruptive technology, is put instead of technology [2, 8, 16].

3 Research Method

Since this research aims to explore health DMS from a Scandinavian point of view to draw out the challenges and proposition of BC-based data subject-centered solutions, the inductive approach has been chosen to present a possible conceptualized model after exploration, data collection, and analysis [20].

3.1 Data Collection

For data collection and data mining, Twitter and Rstudio were used due to their capabilities in the extraction of opinions and sentiment analysis, to understand the scholars' emotions and beliefs around BC technology, GDPD, and regulations of the Directorate for e-health [21]. To understand the patients, as the other driving factor in the smart asset development framework, tweets were collected to achieve a general understanding of their emotions and beliefs around the driving factors. In this regard, two methods were mixed; first, top-quality publications were extracted, and then regulatory documents regarding GDPR, and e-health regulations were added to the selection.

Step one provided 193 documents. Second, the Rstudio programming tool was used to extract data from the 193 documents and the Twitter website. To ensure privacy, collected data from Twitter were anonymized by removing usernames and no names are mentioned in the results. The main sources of data are saved on an internal hard drive with encrypted access. To collect and clean the data, a Twitter Research and a Google Cloud Platform account were created to acquire Twitter API and Google API tokens to be able to use packages and libraries of rtweet, geolocation, lsa, nlp, wordcloud2, etc. [21, 22].

193 documents were categorized into four groups based on their keywords, abstract, and conclusion. These four groups were BC, e-health and BC, data management, and security, privacy, or GDPR. This way it is possible to conduct a thorough document analysis via Natural Language Processing tools that explore emotions, beliefs, negativity, positivity, and neutrality in texts like SentimentAnalysis, and even correlational relationships between a set of documents like Latent Semantic Analysis [21, 22].

The same process of collecting and cleaning the data was conducted for tweets while tweets were categorized into twelve subcategories with three main categories of data management, e-health and BC, and security, privacy, or GDPR each consisting of a subgroup of Norway, Finland, Sweden, Denmark. This way, it is possible to analyze the collected tweets based on text, keywords, hashtags, and locations. Ultimately, different visualization and exporting methods were used to export the analyzed data from Rstudio [21].

3.2 Data Analysis

The most frequent words and concepts of each category were extracted with the help of the RStudio tools to investigate the most important concerns of each category. Moreover, the total emotion around each category and the relationship between the categories were extracted to investigate the common beliefs of scholars around the driving

factors. To extract the most important concepts in the category of e-Health and BC documents, as the technology factor, and its relationship with the category of the documents that include GDPR, security, and privacy, as the policy factor. For this purpose, wordcloud and wordcloud2 were used to extract the most frequent concepts and words both in the pdf texts and in the tweets [22, 23]

To acquire a holistic approach to the attitudes of the scholars and patients, the Natural Language Processing (NLP) and Sentiment Analysis tools from Rstudio were used. This way, the neutrality, negativity, or positivity of the pdf texts and tweets about the driving factors are possible to extract [22, 24]. Latent Semantic Analysis (LSA) was used to create a well-connected representation of the publications and tweets. LSA creates a latent semantic space of concepts and words from publications and tweets, and then links these spaces and extracts the coherence of the concepts in them [22, 25].

4 Findings

The results section is divided into three subsections of collected data, attitudes, and relations. The collected data section relates to the amount of collected data and its relationship with the health data management development framework.

4.1 Collected Data

Publications are divided into data management and its development driving factors based on the smart asset development framework. Tweets are divided into data management and its development driving factors from the smart asset development framework. This division has been made to display data both about the data management as the smart asset itself and about its development driving factors.

Table 1. Collected Tweets

Keywords of the Tweets				
Location of Tweets	Smart Asset	Smart Asset Development Driving Factors		
		Technology	Policy	
	Data management	e-Health/Blockchain	Security/Privacy/GDPR	Total
Norway	100	2,752	6,321	9,173
Sweden	52	1,127	3,781	4,960
Denmark	2	55	284	341
Finland	26	993	1,984	3,003
Total	180	4,927	12,370	17,477

The focus of this study is on a BC-based patient-centered development for the current health DMS in Scandinavia. Accordingly, keywords, abstract, and conclusion of 19 publications were especially regarding data management, which is a smart asset in our development framework, 163 were including BC and 71 were including e-health and BC which are the technology factor that drives our smart asset development framework. Also, 52 publications were especially regarding security, privacy, GDPR, and regulations of the Directorate for e-Health in Norway. Finally, 193 publications were

collected and divided into the smart asset and its development driving factors. However, there is still another development driving factor which is the users that influence the smart asset development.

