UiA University of Agder

Master's Thesis Project Report

Mapping the Path to a Health Data Marketplace in Norway:
An Exploratory Case Study

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“Don't stop when you're tired. Stop when you're done.”

- David Goggings.

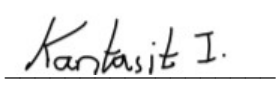
Ex-United States Navy SEAL, ultramarathon runner, triathlete, World Records holder, public speaker.

PREFACE

Our supervisor, Prof. Ilias Pappas, introduced the concept of Data Marketplaces as a potential topic for our master's thesis. To delve deeper into this subject, we conducted a comprehensive literature review on Business Models for Data Marketplaces and interviewed IT industry experts. Through this process, we collaborated with the IT consultancy firm, Egde, and gained invaluable insights into their investment in e-health with their Egde Health Gateway solution. This newfound understanding of Data Marketplaces, Business Models, and the Norwegian e-health landscape sparked our interest and became the foundation for researching this topic.

We want to express our sincere gratitude to everyone who supported us throughout the writing of this thesis. Firstly, we thank our supervisors, Ilias Pappas, and Polyxeni Vasilakopoulou, for their constant guidance and invaluable feedback. We would also like to thank the interview subjects who generously shared their expertise and time. Additionally, we appreciate our partnering firm, Egde, especially our supervisor from their side, Ann-Elizabeth Ludvigsen, for their contributions to our research, including access to essential information and providing us with several interview subjects. We would also like to thank our fellow IT master's students for their companionship and shared experiences within the master's room at UiA, in the cafeteria, and elsewhere. Finally, we thank our families and loved ones who supported us throughout our academic pursuits.

Kristiansand, 01.06.2023



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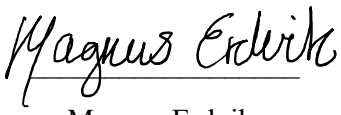

Magnus Erdvik

ABSTRACT

This Master's thesis explores the complex dynamics of health data in the digital age, focusing on its secure and efficient management and ethical considerations. It investigates the potential of implementing a Health Data Marketplace (HDM) in the Norwegian e-health sector, aiming to construct a seamless health data exchange platform. This study proposes the integration of an existing health data gateway, the Egde Health Gateway (EHG), with the HDM.

The research offers an in-depth analysis of existing limitations in health data exchange systems in Norway. It addresses current research gaps in Data Marketplace, Business Models, Gateways, and the Norwegian e-health context. Guided by two central research questions, this thesis delves into identifying essential components required to successfully implement an HDM in Norway and how this marketplace could be established using an existing data platform. Significantly, the thesis underscores the pivotal role of primary stakeholders in the HDM - Platform Operators, Platform Users, and Legal Authorities. The exploration reveals that Platform Operators are vital influencers, fostering collaboration and innovation within the ecosystem, while Platform Users and Legal Authorities ensure the marketplace's innovative and compliance aspects.

Additionally, this study identifies essential components for successfully integrating an HDM into an existing health data platform, including Data Standardization, Interoperability, Integration, Security, Trust, and Legal Frameworks, among others. The thesis marks a significant step towards realizing an HDM in the Norwegian e-health sector. It invites future research to broaden stakeholder perspectives, examine economic aspects of the HDM, and delve into ethical considerations and technological innovations. The findings from this exploration serve as a catalyst for leveraging health data effectively, securely, and ethically, contributing to improved healthcare outcomes, research, and innovation in Norway and beyond

Keywords: Health Data Marketplace, Data Marketplace, Health Data, Data Sharing, Data Exchange, Gateway

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1 INTRODUCTION

Accelerated data usage and data collection have rapidly risen in recent years in this digital era; data has emerged as a fundamental asset, shaping diverse sectors and economies worldwide. The global data landscape has experienced a significant expansion, with data volumes expected to reach 175 zettabytes by 2025, compared to two zettabytes in 2010 (Reinsel et al., 2018). The rise of smart devices, IoT technologies, and sophisticated sensors has driven this transformation, underscoring the importance of data in generating insights and informing strategic decisions within organizations. Following this trend, digital platforms called Data Marketplaces (DMs) have emerged, encapsulating the economic value of data and facilitating its exchange (Abbas et al., 2021; Stahl et al., 2014). In the healthcare sector, these marketplaces hold immense potential. The rapid digitization of health services, in tandem with advances in data science, has resulted in an unprecedented accumulation of health data. This data can improve healthcare services, drive medical research, foster health-related innovations, and increase societal sustainability presenting an invaluable resource (Emberland & Rørtveit, 2016; Pappas et al., 2023).

However, the sensitive nature and complexity of health data require a cautious approach to processes involving handling, security, efficiency, and ethical use. By focusing on the Norwegian e-health context, this master's thesis delves into the intricacies of designing and implementing a Health Data Marketplace (HDM) capable of addressing these complexities by presenting the main components that need attention. HDM can facilitate the exchange and trade of health-related data between multiple actors, such as healthcare organizations, researchers, technology companies, and individuals. Such marketplaces incorporate mechanisms to govern data usage, ownership, and the rights and responsibilities of different participants involved in the data exchange. An HDM can unlock the value of health data by enabling responsible and controlled sharing, fostering collaboration, and promoting innovation in healthcare.

The thesis explores how the HDM solution can utilize Egde Health Gateway (EHG) as its platform infrastructure. EHG is a state-of-the-art data gateway developed by the consulting firm Egde, facilitating seamless data flow between systems and stakeholders in the Norwegian health sector. EHG is a testament to effective data integration, ensuring the exchange of standardized data formats, compatibility with various APIs, and supporting data conversion and storage. It further underscores data security through authentication via the Egde IAM (Identity Access Management) component and compliance with local regulations by operating in a private cloud in Norway (Egde, 2023).

1.1 Motivation for the Study

In the context of international health informatics, Norway distinguishes itself by providing reliable and good-quality health data, mainly attributable to the utilization of a singular, standardized personal identifier, which significantly facilitates the combination and analysis of such data (Bakken et al., 2020; Direktoratet for e-helse, n.d.; Saunes et al., 2020).

Since 2017, the Directorate for E-Health has invested significant resources and collaborated closely with researchers and partners to enhance services for citizens, researchers, and patients across Norway. The primary focus of these development efforts lies in essential functions, including enabling quicker and more secure access to health data. The overarching objective is to apply research and innovation to improve public health, facilitate research, and stimulate business and national economic growth (Emberland & Rørtveit, 2016; Helsedata, n.d.). Several innovative solutions have emerged from these investments, including the Helseanalyseplatformen (Health Analysis Platform) and Helsedata.no. The Health Analysis Platform aimed to optimize health data usage, enhance understanding of diseases, and develop better medications and treatment methods, enabling researchers to interconnect and utilize data across stakeholders in Norway more effectively. Despite its promising and innovative premise, the initiative stopped on December 15, 2021, due to legal and technical challenges related to adequately protecting the data (Direktoratet for e-helse, 2021a, 2021b).

In contrast, Helsedata.no, a part of the health data program focusing on healthcare infrastructure and services, has successfully been established. This platform hosts numerous data and facilitates health data access for research, quality improvement in health services, medical development, and other health-related projects. While the platform primarily targets researchers, healthcare services and commercial enterprises can also benefit. Although Helsedata.no is unique within Norway, operating with data from various sources, it has its limitations. The confinement of data sources to specific categories such as central health registries, national medical quality registries, national health surveys, biobanks, and socio-economic data, and a complex and strict access request process may restrict ecosystem growth and usage, limiting its potential (Helsedata, n.d.).

The observed limitations within present-day health data exchange systems inspired us to delve deeper into their potential. To do this, we embarked on a comprehensive literature review, focusing on DMs, Business Models, Gateway technologies, and the nuances of the Norwegian e-health context. Through this process, we identified critical gaps in our understanding of implementing an HDM solution successfully.

The literature highlights the importance of thorough case studies on DMs and their providers (Fruhwirth et al., 2020) and suggests the need for more research into novel marketplace solutions that tackle niche issues within the DM ecosystem (Bergman et al., 2022; Chakrabarti et al., 2018; Figueredo et al., 2022; Ito, 2016; Rahmani et al., 2015). Research areas that need expansion include understanding the privacy of sensitive data in DMs (Chowdhury et al., 2019; Nguyen & Ali, 2019), creating standardized data formats, and improving interoperability between systems (Giordanengo et al., 2018). Also, there needs to be additional research on data governance frameworks and their influence on DM dynamics (Paparova et al., 2023). Furthermore, the lack of in-depth case studies and research on innovative solutions specific to HMDs highlights the necessity for more rigorous investigation.

1.2 Research Questions & Research Approach

The current study is strategically placed within the research gaps to address these complex issues within an HDM context through an exploratory case study. By doing so, the thesis seeks to offer valuable insights that could be critical for the practical, theoretical, and ethical development and operation of HDMs. The study uses the EHG solution as a case, leveraging its robust infrastructure and the expertise of its operators to propose an HDM framework as an extension of the existing solution. The objective is to map the components required to establish a secure, efficient, and collaborative platform for health data exchange. The extension of EHG with the HDM solution would balance the essentiality of data privacy and security with the demand for data accessibility, fostering growth and development in the Norwegian health ecosystem. Due to the constraints of existing health exchange systems, our primary focus is on health researchers as the target users of the solution.

Hence, this study is guided by two primary research questions (RQs):

RQ1: "What are the essential components for successfully implementing a Health Data Marketplace for researchers in Norway?"

and

RQ2: "How can a Health Data Marketplace be established using an existing data platform?"

To address these RQs, a dual philosophical research approach has been adopted, integrating interpretive and pragmatic perspectives (Myers, 2021; Chua, 1986; Goldkuhl, 2012). This blend provides a comprehensive understanding of the complexities within the research context while maintaining practical, real-world relevance.

Semi-structured interviews (SSIs) are conducted based on a guide developed from an extensive literature review (DeCarlo, 2021; Oates, 2006). The design employs a

purposive sampling strategy to select participants within the health ecosystem whose experiences and perspectives form the core of the data (Palinkas et al., 2015). This method enables the exploration of unanticipated themes and can be tailored to the participant's background and expertise (Clifford et al., 2016; Kallio et al., 2016).

Data analysis follows a systematic approach per Oates (2006) and Miles et al. (2014), assisted by NVivo software for coding the raw data into themes (Gioia et al., 2013). An inter-coder reliability approach is adopted to enhance the validity and reliability of the results (Kurasaki, 2000). Inherent in the study design are ethical considerations to safeguard the rights and information of the participants. This includes obtaining informed consent, adhering to data security measures such as encryption and password protection, and restricting data access under the NSD agreement (NSD - Norsk senter for forskningsdata, n.d.).

This research goes beyond the technical aspects of implementing an HDM, envisioning a future where health data effectively enhances healthcare services, research, and innovation within Norway. By exploring the practical, ethical, and societal implications of establishing an HDM, this study contributes to the broader discourse on responsible and effective usage of health data in a rapidly evolving digital landscape. As we delve into this topic, the subsequent chapters will uncover the complexities, challenges, potential solutions, and the significant impact an HDM could have on the Norwegian healthcare landscape.

1.3 Structure of Thesis

The thesis unfolds as follows:

Chapter 2 – Research Background: provides an in-depth look at the relevant preliminary works, setting the context for our study.

Chapter 3 – Research Approach: outlines the chosen research design and the philosophical perspective that shapes the exploration.

Chapter 4 – Findings: presents the data gathered from our interviews, offering insights into the empirical data that underpins our conclusions.

Chapter 5 – Discussions: compares the findings from our interviews with the results gleaned from existing literature. This comparison provides a robust understanding of our research context. Furthermore, the proposed framework is presented, with components and stakeholder responsibilities.

Chapter 6 – Implications: delves into our comprehensive analysis, covering theoretical, practical, societal, and methodological aspects. This chapter evaluates the system's impact and potential and explores future research directions in this domain.

Chapter 7 – Conclusion: summarizes and concludes the thesis.

2 RESEARCH BACKGROUND

Data Marketplaces (DMs) enable the sharing and exchange of health data, fostering collaboration and accelerating scientific discoveries (Abbas et al., 2021). The increasing availability of health data and advancements in data analytics has led to growing interest in using health data for research (Emberland & Rørtveit, 2016). This master's thesis explores the topic of Health Data Marketplace (HDM), specifically in the Norwegian context. The motivation for this study stems from a comprehensive literature review on the topic of challenges and opportunities with DMs and conversations with Egde, a Norwegian IT consulting firm responsible for creating the Egde Health Gateway (EHG), a data gateway system designed to facilitate data sharing within the Norwegian e-health domain (Egde, 2023).

2.1 Preliminary Work

Initially, we conducted a systematic literature review on DMs and their accompanying business models. We titled the literature review *"The Value Proposition of Data Marketplaces"* to see what values they can bring to their private and public stakeholders. The literature review gave us a deep understanding of the concepts and highlighted the several benefits of such marketplaces and the technical, legal, and financial challenges they face.

Various sources, including electronic health records, medical imaging, and genomic data, characterize Norway's current state of health data. However, challenges persist regarding data accessibility, interoperability, and governance (Emberland & Rørtveit, 2016). Egde's EHG solution addresses these challenges by providing a secure and standardized platform for health data exchange, contributing to a more integrated and efficient health data ecosystem (Egde, 2023).

Preliminary findings from stakeholder interviews emphasize the necessity of such a marketplace in addressing the current gaps and challenges faced by health researchers in Norway. This fact has made health researchers in Norway the target audience for the proposed solution in this study. This solution could extend the pre-existing health data-sharing capabilities of Egde's EHG gateway system. In the next section, we will present an updated literature review on business models for DMs, considering the added topics of Gateways and the Norwegian e-health context.

2.2 Literature Review

The existing literature on DMs, including HDMs, provides valuable insights into their potential benefits, challenges, and business models. This literature review section will assess the current literature on DMs, Business Models, Gateways, and the Norwegian E-Health landscape. Additionally, we will identify gaps in the literature to which our study seeks to contribute.

2.2.1 Method

To explore and summarize existing literature on the research topic, we have utilized a systematic approach for the literature review process. The purpose is to identify gaps, understand the current literature, and create a foundation for our thesis. There are three main phases of the review process. The first phase is planning the review, the second is conducting the review, and the third phase is where we present the review findings (Webster & Watson, 2002). By combining models inspired by several authors (Danielsen et al., 2022; Kitchenham, 2004; Webster & Watson, 2002), we devised the following model visualized in Figure 1.

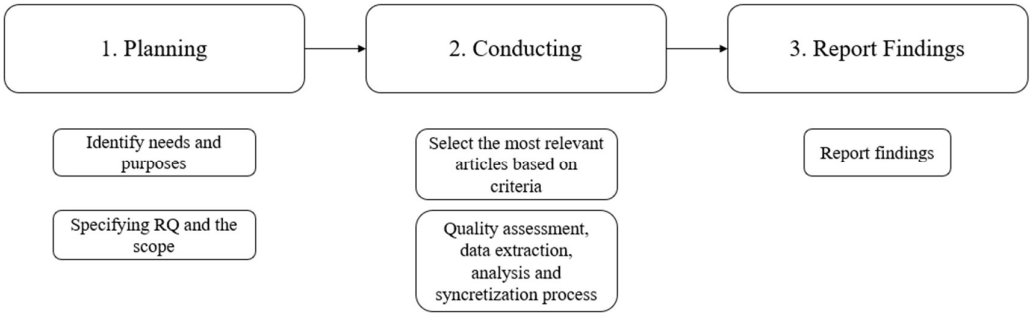

Figure 1 The Review Process

2.2.2 Planning

In the planning process, the first step involves identifying the motivation and objectives to refine the research questions (RQs) (Danielsen et al., 2022; Kitchenham, 2004; Webster & Watson, 2002). This process began with a comprehensive exploration of the field, which enabled us to gain a high-level understanding of the relevant concepts. Upon acquiring a general knowledge of the field, we examined the existing research gaps and

considered our motivations to formulate precise RQs. Subsequently, we initiated a focused literature search using relevant keywords. To facilitate a clear overview of the essential concepts, we have developed Table 1. These concepts are what we deemed most important based on our preliminary work, motivations, and initial RQs. The concept "Data Marketplace" and "Business Model" are derived from the preliminary work while adding two new concepts, namely "Gateway" and "Norwegian e-health Context." We added "Gateway" to give a better understanding of the literature on Gateways since EHG, in this study, is a critical factor in enabling health data sharing in the Norwegian context (Egde, 2023).

Furthermore, we had little initial knowledge of the Norwegian e-health context from the literature. We added this concept to get the perspective from the literature on the e-health situation in Norway, as this will be the focus area for the DM. Table 1 showcases the main concepts and the related concepts we deemed appropriate.

Table 1 Main Concepts

Main Concepts	Related concept
Data Marketplace	Data, Data exchange, Data trading
Business Model	Business strategy, Business value
Gateway	Data transformation, data routing
Norwegian E-health Context	Information systems, Laws & privacy policies, Health data

2.2.3 Conducting

The conducting phase of the review process started by using the main concepts in Table 1 as the search string. We used the database Scopus due to its user-friendly design and reliable features, including the fact that all articles are peer-reviewed and the possibility of using advanced functionality for searching and exporting data (Scopus, n.d.). We also utilized the database provided by the Norwegian Centre for E-health Research (NCER) to obtain relevant articles about the e-health situation in Norway, as this was not as easily obtainable through Scopus (Norwegian Centre for E-health Research, 2023).

We have chosen to divide the searching process into three iterations. Since our preliminary work mainly focused on Data Marketplaces and Business Models, we also need to research the other concept of Gateway and Norwegian E-health Context. To fine-tune our search for DM, we used the keyword "data marketplace" and limited it to English

articles, finding 226 in total. We omitted “business models” from the search string to explore more than just the connection between the two concepts. This approach helped us find articles on various aspects of DMs and their related concepts (Table 1). Table 2 shows the search string used.

Table 2 Final Search String for Data Marketplace & Business Model

Final search string
TITLE-ABS-KEY (“*data marketplace”*) AND (LIMIT-TO (LANGUAGE, *”English”*))

For the Gateway concept, we used the keywords “gateway” and “health” or “healthcare.” These keywords yielded 758 results on Scopus. The result was too large, so we sorted the results by the top 50 most cited articles for our literature review.

Table 3 Final Search String to Cover the Gateway Concept

Final search string
TITLE-ABS-KEY (“gateway” AND (“health” OR ”healthcare”) AND (LIMIT-TO (LANGUAGE, “English”))

At the time of our literature review, the NCER database had published 2130 articles in their database. To pinpoint relevant resources for our study, we applied the keywords “data sharing,” or “health data,” or “data exchange” as a filter (Table 4). This filter produced 140 entries, which we deemed appropriate for the review process.

Table 4 Final Search String to Cover Norwegian E-health Context

Final search string
TITLE-ABS-KEY (“data sharing” OR ”health data” OR ”data exchange”)

We needed to exclude less relevant articles from the results to choose the most relevant literature for the review. In this article selection process, we went through the papers one by one, following a specific method inspired by Danielsen et al. (2022); the process has

six steps, all with exclusion criteria, filtering out papers less relevant to the research purpose (Figure 2).

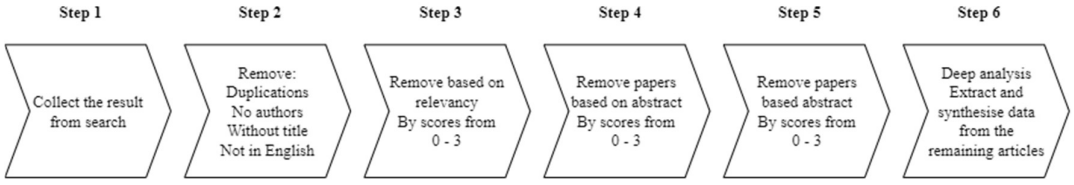

Figure 2 Article Selection Process

Besides the requirements through each step, we also have other criteria to support the selection process; Table 3 illustrates these criteria for the articles.

Table 5 Inclusion Criteria

Inclusion criteria	Further description
Peer reviewed	It is a conference paper or a journal paper. The article evaluated by other peers is more likely to be scientifically valid and have high quality.
Empirical	Results from experiments or observations.
Defined research method	The process of data collection and analysis should be transparent so that it is possible to assess its validity.
Content related to the concepts	The content of the papers should relate to the concepts in Table 1.

The papers for this literature review were selected in three different iterations, using two databases, as illustrated in Figure 3. The first iteration centered on the concept of DMs and Business Models. The initial stages of this process were straightforward; however, the steps from the third stage onwards presented more challenges. This part of the process necessitated reading and analyzing numerous papers, each scored on a scale of zero (not relevant) to three (very relevant). Upon completing the fifth step, we identified 18 papers that met our requirements with a score of two (relevant) or three (very relevant). After refining the RQs, we reassessed these articles and found three overly technical and less relevant, leading to their removal. Similar selection processes were conducted concerning Gateway articles and papers relating to the Norwegian e-health context. Applying the inclusion criteria detailed in Table 5, we filtered our selections to 21 papers within our research field. Though this was a sufficient number of articles, our supervisors later

recommended two additional relevant papers. After carefully reviewing these additional sources, our final paper count came to 23.

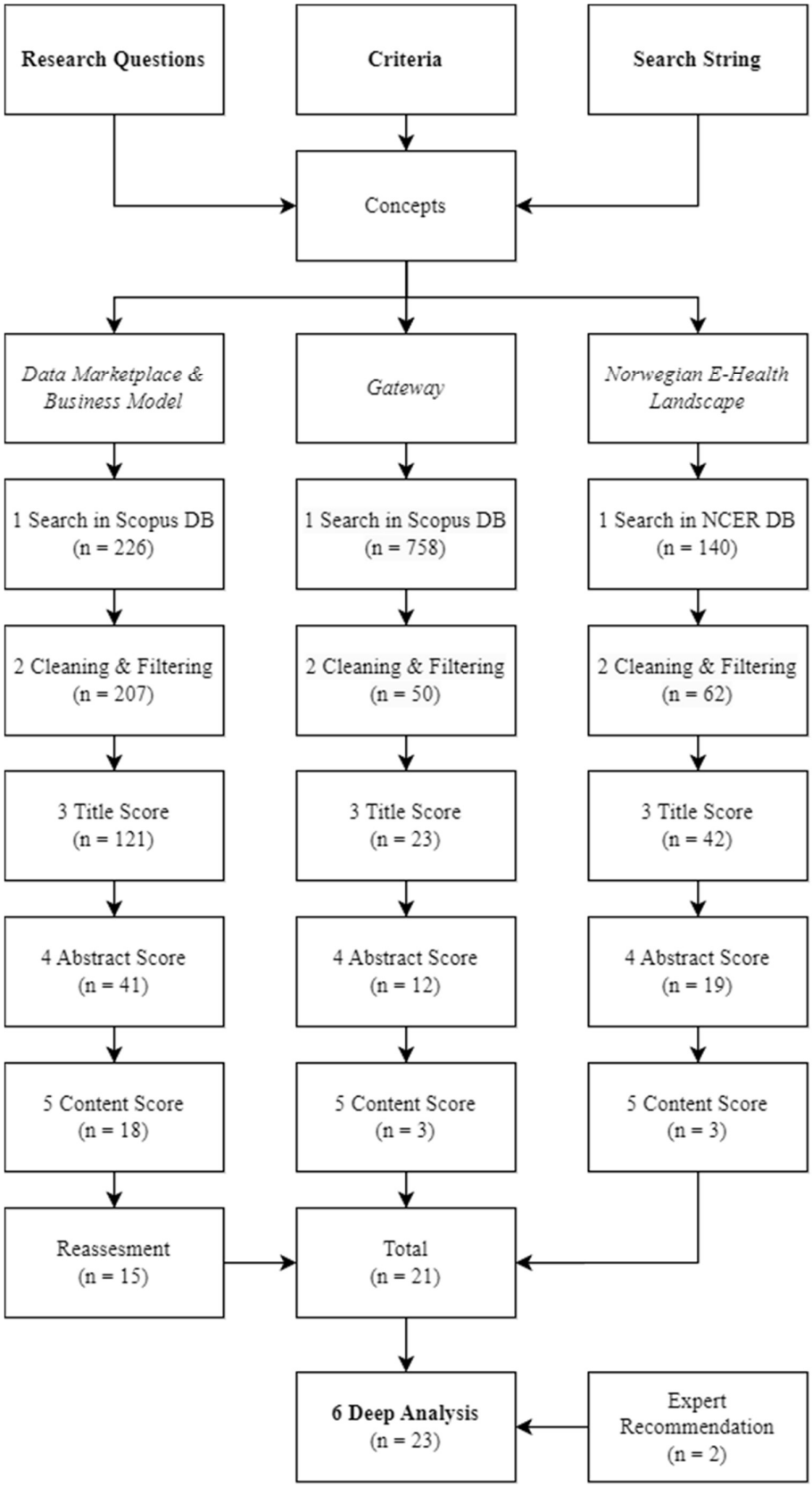

Figure 3 Illustration of the Article Selection Process

2.2.4 Results

This section presents the findings of the systematic literature review conducted in the previous phase. As mentioned, we have carefully identified and analyzed 23 highly relevant articles. The selected articles, along with their titles, publication years, authors, and respective conference or journal names, are listed in Table 6.

The chosen articles shed light on various aspects of the topic. Many focus on the present state of DMs and their potential for creating value and establishing effective business models. Additionally, some papers delve into the intricacies of data transfer within systems, particularly through gateways. Lastly, the papers concerning Norwegian e-health provide valuable insights into the current e-health landscape in Norway. They cover significant aspects such as data governance, data sharing, and data exchange in the context of Norwegian e-health practices.

Table 66 The 23 Selected Papers

Title	Year	Authors	Conference/Journal
The Role of a Data Marketplace for Innovation and Value-Added Services in Smart and Sustainable Cities	2022	Alvsvåg R., Bokolo A., Jr., Petersen S.A.	Communications in Computer and Information Science
Business model archetypes for data marketplaces in the automotive industry	2022	Bergman R., Abbas A.E., Jung S., Werker C., de Reuver M.	Electronic Markets 32, pages 747–765
Goal-oriented modelling of relations and dependencies in data marketplaces	2018	Chakrabarti A., Quix C., Geisler S., Pullmann J., Khromov A., Jarke M.	International Conference on Advanced Information Systems Engineering
Trust modelling for blockchain-based wearable data market	2019	Chowdhury M.J.M., Ferdous M.S., Biswas K., Chowdhury N., Kayes A.S.M., Watters P., Ng A.	Proceedings of the International Conference on Cloud Computing Technology and Science, CloudCom
Towards Trustworthy and Independent Data Marketplaces	2020	Sharma P., Lawrenz S., Rausch A.	ACM International Conference Proceeding Series
Open Data Market Architecture and Functional Components	2019	Demchenko Y., Cushing R., Los W., Grosso P., De Laat C., Gommans L.	2019 International Conference on High Performance Computing and Simulation, HPCS 2019
A Scalable, Standards-Based Approach for IoT Data Sharing and Ecosystem Monetization	2022	Figueredo K., Seed D., Wang C.	IEEE Internet of Things Journal
Discovering business models of data marketplaces	2020	Fruhwirth M., Rachinger M., Prlja E.	Proceedings of the Annual Hawaii International Conference on System Sciences
ID-Link, an Enabler for Medical Data Marketplace	2016	Ito R.	IEEE International Conference on Data Mining Workshops, ICDMW

The significant role of metadata for data marketplaces	2019	Lawrenz S., Sharma P., Rausch A.	Proceedings of the International Conference on Dublin Core and Metadata Applications
YOU SHALL NOT COMPUTE on my Data: Access Policies for Privacy-Preserving Data Marketplaces and an Implementation for a Distributed Market using MPC	2022	More S., Alber L.	17th International Conference on Availability, Reliability and Security
Enabling On-demand decentralized IoT collectability marketplace using blockchain and crowdsensing	2019	Nguyen D.-D., Ali M.I.	2019 Global IoT Summit (GIoTS)
A Semantic Data Marketplace for Easy Data Sharing within a Smart City	2021	Pomp A., Paulus A., Burgdorf A., Meisen T.	Proceedings of the 30th ACM International Conference on Information & Knowledge Management
Digital service innovation from open data: exploring the value proposition of an open data marketplace	2016	Smith G., Ofe H.A., Sandberg J.	2016 49th Hawaii International Conference on System Sciences (HICSS)
Data Marketplaces: Trends and Monetisation of Data Goods	2019	Spiekermann M.	Intereconomics 54, 208–216
Business models and dynamic capabilities	2018	Teece, D. J	Long Range Planning - Volume 51, Issue 1, Pages 40-49
Data governance spaces: The case of a national digital service for personal health data	2023	Paparova D., Aanestad M., Vassilakopoulou P., Bahus M.K.	Information and Organization, Vol. 33, Issue 1, Page 100451
Wearable sensors with possibilities for data exchange: Analyzing status and needs of different actors in mobile health monitoring systems	2020	Muzny M., Henriksen A., Giordanengo A., Muzik J., Grøttland A., Blixgård H., Hartvigsen G., Årsand E.	International Journal of Medical Informatics, Vol. 133, Page 104017
Measuring the Effects of Sharing Mobile Health Data During Diabetes Consultations: Protocol for a Mixed Method Study	2020	Bradway M., Giordanengo A., Joakimsen R., Hansen A.H., Grøttland A., Hartvigsen G., Randine P., Årsand E.	Journal of Medical Internet Research
Systems integrating self-collected health data by patients into EHRs and medical systems: a state-of-the-art review	2018	Giordanengo A., Bradway M., Muzny M., Woldaregay AZ., Hartvigsen G., Årsand E.	Linköping Electronic Conference Proceedings
An Edge-Based Architecture to Support Efficient Applications for Healthcare Industry 4.0	2019	Pace P., Aloi G., Gravina R., Caliciuri G., Fortino G.	IEEE Transactions on Industrial Informatics
An IoT-based mobile gateway for intelligent personal assistants on mobile health environments	2016	Santos J., Rodrigues J.J.P.C., Silva B.M.C., Casal J., Saleem K., Denisov V.	Journal of Network and Computer Applications, 71, 194-204
Smart e-Health Gateway: Bringing Intelligence to Internet-of-Things Based Ubiquitous Healthcare Systems	2015	Rahmani A.M., Thanigaivelan N.K., Gia T.N., Granados J., Negash B., Liljeberg P., Tenhunen H.	12th Annual IEEE Consumer Communications and Networking Conference (CCNC)

2.2.4.1 Meta Data

The selected literature in Table 6 covers a variety of journals and conferences. The papers are primarily from Europe; most are from Norway and Germany, with five from each country. Eighteen out of the papers are from the last five years. Numerous articles are within the context of private (7) and mixed (public and private) sectors (13), while research focusing only on public sectors had only three articles. Ten papers focus primarily on the health industry, seven on the commerce industry, and two on Smart Cities and Automotive. Of the 23 articles, 19 used qualitative methods, and 4 used a mixed method of qualitative and quantitative. None of the papers only used quantitative methods. The field of study is mainly between Computer Science (8) and Information Systems (9); the rest were a combination of other fields, including Business and Medical Informatics. Figure 4 shows an overview of the metadata statistics.

Country	Count
Norway	5
Germany	5
Netherlands	2
USA	2
Austria	2
Japan	1
Ireland	1
Sweden	1
Australia	1
Italy	1
Finland	1
Brazil	1

Year	Count
2015	1
2016	3
2017	1
2018	2
2019	6
2020	4
2021	1
2022	4
2023	1

Field of study	Count
Computer Science	8
Information Systems	9
Medical Informatics	3
Business	2
Computer Networks	1

Industry	Count
Health	10
Commerce	7
Automotive	2
Smart City	2
Transport	1

Sector	Count
Private	7
Public	3
Both	13

Method	Count
Qualitative	19
Mixed	4
Quantitative	0

Figure 4 Metadata & Statistics of the Papers

The research approach within the field of DMs is predominately qualitative (Figure 5). Of the selected literature, 19 papers utilized the qualitative method. At the same time, only one article used a mixed-method approach. This may indicate that the research within this field of study is still immature since there is a lack of quantitative research.

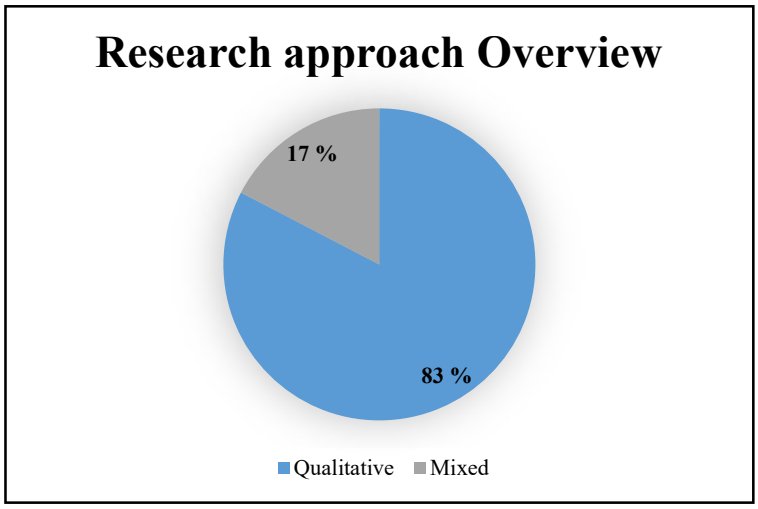

Figure 5 Overview of Research Approach

The distribution of publishing dates of the articles in our study is visualized in Figure 6. Only seven are from 2015 to 2018, while 16 are from 2019 and later (the last five years). This indicates that the field is still developing and that there will be an increase in published articles on the topics in the coming years.

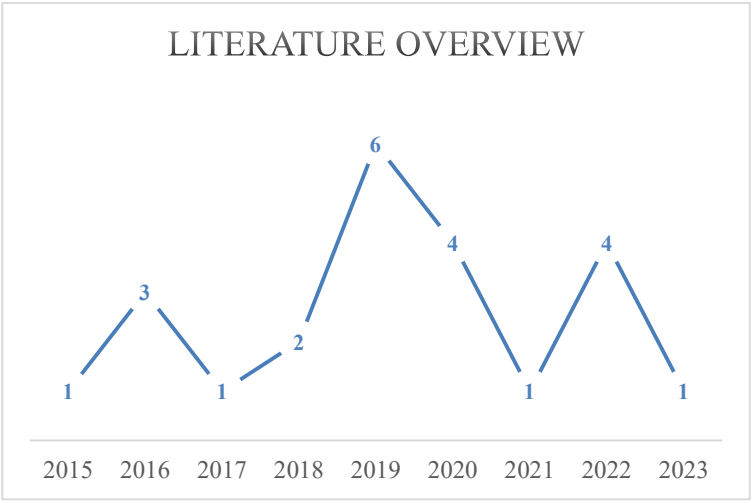

Figure 6 Year Published

*2.2.4.2 **Concept Matrix***

To gain a deeper understanding of the concepts, we developed a concept matrix as a supportive tool for analyzing, synthesizing, and discussing the selected papers (Webster & Watson, 2002). This matrix is grounded in the main concepts outlined in Table 1, but is further refined with additional sub-concepts, reflecting the new insights acquired during the literature review. As seen in Figure 7, the main concepts from Table 1 are now part of the Context concept, while new concepts are added: Technology, Legal Hurdles, Finance, and Other (Other Aspects of DMs) as primary concepts. Sub-concepts are situated directly beneath the primary concepts and maintain a relationship with them. Crosses within the table indicate references to these concepts in the articles. In the subsequent sub-sections, we will explain the concepts and justify their inclusion in the concept matrix.

		Concept																	
		Context				Technology					Legal		Financial				Other		
Authors	Year	Data Marketplace	Business model	Health	Gateway	IoT & sensors	Data sharing/exchange	Data storage	Challenges	Benefits	Privacy and Security	Law and Regulations	Framework / Model	Data price/quality	Challenges	Benefits	Non-Economic value	Stakeholder trust	
Alvsvåg R., et al.,	2022	X	X			X	X	X		X	X	X		X			X		
Bergman R., et al.,	2022	X	X				X	X	X	X	X		X	X	X	X		X	
Chakrabarti A., et al.,	2018	X	X	X			X			X		X	X	X	X		X		
Chowdhury M.J.M., et al.,	2019	X		X		X	X		X	X	X						X	X	
Sharma P., Lawrenz S., Rausch A.	2020	X	X				X	X	X	X	X		X	X				X	
Demchenko Y., et al.,	2019	X	X			X	X	X		X	X			X	X	X	X	X	
Figueredo K., Seed D., Wang C.	2022	X	X			X	X		X	X	X	X	X				X		
Fruhwirth M., Rachinger M., Prlja E.	2020	X	X				X				X		X	X		X		X	
Ito R.	2016	X		X			X			X		X	X				X		
Lawrenz S., Sharma P., Rausch A.	2019	X					X	X	X					X				X	
More S., Alber L.	2022	X					X	X	X	X	X	X					X	X	
Nguyen D.-D., Ali M.I.	2019	X	X	X	X	X	X		X	X	X		X	X	X	X	X	X	
Pomp A., Paulus A., et al.,	2021	X				X	X	X	X	X							X		
Smith G., Ofe H.A., Sandberg J.	2016	X	X				X		X	X		X			X		X	X	
Spiekermann M.	2019	X	X						X	X		X		X	X		X	X	
Teece, D. J	2018		X			X			X	X			X		X	X	X		
Paparova D., et al.,	2023			X		X		X	X	X		X							
Muzny M., et al.,	2020			X		X	X	X	X	X	X	X					X	X	
Bradway A., et al.,	2020			X		X	X	X	X								X		
Giordanengo A., et al.,	2017			X		X	X		X	X	X	X					X		
Pasquale Pace., et al.,	2019			X	X	X		X	X		X	X							
João Santos., et al.,	2016			X	X	X			X	X							X		
Rahmani A., et al.,	2015			X	X	X		X	X	X				X					

Figure 7 Concept Matrix

The Context concept relates to the focus area of the article. The sub-concepts here are directly linked to the initial main concepts developed in Table 1, providing insight into the context of the article. For example, “Data Marketplace” denotes articles in the context of DMs, such as those proposing a new platform architecture or referencing existing ones. The “Business Model” sub-concept encompasses articles discussing business models but is not necessarily exclusive to DMs. The “Health” and “Gateway” sub-concepts also indicate whether the article addresses data gateway technologies or health-related concepts.

The “Technology” concept differentiates the technologies referenced or employed in the articles. We focused on the following sub-concepts: “IoT and sensors”, “Data sharing/exchange”, “Data storage”, “Challenges”, and “Benefits”. The use of IoT and sensors for data collection is prevalent in many articles, warranting a dedicated sub-concept. Data sharing/exchange and data storage technologies are frequently mentioned as critical components of DM architecture. Due to the diverse range of technologies used for both processes, specific technologies are not listed in the matrix but are represented as aggregated concepts. The “Technology” concept also comprises both the benefits and challenges of the mentioned technologies. The preceding sub-concepts facilitate distinguishing articles that acclaim technologies while identifying their limitations and associated challenges.

Our review quickly revealed that legal considerations play a significant role in cases involving data sharing, data storage, personal health data, and more. The literature frequently addresses the laws governing personal data, prompting us to designate “Legal Hurdles” as a concept. The sub-concept “Privacy and Security” refers to legal challenges concerning protecting sensitive data and ensuring its security. At the same time, “Laws and Regulations” specifically target articles mentioning pertinent laws, such as the EU's General Data Protection Regulation (GDPR).

We introduced the “Financial” concept to assess the financial feasibility of an HDM for researchers. Like the “Technology” concept, the “Financial” concept includes sub-concepts for benefits and challenges, addressing whether the article covers financial benefits and existing financial challenges in this domain. The “Framework/Model” sub-concept pertains to articles offering a financial framework or model for monetizing DMs. The “Data Price/Quality” sub-concept encompasses articles discussing data set pricing or quality aspects.

We incorporated an “Other” concept to accommodate relevant sub-concepts that did not fit the mentioned concepts but were deemed significant for the research. “Non-economic value” includes articles demonstrating non-monetary benefits, such as improved individual health or increased insight into population health. The final sub-concept added to the matrix is “Stakeholder Trust,” as numerous articles underscore the importance of fostering stakeholder trust. For instance, data providers must be confident that the DM will not disclose their data without consent to unauthorized entities. By considering these

additional factors, the concept matrix provides a more comprehensive and nuanced understanding of the literature related to the topic.

2.2.5 Findings

This section will delve into the findings of our comprehensive literature review and discuss the results. To facilitate structure, we have organized the content into four primary categories corresponding to the concept matrix: Technology, Legal Hurdles, Financial, and Other Aspects in DMs. While the Context concept plays a crucial role in understanding the articles, we have chosen not to allocate a separate section since its primary purpose is to offer a contextual framework for our research. By highlighting the findings of the concepts presented in the matrix, we aim to establish a robust understanding of the literature on these subjects, enabling us to effectively connect our empirical findings in later sections of this report to existing research. Furthermore, we aim to identify potential research gaps in the literature, which serve as avenues for our contribution to the field.

*2.2.5.1 **Technology***

IoT technology is crucial in gathering data for various purposes, including Smart Cities and healthcare. However, challenges exist in scaling and capitalizing on IoT data, such as creating adaptable architecture, agreeing on standard component-level IoT technologies, and integrating AI technologies with existing IoT solutions (Figueredo et al., 2022). Additionally, standardized communication protocols in wearable IoT devices can improve their seamless integration into healthcare systems (Muzny et al., 2020).

Sharing data in contexts like Smart Cities requires following FAIR (Findable, Accessible, Interoperable, Reusable) principles (Pomp et al., 2021), while in healthcare, there is a need for a standard and stable end-to-end system for sharing patient-collected data with Electronic Health Record (EHR) systems (Giordanengo et al., 2018). IoT-based remote health monitoring systems like UT-GATE and mobile gateways for intelligent personal assistants (IPAs) in mobile health environments can help address some of these challenges (Rahmani et al., 2015; Santos et al., 2016).

DMs differ in their storage solutions, with some using centralized storage in the cloud and others employing decentralized storage across locations (Bergman et al., 2022; Fruhwirth et al., 2020). Blockchain technology can enhance trust, transparency, and user control in data trading (Sharma et al., 2020).

*2.2.5.2 **Legal Hurdles***

More and Alber (2022) point out that the challenge in privacy is balancing valuable insights with privacy requirements. Private DMs attempt to solve this problem by conducting computations on personal data without accessing the plain data, allowing personal data protection while selling insights derived from the data. Privacy concerns, especially in health data, have gained importance due to regulations like the European Union's General Data Protection Regulation (GDPR). GDPR limits how companies collect and retain data, especially personal data, which cannot be held longer than necessary (Alvsvåg et al., 2022; More & Alber, 2022).

Chowdhury et al. (2019) emphasize privacy as a significant concern in health data sharing and propose a framework addressing these issues to provide a secure environment for sharing personal health data. Spiekermann (2019) identifies challenges in data trading, such as the lack of trust and security, the absence of legal frameworks, and the need for clear valuation procedures. The absence of intellectual property rights protection for data results in unclear liability rules, creating uncertainty for stakeholders in DMs and hindering their progress. Addressing these legal concerns could lead to DMs becoming a safer solution for data trading.

Paparova et al. (2023) conducted a case study on data governance for digital health services in Norway, revealing differences between governing data and IT. The study highlights the active role of law in shaping data governance and provides valuable insights into the Norwegian digital health ecosystem and its governing structures. These insights can inform research on DMs within the health space of Norway.

Muzny et al. (2020) discuss the implications of GDPR and the Health Insurance Portability and Accountability Act (HIPAA) on wearable health devices. They note that GDPR requires explicit user consent for data collection and processing for Mobile Health (mHealth). At the same time, HIPAA applies to wearable data only when transferred to an Electronic Health Record (EHR).

*2.2.5.3 **Financial***

Bergman et al. (2022) identified four business model archetypes for DMs in the automotive industry, suggesting that this taxonomy is helpful when designing DMs in other fields. Fruhwirth et al. (2020) also identified four primary business model archetypes for DMs and proposed their taxonomy for designing future DM business models. Nguyen and Ali (2019) discuss a sharing economy model for data collectability that benefits data consumers and providers. Teece (2018) emphasizes the importance of strong dynamic

capabilities in creating and implementing practical business models and the role of organizational design in shaping a firm's capabilities and competences.

Chakrabarti et al. (2018) evaluated the Industrial Data Space (IDS) to identify appropriate business models for data exchange, noting to avoid dependency models to prevent a lack of motivation to contribute to data exchange. Giordanengo et al. (2018) emphasize the limitations of closed, proprietary applications in health sensor companies' business models, suggesting that more open solutions may be necessary for long-term success. Alvsvåg et al. (2022) found that a DM for Smart Cities could serve as a hub for researchers to discover and explore datasets, facilitate data sharing, enable data selling, provide insights to stakeholders, and manage resources within the energy sector.

Alvsvåg et al. (2022) further suggest that enhancing data quality and supporting participation should be the focus, with smart contracts as a tool for verifying data quality. Demchenko et al. (2019) highlight the properties that traded data should possess, including measurable quality, identifiability, veracity, non-rivalry/re-usability, privacy, and compliance with the FAIR principles.

Lawrenz et al. (2019) stress the importance of metadata in assessing data quality and facilitating data trading. Bergman et al. (2022) discuss various revenue streams and data pricing mechanisms in DMs. Fruhwirth et al. (2020) explore different pricing models and the use of cryptocurrencies vs. fiat currencies for transactions.

2.2.5.4 ***Other Aspects in Data Marketplaces***

Figueredo et al. (2022) found that the one-TRANSPORT DM platform, which focuses on utilizing dynamic data from IoT sensors, has the potential to create value and innovate business models in small and large IoT ecosystems. Smith et al. (2016) highlight the non-economic benefits of open DMs, such as knowledge transfer and lower thresholds for data usage. Nguyen and Ali (2019) discuss the societal benefits of the IoT Collectability Marketplace Model, including applications in environmental monitoring, smart mobility, and smart healthcare. Giordanengo et al. (2018) note that patient-centered healthcare trends have led to the development of medical protocols and procedures that empower patients and enable more informed healthcare decisions.

Privacy, trust, and confidence in DM platforms are challenges mentioned by various authors (Chowdhury et al., 2019; More & Alber, 2022). Decentralization and blockchain technology can help address these challenges by establishing trust, preventing market control by a few entities, and improving transactional confidence. Secure cryptographic technology, enabled by blockchain, can facilitate transparent trade between buyers and traders while protecting privacy.