Table 1 shows the tweets of the tweeter users that are considered as users or patients of the smart asset. The results of 30 days of Twitter data collection that has resulted in the collection of 17,477 tweets. A general view of the results indicates that users are the most concerned about security, privacy, GDPR, and related topics. 70.8% of the collected tweets are in this category.

4.2 Most Discussed Concepts and Attitudes

The most frequent concepts and attitudes were extracted from the publications about data management and its technological and regulative driving factors, which are BC and security and privacy-related documents.

Table 2. Top 10 Discussed Concepts from the Publications and Twitter Sources

Top 10 Discussed Concepts					
Source	Smart Asset		Development Driving Factors		
			Technology	Policy	Communities
	Data Management		Blockchain/e-Health	GDPR/e-Health Director/Security/Privacy	Patients
	Publications	Blockchain	Technology	Blockchain	No Direct Data
		Healthcare	Smart	Data	No Direct Data
		Technology	Security	Healthcare	No Direct Data
		Information	Network	Smart	No Direct Data
		Security	Information	Technology	No Direct Data
		Network	Access	Information	No Direct Data
		Smart	Application	Security	No Direct Data
		Applications	Management	Network	No Direct Data
		Access	Privacy	Access	No Direct Data
		Privacy	Transaction	Applications	No Direct Data
	Twitter	Services	Crypto	Data	No Direct Data
		Utilities	Bitcoin	New	No Direct Data
		Systems	NFT	People	No Direct Data
		Customer	Ethereum	Cybersecurity	No Direct Data
		Help	Web	Need	No Direct Data
		Analytics	Metaverse	Right	No Direct Data
		New	Decentralized	GDPR	No Direct Data
		Time	News	Threat	No Direct Data
		Needs	Gaming	Social	No Direct Data
		Research	Project	Think	No Direct Data

They were mined both solely and in integration with each other. Tweets were mined in three categories of data management, e-health and BC, and security, privacy, and GDPR. Table 2 indicates the most discussed concepts based on the health data management development framework. After 3 times of publication text mining, the concepts of technology, information, security, network, smart, applications, and access have appeared 3 times in the most discussed topics. The BC, healthcare, and privacy concepts each have appeared 2 times, and management, data, and transaction concepts each 1

time. Interestingly, after 3 times of tweet mining, none of the most discussed concepts on Twitter have appeared with the same name; however, they are highly related to some of the other concepts. Their relation will be discussed in the discussion section.

To identify the sentiment of the publications and tweets, a sentiment, negativity, positivity, and polarity analysis has been made based on the smart asset development framework.

Table 3 indicates that 687,702 words from the publications and 242,261 words from tweets have been mined which is an aggregate of 929,963 mined words.

Table 3. Sentiment Analysis from the Publications and Twitter Sources

Sentiment Analysis of Attitudes						
Source		Smart Asset		Development Driving Factors		
				Technology	Policy	Communities
		Data Management		Blockchain/e-Health	GDPR/e-Health Directorate/Security/Privacy	Patients
	Publications	Word Count	121,652	494,131	71,919	No Direct Data
		NegativityIG	0,05847862	0,057411292	0,076636743	No Direct Data
		PositivityIG	0,163541296	0,172581769	0,213943785	No Direct Data
		SentimentIG	0,105062674	0,115170477	0,137307042	No Direct Data
		NegativityQDAP	0,035730617	0,034460107	0,053484551	No Direct Data
		PositivityQDAP	0,112967389	0,118324755	0,155297153	No Direct Data
		SentimentQDAP	0,077236772	0,083864648	0,101812602	No Direct Data
	Twitter	Word Count	3,392	63,527	175,342	No Direct Data
		NegativityIG	0,04852878	0,052658364	0,085900945	No Direct Data
		PositivityIG	0,223531406	0,152597192	0,228006948	No Direct Data
		SentimentIG	0,175002626	0,099938827	0,142106003	No Direct Data
		NegativityQDAP	0,021457515	0,032472618	0,061337936	No Direct Data
		PositivityQDAP	0,163212573	0,114466818	0,17004787	No Direct Data
		SentimentQDAP	0,141755057	0,0819942	0,108709934	No Direct Data

4.3 Relationships

A Latent Semantic Analysis (LSA) was conducted to extract the correlations between the elements of the smart development framework. In the context of this study, data management is the smart asset, BC represents the technological driving factor, and security, privacy, GDPR, and regulations of the Directorate for e-Health represent the policy factor. Furthermore, Patients represent the community factor which is the Twitter users in our data collection.

A latent semantic space was created to be able to examine the correlations between the elements based on the Pearson method. The publications and tweets were categorized into seven subsets of documents to explore the correlation between them.