Chowdhury et al. (2019) emphasize the importance of trust in health data sharing and propose a framework to help overcome security concerns and foster trust among stakeholders. Nguyen and Ali (2019) suggest a reputation system built using historical transactions in a shared, tamper-proof, and immutable ledger to ensure transparent, traceable, and trusted transactions for data providers and consumers.

2.2.6 Research Gaps

The literature highlights several vital challenges impacting the development and use of DMs, encompassing technological, legal, financial, and other essential factors. However, gaps remain in comprehending the effectiveness of proposed strategies and solutions in addressing these challenges, particularly in the health sector. Specifically, the literature points to the need for more research in areas such as the privacy of sensitive data within DMs (Chowdhury et al., 2019; Nguyen & Ali, 2019), the creation of standardized data formats, and enhancing interoperability between systems (Giordanengo et al., 2018). Additionally, studies should evaluate data governance frameworks and their role in shaping data marketplace dynamics (Paparova et al., 2023).

Furthermore, the literature emphasizes the importance of conducting in-depth case studies of DMs and their providers (Fruhwirth et al., 2020) and encourages further research on the development of novel DM solutions that address niche problems within the DM ecosystem (Bergman et al., 2022; Chakrabarti et al., 2018; Figueredo et al., 2022; Ito, 2016; Rahmani et al., 2015).

2.2.7 Implications

This literature review explores the challenges and potential solutions in developing and using DMs, particularly within the health sector. The review examines the technological, legal, financial, and other aspects of DMs, highlighting the key issues and opportunities in the area.

Technological advancements play a crucial role in the functioning of DMs, with the adoption of IoT, blockchain, Smart Cities, and Cloud technologies facilitating data trade and value creation. However, the literature reveals persistent scalability, standardization, and integration challenges, emphasizing the importance of adhering to FAIR principles and establishing standardized systems. Legal challenges, including privacy, security, and regulatory concerns, significantly impact DMs. These findings highlight the importance of striking a balance between valuable insights and the preservation of privacy. It is crucial to address the absence of legal frameworks for protecting intellectual property rights

and to comply with regulations such as GDPR, aiming to facilitate safer and more efficient data trading. The financial aspects of DMs involve business models, data price, and data quality considerations. Our review highlights various business model archetypes, sharing economy models, dynamic capabilities, data quality assurance methods, smart contracts for verification, and pricing mechanisms that contribute to the financial success of DMs. Other aspects, such as non-economic and stakeholder trust in DMs, can be achieved through innovative IoT and data-sharing ecosystems, knowledge transfer, and societal benefits across domains. Building stakeholder trust is crucial, with potential solutions including decentralization, blockchain technology, and reputation systems.

The findings of this literature review provide an overview of the current state of DM research and highlight the existing research gaps in the field. These insights will serve as a foundation for our study, enabling us to address the identified gaps and contribute to the evolving field of DMs.

3 RESEARCH APPROACH

This study explores the essential components required to successfully operate a Health Data Marketplace (HDM) tailored to researchers in Norway. Our research design will primarily focus on the perspectives of two critical stakeholders: the platform operator responsible for the development, management, and maintenance of the solution, and the primary users, the health researchers. Understanding the operator's and user's needs and priorities is crucial for the platform's success.

While the current Data Marketplace (DM) literature mainly emphasizes technical research, there is a growing demand for empirical studies in non-technical areas, such as practical strategies for effectively operating these solutions in real-world scenarios (Abbas et al., 2021). As a result, our study seeks to address the following research questions (RQs):

RQ1: "What are the essential components for successfully implementing a Health Data Marketplace for researchers in Norway?"

and

RQ2: "How can a Health Data Marketplace be established using an existing data platform?"

This section outlines our research approach, including the philosophical assumptions, research design, and data collection and analysis methods.

3.1 Philosophical Perspective

According to Myers (2021), every research, whether quantitative or qualitative, relies on certain assumptions about the definition of "valid" research and suitable research methodologies. Awareness of these implicit assumptions is crucial in the execution and evaluation of research. Chua (1986) categorized research into three groups based on their underlying philosophical perspective (i.e., assumptions): positivist, interpretive, and critical. However, there is an ongoing debate among social researchers regarding whether positivist, interpretive, and critical research perspectives are necessarily in opposition to each other (Myers, 2021). In addition to the perspectives mentioned by Chua (1986), an additional philosophical perspective, pragmatism, has gained attention, specifically in the IS field (Goldkuhl, 2012). This study takes inspiration from interpretive and pragmatic perspectives to address its RQs.

The interpretive paradigm emphasizes obtaining a comprehensive understanding of the subject matter by exploring the meanings and experiences of stakeholders (Creswell, 2014). This approach is well-suited for delving into the complexity of human experiences and social phenomena, offering a nuanced perspective. This study uses the interpretive approach to gather rich and context-specific data from stakeholders. On the other hand, the pragmatic approach focuses on generating practical knowledge with real-world applicability by gathering information from various sources and considering multiple perspectives (Morgan, 2014). In the context of this study, the pragmatic perspective aligns with the study's goals of identifying solutions to the research problem and creating knowledge that contributes to practical action and decision-making.

By incorporating elements from both interpretive and pragmatic perspectives, this study aims to address its RQs while maintaining a balance between understanding and practical applicability. The interpretive approach serves as a foundation for collecting in-depth information from stakeholders, and the pragmatic approach ensures that the generated knowledge is relevant to decision-making and is applicable in the real world (Goldkuhl, 2012).

3.2 Research Design

Qualitative research methods enable researchers to understand individuals and the social and cultural contexts in which they live (Myers, 1997). In contrast, a quantitative approach focuses on obtaining data from a more significant number of participants but with less detailed information on each individual, allowing for a generalization of the findings to the broader population under study (Grønmo, 2020). In this research, we have employed a qualitative design. As Kaplan and Maxwell (2005) assert, the goal of comprehending a phenomenon from the participants' viewpoint and its specific social and institutional context is largely diminished when textual data are quantified. Given that this study seeks to uncover the unique perspectives of key stakeholders within the health data ecosystem, we determined that a qualitative approach would be more appropriate. Qualitative research allows for the exploration of human experiences that are challenging to quantify. It involves delving into the everyday realities of social phenomena and examining essential questions as they manifest in real-life situations. Through these methods, qualitative research expands knowledge and understanding (Cleland, 2017).

The framework for qualitative research proposed by Sarker et al. (2018), which comprises four essential components, was adopted to design the study:

Conception and use of data: The study utilizes a semi-structured interview approach with stakeholders. These interviews were researcher-provoked and focused on eliciting subjective understanding (capturing personal experiences and feelings), socially

constructed reality (exploring shared meanings and social context), and negotiated meanings (co-constructing meaning through interactive dialogues). This design enabled us to delve effectively into the complexity of stakeholders' experiences and perspectives, ensuring that our investigation aligned with the core principles of qualitative research.

Nature and role of theory: Theoretical interaction is an essential aspect of qualitative research since it imparts structure, understanding, and significance to the data (Harrington, 2005). The role of theory varies depending on the research approach; in our case, we engaged with theory throughout the study, using it to guide our research design, support our data collection and analysis process, and develop insights based on our findings.

Data analysis strategy: Following the analysis strategies described by Sarker et al. (2018), our study employed polyphonic presentation, induction/abduction, deduction, and interpretation. The polyphonic presentation involved presenting parts of the interview findings through word-for-word quotes. Induction/abduction was applied by abstracting from the findings and using coding techniques to identify patterns and themes. We partially applied deduction by comparing the interview findings with our literature review, while interpretation involved validating the literature review using interview findings. These strategies enabled us to analyze our data and draw meaningful conclusions from the stakeholders' perspectives.

Nature of claims regarding the findings: Our philosophical perspective, which combines elements from interpretive and pragmatic perspectives (as described in Section 3.1), influences the nature of claims we can make in this study. Our study aims to develop a plausible understanding of a poorly understood phenomenon (Walsham & Sahay, 1999), generate new concepts and novel insights (Walsham, 1995), and move from description to abstraction (Eisenhardt, 1989; Klein & Myers, 1999). This approach aligns with our interpretive and pragmatic perspectives, emphasizing the importance of in-depth, context-specific information and actionable insights for effective decision-making and implementation.

3.3 Research Genre

An exploratory case study approach was the most suitable choice in determining the research genre for this study, considering the context of the research design and its alignment with different qualitative research genres (Figure 8). This section explains the rationale for choosing the exploratory case study methodology and its application within the research process.

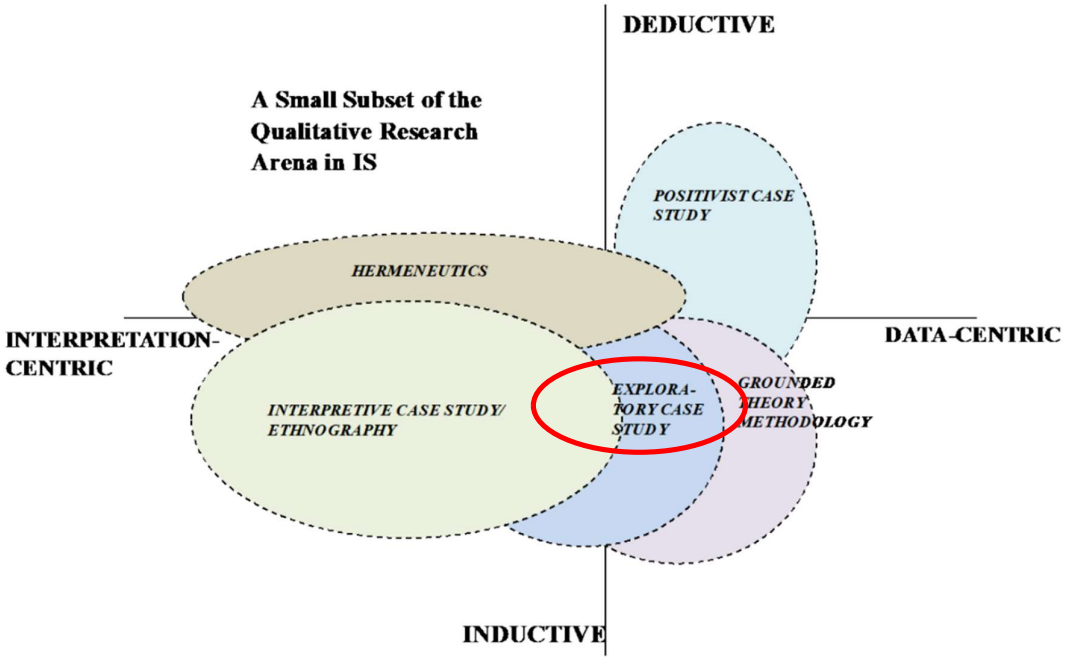

Figure 8 Overview of Research Genres

The exploratory case study methodology is well-suited for investigating complex, real-life situations in depth, generating insights, and exploring unknown phenomena (Yin, 1994). The RQs necessitate a deep understanding of the context and stakeholder perspectives, which aligns with this approach. Furthermore, the study's emphasis on subjective understanding, shared meanings, and co-constructed meanings supports the alignment with the exploratory case study genre.

While the exploratory case study genre is most fitting for the study, it also exhibits some characteristics of Grounded Theory Methodology (GTM) and Ethnography / Interpretive Case Study. GTM is evident in the study's use of induction/abduction during data analysis to identify patterns and themes, and the interpretive perspective guiding the research design highlights elements of Ethnography / Interpretive Case Study. However, the study does not solely focus on theory generation (as in GTM) nor involves prolonged immersion in the field (as in Ethnography). As a result, this study aligns mainly with the exploratory case study methodology. While mixing methods can cause inconsistencies and confusion, researchers can appropriately employ this approach by thoughtfully providing explanations and justifications regarding how they address the four elements of qualitative research (Sarker et al., 2018).

3.4 Exploratory Case study

This section presents a detailed account of the performed exploratory case study process, including subject selection, data collection, and analysis.

3.4.1 The Unit of Analysis and Subject Selection

To thoroughly explore the essential elements necessary for creating an HDM that caters to the needs of researchers, engaging a diverse group of stakeholders within the ecosystem is crucial. Before conducting this research, we established a collaboration agreement with Egde, the developers of Egde Health Gateway (EHG), which provided us access to essential connections and resources within the ecosystem. As a result of this collaboration, we identified various interview candidates from both the private and public sectors within Egde's organization and their partner network.
These stakeholders significantly impact the platform's development, utilization, and success. The primary stakeholder groups consist of:

- Data providers: healthcare institutions, private healthcare providers, or platforms.
- Data users: Researchers and healthcare professionals.
- Consultants: Platform developers and Managers.

A purposive sampling strategy was employed to select research subjects, ensuring the representation of different stakeholder groups within the ecosystem (Palinkas et al., 2015). This method involved identifying and recruiting individuals possessing extensive knowledge and expertise in their respective fields. We established selection criteria for interview subjects through consultation sessions with supervisors from both Egde and the University of Agder:

- Participants must be directly involved in the health ecosystem as data providers, data users, or platform administrators/developers.
- Participants must have expert knowledge and experience in their respective fields, particularly regarding health data management, sharing, and privacy.
- Participants must be affiliated with organizations from either private or public sectors to ensure the understanding of both perspectives.

Although Patton (1990) suggests that there are no fixed rules for determining the sample size in qualitative research, this study aimed to conduct a minimum of 10 interviews, reaching this goal by successfully conducting 12 interviews. Table 7 presents the

interview participants' IDs, descriptions, and categories identified during the interviews from multiple organizations.

Table 7 Overview of Interviewees

Interviewee ID	Description	Category	Organization
HRE1	E-health Executive	Healthcare & Research	Egde
HRE2	Medical Researcher	Healthcare & Research	Academic Institution
HRE3	Healthcare Researcher	Healthcare & Research	Academic Institution 2
HRE4	Academic Researcher	Healthcare & Research	Academic Institution
TDS1	IT Consultant	Technology & Data	IT Consultancy firm 2
TDS2	Data Specialist	Technology & Data	Egde
TDS3	Data Consultant	Technology & Data	Egde
PMI1	Innovation Consultant	Project Management	Egde
PMI2	Project Manager	Project Management	Egde
PMI3	Innovation Consultant	Project Management	Egde
PHP1	C-Level Executive	Private Health Provider	Private Health Company
PHP2	C-Level Executive	Private Health Provider	Private Health Company

3.4.2 Data Collection

Qualitative data, typically generated in qualitative studies, encompasses non-numeric information such as images, words, and sounds (Oates, 2006). To address the RQs, we opted for semi-structured interviews, which are particularly effective in examining social processes (DeCarlo, 2021). Unlike typical conversations, interviews involve specific assumptions, are pre-planned, and utilize an agenda to explore research subjects' behavior, opinions, and experiences (Oates, 2006). The interview questions were formulated based on the literature review (Section 2.1). This approach allowed us to tailor questions that contribute meaningfully to the research. Specifically, we employed the concepts of Technical, Legal, and Financial as guiding principles for developing the interview guide while remaining receptive to other concepts that might emerge.

One inherent limitation of interviews is that they can feel like staged interactions (Langley & Meziani, 2020). Participants may only share what they believe the researcher wants to hear or resort to standardized answers without profoundly reflecting on the questions. Moreover, they might develop responses during the interview, influenced by the potentially stressful situation or insufficient time to contemplate the question. We informed participants that the interview would be anonymized to mitigate these issues. The participants received the interview guide in advance, allowing them to reflect on the

questions before the interview. While this approach might make the interview less spontaneous, we prioritize obtaining well-thought-out answers. Semi-structured interviews are highly regarded as a valuable qualitative research tool, enabling researchers to acquire knowledge through interactive dialogues with individuals of diverse backgrounds and experiences (Kakilla, 2021). Semi-structured interviews unfold conversationally, allowing participants to explore issues they feel are significant (Clifford et al., 2016). This interview format allowed us to ask follow-up questions and encourage participants to think on their feet about the topics we wanted to explore further. Unlike structured interviews, this format permits the exploration of unanticipated themes, helping us better understand participants' thoughts and experiences in their daily tasks. This approach encouraged respondents to speak candidly and enabled us to gather more in-depth information when necessary.

We followed Kallio et al. (2016)'s systematic framework for developing a qualitative semi-structured interview guide to ensure the relevance and appropriateness of our interview questions in addressing our research objectives. The process follows these steps:

Conduct a literature review: We conducted a thorough literature review (Section 2.1) to understand the topic comprehensively.

*Develop a preliminary interview guide***:** We created a preliminary interview guide containing the initial questions based on the insights gained from the literature review.

*Pilot test the interview guide***:** We pilot-tested the preliminary interview guide to gain experience conducting interviews and identify areas where questions needed refinement or clarification to elicit more informative responses.

*Finalize and tailor the interview guide***:** Following the pilot test, we finalized the interview guide and customized it for three primary types of interviews: specialized interviews for participants with technical backgrounds, interviews with researchers, and interviews with service providers (Appendix 9.2).

While we employed three distinct interview guides, the central themes remained consistent across all versions. However, we structured the follow-up questions differently to accommodate each interviewee's background and expertise, ensuring that the information collected was relevant and insightful.

There are both benefits and drawbacks to employing semi-structured interviews in the study. While the format enables the acquisition of detailed information, the process is time-consuming and labor-intensive, necessitating thorough preparation and demanding heightened focus and active listening skills during the interviews. Flexibility and diligence are also crucial, as one must follow up on responses that could significantly contribute to the research. Furthermore, the interview's semi-structured nature can lead to variability in the data collected, making it challenging to compare responses across different participants. However, this flexibility can also be seen as a strength, as it allows

for exploring diverse perspectives and experiences, aligning with the study's exploratory nature (DeCarlo, 2021).

3.4.3 Data Analysis

The data analysis process constitutes a crucial component of qualitative research. The analysis process encompassed multiple cycles, including coding and pinpointing similarities, differences, sequences, and patterns within the data. Subsequently, we consolidated the responses into themes, presented in the findings section (Section 4) as assertions and propositions supported by the data and compared them to existing knowledge from the literature (Miles et al., 2014; Oates, 2006).

We recorded the interviews to address the potential weakness of misrepresenting interviewees' statements during notetaking and transcription. The recordings enabled us to review the interviews multiple times, making them a more reliable data source. Following the interviews, we transcribed the results, coded the transcribed responses into themes, discerned patterns and trends in the data, and synthesized the findings into a coherent and succinct narrative that accurately represented the RQs. We upheld transparency about how we transformed raw data into various themes. Specifically, we used NVivo, a software tool, to code this raw data into respective categories (Gioia et al., 2013). Moreover, we utilized the inter-coder reliability approach, in which both authors individually coded the themes from the interviews to enhance the validity of the process (Kurasaki, 2000).

3.5 Ethical Considerations

Ethical considerations in research are crucial for safeguarding the rights of participants and ensuring treating their information with respect and confidentiality. By providing comprehensive information about the study's procedures and following the NSD (Norsk Senter for Forskningsdata) agreement, we ensured that participants were well-informed of the research implications and could make informed decisions regarding their involvement. This approach also contributed to maintaining the integrity of the research and adhering to ethical guidelines (NSD - Norsk senter for forskningsdata, n.d.).

We obtained informed consent from participants before conducting interviews, ensuring they comprehended the research's purpose and procedures. When contacting participants before the interviews, we informed them of the study's procedures, emphasizing their right to decline to answer sensitive questions and ensuring the protection of their anonymity. We underscored the importance of safeguarding their information and explained the NSD application agreement, which outlines how information is collected,

processed, and presented in the study and the thesis (Appendix 9.1). This approach guarantees that the collected data is not traced back to the participants, preventing any linkage between the data and the individuals. In addition, we ensured voluntary participation, confirming that participants willingly engaged in the study without coercion or pressure and that they understood they could withdraw from the study at any time and have their answers deleted (NSD - Norsk senter for forskningsdata, n.d.).

By maintaining awareness of potential biases and adopting a non-judgmental attitude, we aimed to prevent the imposition of personal beliefs or values on the interview process. To protect participants' information, we implemented strict data security measures, including encryption and password protection, and restricted access solely to the authors and the study's supervisor. For this purpose, we utilized the University's Microsoft account, which met these stringent security criteria (Bariås & Hauso, 2023).

4 FINDINGS

In this section, we present the findings from the interviews. The findings divide into Technical, Legal, Financial, and Other findings based on the themes from the data analysis. Figure 9 showcases the themes and sub-themes that emerged from the analysis of the interviews. The rightmost column showcases the interview ID for the subjects that mentioned the subtheme in their answers (same line). The following sections in this chapter are subsequently divided into the themes and their respective subthemes. See Appendix 9.3 for extended transcripts of the interviews.

Theme	Subtheme	Interviewee ID
Technical	Data Standardization and Interoperability	HRE1, HRE4, PMI3, PHP2
	Integration and Collaboration	HRE1, TDS1, TDS3, PMI2
	Data Storage and Accessibility	HRE2, PMI1, HRE4, PMI2
	Potential of Emerging Technologies	PMI1, PMI3, TDS2
Legal	Regulatory Compliance and Privacy	HRE1, PMI1, PMI3, HRE2, HRE4, PMI2
	Ethical and Anonymization Challenges	HRE3, TDS1
	Balancing Innovation and Overcoming Legal Barriers	HRE4, PMI3, PHP2, PHP1
Financial	Emerging Business Models and Collaboration	HRE1,TDS3, HRE2
	Data Marketplaces as a Source of Financial Benefits	HRE1, PHP1, TDS1
	Financing and Financial Incentives	HRE2, HRE3, PHP1, PHP2
Other	Trust between Stakeholders	HRE2, HRE4, TDS2
	Usability and Acceptability	HRE3, PHP1
	Ongoing Projects and Initiatives	HRE4, HRE3, PMI2

Figure 9 Themes/Subthemes and Interview Mentions

4.1 Technical Findings

The operation of a Health Data Marketplace (HDM) for researchers in Norway hinges on the ability to address various technical aspects, including data standardization, integration, interoperability, and security. This chapter provides an in-depth analysis of the technical findings from the interviews.

4.1.1 Data Standardization and Interoperability

A recurring theme in the interviews is the importance of data standardization and interoperability. HRE1, HRE4, PMI3, and PHP2 mentioned using standardized data formats,

such as HL7's (Health Level 7) FHIR (Fast Healthcare Interoperability Resources), to facilitate data sharing among healthcare systems. HRE1 stated that:

> *"By having intentional standardizations, the more people use it, the better it gets."*

PMI3 discussed the use of FHIR standardization, noting:

> *"Probably about 12 years ago, a group of people launched the FHIR standard to try and make exchanging health data easier, and it goes under the HL7 (Health Level 7) organization. HL7 made it [FHIR] trying to cover 80% of the requirements and keep it flexible so that people could customize it for the other needs".*

PHP2 shared that their organization (a customer of Egde) switched to FHIR since

> *"…that is what Egde [Health Gateway] uses."*

PMI3 also highlighted the importance of health terminology standards like SNOMED CT and LOINC within health data, which ensure that data can be understood when received by other systems:

> *"We should also talk about another aspect of health data, apart from how the data is structured and formatted. There is the whole terminology side of things, the semantics of health data, and there are a number of standards there, one is called SNOMED CT that is a terminology standard used in many countries. It is a long list of codes about all sorts of things, for example the femur that will have a code, diseases have codes, all sorts of aspects of human biology and medicine have codes. There is also another one called LOINC which is also used, a little bit more pharmacology based."*

4.1.2 Integration and Collaboration

The interviews revealed how collaboration is possible between actors by integrating with the Egde Health Gateway (EHG). HRE1 mentioned EHG, a project with Norsk Helsenett, which aims to provide an integration platform for standardized and secure sharing and interaction of health data. Furthermore, HRE1 talked about a collaboration with DigiMe, which

> *"…takes personal data from various cloud solutions and stores them in a personal location such as one drive… meaning we own our health data".*

TDS1 and TDS3 mentioned the development of a data platform that integrates several platforms to connect health data with services, facilitating communication and sharing of data across organizations. TDS3 specifically mentioned Egde's role in this process, stating,

"This is where Egde helps these organizations to integrate, by establishing a data platform that makes it possible for parties to share the data."

This statement is further acknowledged by an employee at Egde, PMI2, which said:

"We see that customers communicate using the gateway [EHG], sharing services that can be complementary to each other."

4.1.3 Data Storage and Accessibility

Interviewees identified several challenges related to data accessibility, storage, and management. HRE2 noted the high cost and need for data storage for medical research projects and suggested having a resource person to manage data across different research departments to reduce costs and improve efficiency. HRE2 also acknowledged the challenge of including individuals who are not tech-savvy or lack access to technology in research data, resulting in an underrepresentation in research projects.

PMI1 mentioned difficulties in data sharing within the health sector:

"There is quite silo in this sector, if we call our doctor the knowledge about you can be varied. Since it really depends on which systems you are registered in, if it is connected and communicated well with the central system, and if they update your logs so it is up to date. It not working that smoothly right now".

HRE4 further highlighted the challenges:

"So what's happening right now is that usually these data are stored in the cloud by the vendors. That means that the hospital, if you are a hospital specialist and you use an EPR system. Only a limited set of these data will be shared with the EPR system. Most of it will be stored by the vendor that provides these digital home follow up services, and if you as a hospital specialist want to have an insight into these data, you have to log in into a separate system for digital home follow up so you don't see these data from the EPR system."

And PMI2 indicating that the problem may be due to the difference in data formats:

"It's the one-to-one or one-to-many issue that I'm experiencing. […] Many of these have formats and forms of things that are different. This is something they struggle with in the healthcare platform in central Norway, where the communications work poorly among each other."

4.1.4 Potential of Emerging Technologies

The interviewees frequently mentioned emerging technologies such as artificial intelligence (AI), machine learning (ML), and blockchain as having possible use cases in HDMs. PMI1, for example, suggested that blockchain could play a significant role in Data Marketplaces (DMs) and potentially remove broker services.

PMI3 discussed the potential for AI and ML to enhance EHG's capabilities and contribute to pattern recognition and diagnostics in medicine:

> *"On the AI side of things, there is definitely a lot of scope there, I think. There is a lot of pattern recognition going on in medicine and diagnostics, that could help a lot."*

Moreover, TDS2 shows the importance of data for AI/ML applications:

> *"When ML and AI are to be developed as services for end-users, for example, to provide recommendations, they need data input to be able to give good recommendations. This data can be tapped into and obtained from such a data marketplace".*

However, some interviewees expressed uncertainty about the immediate applicability of these technologies in the healthcare data domain. PMI3, for instance, acknowledged the potential role of blockchain technology in tracking the flow of individual patients across different health professionals but was uncertain about its current relevance:

> *"I am not too sure where blockchain is going to come in right now, to all of this... As you get handed over between different health professionals, there could be a need for tracking the flow of an individual patient on the blockchain."*

While TSD2 shared their concerns about accountability:

> *"Immediately, I think that one must take responsibility for data quality, which means that if you are going to use such a solution [blockchain] in a healthcare context, there should be an expectation that there should be a name behind it so that you know who is accountable ...It's a technology that is still searching for use cases."*

4.2 Legal Findings

This chapter presents the legal findings from the interviews conducted with various stakeholders involved in the health data sector in Norway. The aim is to comprehensively understand the legal aspects and challenges of operating an HDM.

4.2.1 Regulatory Compliance and Privacy

The crucial role of the General Data Protection Regulation (GDPR) and privacy regulations in an HDM was a common theme among interviewees.

HRE1 stated,

> *"GDPR, laws, and privacy are the challenges that come to mind. The whole world looks to the Nordics when it comes to ethical guidelines regarding data. We have a higher norm of privacy, not many others have our standards. We have strict rules that govern privacy in nordic countries."*

Pointing out that the Nordic countries maintain stricter privacy standards. Similarly, PMI1 said:

> *"There are challenges such as GDPR. Privacy and security around these issues is a bit of a challenge. There is a need to not break these."*

This point aligns with PMI3, which mentioned the comprehensive security framework provided by "*Normen*," encapsulating all security and privacy measures, including GDPR, as

> *"probably the most comprehensive security framework for health data in Europe."*

In healthcare, HRE2 and HRE4 brought attention to the risks involved in sharing personal health information, particularly through email, due to stringent privacy and legal concerns. HRE2 highlighted,

> *"You are not allowed to send personal information by email; we are not allowed to do that."*

Echoing this sentiment, HRE4 emphasized that:

> *"The regulation is very strict, and it's followed very thoroughly and especially if you consider health data, it's followed particularly thoroughly."*

The importance of understanding the regulatory frameworks surrounding health data was a recurring theme. PMI2 indicated that:

> *"Once these regulatory frameworks around health data in the EU become more relaxed, we can process data better, maybe process health data more easily through Azure and not private clouds."*

PMI3 referenced specific regulations, including the "patient journal law" and medical device regulations, and recognized that the

> *"European health data spaces [EHDS] coming through will have consequences for us as well in regulatory terms."*

However, PMI3 highlighted that there is a difference in regulatory compliance depending on the provided health service:

> *"If you are providing a diagnostic service that is actually giving you an answer (like a blood sample) then it is at a quite a high level of regulation.*

If it is a service helping you track how many minutes of running you do every week then it is very low on the regulatory scale."

4.2.2 Ethical and Anonymization Challenges

Beyond legal compliance, interviewees highlighted the significant ethical challenges and difficulties associated with anonymizing large population datasets in the HDM.

HRE3 raised the issue of anonymizing large datasets, particularly for small cohorts:

"It is often difficult with large population data... if we have population data for small cohorts, we will have huge problems right away."

This quote underlines the intricacy of anonymization, especially when dealing with detailed, population-scale data.

HRE3 further emphasized the complexity of securing multi-tiered approvals, stating that there is a need for

"...approval from the data owner at the service level... and you must have an overarching national ethical approval."

This layered consent system underscores the depth of ethical considerations, extending beyond individual data owners to incorporate national ethical approvals for exchanging health data.

In parallel, TDS1 underscored the potential ethical issues tied to DMs and broader data exchange, suggesting that these platforms may inadvertently foster a surveillance society. TDS1 queried,

"There are a lot of ethical issues; for example, Google is interested in knowing what you think. Is that good? We get personalized ads. We could become more of a surveillance society."

This comment highlights the broader societal implications and ethical considerations surrounding data privacy and the commercialization of personal data.

4.2.3 Balancing Innovation and Overcoming Legal Barriers

In HDMs, striking a balance between encouraging innovation and adhering to regulatory compliance is crucial. This balance poses a substantial challenge, as organizations tend to err on the side of caution, preferring to mitigate risks in advance rather than managing them post-event. HRE4 articulated,

"many times, instead of taking the risk, you decide to be cautious. So, you would rather not do too much instead of trying to manage the risk afterward."

Despite numerous legal obstacles, many interviewees are optimistic about overcoming these challenges. PMI3, for instance, highlights the European Health Data Spaces initiative as an embodiment of such optimism. This endeavor, according to PMI3,

> *"...goes beyond GDPR to make sure that individuals have more rights to their health data, and also you can share the data with researchers,"*

This showcases the potential approaches to untangling legal intricacies.

PHP1 spotlighted the differing regulatory terrain for public health entities and private companies. The interviewee elaborated,

> *"Public health actors require ethical clearance for data collection projects, and this data cannot be reused or commercialized. It must also be deleted after a limited time. In contrast, private companies do not require the same permissions and can handle their data according to GDPR regulations. Thus, commercialization may be possible if a private entity collects and stores the data."*

PHP2 added to the discussion, highlighting researchers' varied perspectives due to the diverse types of health data. The interviewee said,

> *"Because there are different categories of health data. You have the most sensitive ones, and then you have non-sensitive data, which means general data. And when it is anonymized, there is another regulation you have to comply with. And especially in research, it is when there is consent, it is allowed to conduct research. So, you could say that as long as they obtain consent from patients or participants, it is completely legal."*

The statement from PHP2 underscores the importance of obtaining consent and distinguishing between data types in the research context.

4.3 Financial Findings

In this section, we present the financial findings gathered from interviews to investigate the operation of an HDM for researchers in Norway.

4.3.1 Emerging Business Models and Collaboration

The interviewees frequently alluded to the evolving trend in the industry, where traditional consultant services are being gradually superseded by subscription-based services, sparking new business models. As HRE1 put it,

> *"consultant services are being replaced by subscription-based services, with a connection fee."*

TDS3 presented an intriguing concept about the prospect of consume-based services in DMs. In this model, consumers pay for the data they utilize on the platform, which resonates with the ongoing transition toward subscription-based services. TDS3 explained,

> *"The business model which I think will work well with Data Marketplaces is to sell consume-based services. Here, consumers pay for the data that exists on the platform, that other parties sell. The price can also be based on usage of the marketplace."*

Further extending the discourse on potential business models, both HRE2 proposed opportunities for collaborative ventures. HRE2 suggested that pharmaceutical companies could take part in the costs of data storage and management infrastructure in hospitals and get access to research data in return:

> *"So, I think that one should then make such agreements that they should pay hospitals to upgrade such data storage capacity […] but also good servers and everything you need, and people to help operate, and if they are to conduct research at our hospital, they must contribute to that pot".*

4.3.2 Data Marketplaces as a Source of Financial Benefits

Multiple interviewees conveyed the future financial benefits derived from DMs. HRE1 pointed out the opportunity for entrepreneurs to streamline their operations by circumventing the need to establish separate integrations with data providers. HRE1 highlighted that entrepreneurs could instead rely on a service to access the necessary data, stating,

> *"For instance, our solution, Egde Health Gateway, allows entrepreneurs to bypass the complexities of setting up different integrations with data providers. They can simply connect to our service and obtain the data required to build their applications."*

In a similar vein, PHP1 concurred, suggesting that the use of an HDM could fill data gaps in their organization, thereby delivering a solution for their customers*:*

> *"From our [organization's] perspective, we are immensely interested. This interest is primarily because it could offer a ready-made solution for our customers. It could drive more initiatives within our organization, ranging from innovative projects to research efforts. This would be possible when our customers approach us with their challenge of data scarcity, which is a gap we currently need to address."*

TDS1, in the same context, augmented this discussion by asserting,

> *"Certainly, a data marketplace can enhance our capabilities, offer deeper insights, and improve adaptability."*

4.3.3 Financing and Financial Incentives

HRE2 and HRE3 highlighted the financial challenges related to data storage and a lack of institutional support. HRE2 pointed out the importance of external funding in meeting the expenses of data storage, as hospitals and institutions typically do not finance these costs:

> *"We pay quite a large sum to TSD, that is, to Oslo. But I don't have that amount in my head, but it is also many 1000 NOK a year, and the price increases every year, and you did not know that when you applied."*

HRE3 also underscored that researchers are often liable to pay for data access and bear the overall costs:

> *"...currently, one pays... one must pay to be part of bearing the total costs."*

PHP1 and PHP2 explored the funding and costs for financial incentives in an HDM and the challenges of determining a fitting business model for such marketplaces. PHP1 stressed the need for a just and transparent pricing model to foster widespread adoption:

> *"The pricing model should be fair and transparent to encourage widespread adoption. It should incentivize data providers to share their data while ensuring that researchers can access the data they need at an affordable price."*

PHP2, on the other hand, focused on the importance of financial incentives as a motivator for work, stating,

> *"Money is the most important incentive for them [researchers] to go to work. And then there are other things in addition. Therefore, one must facilitate incentives that are financial."*

4.4 Other Findings

This section showcases the findings from the interviews that we deemed important but did not fit neatly into the abovementioned concepts.

4.4.1 Trust Between Stakeholders

A dominant theme during the interviews was the critical role of trust among stakeholders. In discussing the quality assurance of collected health data, HRE2 underscored the significance of reliance on colleagues,

> *"We need to trust our colleagues. If we perceive something as unreliable, it's important that we address it, investigate, and report as necessary. Trust plays a key role in this process."*

HRE4 further highlighted the fragility and long-term repercussions of a breach of trust and cautioned about the difficulty of restoring faith following an incident,

> *"Even one scandal can make it very difficult to regain trust subsequently. [...] That's why we shy away from directly researching commercialized E health data. It could significantly erode trust. On the contrary, conducting research-oriented studies may be perceived as more innovative and thus more acceptable to society."*

This statement implies that an HDM focused on research might be more readily accepted by society.

On the commercial side, TDS2 acknowledged the business development value of gaining access to and familiarity with other stakeholders:

> *"Having access and getting to know other actors can be of value for business development for commercial actors, at least in theory."*

This sentiment underscores the necessity of trust-building for ethical and quality reasons and business development in DMs.

4.4.2 Usability and Acceptability

The usability and acceptability of data solutions surfaced as a significant theme in numerous interviews. HRE3 expressed the need to

> *"...gauge whether users engage with the solutions."*

noting the relevance of usability and acceptability in an HDM solution.

PHP1 echoed this sentiment, stating that an intelligible, well-structured data solution is key for acceptance within the research and health services community. Users should be able to discern data types, like sleep data, with details about the environment, length, and sleep conditions. The importance of data description, recognition of data providers, and awareness of potential price disparities were stressed as critical elements for an acceptable, user-friendly solution. With Finn.no as a reference, PHP1 envisioned a system where users could specify data attributes, leading to the display of appropriate datasets. In a more condensed form, PHP1's statement reads:

> *"Data solutions must be transparent and user-friendly, offering clear data type descriptions, including details like sleep data. Awareness of the data providers and price variations is critical. I see a marketplace, akin to Finn.no, where users specify desired attributes to reveal relevant datasets."*

4.4.3 Ongoing Projects and Initiatives

Interviewees provided insights into various ongoing projects and initiatives related to HDMs. A prominently discussed project was "Godt Begynt," which collects and researches data from an individual's childhood to adulthood, aiming to predict and possibly mitigate diseases. HRE4 described the project:

> *"One project is called "Godt Begynt", where they are going to track and research data from the day you are a child until you grow up to kind of predict and help you foresee diseases and so on."*

Contributing further to the discussion, HRE3 revealed that Godt Begynt utilizes questionnaires in partnership with health stations and school health services. The project aims to enhance knowledge-based initiatives for children's mental health and reduce social inequality in health. To encapsulate HRE3's statement:

> *"Agder county municipality, on behalf of several municipalities, leveraged funds from the Health Directorate to develop measures improving mental health and reducing social inequality among children and young people."*

PMI2, who works on the EHG, outlined their collaboration with Kristiansand municipality and partners like Siemens Healthineers, Fundable, and Zyberia, working together to advance health data solutions:

> *"We are working with Kristiansand municipality, and 3-4 other partners, Siemens Healthineers, Fundable, Zyberia."*

HRE4 shed light on another project called "Helseanalyseplattformen," which started in 2018 and ended in 2021. This platform was conceived as a public sector resource for researchers who wanted to use health data. However, legal issues around the use of a US-based cloud solution led to the discontinuation of the project:

> *"In Norway, there was a project called "Helseanalyseplattformen", which started 2018, and it was stopped December the previous year [2021]... This platform was supposed to be an official public sector platform... for researchers who want to use health data for research."*

Furthermore, interviewees highlighted the European Health Data Space (EHDS), an EU initiative to enhance cross-border health data exchange. This infrastructure aims to improve patient care, support healthcare research, and aid in policymaking, making it a significant ongoing effort in the HDM ecosystem.

5 DISCUSSIONS

This chapter discusses the essential components and implementation framework for a Health Data Marketplace (HDM) for researchers in Norway. The discussion contributes to advancing healthcare research and innovation in Norway by addressing these aspects. Through a consolidated analysis, we identify stakeholder implications and propose an integration framework that combines the Egde Health Gateway (EHG) with the HDM. This framework aims to ensure secure, compliant, and efficient data exchange while fostering collaboration and innovation in healthcare research.

5.1 Critical Examination and Synthesis of Findings

This section compares and synthesizes background literature to validate the interviews against existing literature. The method uses deductive reasoning and interpretation. This increases the validity of our suggested framework by emphasizing common findings (See Section 3.2).

5.1.1 Technical

Data Standardization and Interoperability: Both interviewees and the literature emphasize the importance of data standardization and interoperability. Interview participants (HRE1, HRE4, PMI3, and PHP2) mentioned using standardized data formats, like HL7's FHIR, to facilitate data sharing among healthcare systems. Similarly, Muzny et al. (2020) and Giordanengo et al. (2018) discuss the need for standardized communication protocols and a stable end-to-end system for sharing patient data. The interviewees' mention of health terminology standards like SNOMED CT and LOINC also aligns with the need for standardization highlighted in the literature.

Integration and Collaboration: The interviews and literature findings echo the importance of collaboration and integration. Participants in the interviews, such as HRE1, TDS1, TDS3, and PMI2, emphasized the role of EHG as an integration platform. Similarly, the literature underscores the necessity of IoT-based remote health monitoring systems for addressing challenges in data integration (Rahmani et al., 2015; Santos et al., 2016).

Data Storage and Accessibility: Both sources identified challenges related to data accessibility, storage, and management. Interviewees like HRE2, PMI1, and HRE4 highlighted issues with data storage costs, inclusivity, and vendor-based data silos. The interviews aligned with the literature findings, which mention the variation in Data Marketplace (DM) storage solutions, ranging from centralized cloud storage to decentralized across locations (Bergman et al., 2022; Fruhwirth et al., 2020).

Potential of Emerging Technologies: Both interview findings and literature express the potential of emerging technologies, notably AI, machine learning, and blockchain. Interviewees PMI1, PMI3, and TDS2 discussed the potential of AI, machine learning, and blockchain to enhance HDMs. These interview findings are consistent with the literature, where Figueredo et al. (2022) discuss integrating AI technologies with IoT solutions. Moreover, the potential of blockchain for enhancing trust, transparency, and user control in data trading mentioned in the literature (Sharma et al., 2020) is also mentioned by PMI1 in the interviews.

5.1.2 Legal

Regulatory Compliance and Privacy: The interviewees (HRE1, PMI1, PHP2, TDS1, PMI3) and More and Alber (2022) shared a similar emphasis on the critical role of GDPR and privacy in the HDM. They all recognized GDPR's challenges, specifically regarding compliance and security in data sharing. More and Alber (2022) also mentioned the importance of balancing obtaining valuable insights from health data while maintaining privacy standards, which echoes the remarks from PMI3 on the comprehensiveness of the "Normen" security framework. Chowdhury et al. (2019) proposed a framework to address privacy concerns in health data sharing, which resonates with HRE2 and HRE4's observations about the strict regulations on sharing personal health data via email. PMI2's mention of a potential relaxation of regulatory frameworks in the EU aligns with Alvsvåg et al. (2022), which points to the GDPR limitation on data retention. The interviewees also touched on data governance, with PMI3 mentioning the upcoming European Health Data Spaces (EHDS) initiative and its regulatory impact. The mention of EHDS aligns with Paparova et al. (2023)'s study on data governance for digital health services in Norway.

Ethical and Anonymization Challenges: The issue of anonymizing large datasets, raised by HRE3, aligns with More and Alber (2022)'s exploration of privacy preservation in private DMs. HRE3 mentioning the difficulty in anonymizing large population data ties into the concerns raised by Alvsvåg et al. (2022) about data retention and GDPR. The ethical challenges, particularly in securing multi-tiered approvals, mentioned by HRE3 and TDS1 align with the ethical considerations noted in the literature, including those

presented by Chowdhury et al. (2019). Concerns raised by TDS1 about potential surveillance society echo Spiekermann (2019)'s identification of trust and security as key challenges in data trading.

Balancing Innovation and Overcoming Legal Barriers: The interviewees (HRE4, PMI3, PHP1, PHP2) and the authors (Alvsvåg et al., 2022; Bergman et al., 2022; Spiekermann, 2019) pointed to a need for balancing innovation with regulatory compliance and privacy protection in the context of DMs. HRE4 noting about erring on the side of caution mirrors the challenges Spiekermann (2019) highlighted, including the lack of legal frameworks and the absence of clear valuation procedures. PMI3 emphasizing initiatives like the EHDS aligns with the literature's focus on addressing legal issues (Bergman et al., 2022; Spiekermann, 2019). Furthermore, PHP1 differentiating between public health actors and private companies regarding regulatory requirements resonates with Muzny et al. (2020)'s discussion of explicit user consent requirements under GDPR and HIPAA.

5.1.3 Financial

Emerging Business Models and Collaboration: In the interview findings, subscription-based and consume-based services are identified as emerging trends in business models (HRE1, TDS3). This is consistent with the literature findings (Bergman et al., 2022; Fruhwirth et al., 2020) identifying multiple business model archetypes for DMs, encompassing subscription and consume-based models. However, unlike the interview findings, the literature also discusses a sharing economy model that could benefit both data consumers and providers (Nguyen & Ali, 2019).

Data Marketplaces as a Source of Financial Benefits: Interviewees highlighted the financial benefits of DMs regarding operational efficiency and filling data gaps (HRE1, TDS2, TDS1). This aligns with the literature findings where Alvsvåg et al. (2022) stated that a DM could be a hub for researchers, enable data selling, and manage resources within sectors such as energy. The literature also stresses the importance of strong dynamic capabilities for creating and implementing practical business models (Teece, 2018), which complements the interview findings about operational efficiency and adaptability (HRE1, TDS2, TDS1).

Financing and Financial Incentives: The interview findings highlighted the financial challenges related to data storage and a lack of institutional support, emphasizing the importance of external funding and financial incentives (HRE2, HRE3, PHP1, PHP2). The literature findings reinforce these views, stressing various revenue streams, data pricing mechanisms, and using different currencies for transactions (Bergman et al., 2022; Fruhwirth et al., 2020). However, unlike the interviews, the literature also mentions the

role of smart contracts as a tool for verifying data quality, suggesting another potential financial incentive (Alvsvåg et al., 2022). The two sources both recognize the importance of transparent, fair pricing models and financial incentives for participation. However, the literature provides more specific examples, such as using cryptocurrencies vs. fiat currencies for transactions (Fruhwirth et al., 2020), which the interviews do not mention.

5.1.4 Other

Trust between Stakeholders: Trust is identified as a vital aspect both in the interview findings and literature review. Interviewees like HRE2 and HRE4 emphasize trust's crucial role in ensuring reliable data exchange and its potential damage due to mishandled or commercialized data. This sentiment aligns with Chowdhury et al. (2019), who emphasize the importance of trust in health data sharing, and More and Alber (2022), who point out trust as a challenge in DMs. Nguyen and Ali (2019)'s suggested reputation system can further help foster trust, as indicated by the interviewee TDS2, emphasizing the business development value of trust.

Usability and Acceptability: Usability and acceptability of data solutions have been a significant focus in both the interview findings and the literature review. Interviewees like HRE3 and PHP1 highlight the need for user-friendly and transparent data solutions, reflecting Giordanengo et al. (2018)'s emphasis on patient-centered healthcare trends that demand more informed and empowered users. PHP1 envisioning a system akin to Finn.no, where users specify attributes to reveal relevant datasets, echoes Smith et al. (2016) regarding the benefits of open DMs, such as lower thresholds for data usage.