Each correlation between each two of these seven subset documents represents one of the direct or indirect relationships between the elements of the smart asset development. There are three two-way relationships between the smart asset development driving factors and three two-way relationships between the smart asset and its three development driving factors. Fig. 2 shows three different correlation groups that each

represent the sets of correlations when users talk about either data management, BC and e-Health, or security, privacy, and GDPR.

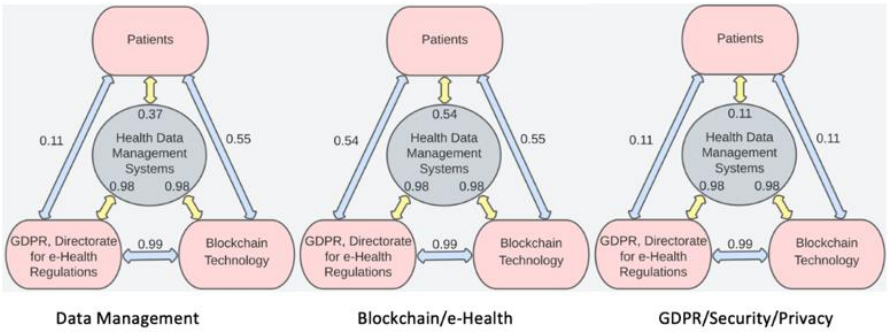

Fig. 2. Correlation Groups Divided by Users' Discussed Concepts

As depicted in Fig. 2, a general view of the correlations reveals that when the users discuss BC and e-Health, their notions correlate the most with the health data management smart development framework extracted from the publications. However, when they discuss data management correlations decrease a bit, especially regarding policy factors. Finally, when they discuss GDPR, security, and privacy their notions are somehow not correlated at all to the framework. It is noteworthy to remind, correlations that come from health DMS and their technology, and policy factors are calculated from the discussed topics in the publications. This differentiation of correlations will be explained in detail in the discussion section.

5 Discussion

The contribution of this study is to explore the common belief around BC-based developments for the current health DMS. This exploration is patient-centered and includes real anonymized data from Norwegian, Swedish, Danish, and Finnish users.

5.1 Blockchain-Based Health Data Management Development

Looking at the distribution of the documents from the publications shows that there is a vast amount of text supporting health data management and its development technology and policy factors. In 19 publications discussing data management, the concepts of BC, healthcare, technology, information, security, network, smart, applications, access, and privacy have been the top 10 discussed. The coexistence of information and healthcare amongst the top 10 discussed concepts shows that the publications have also pointed out the importance of healthcare data management as it was also perceived by the Norwegian citizens as one of the most significant indicators of their country [2]. Moreover, the coexistence of smart, technology, BC, and applications amongst the top 10 discussed concepts shows how publications relate to the applications of BC in the smart asset development framework that defines technology and policy as the driving

factors of health data management development [16]. In addition, the coexistence of security, privacy, and access among the top 10 discussed concepts shows how publications prioritize policy-related matters in health data management as it also has been significantly important for both smart asset development and for Scandinavian users [2, 16].

71 e-Health and BC-related publications have discussed the concepts of technology, smart, security, network, information, access, application, management, privacy, and transactions the most. Here also, the coexistence of smart, technology, information, application, and management deliver the importance of BC uses in healthcare data management developments based on the smart asset development framework [16]. Technological advancements have pushed healthcare data management toward BC; however, security, privacy, and access concerns are also coming along with it [26, 27]. Interestingly, here among the top 10 discussed concepts in e-Health and BC, there are security, privacy, and access that confirm their significance in a BC-based healthcare data management development.

5.2 Patient-Centricity of Health Data Management System

Looking at the distribution of the tweets from the users indicates that users are discussing security, privacy, and GDPR-related concepts the most. Only 1% of the tweets are discussing data management and the top 10 discussed concepts are services, utilities, systems, customer, help, analytics, new, time, needs, and research. The coexistence of the mentioned concepts indicates the fact that users prioritize services and utilization of health DMS the most as it has also been identified by the Directorate for e-Health. Directorate for e-Health defines patients as the most important part of the architecture and entitles them the right to follow their treatments, decide about their treatments, repeat advice during the consultation, seek reassessment, choose selective accession for anyone other than themselves, and know the holders of their information [28]. Moreover, the coexistence of the concepts of customers, help, and needs clarifies the importance of user-centricity or patient-centricity in a Scandinavian health DMS as it has also been pointed out that Nordic countries are well-known digital service providers who engage the citizens with public institutions by collecting combinable data from them [8].

The combination of BC and the transformation of healthcare to a patient-centered approach helps consolidate and exchange patient data securely across interoperable health systems [4]. Consent-based use of personal health data is vital and requires a specific personalized service architecture for patient-centered health data management [3]. A patient-centered health DMS elevates personalized treatments, and entitles the rights of control, access, and sharing of data to the patients; however, a shift from the current centralized to a decentralized health care system is required [15]. BC, distributed ledgers, smart contracts, consensuses, etc. help overcome the challenges of patient-centricity, security, and privacy [11]. However, it brings up challenges like cost, data size, and privacy [5].