Ongoing Projects and Initiatives: The interview findings cover ongoing projects like "Godt Begynt," "Helseanalyseplattformen," and the EHDS initiative. These initiatives align with the literature findings (Figueredo et al., 2022; Nguyen & Ali, 2019), which discuss dynamic data platforms' potential and societal benefits.

5.1.5 Consolidated List of Components

The extensive investigation into the potential development of an HDM in Norway has identified several key components, each of which plays a vital role in the overall system. However, to facilitate a comprehensive understanding, grouping these components into broader consolidated components is helpful based on shared themes and overlapping areas of concern. This approach supports the dual goals of reducing complexity without losing sight of the multifaceted nature of the challenge. Below is the resultant consolidated list of components, based on both interview and literature findings, that form the

backbone for further investigation of an HDM framework. The previously identified components from Section 5.1.1 to Section 5.1.4 are in parenthesis, while the new consolidated components are in *italic* font:

Data Standardization, Interoperability, and Integration (Data Standardization and Interoperability, Integration and Collaboration): This consolidated component embodies the technical requirements for effective data exchange. Interoperability ensures that different systems and software applications can communicate and exchange data efficiently, whereas standardization promotes consistency and facilitates compatibility between different data sets. Integration and collaboration ensure that these standardized and interoperable data can be effectively combined and used across various healthcare platforms and institutions.

Data Security, Trust, and Legal Frameworks (Regulatory Compliance and Privacy, Trust between Stakeholders): The dual challenges of maintaining data security while also fostering trust between various stakeholders are encapsulated in this consolidated component. Building trust between stakeholders requires the establishment of clear, consistent, and enforceable legal frameworks that protect data rights while facilitating cooperation and data sharing. Ensuring regulatory compliance, particularly in data privacy, is a crucial part of this component.

Anonymization, Ethical, and Legal Considerations (Ethical and Anonymization Challenges): Despite having only one component, this category warrants singular attention due to ensuring anonymity in an HDM. Anonymizing personal health data is an ethical necessity, not just a legal requirement. Striking a balance between utilizing health data for public benefit and protecting individuals' privacy is a delicate task and, therefore, a consolidated component in its own right.

Overcoming Legal and Regulatory Barriers (Balancing Innovation and Overcoming Legal Barriers): Navigating the complex legal and regulatory requirements is critical to successfully establishing an HDM. Identifying and overcoming potential legal hurdles is a significant challenge that merits dedicated attention. Innovation must be balanced with compliance, ensuring technological advancements do not violate existing laws or regulations.

Exploration of Emerging Technologies (Potential of Emerging Technologies): The solitary component here reflects the necessity of keeping abreast of cutting-edge technological developments. Utilizing emerging technologies such as AI and blockchain technologies could significantly enhance the functionality and capabilities of an HDM. However, it requires careful exploration and evaluation to determine the most appropriate and beneficial applications.

Business Model Development and Sustainability (Emerging Business Models and Collaboration): This category emphasizes the significance of having viable and sustainable

business models. A collaborative approach is essential to drive innovation and ensure sustainability in a rapidly evolving marketplace.

Financial Benefits and Incentives (Data Marketplaces as a Source of Financial Benefits, Financing and Financial Incentives): The potential financial benefits derived from HDMs must be thoroughly assessed. Moreover, creating incentives to promote data sharing and exploring innovative financing methods for infrastructure and data storage is crucial to ensuring the marketplace's financial viability.

Collaboration and Innovative Solutions (Integration and Collaboration, Ongoing Projects and Initiatives): This consolidated component underlines the importance of a cooperative approach, pooling resources, and leveraging existing projects to drive innovation in the marketplace. Collaboration saves resources and promotes a sense of shared ownership and responsibility, fostering an environment conducive to innovation.

Usability and Acceptability of Data Solutions (Usability and Acceptability): This component stands alone due to the vital importance of user experience in adopting any data solution. A user-friendly, transparent, and acceptable system is essential for ensuring the efficient utilization of health data, thereby driving the marketplace's success.

5.2 The Implication of Components for Stakeholders

This section presents the intersection of crucial components of the HDM with the roles and responsibilities of its primary stakeholders: Platform Operators, Platform Users, and Legal Authorities. It underscores the central role of Platform Operators, paving the way for a deeper examination of their influence within this ecosystem.

5.2.1 Stakeholders

After delineating the key elements vital for a successful implementation, it is essential to comprehend these components from each stakeholder's perspective and their corresponding implications. Within the context of the HDM solution, three main stakeholders have been identified:

- *Platform Operators:* These stakeholders manage and operate the HDM. In our case study, the IT consulting firm, Egde, exemplifies a platform operator, given their existing IT infrastructure beneficial to the solution's implementation.
- *Platform Users:* These stakeholders are the platform's users, encompassing researchers, citizens, or corporations, each with distinct motivations for platform usage. For instance, researchers or corporations might procure data from the marketplace for their research or product development, whereas citizens might

opt to sell or donate their data. Furthermore, there could be companies interested in vending their health-related data and citizens keen on purchasing it, thereby highlighting the diverse motivations of platform users.

- *Legal Authorities:* Given the regulatory significance in the health domain, the third stakeholder category comprises entities accountable for establishing and enforcing laws, regulations, and policies concerning data and health and supervising compliance with these laws by platform operators and users. Although we did not speak with this stakeholder, their function as one of the main stakeholders and the impact of their legislation has been explored in both interviews and the literature.

5.2.2 Stakeholder Component Implications

Figure 10 conceptualizes the complex interplay of various components and stakeholders in HDMs. This diagram comprises three intersecting circles, each representing a stakeholder group. By examining the interconnections between these stakeholders and critical components, we can better understand their roles and areas of overlap in the ecosystem.

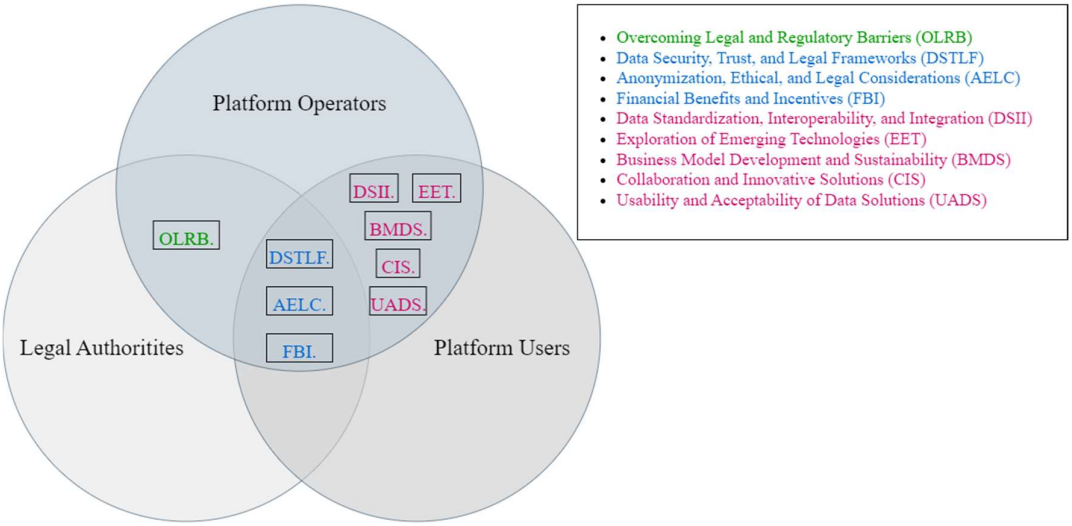

Figure 10 The Relationship Between Stakeholders and Components

Data Standardization, Interoperability, and Integration (DSII): This component is primarily the responsibility of the Platform Operators, as they manage the technical aspects of the marketplace. However, the standards must also be acceptable to the Platform Users who will use the data. Therefore, this component goes in the overlapping area of Platform Operators and Platform Users.

Data Security, Trust, and Legal Frameworks (DSTLF): This component is in the center of the Venn diagram (Figure 10), as it is critical to all three stakeholders. Platform Operators need to ensure security, Platform Users need to trust the platform, and Legal Authorities need to ensure the platform complies with laws and regulations.

Anonymization, Ethical, and Legal Considerations (AELC): This component is also at the intersection of all three stakeholders. Platform Operators need to implement anonymization techniques, Platform Users need to trust that their data will be anonymized, and Legal Authorities need to ensure the platform complies with the relevant ethical guidelines and laws.

Overcoming Legal and Regulatory Barriers (OLRB): This primarily lies within the domain of Legal Authorities who create and revise the regulations. However, Platform Operators also need to be involved in understanding and implementing these regulations. Therefore, this component goes into the overlapping area of Platform Operators and Legal Authorities.

Exploration of Emerging Technologies (EET): This component is primarily the responsibility of the Platform Operators who decide which technologies to adopt. However, these technologies need to be acceptable to Platform Users. Hence, this component goes in the overlapping area of Platform Operators and Platform Users.

Business Model Development and Sustainability (BMDS): This component is primarily the Platform Operators' responsibility as they design the business model. However, the model needs to be acceptable to the Platform Users. Therefore, this component goes in the overlapping area of Platform Operators and Platform Users.

Financial Benefits and Incentives (FBI): This component is primarily the Platform Operators' responsibility as they design the incentive system. However, the incentives must be attractive to the Platform Users and in compliance with the guidelines set by Legal Authorities. Therefore, this component goes in the overlapping area of all three stakeholders.

Collaboration and Innovative Solutions (CIS): This component naturally occurs at the intersection of Platform Operators and Platform Users. It provides fertile ground for innovation, as users, including researchers and corporations, bring unique perspectives and needs to the platform.

Usability and Acceptability of Data Solutions (UADS): This component naturally occurs between Platform Operators and Platform Users. It provides fertile ground for innovation, as users, including researchers and corporations, bring unique perspectives and needs to the platform. Additionally, non-users may participate in service exchanges, indirectly influencing the platform's development. The convergence of diverse motivations and resources in this intersection fosters innovative solutions.

5.2.3 Implementation Perspective

An analysis of Figure 10 reveals the pivotal role that Platform Operators play in the HDM. Their influence extends across all essential components, from technical implementation and user trust to legal compliance, innovation, and the shaping of business models and user experiences. Platform Operators act as crucial intermediaries, bridging the gap between Platform Users and Legal Authorities and fostering a dialogue addressing legal and ethical concerns while developing incentives to satisfy all stakeholders. Their unique position also offers the potential to spur collaboration and inspire innovative solutions by harnessing the diverse motivations and resources of Platform Users. While all stakeholders contribute significantly to the HDM ecosystem, our analysis will primarily concentrate on the role of Platform Operators, given their substantial impact on the ecosystem.

5.3 Framework for Extending a Platform to Health Data Marketplace

The implementation framework provides a structured approach for platform operators, specifically Egde, to integrate and extend the EHG with the HDM. This framework will guide Egde or other platform operators with similar capabilities, aiming to develop a secure, compliant, and efficient HDM solution that fosters collaboration and data reuse for healthcare research and innovation. This section analyzes the components and their roles within the framework.

5.3.1 Egde Health Gateway and Health Data Marketplace

EHG is a collaboration and integration platform that ensures seamless data flow between systems and stakeholders in the health and care sector. Designed following the Directorate of E-Health's target architecture for data sharing, EHG supports the exchange of standardized data formats, such as HL7 FHIR, HL7v2, CDA, ebXML, or KITH. Furthermore, the platform is compatible with APIs (REST, SOAP), electronic message exchange (e.g., EDI and AMQP), and sensors (e.g., MQTT). Subscribers to EHG include stakeholders that produce and consume health data and are from private and public sectors, such as Helsepartner Nord-Norge (private) and Sykehuspartner (public). These organizations can access a comprehensive ecosystem that enables secure data exchange, flow, conversion, and storage. The platform also incorporates authentication through the Egde IAM component, bolstering the overall security of health data exchange. EHG relies on Egde Cloud as its infrastructure. This flexible cloud service setup is tailored to customer needs, operating in a private cloud in Norway to ensure data security and compliance with local

regulations. Additionally, EHG supports integration with solutions running in public clouds, offering the possibility of hybrid cloud configurations to address specific customer requirements. Figure 11 shows the model of the current state of EHG.

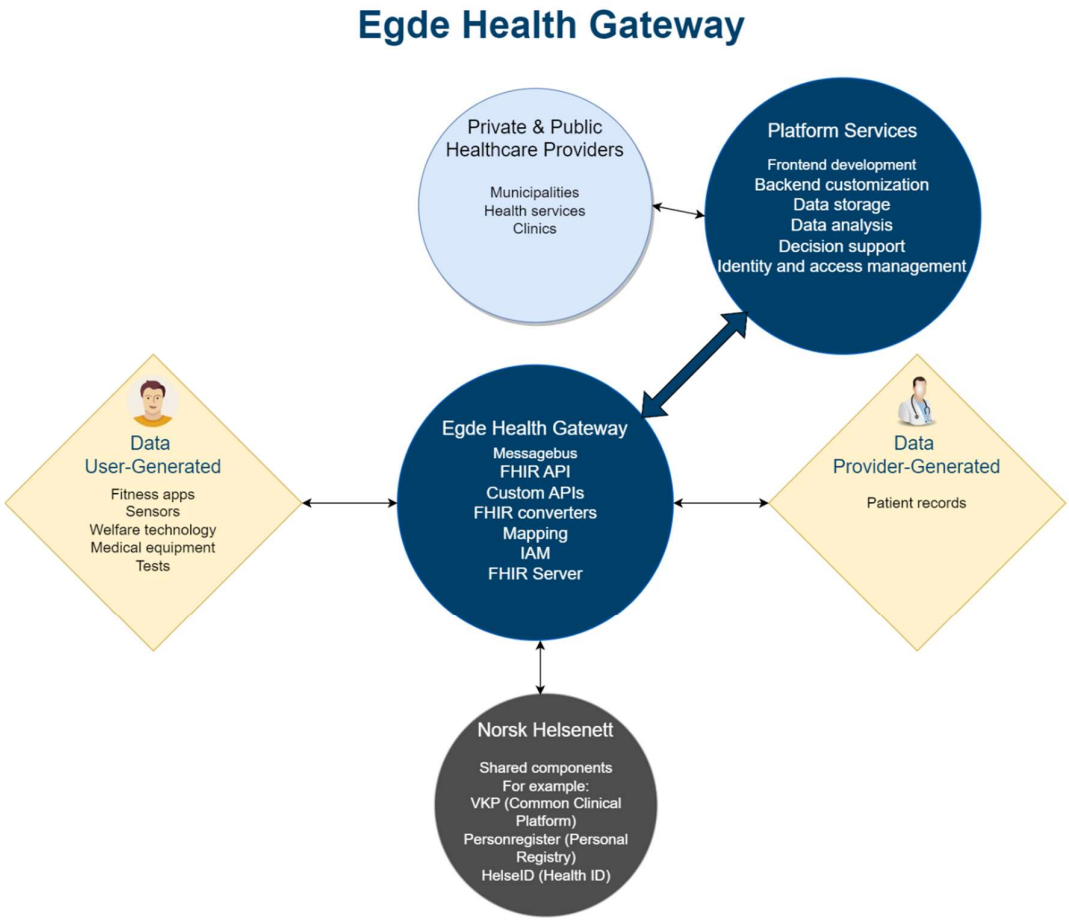

Figure 11 The Current State of Egde Health Gateway

In contrast, the proposed HDM solution will provide a secure and compliant platform for exchanging health data, ensuring data quality, security, standardization, and anonymization while adhering to regulations relative to EHG. This approach enables researchers and approved third-party providers to collaborate and reuse data, as they can purchase qualified datasets for research through the HDM.

By integrating EHG with the HDM, Egde can leverage its expertise in health data handling to facilitate a seamless and efficient HDM solution. This integration will also help ensure that the health data provided through the HDM is standardized, secure, and compliant with relevant regulations.

5.3.2 Platform Integration: Connecting EHG with HDM

Integrating EHG with the HDM facilitates seamless data exchange, ensuring data standardization, quality, and security while adhering to relevant legal guidelines and HDM policies. This integration paves the way for a data-sharing ecosystem that allows health data to be used and reused for research and innovation, fostering collaborative efforts and accelerating advancements in the healthcare sector.

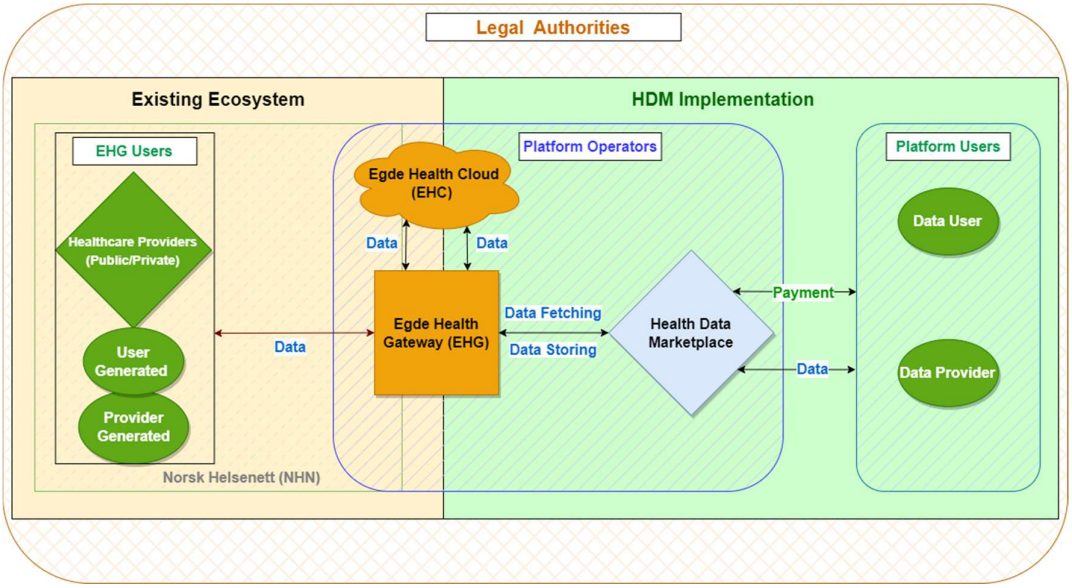

Figure 12 Framework for Extending EHG with HDM

Figure 12 depicts the implementation framework for the HDM solution. The existing ecosystem, represented on the left side of the diagram in beige color, encompasses the existing EHG solution and its corresponding stakeholders, including healthcare systems and customers. The EHG operates within the sphere of influence of Norsk Helsenett (NHN), facilitating data exchange between these systems and stakeholders.

Data from EHG is stored in the Egde Health Cloud (EHC), a secure and compliant cloud storage solution that ensures the integrity and privacy of health data. As the EHG and EHC are critical components in the current health data ecosystem, they serve as a bridge between the existing environment and the new HDM implementation, represented in green on the right side of the framework.

The HDM, connected to the EHG, leverages the latter's capabilities for data fetching and storage, harnessing the advantages of the EHG and EHC regarding health data transfer and storage. This integration allows the platform users, data users, and data providers to interact with the HDM, requesting and providing data. The HDM is also equipped to handle the transactional aspects of data exchange, including consent management and

potential payment processing. Surrounding the whole framework are the Legal Authorities, who dictate the legalities and regulations that govern the entire ecosystem. They play a pivotal role in ensuring the system's compliance with relevant laws and regulations.

To illustrate the framework further, consider the following user stories from the perspective of the Platform User stakeholders:

Data User (Researcher): As a researcher, I want to access datasets suitable for my research project through the HDM. Upon identifying the necessary datasets, I expect the platform to manage the transaction, adhering to all necessary approval processes. Following approval, the platform should send a data request to the EHG, which fetches the data from the secure EHC. This process should give me access to the purchased datasets to fulfill my research needs.

Data Provider: As a data provider, I aim to contribute to the scientific community by sharing my research findings with the HDM. After uploading my data, I expect the platform to send it to the EHG for review to ensure it complies with the necessary standards and policies, guaranteeing the quality of the data. The validated data should then be securely stored in the EHC. When another user purchases my data, I expect to receive the agreed-upon payment as a part of the data exchange process.

This integration framework establishes the foundation for a secure, efficient, and compliant HDM solution. Blending EHG's established capabilities with the HDM's innovative approach allows Edge to construct a platform promoting data reuse. This not only promotes collaboration but also accelerates healthcare research and innovation. Moreover, it offers the dual benefits of reducing research costs and mitigating the time-intensive data-gathering process.

5.3.3 Component Placement in the Framework

This section will detail the role and placement of each key component identified in the proposed framework's consolidated list of components (Section 5.1.5). The focus is primarily on the HDM implementation part of the framework and the identified stakeholders. Each component has been placed according to its primary influence and responsibility within the HDM. The placement of the components in the framework is visualized in Figure 13, with an explanation of placement below the figure.

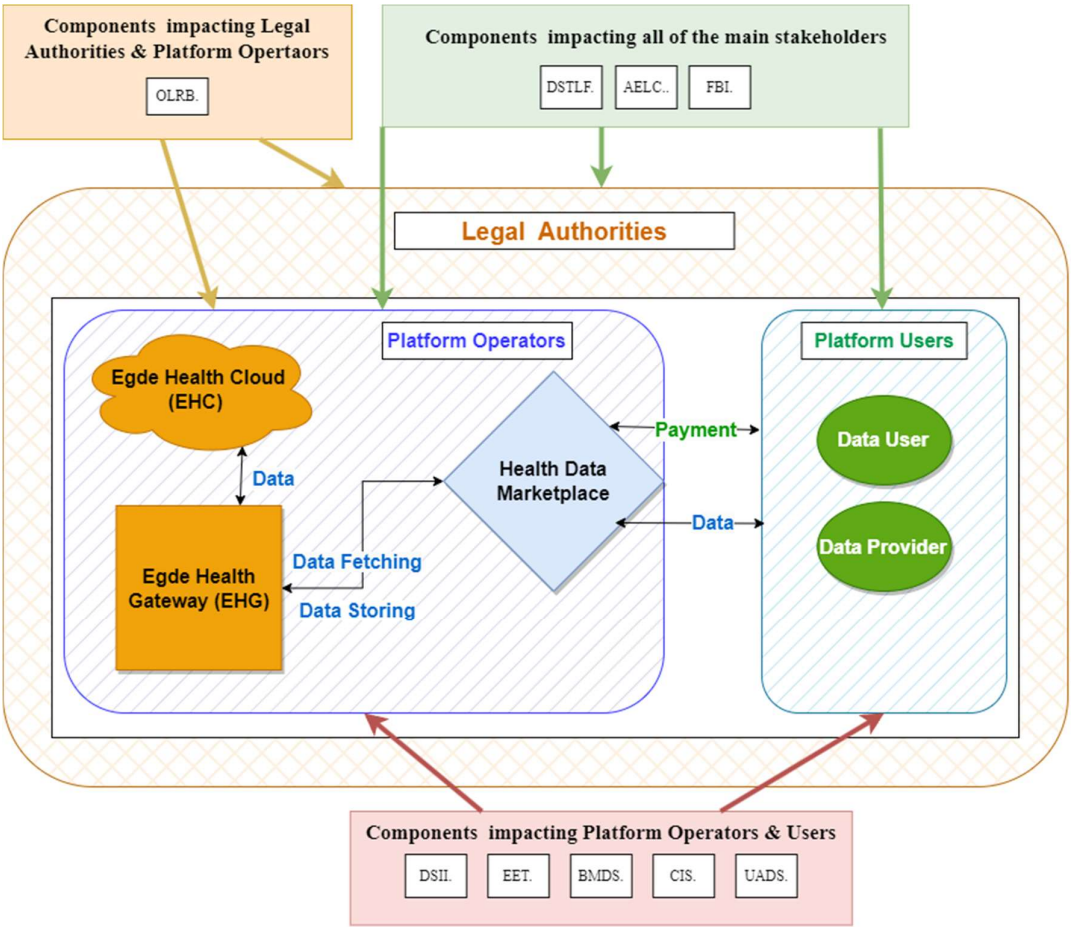

Figure 13 Component Placement in the Framework

- *Data Standardization, Interoperability, and Integration (DSII):* This component is primarily managed by the EHG, which already has established data standardization and integration mechanisms. The EHG's adherence to the Directorate of E-Health's target architecture ensures that data shared through the platform aligns with standardized data formats, facilitating interoperability.
- *Data Security, Trust, and Legal Frameworks (DSTLF):* This component is central to all three system parts. The EHG ensures data security in transit and at rest, while the HDM manages user trust and transparency through secure and compliant data transactions. Legal Authorities oversee the legal frameworks dictating security measures and trust-building mechanisms.
- *Anonymization, Ethical, and Legal Considerations (AELC):* The EHG and HDM handle data anonymization, ensuring that personally identifiable information is adequately protected. The HDM manages Ethical considerations, which must maintain transparency and gain informed consent from users. Legal Authorities set out the laws and guidelines relating to data anonymization and ethical use of health data.

- *Overcoming Legal and Regulatory Barriers (OLRB):* This component lies mainly within the sphere of Legal Authorities, who establish and revise the regulatory landscape. However, the EHG and HDM must be cognizant of these regulations and adapt accordingly to ensure compliance.
- *Exploration of Emerging Technologies (EET):* The exploration and adoption of emerging technologies fall under the purview of the EHG, which must keep pace with technological advancements to optimize data exchange and integration. The HDM may also explore new technologies to enhance user experience and data transactions.
- *Business Model Development and Sustainability (BMDS):* This component is primarily managed by the HDM, which is responsible for creating a sustainable business model that meets the needs of all stakeholders. The HDM must ensure that the model is viable and can support the continuous operation and growth of the marketplace.
- *Financial Benefits and Incentives (FBI):* The HDM is primarily responsible for the system of financial incentives, designing a structure that encourages participation from data providers and users. Legal Authorities provide the regulatory guidelines for such financial transactions and incentives.
- *Collaboration and Innovative Solutions (CIS):* This component is shared between the HDM and EHG, with the HDM fostering a collaborative environment for users and the EHG enabling the technical aspects of these collaborations. Innovative solutions can arise from the intersection of these stakeholders' diverse needs and resources.
- *Usability and Acceptability of Data Solutions (UADS):* This component falls predominantly under the HDM purview, which ensures the platform is user-friendly and caters to user needs. This can be achieved through an intuitive web application interface and an API that integrates seamlessly. The EHG also contributes by optimizing the platform's technical aspects for usability.

This framework provides a clear visualization for Platform Operators to address components and their relative placement in the framework. By understanding these components' impact and role within the framework, Platform Operators can map the path to a successful HDM solution. Each component influences the others, creating a complex interplay that must be carefully managed to ensure the system's overall success. See Appendix 9.4 for an implementation guide for Platform Operators.

6 IMPLICATIONS

This chapter thoroughly examines the research implications regarding the Research Questions (RQs). The analysis encompasses theoretical, practical, societal, and methodological aspects, comprehensively evaluating the study's impact and potential and exploring future research avenues in this domain.

6.1 Theoretical Implications

The synthesis of literature and novel empirical insights in a comprehensive framework, with its associated processes and outcomes, contributes valuable insights to the existing body of knowledge on Data Marketplaces (DMs). Particularly in the health sector, and how to integrate an HDM with an existing data gateway solution. This research reveals the alignment of the proposed framework with current theories and suggests new theoretical trajectories.

The framework aligns with Chowdhury et al. (2019) and Nguyen and Ali (2019), emphasizing the critical importance of privacy in handling sensitive data within DMs. The framework, focusing on secure data handling, anonymity, and compliance with regulations like GDPR, supports this notion and provides an applied example of how this can be achieved in a health data context. Giordanengo et al. (2018) highlighted the need for standardization and enhanced interoperability. EHG supports standardized data formats like HL7 FHIR, HL7v2, CDA, ebXML, and KITH, and is compatible with various APIs, electronic message exchanges, and sensor data protocols. However, the practical implementation of these standards and the resultant interoperability across different health systems may pose challenges. Further research is required to evaluate the effectiveness of these standards in actual operational contexts.

Building on Paparova et al. (2023), our study also underscores the critical role of data governance frameworks in shaping DM dynamics. The framework's integrations approach to data governance, mainly focusing on data standardization, security, and compliance with regulations, provides a valuable case study for how data governance can be operationalized within an HDM. Further, our research contributes new insights into the development of niche solutions within the DM ecosystem (Bergman et al., 2022; Chakrabarti et al., 2018; Figueredo et al., 2022; Ito, 2016; Rahmani et al., 2015). The framework, focusing on health data and specific features like data donation and

monetization, represents a novel solution that addresses unique challenges within the health data sector.

Additionally, the study provides a unique perspective on the role of HDMs in promoting sustainability. By reducing the resources needed for data acquisition, storage, and exchange, the framework suggests a new direction for research on sustainability and responsible data use in DMs, specifically HDMs (Pappas et al., 2023). Lastly, our research provides a novel view on democratizing health data. By enabling various stakeholders, including citizens, to donate or sell their data, our research suggests a new direction for theoretical exploration in data ownership, monetization, and their implications on HDMs.

6.2 Practical and Societal Implications

The integration of the EHG with the HDM holds significant practical implications. Foremost, implementing the framework can enhance data sharing and reduce data acquisition costs by centralizing health data into a single, accessible platform, streamlining the process of obtaining and sharing data. Additionally, it allows for data donation and monetization, creating new revenue streams and encouraging participation in the health data ecosystem. This integration also promotes sustainability by mitigating the need for repetitive data collection, leading to more efficient resource usage. Furthermore, the ready availability of health data facilitates the development of AI models tailored to the needs of specific populations and bolsters healthcare research by offering a diverse and accessible data source. Implementing the framework can create an environment conducive to innovation and cross-sector collaboration with easy data access and sharing. Finally, it augments transparency and trust in health data exchange by upholding stringent data standardization, quality, and privacy regulations.

On a societal level, implementing the framework can be transformative. It places control of health data into the hands of patients, allowing them to determine who gets access to their data and for what purposes. This empowerment could lead to increased patient engagement and enhanced healthcare outcomes. Furthermore, the solution provides practical policy-making and public health insights by collecting comprehensive and standardized health data. These insights could influence informed and effective health policies and strategies. The ability to gather health data also facilitates the tracking of public health trends and aids in the early detection of health crises, contributing significantly to broader public health objectives.

6.3 Methodological Considerations and Future Research

This section addresses the study's methodological limitations, suggests improvements for future research, and outlines potential areas for future investigation in the HDM domain.

6.3.1 Methodological Limitations

Despite the rigorous approach adopted in this study, several methodological limitations must be acknowledged, which may have impacted the validity or reliability of the findings. Firstly, the study involved only twelve interviews, with uneven representation from each stakeholder group. While the selected participants provided valuable insights, more stakeholders in the ecosystem, such as patients or citizens who can donate/sell health data, were not interviewed. Additionally, the study lacked the perspectives of Legal Authorities, an important stakeholder group that remained unexplored. This inevitably constrained the breadth and diversity of viewpoints, thereby reducing the comprehensiveness of the study's findings.

Using semi-structured interviews as a primary data collection method poses inherent challenges. As detailed in the research approach section, these challenges include potential interviewer bias, variability in participant responses, and reliance on participant memory and honesty. Also, the relatively small sample size of interview subjects does not fully represent the breadth of opinions on the topic. As with all qualitative research, it is essential to remember that the findings are not generalizable to all stakeholders within the HDM ecosystem. Finally, the literature review may not have captured the entire breadth of literature on the topic. While efforts were made to ensure a comprehensive review, the possibility of oversight or missing out on relevant studies cannot be entirely ruled out.

6.3.2 Reflections on Research Design

The research design offered strengths and weaknesses, including a literature review, semi-structured interviews, and thematic coding using NVivo. The literature review was instrumental in grounding our research in existing theories and findings. However, it also confined our scope of investigation to previously explored areas, potentially limiting our ability to uncover new insights. Semi-structured interviews allowed for flexibility and depth, providing rich, nuanced data. Nevertheless, they also presented challenges regarding the consistency and comparability of data across different interviews. Thematic coding using NVivo proved to be an effective tool for organizing and analyzing our

qualitative data. Nonetheless, the coding process is inherently subjective and dependent on the researcher's interpretation, which may introduce bias.

6.3.3 Recommendations for Methodological Improvements and Future Research

Several recommendations for methodological improvements and future research directions have been identified for enhancing the understanding of the HDM ecosystem. For future studies, the validity and reliability of the findings could be significantly improved by implementing specific methodological enhancements. This includes broadening the scope of data collection by increasing the number of interviews and ensuring a balanced representation of all stakeholder groups. This approach would provide a more comprehensive understanding of the HDM ecosystem. Additionally, it would be beneficial to supplement semi-structured interviews with other data collection methods, such as quantitative methods. This could provide additional data for triangulation, enhancing the findings' robustness. Moreover, the literature review process could be enriched by including a more comprehensive range of literature databases and literature from other similar countries to Norway to ensure exhaustive coverage of the existing literature on the topic.

A notable future research direction would be addressing this study's methodological limitations by broadening stakeholder perspectives. Interviewing more stakeholders, including patients or citizens, about their willingness to donate or sell health data can paint a more comprehensive picture of the health data ecosystem. Longitudinal studies also present a significant opportunity, tracking changes and trends over time to offer insights into the evolution of the HDM ecosystem and its adaptation to new challenges and opportunities. As the regulatory landscape for health data continues to evolve, future research could explore the implications of these changes on the marketplace dynamics. A more detailed economic analysis of the HDM ecosystem could also be valuable, examining aspects such as pricing mechanisms, business models, and the economic benefits and costs associated with data sharing.

Ethical considerations remain critical. Future research is needed to delve deeper into privacy, consent, and the potential misuse of health data, offering guidelines for ethical data practices. Technological innovations also offer an exciting field of investigation, with emerging technologies such as AI and blockchain suspected to reshape the health data ecosystem. Future research could explore how these technologies can address current challenges, such as data security and interoperability, or create new opportunities for innovation.

7 CONCLUSION

This master's thesis embarked on an intricate journey of investigating the evolving significance of health data in the digital age and its associated complexities, emphasizing data handling, security, efficiency, and ethical use. The study explored the potential implementation of a Health Data Marketplace (HDM) in the Norwegian e-health sector, aiming to construct a secure, efficient, and ethical platform for health data exchange, integrating with an existing health data gateway, the Egde Health Gateway (EHG).

The study started with an in-depth analysis of the prevailing limitations of health data exchange systems in Norway and current research gaps in Data Marketplaces (DMs), Business Models, Gateways, and the Norwegian e-health context. The study introduced two guiding research questions:

> *RQ1: "What are the essential components for successfully implementing a Health Data Marketplace for researchers in Norway?"*

and

> *RQ2: "How can a Health Data Marketplace be established using an existing data platform?"*

The study adopted a dual philosophical approach, blending interpretive and pragmatic perspectives, using purposive sampling and semi-structured interviews supported by systematic data analysis techniques. A critical facet of this thesis was the emphasis on understanding the roles of primary stakeholders in the HDM ecosystem: Platform Operators, Platform Users, and Legal Authorities. This exploration revealed that Platform Operators are pivotal in influencing essential components and fostering stakeholder collaboration. At the same time, Platform Users and Legal Authorities contribute significantly to the HDM's innovative solutions and compliance aspects.

A cornerstone of this study was the development of a framework for integrating an HDM with an existing data platform. This integration aimed to leverage the EHG's capabilities in health data handling to establish a seamless and efficient HDM, ensuring data standardization, security, and compliance. Essential components for the successful implementation of this integrated framework were identified, including Data Standardization, Interoperability, and Integration (DSII), Data Security, Trust, and Legal Frameworks (DSTLF), Anonymization, Ethical, and Legal Considerations (AELC), Overcoming Legal and Regulatory Barriers (OLRB), Exploration of Emerging Technologies (EET), Business Model Development and Sustainability (BMDS), Financial Benefits and

Incentives (FBI), Collaboration and Innovative Solutions (CIS), and Usability and Acceptability of Data Solutions (UADS).

Beyond its theoretical implications, such as supporting existing theories about privacy, standardization, and data governance, implementing the proposed framework can have substantial practical and societal benefits. For instance, it could lead to reduced data acquisition costs, efficient resource usage, the promotion of AI models tailored to specific populations, and enhanced healthcare outcomes through engagement with the HDM. At the same time, the research also acknowledged certain methodological limitations and provided recommendations for future studies to build on this foundational work. This study represents a significant milestone toward realizing an HDM for researchers in Norway. It opens the door for future research to broaden stakeholder perspectives, perform longitudinal studies, conduct a detailed economic analysis of the HDM, and delve deeper into ethical considerations and technological innovations. This exploratory case study serves as a catalyst for leveraging health data more effectively, securely, and ethically, contributing to better healthcare outcomes, research, and innovation in Norway and beyond.

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9 APPENDIX

9.1 NSD application form

We submitted an application to the Norwegian Centre for Research Data (NSD) to facilitate the data collection process, which was subsequently approved. We then distributed information and consent forms to the participants. These forms, providing the participants with comprehensive information about the study, were duly signed and returned by the participants, affirming their informed consent:

Vil du delta i forskningsprosjektet

«A Case Study of the Edge Health Gateway: Potential Benefits and Challenges»?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å undersøke potensielle fordeler og utfordringer ved Edge Health Gateway-plattformen, en plattform for digital kommunikasjon av helsedata som brukes av private og offentlige helseleverandører i Norge. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

☐ **Formål**
Formålet med prosjektet er å undersøke potensielle fordeler og utfordringer ved Edge Health Gateway-plattformen, en plattform for digital kommunikasjon av helsedata i Norge. Dette vil gjøres gjennom intervjuer med relevante aktører. Resultatene vil analyseres med tematisk analyse og presenteres i en rapport, inkludert anbefalinger for forbedringer av plattformen. Målet er å bidra til den digitale transformasjonen av det norske helsesystemet ved å forstå plattformen og hvordan den brukes. Dette er en masteroppgave fra studenter på Universitetet i Agder på studiet «Master i Informasjonssystemer».

Hvem er ansvarlig for forskningsprosjektet?
Fakultet for samfunnsvitenskap / Institutt for informasjonssystemer ved Universitetet i Agder
er ansvarlig for prosjektet. Prosjektansvarlig er Ilias Pappas (Professor).

Hvorfor får du spørsmål om å delta?
Vi har sendt henvendelser til et representativt utvalg av helseleverandører, apputviklere, Edge Consulting (skaperne av plattformen) og Norsk Helsenett, med sikte på å få

innspill fra en rekke ulike perspektiver og erfaringer. Utvalgskriteriene for alle aktørene er at de må ha erfaring med å bruke eller være interessert i å bruke Edge Health Gateway-plattformen. Vi vil også inkludere aktører som tilbyr ulike typer helsetjenester og aktører med ulike størrelser og erfaring. Vi tenker å sende henvendelser til interessentene nevnt overnfor og forventer å intervjue omtrent 10 av dem. Gjennom å inkludere alle aktørene i undersøkelsen på lik måte, vil vi få en bredere forståelse av hvordan Edge Health Gateway-plattformen brukes og hvilke perspektiver de har på eventuelle fordeler og utfordringer som er forbundet med plattformen. Dette vil bidra til å sikre at undersøkelsen gir et representativt bilde av hvordan plattformen brukes og hvordan den kan videreutvikles.

☐ **Hva innebærer det for deg å delta?**
For å samle inn informasjon, gjennomfører vi intervjuer på omtrent 45 min. som vi tar opp på lydopptak. Opplysningene vi innhenter om deg inkluderer navn, lyd- og videoopptak av intervjuet, arbeidssted, stilling, arbeidserfaring og omtrentlig alder. Disse opplysningene blir først registrert elektronisk i opptaket, deretter transkriberes de og lagres elektronisk i dokumenter.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. Kun vi to studentene og eventuelt vår veileder vil ha tilgang til opplysningene du gir. Vi vil erstatte navnet ditt og kontaktopplysningene med koder som lagres på en egen navneliste, adskilt fra øvrige data. Dataene vil bli lagret på Universitetet i Agder's (UiA) organisasjonsplattform, som har tilstrekkelig datasikkerhet. Dataene vil også bli lagret i en kryptert kanal gjennom UiA's Microsoft plattform, som kun vi har tilgang til. Vi kommer til å bruke Microsoft Teams til å ta opp intervjuene. Deretter vil vi bruke verktøyet Nvivo til å transkribere, lagre og analyisere dataene fra intervjuene. I den endelige rapporten vil dine opplysninger være anonymiserte.

Hva skjer med personopplysningene dine når forskningsprosjektet avsluttes?
Ifølge planen vil prosjektet avsluttes når oppgaven er godkjent, som forventes å være rundt 31. mai 2023. Video- og lydopptakene vil bli slettet etter at prosjektet er avsluttet. De lagrede personopplysningene (i Nvivo og i dokumenter) vil bli slettet når prosjektet er avsluttet.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra UiA har Personverntjenester vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Dine rettigheter
- Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke opplysninger vi behandler om deg, og å få utlevert en kopi av opplysningene
- å få rettet opplysninger om deg som er feil eller misvisende
- å få slettet personopplysninger om deg
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger

Hvis du har spørsmål til studien, eller ønsker å vite mer om eller benytte deg av dine rettigheter, ta kontakt med:

- Ilias Pappas (Veileder), E-post: ilias.pappas@uia.no. Telefon: 48503063
- Kantasit Intaraphasuk (Student), E-post: kantai18@uia.no, Telefon: 94540344
- Magnus Erdvik (Student), E-post: magnue16@uia.no, Telefon: 97082613

Vårt personvernombud:

- Trond Hauso, E-post: Personvernombud@uia.no

Hvis du har spørsmål knyttet til Personverntjenester sin vurdering av prosjektet, kan du ta kontakt med:

- Personverntjenester på epost (personverntjenester@sikt.no) eller på telefon: 53 21 15 00.

Med vennlig hilsen

Ilias Pappas (Forsker/veileder)	Kantasit Intaraphasuk (Student)	Magnus Erdvik (Student)

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *«A Case Study of the Edge Health Gateway: Potential Benefits and Challenges»*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i intervju

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

---

(Signert av prosjektdeltaker, dato)

9.2 Interview Guides

Interview guides were thoroughly adjusted to match the participant's background focusing on technical, research-oriented, and provider-focused backgrounds. The interviews were conducted bilingually, with equivalent content in both languages.

9.2.1 Interview Guide – Technical

The interviews were conducted bilingually, with content that was equivalent in both languages. The following is an English variation.

<u>About the interview subject</u>

1. Can you tell us about your work experience?
2. What do you specialize in currently?
3. Can you explain your role?
4. What responsibilities do you have related to e-health?

<u>About Egde Health Gateway</u>

5. What do you know about Egde Health Gateway (EHG)?
    a. What is your role?
6. What problems does EHG solve?
    a. Benefits
    b. For who?
    c. Any challenges?
7. What is the current business model for EHG?
    a. Value proposition
    b. Create value
    c. Deliver value
    d. Capture value
    e. Non-economic value?

<u>Strategy / Business model / Dynamic capabilities</u>

8. Can you describe Egde's overall strategy and how it relates to the healthcare industry?
9. What is the strategic vision of EHG?
10. How does the business model for EHG fit with the strategy?
11. Can you explain how the company identified the need for a solution like EHG (Sense)
    a. Technological possibilities
    b. Technology development

12. How did Egde develop EHG? (Seize)
    a. Anticipate competitor Reactions
    b. Defend intellectual property
13. Can you describe to what extent Egde transformed its organization to effectively deliver the EHG to customers? (Transform)
    a. Align existing capabilities
    b. Invest in additional capabilities

Data marketplace / Data ecosystems

14. How does EHG facilitate data exchange between different sources in the healthcare industry?
15. How does EHG support the creation of a data ecosystem in the healthcare industry between existing stakeholders?
16. Can you describe how EHG allows different stakeholders to access and use health data
    a. In a secure and compliant way
    b. Ensure data quality and integrity.
17. Can EHG become a platform?
    a. If yes, what would be the core and how would it be governed?
18. What are your thoughts about technologies such as blockchain, AI, or cloud computing to enhance EHG?
19. How does EHG support the creation of new revenue streams and business models in the healthcare industry?
    a. For Egde
    b. For others
20. Can you discuss any regulatory compliance issues and how EHG addresses them?
    a. GDRP

9.2.2 Interview Guide – Researchers

The interviews were conducted bilingually, with content that was equivalent in both languages. The following is an English variation.

1. What is your background and what do you research currently?
2. How do you currently gather data for your research in the field of e-health?
3. Can you describe the types of data you typically use in your research?
4. Do you use any specific tools or technologies (such as sensors, IoT devices, or smart devices) to gather data?
5. In what ways can e-health data be used for research purposes (e.g. AI, medicine, social changes, national health)?
6. What challenges do you face in obtaining data for your research? (e.g. data structure, security, standardization, lack of data, poor data quality, time constraints, outdated data, redundancy)

7. Do you see the need for a data marketplace platform in the e-health research field?
8. How do you think a data marketplace platform could address these challenges and improve access to data for researchers in the e-health field?
9. How do you think data privacy and security concerns should be addressed in a data marketplace platform for e-health research?
10. How can a data marketplace platform ensure the quality and accuracy of the data available?
11. How much are you willing to pay for data access on a marketplace platform?

9.2.3 Interview Guide – Data/service providers

The interviews were conducted in Norwegian, since all of the participant was most comfortable with the language. The guide is in Norwegian as the result of this.

Teknisk:

1. Hvordan integrerer deres helse-app med EHG?
2. Hvilke tekniske hensyn må tas for å kunne delta i en helsedata-markedsplass?
3. Hvilke dataformater og standarder bruker deres helse-app, og hvordan kan disse standardiseres for å lette deling på en helsedata-markedsplass?
4. Hvilke sikkerhets- og personverntiltak har deres helse-app implementert, og hvordan kan disse forbedres for å sikre trygg deling av data på en helsedata-markedsplass?
5. Hvilke funksjoner eller egenskaper ville deres helse-app trenge for å gjøre deltakelse i en helsedata-markedsplass enklere?

Finansiell:

1. Hva er potensielle fordeler for deres helse-app ved å delta i en helsedata-markedsplass for forskere i Norge, og hvordan samsvarer disse med deres selskapets økonomiske mål?
2. Hva er potensielle inntektsstrømmer for deres helse-app i en helsedata-markedsplass, og hvordan kan disse maksimeres?
3. Hva er potensielle kostnader knyttet til deltakelse i en helsedata-markedsplass, og hvordan kan disse minimeres?
4. Hva er potensielle risikoer og usikkerheter knyttet til investering i en helsedata-markedsplass, og hvordan kan disse håndteres?
5. Hva er potensielle insentiver for deres helse-app for å delta i en helsedata-markedsplass, og hvordan kan disse utnyttes for å fremme bruk og bærekraftighet?