5.3 Attitudes

Interestingly, all the publications and users have shown positive sentiments about the health data management BC-based development. Publications discussing data management have shown positive IG sentiment of 0.10 and users discussing data management have shown positive IG sentiment of 0.17. However, these are not clearly positive attitudes, and based on the most discussed concepts, these may have been impacted by security, privacy, and access concerns from the publications' side, and by the help and needs concerns from the users' side. It is also indicated by the scholars that policy-based accessing is one of three fundamental processes of any DMS [1, 29]. Although Scandinavian users are not clearly positive about DMS, Nordic countries are increasingly using analytical tools like health DMS to provide management with information about clinical and financial aspects of the organization [8]. Accordingly, a patient-centered approach that perceives the patients as the owner of their data can increase engagement and interest in patients for managing their health data [8, 11, 15].

When discussing e-Health and BC, publications and users have shown a positive IG sentiment of, respectively, 0.11 and 0.09, although not a clear positivity. As a result, from the publications' side, there are concerns about security and privacy. However, BC-based medical data protection is a powerful tool that provides confidentiality, authentication, integrity, and defined access if designed based on a framework that signifies architecture, data integrity, data sharing, access control, distributed data, patient encryption key, framework, and algorithm [30, 31]. Users have shown a positive attitude toward the uses and applications of BC.

5.4 Proposed Development Solution

Scandinavian governments are increasingly digitalizing public services like health data management, and Norway, as a sample, has been doing it leadingly in the framework of smart cities [2, 3, 8].

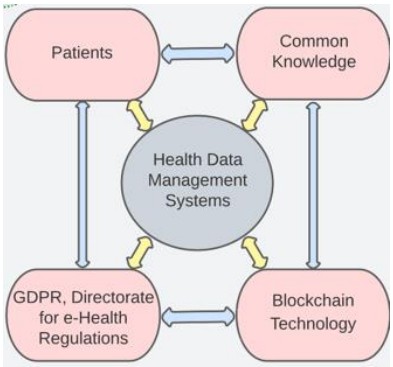

Fig. 1. Proposed Blockchain-Based Patient-Centered Health DMD Framework

If a BC-based patient-centered development is ever required, there should be a shared common knowledge factor for successful implementation [7]. This common

knowledge factor includes public knowledge regarding the regulative, technological, and core factors of health data management, as illustrated in Fig. 3. It has been previously mentioned as technology savviness, one of the smartness dimensions in the government [9]. However, in the case of health data management development, it is a driving factor that should be considered an infrastructure for the development [7].

In the literature, complexity, miscomprehension, and user acceptance were mentioned as some of the challenges of BC technology [6, 32]. However, the proposed common knowledge factor aims to fill the gap and notify the users of health DMS about policy rights, interoperable abilities, technological utilities, and self-managed health data protection.

This framework proposes the concepts of Electronic Health Wallet (EHW), off-chain permissioned BC, and tree-based ledger and linear sub-chains to create a health DMS that stores data lawful, fair, transparent, restricted, encrypted, accurate, erasable, integrated, confident, and accountable, as requested by GDPR and the Directorate for e-Health [18, 19, 28]. This EHW allows the patients to access their up-to-date health data in a real-time manner [5]. EHW should be able to collect data from IoT devices, EHRs, and patients, and use the measures provided by the data management layer to authorize users, manage accessions, and apply incentives [5]. This study proposes to minimize the main actors of the EHWs to patients and healthcare service providers.

6 Conclusion

Digitalization has empowered healthcare with various digital health services like electronic health records, patient monitoring, disease diagnostic, treatment enhancement, etc. On the other hand, it has brought big data, reliability, privacy, and security challenges and has made healthcare highly dependent on health data management [1,2]. Moreover, recently, patient-centricity in health data management has been emerging as a must [3]. Different regulations like the GDPR act, HIPAA act, or the regulations of the Directorate for e-Health all share the same rights which define the patients as the owner of their health data and the ones who make proactive decisions regarding sharing their data [14, 18, 19]. In addition, Nordic countries are prominent world leaders in public service digitalization with the help of data they collect from their citizens. This elevates the citizens' engagement with the public institutions [8]. One of these public services being digitalized in Scandinavia increasingly is the health services [8]. Accordingly, our work has investigated health data management development in the framework of smart asset development [16]. In this regard, health data management development driving factors are explored both from the point of view of the publications and Scandinavian Twitter users. It is believed that BC can enhance security and reliability; however, it may bring some challenges also [4].

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