Juridisk:

1. Hvilke rettslige rammer og forskrifter påvirker deres helse-apps evne til å delta i en helsedata-markedsplass for forskere i Norge?
2. Hvordan overholder deres helse-app allerede personvernlovgivning og forskrifter, og hvilke ytterligere tiltak ville måtte iverksettes for å delta i en helsedata-markedsplass?
3. Hva er vurderinger når det gjelder eierskap og immaterielle rettigheter for deres helse-apper data som ville måtte adresseres for å delta i en helsedata-markedsplass?
4. Hvilke potensielle juridiske utfordringer kan oppstå for deres helse-app ved deltakelse i en helsedata-markedsplass, og hvordan kan disse håndteres?
5. Hvordan håndterer deres helse-app etiske vurderinger ved bruk av helsedata for forskning, og hvilke ytterligere tiltak ville måtte iverksettes for å delta i en helsedata-markedsplass?

Oppfølging:

Kan du forklare hvordan helse-appen deres fungerer?

1. Hvilke kunder har dere, og hvordan bruker de appen deres?
2. Hvordan integreres appen deres med EHG og eventuelt helsesystemer i Norge?
3. Hvordan fungerer deres forretningsmodell?

Forklaring av konseptet om Data markedsplass, og hva som forskes på:

1. Ser dere muligheten for en helsedata-markedsplass for forskere i Norge?
2. Hva slags verdi tror dere en slik løsning kan skape, både for dere og for samfunnet eller andre aktører?
3. Kan det være interessant for dere å delta i en helsedata-markedsplass?

a. Hvis ja, hvordan?

b. Hvis nei, hvorfor?

4. Hvilke insentiver kunne være gunstige for private aktører for å delta i en helsedata-markedsplass?
5. Ser dere noen utfordringer i forhold til lovverket som må tas hensyn til?

a. Hvilke sikkerhets- og personverntiltak har deres helse-app implementert

Hvordan kunne dette henge sammen teknisk?

1. Hvordan kan deres helse-app integreres med datamarkedsplassen?

a. Hvilke tekniske hensyn må tas for at løsningen kan fungere optimalt?

2. Hvilke dataformater og standarder bruker dere, og hvordan kan disse standardiseres for å lette deling på en helsedata-markedsplass?

a. Hvordan sikre trygg deling av data på en helsedata-markedsplass?

3. Hvilke funksjoner eller egenskaper ville deres helse-app trenge for å gjøre deltakelse i markedsaplassen enklere?

9.3 Extended Interview Transcriptions

This section is divided into the sections from the findings, with the interview subjects' ID and the transcript from which their quote is taken. Only the relevant parts of the transcriptions are present and not the transcriptions from the whole interview due to the large amounts of text from the interviews. The questions from the interviewer are after the letter «Q,» while the answer from the interview subject is after the letter «A.» The extended interview transcriptions are in the original language in which the interview was done. This means that the Norwegian transcripts have not been translated to English due to the resources needed; only the parts of the transcripts used in the findings section have been translated.

9.3.1 Data Standardization and Interoperability

9.3.1.1 HRE1

Q: What's the benefit of the use of data marketplaces?
A: There are several benefits. For example in our solution Egde Health Gateway, entrepreneurs can avoid the hassle of creating different integrations with data providers. Instead, they can just connect to the service and get the data they need to create their applications. By having intentional standardizations, the more people use it, the better it gets. We see good examples of data marketplaces, the Ziberia app, and Siemens digital home solution. Data marketplaces can also create cooperation between actors in the ecosystem. Also, data can be shared between different industries. In the banking sector, they have a slogan of «knowing your customer», «the empirical bank». That way they can give a better service to their customers. A smarter bank in some sense. In the energy-sector data is used to get insight into what we use electricity on. That way one can know when you should use the energy, based on the prices. Overall, there are many use cases for data marketplaces. It could fit well with data-hungry organizations that rely a lot on data.

9.3.1.2 PMI3

Q: What do you know about Egde Health Gateway (EHG)?
A: A lot more after yesterday, when I had a long session with [employee] around the technical components. I have not been terribly involved in the last 6 months. Having been involved in lot of the projects that led us to the conclusion that we needed the gateway. I

know what it does, I know what I like it to do in the future. I think it is best with a bit of background of what health data looks like in Europe and Norway right now. You have the source of data for most people in the Journal systems (EPJ in Norwegian). There are many of those around, Visma have several types, Dips is a big journal system in the ”sykehus” market. We have different types of journal used by doctors for “fastlege”, infodoc, paseintsky is another one. We have others that are used in the “kommune”, Visma Profil, can be used within the “kommune” to store patient information. And there are others that are used more in the rehabilitation side of things.

Q: So there is not like one standardized solution?

A: No, you hear about projects like the “felleskomune”. So you hear we have all these journals, should we have our own, should Norway build one for everybody to use, and then there is conflict in the private sector, because these are mostly private companies building the journals vs. the directory of e-health and the Norsk Helsenett building stuff for the greater good. Most of these systems are fairly old fashioned so they have grown up with their own data models and data bases and sometimes with internal APIs, but often with external APIs. Because of the strong requirements for security, privacy and the Journal laws they are very protective with the data, which means if they do have capabilities to send data, you are more likely to be able to send data in, than to get it out. There are no standardized APIs or connectors. There is also all the health registers, probably around 120 of them in Norway, that store and collect data from all sorts of things. There is a requirement on many systems to send data. So you will have “Kreftregister” for example which if certain notifiable diseases are found in a patient then the doctor trough the journal system has to send a message to the appropriate register to store that information, so that FHI and health researchers can see what is the big picture in Norway and what are the trends in all their research databases. Over the years there is an EDI mechanism (Electronic Data Interchange), it is a long established XML based messaging system, which is basically like sending an XML file by email. It is a mechanism that has been established… it works, it is primitive, it is the primary mechanism if you send information into a journal system (e.g. henvendelse, epikrise, diagnostic report). Probably about 12 years ago a group of people launched FHIR (Fast Healthcare Interoperability Resources) standard, to try and make exchanging health data easier, and it goes under the HL7 (Health Level 7) organization. HL7 made it [FHIR] trying to cover 80% of the requirements and keep it flexible so that people could customize it for the other needs. The director of e-health came out with some advisories quite a few years ago saying “Norway will standardize on FHIR”, whatever standardizing means. But there are almost no mechanisms to use FHIR in the established system because the registers don’t use it, the journal systems doesn’t use it (for the most part). At the same time, there was the initiative VKP (Velferdsteknologisk knutepunkt) which was designed as a FHIR data exchange

mechanism so that people could talk using FHIR between two systems, even though those systems don't use FHIR. So, the government created their own gateway for use in "velferdsteknologi" which is things like medicine dispensers, door alarms – to allow some of our partnes like Teliou and Siemens healthioneers to connect their call centers that handle alarm systems and medicine dispensers and allow them to connect and send reports into the journals. So that exists, and we thought well, will that expand developing to a general purpose gateway that many actors could use in Norway, but it has not turned out that way. There are similarities with this [government gateway] and the Egde Health Gateway.

9.3.1.3 PHP2

Q: Hvilke dataformat eller standarder blir brukt hos dere?
A: Vi har oversatt til FHIR, siden det er det Egde bruker. Men det det er ikke vanskelig det tekniske som sagt, det er kjempeenkelt. Utfordringen her er at det er ikke lov. Det er den eneste grunnen til at det ikke funker per nå.

9.3.1.4 PMI3

Q: How does EHG support the creation of a data ecosystem in the healthcare industry?
A: We should also talk about another aspect of health data, apart from how the data is structured and formatted. There is the whole terminology side of things, the semantics of health data, and there are a number of standards there, one is called SNOMED CT that is a terminology standard used in many countries. It is a long list of codes about all sorts of things, for example the femur that will have a code, diseases have codes, all sorts of aspects of human biology and medicine have codes. There is also another one called LOINC which is also used, a little bit more pharmacology based. In terms of when we look at modeling data for a customer, we don't necessarily store it as FHIR, but we will typically model it so it looks like FHIR, but it might be flatter and simpler for developers. It means we can transform it into FHIR when we need FHIR gateway, but we also use the coding terminology, SNOMED CT is the one that the directory of e-health is currently focused a lot on. That means you can send information out, say there is an observation on height, you can send it out with the SNOMED CT code, so anybody receiving that will know that number with that code represents the weight of a human, and that it is coded in kilograms for example. A combination of the data structure and the terminology creates a data artifact that almost anybody can understand when it is received by another system. For our customers it means that they have data that drives their business, but is in a format with

the right terminology, that they can easily share with anybody else that they want to interact with within the ecosystem. If they want to create a strategic partnership with another company, then they are ready to share data between the two. Easier to share, ready to create bigger ecosystems. These companies don't exist on their own, you got to become part of the overall health system. So, you got primary use of data by healthcare professionals, secondary use of data by researchers.

9.3.2 Integration and Collaboration

9.3.2.1 HRE1

Q: What's your relationship with data marketplaces and data sharing?
A: My relationship with data marketplaces and data sharing internally in Egde is through a DigiMe collaboration. DigiMe takes personal data from various cloud solutions and stores them in a personal location such as OneDrive. Through consent, the data can be shared with third-party apps. This is a disruptive service because it means that we own our health data. This is also in line with the GDPR initiative. Another service is UBDI which is a marketplace for personal data, that charges for each time the data is sold. Externally I have noticed banks like DNB sell their customer data. This practice is prevalent in the industry. This reduces the control of personal data.

9.3.2.2 TDS3

A: Parties such as "Helse Sport Nord-Norge" work with fitness journals and other services related to health and fitness is one of the parties. Their goal is to connect these data with the patient's journal. There are no direct profits for any of the parties yet and there are challenges with integrating these data that are important from the user's perspective. This is where Egde helps these organizations to integrate, by establishing a data platform that makes it possible for parties to share the data.

9.3.2.3 PMI2

Q: Så det er litt begrensa hva dere kan gjøre?
A: Ja det er det, da er spesifikke lovverk og tilpasning vi må gjøre for kunden. Også kommer vi videre til markedsplass osv. Vi ser nå kunder som snakker sammen og som

ser at de kan kommunisere via oss. Med sine tjenester som er komplementære. Da har vi skapt markedsplass ved at via vår gateway.
Q: Det er direkte via gateway?
A: Ja stemmer gjennom gateway via API. Det blir på en mate en IASS, infrastructure as a service. Kan kanskje gå mot IPAS, ifrastructure platform as a service. Man kan sikkert knyttet det på ulike måte.

9.3.3 Data Storage and Accessibility

9.3.3.1 PMI1

A: There are challenges such as GDPR. Privacy and security around these issues is a bit challenge. There is a need to not break these. Patient Journal is other actors that can be a part of the example.
There is a need to records patient's log. There is quite silo in this sector, if we call our doctor the knowledge about you can be varied. Since it really depend on which systems you are registered in if it connected and communicated well with the central system and update your logs so it is up to date. It not working that smoothly right now.
There is a project that try to solve this issue called Akson, this project failed, and it budget was way to large (22 billion nok) and it will take long time to build this.
Even though the project failed there are some needs there. Different parts Norway creates their own system.

9.3.3.2 HRE4

Q: You mentioned several projects related to the EPR and the infrastructures and then and how the the gathering of data from smartphone smart devices and sharing these data. How does that work right now?
A: Uhm, well, it's kind of very complicated. I mean, these smartphone apps, wearable devices, they are used in isolated. If I could focus on hospitals, for example, or municipal services, they are used in isolated work practices. I'll talk about hospitals so that we keep it clear, because otherwise we'll just extend too much. So let's say you go to to a hospital, you already have a diagnosis. Let's say you are chronically ill, you have diabetes, you go to the hospital, you do some checkups and then they give you certain equipment which you take with you home. Some of it can be based on sensors. Some of it can be like you doing tests for yourself, like measuring your blood pressure or your blood sugar, and also

usually they couple this with digital forms. So digital forms are they work like questionnaires which are developed by the healthcare sector and your GP or your hospital specialist or your municipal service would would give you a link or we'll send you a link on let's say on your mobile phone to get access to these forms where you fill in certain measurements and information about your well-being while you are at home. So it kind of works as a virtual hospital. You are at home and you fill in information, but certain information such as let's say from sensors are generated automatically and this is usually so kind of variables and parameters which are defined by the healthcare sector. So this is usually treatment related data which you then generate to the healthcare sector. So what's happening right now is that usually these data are stored in the cloud by the vendors. That means that the hospital, if you are a hospital specialist and you use an EPR system. Uh, only a limited set of these data will be shared with the EPR system. Most of it will be stored by the vendor that provides these digital home follow up services, and if you as a hospital specialist want to have an insight into these data, you have to log in into a separate system for digital home follow up so you don't see these data from the EPR system. So there is no data sharing in that way at this point. That's from the hospital perspective.

9.3.3.3 PMI2

Q: Hvordan fungerer dette teknisk? Hvordan snakker alt sammen?
A: Da må vi tegne litt. Vi har en app som skal hjelpe fysio med å lagre og kommunisere data som blir generert. De må journalføre noe i journal system i EPJ, elektronisk pasient journal. Dette kan ikke sendes gjennom internett.
I Norge bruker de Norsk Helsenett der helse data kan bli overført. Det vi gjør er å sette oss mellom fysio og helsenett. Vi gir tilgang til vår API og kjører det i EHG og dette kjøres via NHN. Hvis Appen fysioen bruker samarbeider med flere aktører som er kan ha ulike journal systemer (info dock, DIPPS, Pri doc osv) så kan Egde lage API som kan sendes til flere av disse EPJ-ene.
Q: Okei da begynner jeg å skjønne behovet.
A: Ikke sant, de snakker ikke så godt sammen, de snakker over helsenettet. «La oss si at du går til fastlegen din, når kommer inn der og brukket armen og finner ut at du må ta prøve. Så sender de henvisning gjennom helsenettet og til sykehuset, men av og til så fungerer dette ikke. Siden systemene ikke kan snakke sammen. Da må du ta med papiret til sykehuset istedenfor, og hvis sykehuset har for mange på gang og sender deg videre til røntgensenter da må du ta med deg papiret videre. Her kunne denne meldingen bli tatt via oss slik at det blir tilpasset riktig standard og fungerer feilfritt.
Q: Er det noe grunn til at det ikke fungerer så bra mellom journal systemene?

A: Det er en til en eller en til mange problematikken jeg opplever. Dette er jeg usikker på så jeg kan ha feil. Mange av disse har formater og former for ting som er ulikt. Dette er noe de sliter med i helseplattformen i midt Norge der kommunikasjonene fungerer dårlig mellom hverandre.

9.3.4 Potential of Emerging Technologies

9.3.4.1 PMI3

Q: What are your thoughts about technologies such as blockchain, AI, or cloud computing to enhance EHG?
A: Could well be. There is a project we have just won in the first phase called Crane. In that, the specification we responded to kind of requires a federated approach. We are looking at a European wide program called gaia-x, as a potential mechanism/protocol for federating data. So that has some potential. I believe there is some blockchain use in that. I am not to sure where blockchain is going to come in right now, to all of this. I don't know if we need nonrepudiation very often, could help there. The sort of public blockchain like Bitcoin style is not that appropriate, here we don't want to put things out on the public ledger, definitely not what we want to do. As you get handed over between different health professionals, there could be a need for tracking the flow of an individual patient on the blockchain. On the AI side of things, there definitely a lot of scope there I think. There is a lot of pattern recognition going on in medicine and diagnostics, that could help a lot. Certainly with [redacted] we might have a project soon. Professor [redacted] started it. That is about picking out terms in big texts, big medical texts for example, so that could transfer all the journal notes into something that is structured and usable, so that has potential. I think its like the old saying you know a technology is successful when it disappears, its just there, like turning a light switch on.

9.3.4.2 TDS2

Q: Hvordan bidrar EHG til datautveksling mellom forskjellige kilder i helsevesenet?
A: Definitivt et stort potensial. Innen helsedata er det alltid utfordringer med lovverket over hvilke data som kan deles. Det er nok ganske strengt. En stor betingelse er anonymisering og det ikke skal være sporbart.
Jeg ser flere bruksområder her altså.

Noen av det er innen forskning: få tilgang til grunndata, primærdata fra ulike aktører, sette sammen data fra ulike aktører som ikke har blitt gjort før. Sammele de inn slik, og kan bli brukt til kvantitativ analyse hvis det gir mening. For eksempel ulike «devices», måle blodet osv. Mange tusen av slik data kan gi deg innsikt som du har aldri vært bort i før.
Når ML og AI skal bli utviklet som tjenester for sluttbruker, til eks gir deg anbefalinger så trenger den data inn å kunne gi gode anbefalinger. Det kan man tappe inn og får tak i data på en slik data markedsplass.
Utvikling av medisiner, apparater kunne vært interessant, kunne fått tilgang til data.
Mulighet for å skape innovasjon. Vi ser offentligheten arbeider med å tilgjengeliggjøre data ikke sant, om de skal gjøre slik med helse data så få vi la tiden vise.

[…]

Q: Hva synes du om teknologier som blockchain, AI eller skyteknologi for å forbedre EHG?

AI er et kjempe potensiale, mulighet for å utvikle nye tjenester og bruker det. Block-chain er jeg mer usikker på om vil gi verdi å gi til en sånn settings.

Q: I litteraturen er det en del diskusjon rundt desentralisert, mot sentralisert og hvem som har makt, at det skal være anonymisert og sikkert osv. Men de er fortsatt umodent.

A: Umiddelbart så tenker jeg jo at man må stå ansvarlig for datakvaliteten, som gjør at hvis du skal bruke sånn løsning i en helse kontekst, så burde man ha forventning på at det skal stå et navn bak slik at man vet hvem som er ansvarlig. Jeg ser ikke helt meningen, det kan være fordi jeg er litt for gammel og synes at blockchain er fantasktisk. En tekno-logi som fortsatt leter etter use-case.

Q: Teknologi og markedet er fortsatt umodent, og det er få ting som fungerer ordentlig der.

Q: Jeg har sett noen caser. De kan jo ha sine sider. Det krever at det er noen bak som er «trusted-entity» som er en parter som kan stoler på.

9.3.5 Regulatory Compliance and Privacy

9.3.5.1 HRE1

Q: Do you see any challenges with data marketplaces?
A: GDPR, laws, and privacy are the challenges that come to mind. The whole world looks to the Nordics when it comes to ethical guidelines regarding data. We have a higher norm of privacy, not many others have our standards. We have strict rules that govern privacy in nordic countries. The health sector has a very complicated structure, which is divided

into regions, counties, and municipalities. The «Samhandlingsreform» tried to solve this, but it is not working optimally today. A challenge is to enable the flow of data between the different levels in the health sector. The aim is to get the health service where you are located. However, the data is not following you as it should. There are a lot of limitations, especially in the legislation.

9.3.5.2 PMI1

Since these data are open and available for other, third-parties can create value through them by process and make it more userfriendly and understandable. There are challenges such as GDPR. Privacy and security around these issues is a bit challenge. There is a need to not break these. Patient Journal is other actors that can be a part of the example.

9.3.5.3 PMI3

Q: Can you discuss any regulatory compliance issues and how EHG addresses them?
A: We have talked about Normen. That encompasses all of the security and privacy including GDPR within it. We think it is probably the most comprehensive security framework for health data in Europe.

9.3.5.4 HRE2

Q: Det var en veldig god idé, fordi det er jo det vi ser på nå da, som vi nevnte vi ser vi på ulike private aktører som har sånn blodprøver du kan ta hjemme, så kan legen din se hva slags resultat blodprøven gir da også nå sånn fitbit monitorering for diabetes og ulike sykdommer da som private aktører har apper som kan hjelpe legene å ha mer kontroll på hva som skjer i kroppen din, og hvis de er villig til å dele disse dataene, eventuelt med forskere og forskere kan bruke de og motsatt, så kunne de kanskje ha vært noe nytt som skjer i markedet, for eksempel?

A: Det er jo det, og så litt sånn problematisk fordi at vi har. Jeg kan ta ett eksempel, hvis du har et problem som du gjerne vil diskutere med meg for det du vet jeg er nevrolog og så sender du meg en mail så sarer jeg at du får ikke lov å sende personlige opplysninger på mail, det har vi ikke lov til. Og så sier han/hun at det bryr ikke jeg meg noe om fordi at jeg vil bare ha svar på dette her. Og jeg bryr meg ikke om noen vet at jeg har en klump på hånda eller ikke, så har jeg allikevel ikke lov til å si at det er greit fordi at det er mitt

ansvar at det kommer noe inn på min mail som har noe med din helse eller dine forhold å gjøre. Det er også en sånn vanskelig ting, for eksempel med Facebook, vi har jo ikke noe privatliv lenger, men allikevel så har ikke vi lov til å ta det inn og forske på det i helseforskning. Jeg lurer jo på om det reglementet er kanskje litt stivbeint. Det er jo nesten ingen hemmeligheter lenger. Alt er jo offentlig.

9.3.5.5 HRE4

Q: Because I mean those data are really important and if they are used to research and try like you mentioned to prevent or detect disease in early stages it can change very much.
A: Yep, yeah, I agree. I agree. It's important. There's just, I think it's difficult for especially Norway because the regulation is very strict and it's followed very thoroughly and especially if you consider health data, it's followed particularly thoroughly. And many times, instead of taking the risk you decide to be cautious. So, you would rather not do too much instead of trying to manage the risk afterwards, because you know this is not Facebook, there's a need for transparency and trust. By the by the population, and if you have such a scandal, even if it's just one scandal, it's very difficult afterwards to regain trust. It's a public institution, so the risk many times the risk outweighs the benefits of what they want to do.

9.3.5.6 PMI3

Q: Can you discuss any regulatory compliance issues and how EHG addresses them?
A: We have talked about Normen. That encompasses all of the security and privacy including GDPR within it. We think it is probably the most comprehensive security framework for health data in Europe.
Q: Is FHIR a part of that?
A: FHIR is not specific to that, you can have the data in any form you like as long as it is within the right security compliance mechanism. So that's one area. There are things like the "pasientjournal loven" as well as the equivalent for health professionals, they have legal obligations of course. There is European health data space coming through will have consequences for us as well in regulatory terms. There is a whole list of ISO type standards that we have to be aware of and things like the medical device regulations, we sometime come across those. If you are providing a diagnostic service that is actually giving you an answer (like a blood sample) then it is at a quite a high level of regulation. If it is a service helping you track how many minutes of running you do every week then it is very low on the regulatory scale. We do some advisory on helping potential customers

understand where they should be in the regulatory framework, but we are not qualified to do compliance, but we help many people get ready for compliance.

9.3.6 Ethical and Anonymization Challenges

9.3.6.1 HRE3

Q: Ja ser et behov der, men som du sier det er mye vanskelig lover å altså rundt dette her da at det skal funke i praksis.
Men du sier det er kanskje mulig for mer sånn der data fra Garmin og disse appene her som ikke er så sensitive, stemmer det, eller er det bare en annen type data enn det som for eksempel kommunen sitter på?

A: Det det jeg vil tro, er jo at disse private aktørene de altså Garmin og fitbit av hva det måtte være. Jeg tror at de sitter på de sitter på en såpass høy verdi i de de gjør selv, og det hadde jeg lyst til å bruke til sin markedsposisjon heller enn til forskningen nødvendigvis så det kan jo være en liten hindring, men jeg tenker at hvis. Hvis de hadde, hvis de som er sånn private aktører hadde på en måte at man kunne koble de heller på. Altså dess mer man kunne ha brukt gode, altså gode innputt av data person genererte data koble inn i ordinære tjenester. Så har man på en måte sikret data inn i en trygg kontekst man tar. Man tar på en måte man, og det er viktig at kommunen altså det er viktig. Kommunene er jo på en måte, og det offentlige generelt er jo. Det er jo det er jo oss. Det er jo en serviceorganisasjon på vegne av oss som innbyggere, så det å ha en det å ha en sånn type markedsplass som hjelper, organiserer og håndterer det jeg tror jeg vil tror jeg ville vært hovedgreia så det å ha en gate er det å lage en sånn type at alle dataene finnes der, og så lenge så lenge du vet hvem det er som eier dataene, og så lenge du kan få en godkjenning ut fra et spesifikt formål. Godkjent opp disse dataene kan være mulige, altså da må du ha godkjenning fra den som eier dataene på tjenestenivå. Og her har fått det inn fordi at uniformene og på en måte hjelpe innbyggerne. Og så må du ha en godkjenning for en overordnet nasjonal etisk godkjenning for at du skal få lov å bruke det sånn medisinsk og helsefaglig forskning. Ellers så kan du få lov å bruke det ut fra godkjenning fra kommunen selv til kvalitetsutvikling. Så de 2 tingene, så hvis du hadde en sånn type struktur på det og at det var en del av. Så det må være en integrert del av det man altså. En dataportal for å få ut forutsetter jo at det er en gate der det er masse systemer som kan levere inn og den typen samtykke, godkjennings funksjonalitet og infrastruktur for å få ut og infrastruktur for å kunne ut. Du ta ut analysere et. Vil jo kunne være nyttig for en forsker, så ville det være altså det er jo en annen ting hvis vi hvis jeg skal forsker på personopplysninger.

Så kan du ikke bare laste det ned på en hvilken som en datamaskin hvor som helst så en annen ting. Jeg ville jo bare ha på en måte en sånn type desktop logikk, der man faktisk kan gjøre analysen det ferdig så er så enten så kan man jo helt avidentifisert eller anonymisere de, men det blir ofte vanskelig med store befolkningsdata, for det er så mange ting som gjør at vi er likevel kan koble eller det det vil, særlig hvis vi da kommer på befolkningsdata for Valle kommuner med små kull, så vil vi få kjempeproblemer med en gang. Det vil være umulig å få det ut uten å etablere på en måte du bryter. Hvis det ikke sant, hvis det er en i 10. klasse, én i åttende klasse i Valle kommuner som oppgir at de er homofil, så vidt heller Valle kommunene hvem det er og da kan ikke det ligge i datasettet som en informasjon, for da har man brutt personvernet.

9.3.6.2 TDS1

Q: Do you see any challenges with data marketplaces?
A: Well yes, there could be some headaches. There are a lot of ethical issues, for example, Google is interested in knowing what you think, is that good? We get personalized ads. We could become more of a surveillance society. With emergency services, they know where every phone is located. When it comes to AI/Ml we see that they take more and more decisions on our behalf, for example in credit ratings. “The road to hell is paved with good intentions”. There is also a fear of change, that AI will remove workplaces. I think it is important that the scope of these solutions is not too big, and that they are limited in some way.

9.3.7 Balancing Innovation and Overcoming Legal Barriers

9.3.7.1 HRE4

Q: Because I mean those data are really important and if they are used to research and try like you mentioned to prevent or detect disease in early stages it can change very much.
A: Yep, yeah, I agree. I agree. It's important. There's just, I think it's difficult for especially Norway because the regulation is very strict and it's followed very thoroughly and especially if you consider health data, it's followed particularly thoroughly. And many times, instead of taking the risk you decide to be cautious. So, you would rather not do too much instead of trying to manage the risk afterwards, because you know this is not Facebook, there's a need for transparency and trust. By the by the population, and if you have such a scandal, even if it's just one scandal, it's very difficult afterwards to regain trust. It's a

public institution, so the risk many times the risk outweighs the benefits of what they want to do.

9.3.7.2 PMI3

Q: There is no specific platform or place where they can share their data right now?

A: You have to pretty much do it point-by-point. Actually, one of the potential strategies is to start to get everything into a data warehouse or data lake, that you can help our customers share data into a greater ecosystem for the benefit of mankind or something. That creates a lot of innovation opportunities which is kind of what your question, it was about how that creates a wider ecosystem for innovation. If I am collecting data with my customers and helping them to do specific things, keep fit or track their blood sugar, if I can then make that available to a wider group of people, then you got sources of data, quantity of data, for getting artificial intelligence (AI) and machine learning (ML) to have something to work on. There is another important aspect of that, think of European health data spaces, which is an initiative that goes beyond GDPR to make sure that individuals have more right to their health data, and also you can share the data with researchers. Right now health professionals find it very hard to reshare data with others. We still have a lot of situations where somebody will have data, the only way they can share it is to print it out as a PDF and scan it into another system. The systems don't communicate. You have a small country like Norway, 5.5 million people with four different systems that don't communicate. You translate that to the UK, Germany, or France [then the problem is even bigger]. There is also the problem of sharing data across borders. One thing that hasn't happened yet, that we are trying to enable with some future projects is that instead of having centralized data repositories, we are looking at federating data, so that me as an individual have the right to my data, and in some case only I have the data from a fitness tracker for example. If I can then get my data from the journal system or from helsedata or helsenorge, and I can then share it with anybody I like because it is my data and I have the right to share it with anybody. Whereas my doctor can't just share my data. If we can start to sort of take it out of these big silos via the individual patients, then we can create a completely different data sharing. Kind of the dream. We think our health gateway and platform can help to enable that.

9.3.7.3 PHP1

Q: Det er noe i den samme tankegangen, hvor på en måte man kan dele eller eventuelt kjøpe data da sånn sett. Det vi prøver å se på nå er på det er det mulig å gjøre dette her med forskningsdata, altså si hvis man tar inn hvis man forsker på et eller annet, for eksempel blodtrykk hos dere med disse simulatorene og har viss data, går det an å gjenbruke disse dataene til annen forskning, slik at man slipper å samle det inn på nytt. Ja gjenskape det og uten å bruke ekstra ressurs for for å gjøre det.

A: Det kan det være, men det har noen begrensninger hvis det er en offentlig helseaktør som er med sykehuset eller kommune, så må de ha tillatelse fra noen som heter REK, som dere kanskje er kjent med, Regional Etisk Komité.
For å gjennomføre et prosjekt som samler data tilpasset behandling.
Den dataen kan ikke gjenbrukes. Den kan ikke under noen omstendighet kjøpes og selges. Den skal også kunne slettes etter kort tid. Og man kan lagre den med tillatelse fra NSD i en tidsbegrenset prosjektperiode. Så hvis det er offentlig helsesektor som er med og utvikler noe og gjør og måler data som skal måtte gjenbrukes til pasientbehandling, den dataen kan ikke kommersialiseres på noe vis.
Men hvis det er data fra et privat firma som skal lage en robot arm for eksempel. Så har vi lagret data om bevegelsesmønsteret. Da behøver de ikke å søke regional etisk komité om gjennomføring. Da er det jo GDPR reglementet som sier hvordan de skal håndtere den dataen. Så da vil jeg dele de 2 boksene. Altså hvis du har offentlig helsetjeneste med som aktør; ikke kommersialiserbart på noen måte, ikke som jeg kan se for meg, men hvis en privat utvikler av enten en hardware løsning eller en software løsning lagrer noe av den dataen de har brukt i utviklingen, så kanskje det er mulig.

9.3.7.4 PHP2

Fordi det er ulike kategorier av helsedata.. Du har de mest sensitive, og så har du liksom ikke-sensitive data, det vil si generelt data, og når det anonymiseres, så blir det en annen forskrift du må holde det til igjen. Og eventuelt innenfor forskning, så er det jo når det er samtykket, så er det lov å forske på. Så vil du si at det er så lenge de får samtykke fra pasienter eller de som deltar, så er det fullstendig lov.

9.3.8 Emerging Business Models and Collaboration

9.3.8.1 HRE1

Q: Do you see any changes to business and operational models in your industry?
A: Yes, DevOps is more prevalent. We see that consultant services are being replaced by subscription-based services, with a «connection fee». These changes in the ecosystem create the possibility for new business models to emerge.

9.3.8.2 TDS3

Q: Do you know the business model and operational model that can work well with DMs?
A: The business model which I think will work well with DMs is to sell consume-based services. Here, consumers pay for the data that exists on the platform, that other parties sell. The price can also be based on usage of the marketplace.

9.3.8.3 HRE2

Q: Og bort til en ting vi prater om i stad, altså du er nevnte det at det koster mye penger å lagre data og ta vare på data, og data kommer i ulike størrelser. Og at MR data var veldig store og veldig dyrt å ta vare på. Er det dere som betaler for dataene og lagringen hvor mye er forskerne eller institusjonen villig til å betale for dataene de har lyst til å hente inn?

A: Den summen kan vi. Vi lagrer ganske mange spinalveskeprøver og blodprøver på folkehelsa sine frysebokser. De har jo svære sånne bygg med frysebokser, og tror vi betaler 50.000 i året for å leie 2 sånne -80 frysere der. Og de pengene er jo ingen steder. De må tas fra prosjektet. Det må du tenke på forhånd at det kommer til å koste så mye som du legger det inn når du søker inn penger til prosjektet, hvor vi har eksternt finansiert alt vi gjør egentlig. Og også på de MR dataene. Da betaler vi en ganske høy sum til TSD, altså til Oslo. Men den summen har jeg ikke hodet, men det er også mange 1000kr i året, også stiger den prisen hvert år, og det visste du ikke når du søkte, for det kan jo ta av 10 år fra du søkte til du faktisk sitter og skal betale alle disse regningene.
Så og institusjonen har jeg ikke penger til sånt noe, sykehuset har ikke ett rødt øre til sånt noe. Det er også et problem. Vi vil jo helst ha hatt tilgjengelig hos oss at vi kunne ha brukt våre egne systemer, men. Det må jo være tracking og altså det. Frysebokser må være

sikra, og at ikke strømmen går, og det må være planer for katastrofe hvis det strømmen går eller ja, masse sånn, det er dyrt å drive på.
Vi prøvde egentlig å få til at vi skulle ha en sånn oppe i Froland der. Gullknapp heter det, med en flyplass som ligger i Froland ned på siden av at et elektrisitetsverk, en svær foss som egentlig ligger midt i skogen. Så der var det jo snakk om å lage sånn fysiske sted hvor vi kunne samle prøver og data, men det tror jeg ikke det ble noe av for sykehuset har ikke kapasitet til å fikse det selv egentlig. Og hvis du er snakk om en fysisk frys eller et rom, så er det klart at man kan jo dele på de utgiftene, og så må man jo ha systemer, så det blir lagt inn som en helt naturlig del av alle søknader til prosjekter og ikke bare søker penger til å betale en forsker, men at man søker penger til å betale de tingene der. Og det er jo noe veldig interessant som skjer på sykehuset nå, fordi at nå skal de begynne med masse kliniske studier, altså de skal det over hele landet, kliniske studier, og i mange år fikk vi ikke lov til det. Og det innebærer ofte samarbeid med industrien, og det var veldig «fysh fysh», så det skulle vi ikke gjøre, så vi. Når jeg var ung lege, så har vi inni sånn medikamentutprøving studio hele tiden, og da tjente jo vi litt penger inn til avdelings kassene som vi kunne bruke til å kjøpe PCer eller dra på en kongress eller sånn ting. Men så var det vekk. Jeg tror det var vekk i 15 år, det var lenge i alle fall. Men nå skal det inn på fullt igjen, og det er jo det er jo pengesterke aktører som disse som var pharma-firmaene. Så jeg tenker det at man burde da lage sånne avtaler at de skal betale sykehus for å ruste opp sånn datalagringskapasitet både fysisk på en fryser, men også gode servere og alt hva man trenger, og folk til å hjelpe å betjene, og at hvis de skal drive forskning på vårt sykehus, så må de være med å betale inn i den potten. Er ikke det en forretningsmodell?

9.3.9 Data Marketplaces as a Source of Financial Benefits

9.3.9.1 HRE1

Q: What's the benefit of the use of data marketplaces?
A: There are several benefits. For example in our solution Egde Health Gateway, entrepreneurs can avoid the hassle of creating different integrations with data providers. Instead, they can just connect to the service and get the data they need to create their applications. By having intentional standardizations, the more people use it, the better it gets.We see good examples of data marketplaces, the Ziberia app, and Siemens digital home solution. Data marketplaces can also create cooperation between actors in the ecosystem. Also, data can be shared between different industries. In the banking sector, they

have a slogan of «knowing your customer», «the empirical bank». That way they can give a better service to their customers. A smarter bank in some sense. In the energy-sector data is used to get insight into what we use electricity on. That way one can know when you should use the energy, based on the prices. Overall, there are many use cases for data marketplaces. It could fit well with data-hungry organizations that rely a lot on data.

9.3.9.2 PHP1

Q: Hadde dere vært interessert i å delta på en slik helse datamarkedsplass da?
Og på hvilken måte kunne dere tenkt dere det hvis dere er interessert?

A: For [redacted] sin del så er vi jo kjempeinteressert og vi hadde vært interessert fordi at vi da hadde hatt en løsning tilgjengelig for kundene våre.
Vi vil kunne generere mer aktivitet hos oss, med flere innovasjonsprosjekter og forsk-ningsprosjekter. Ved at kundene kommer her, og så sier vi har en utfordring, og det er å få tak i dataene, vi har ikke tilgang på dataene. Ok, men igjen, så har vi da en rammeavtale med Egde som tilsier at våre kunder kan kjøpe de og de datasettene på de og de vilkårene, så det ville jo vært en kjempefordel selvfølgelig.
Vi hadde ikke selv brukt det I [redacted]. Vi selger ikke teknologi eller helsetjenester, vi tilrettelegger for at kundene kan gjøre det.

9.3.9.3 TDS1

Q: Could data marketplace be a part of your business model?
A: Yes, it could provide more possibilities and insights, and better adaptability. We could have a better overview of what is happening, instead of just looking at the monetary val-ues.

9.3.10 Financing and Financial Incentives

9.3.10.1 HRE2

Q: Og bort til en ting vi prater om i stad, altså du er nevnte det at det koster mye penger å lagre data og ta vare på data, og data kommer i ulike størrelser. Og at MR data var veldig

store og veldig dyrt å ta vare på. Er det dere som betaler for dataene og lagringen hvor mye er forskerne eller institusjonen villig til å betale for dataene de har lyst til å hente inn?

A: Den summen kan vi. Vi lagrer ganske mange spinalveskeprøver og blodprøver på folkehelsa sine frysebokser. De har jo svære sånne bygg med frysebokser, og tror vi betaler 50.000 i året for å leie 2 sånne -80 frysere der. Og de pengene er jo ingen steder. De må tas fra prosjektet. Det må du tenke på forhånd at det kommer til å koste så mye som du legger det inn når du søker inn penger til prosjektet, hvor vi har eksternt finansiert alt vi gjør egentlig. Og også på de MR dataene. Da betaler vi en ganske høy sum til TSD, altså til Oslo. Men den summen har jeg ikke hodet, men det er også mange 1000kr i året, også stiger den prisen hvert år, og det visste du ikke når du søkte, for det kan jo ta av 10 år fra du søkte til du faktisk sitter og skal betale alle disse regningene.

9.3.10.2 HRE3

Q; Ja ser et behov der, men som du sier det er mye vanskelig lover å altså rundt dette her da at det skal funke i praksis. Men du sier det er kanskje mulig for mer sånn der data fra Garmin og disse appene her som ikke er så. Er så sensitive, stemmer det, eller er det bare en annen type data enn det som for eksempel har kommunen sitter på? Eller er det sånn tenker?

A: Det det jeg vil tro, er jo at disse private aktørene de altså Garmin og fitbit av hva det måtte være. Jeg tror at de sitter på de sitter på en såpass høy verdi i de de gjør selv, og det hadde jeg lyst til å bruke til sin markedsposisjon heller enn til forskningen nødvendigvis så det kan jo være en liten hindring, men jeg tenker at hvis. Hvis de hadde, hvis de som er sånn private aktører hadde på en måte at man kunne koble de heller på. Altså dess mer man kunne ha brukt gode, altså gode innputt av data person genererte data koble inn i ordinære tjenester. Så har man på en måte sikret data inn i en trygg kontekst man tar. Man tar på en måte man, og det er viktig at kommunen altså det er viktig. Kommunene er jo på en måte, og det offentlige generelt er jo. Det er jo det er jo oss. Det er jo en serviceorganisasjon på vegne av oss som innbyggere, så det å ha en det å ha en sånn type markedsplass som hjelper, organiserer og håndterer det jeg tror jeg vil tror jeg ville vært hovedgreia så det å ha en gate er det å lage en sånn type at alle dataene finnes der, og så lenge så lenge du vet hvem det er som eier dataene, og så lenge du kan få en godkjenning ut fra et spesifikt formål. Godkjent opp disse dataene kan være mulige, altså da må du ha godkjenning fra den som eier dataene på tjenestenivå. Og her har fått det inn fordi at

uniformene og på en måte hjelpe innbyggerne. Og så må du ha en godkjenning for en overordnet nasjonal etisk godkjenning for at du skal få lov å bruke det sånn medisinsk og helsefaglig forskning. Ellers så kan du få lov å bruke det ut fra godkjenning fra kommunen selv til kvalitetsutvikling. Så de 2 tingene, så hvis du hadde en sånn type struktur på det og at det var en del av. Så det må være en integrert del av det man altså. En dataportal for å få ut forutsetter jo at det er en gate der det er masse systemer som kan levere inn og den typen samtykke, godkjennings funksjonalitet og infrastruktur for å få ut og infrastruktur for å kunne ut. Du ta ut analysere et. Vil jo kunne være nyttig for en forsker, så ville det være altså det er jo en annen ting hvis vi hvis jeg skal forsker på personopplysninger.
Så kan du ikke bare laste det ned på en hvilken som en datamaskin hvor som helst så en annen ting. Jeg ville jo bare ha på en måte en sånn type desktop logikk, der man faktisk kan gjøre analysen det ferdig så er så enten så kan man jo helt avidentifisert eller anonymisere de, men det blir ofte vanskelig med store befolkningsdata, for det er så mange ting som gjør at vi er likevel kan koble eller det det vil, særlig hvis vi da kommer på befolkningsdata for Valle kommuner med små kull, så vil vi få kjempeproblemer med en gang. Det vil være umulig å få det ut uten å etablere på en måte du bryter. Hvis det ikke sant, hvis det er en i 10. klasse, én i åttende klasse i Valle kommuner som oppgir at de er homofil, så vidt heller Valle kommunene hvem det er og da kan ikke det ligge i datasettet som en informasjon, for da har man brutt personvernet. Så man så det. Det er jo ja man kan man kan tenke seg 2 løsninger man kan tenke seg type sånn gateway der man også har en type sånn desktop at man får lov å gjøre analyser, visualiseringer og den slags type at det også ligger som en del av det. Det har vi forsåvidt litt altså uio har jo det vi TSD siden sin løsning eller så kan vi tenke at gatewayen har på en måte løsninger der sånne typer disk topper ligger inne fra før da det er jo egentlig uendelig mange, men gateway logikken er jo egentlig det at du får veldig mange ting til å snakke sammen, og så er det jo funksjonaliteten for det som er tungvint og krevende, og det er jo dette med samtykke, dokumentasjoner, utlevering, kobling, egentlig en funksjonalitet som jeg tror forskere vil kunne betale for. Som sådant, og så må det jo være en type. Per nå, så er det jo sånn at man betaler. Man betaler kost kostpris stort sett før for tilgang til data enten det er fra server eller registeret eller hva det er, så man må betale for å være med å bære totalkostnadene da

9.3.10.3 PHP1

Q: Hva slags forretningsmodeller kan være mellom disse aktørene. Må det være noen som regulerer forhandlingene mellom disse aktørene, eller?
A: Det blir jo som all annen data, som musikk, film, forskningsartikler. Forskningsartikler distribueres jo på samme måte egentlig. Det er jo data som noen har produsert, lastet opp

hos en «publisher», som igjen distribuerer det. Vi har [redacted], eller via PubMed, eller en eller annen data håndterings[aktør], og så får de en royalty hver gang noen kjøper denne artikkelen. Som kunde så må jeg betale et fast abonnement uansett hvor mange jeg kjøper. Den faste [prisen] og så har du en variabel kost per artikkel eller hvor mange artikler jeg kjøper. Og så må du selvfølgelig regulere IP [immaterielle rettigheter] her da sånn at ikke man kopierer og videreselger de datasettene, men PirateBay for datasett. Det vil sikkert komme etter hvert og det finnes nok eller det finnes jo faktisk ja.
Ja altså igjen. Det er jo litt tillitsbasert, men forretningsmodellen som man liksom tar utgangspunkt i hvis alle er snille og greie. Den tror jeg må være litt på samme måte vi deler data om forskning i dag.

9.3.10.4 PHP2

Det det er viktig med reell data. Hvis ikke, så blir dere bare ført bak lyset, og forskerne, og også veldig mange innen helse, snakker ikke sant. Fordi det som er sant er at de ikke ville gått på jobb hvis de ikke fikk penger, så penger er det viktigste insentivet for at de går på jobb. Og så kommer de andre tingene i tillegg. Ergo, så må man legge til rette for insentiver som er økonomisk. Og så kommer de her tingene som er rett å gjøre, og det er egentlig bare hva som er lov å gjøre. Og det er de to tingene som må finne ut av, hva skal man gjøre til er at folk får lyst til å gjøre det. Og hva er det som hindrer de rent juridisk for å gjøre det.

9.3.11 Trust Between Stakeholders

9.3.11.1 HRE2

Q: Hva med kvaliteten da? Hvordan skal dere sikre kvaliteten mellom de data som er hentet inn og delt i en markedsplass?
A: Nå er jo at vi må stole på kollegene våre, og hvis vi merker at noe ikke virker tilforlatelig, så må vi ta det opp og undersøke det og melde det i tilfelle. Så det går vel mye på tillit, tror jeg rett og slett.

9.3.11.2 HRE4

Q: Because I mean those data are really important and if they are used to research and like you mentioned try to prevent or detect disease in early stages it can change very much.
A: Yep, yeah, I agree. I agree. It's important. There's just, I think it's difficult for especially Norway because the regulation is very strict and it's followed very thoroughly and especially if you consider health data, it's followed particularly thoroughly. And many times, instead of taking the risk you decide to be cautious. So, you would rather not do too much instead of trying to manage the risk afterwards, because you know this is not Facebook, there's a need for transparency and trust. By the by the population, and if you have such a scandal, even if it's just one scandal, it's very difficult afterwards to regain trust. It's a public institution, so the risk many times the risk outweighs the benefits of what they want to do.

9.3.11.3 TDS2

Q: Hvordan støtter EHG skapingen av nye inntektsstrømmer og forretningsmodeller i helsevesenet?
A: Litt tilbake til det jeg nevnte tidligere. For Egde sin del så er det at vi kobler sammen ulike aktører, en kommersiell interesse for å fa mest mulig aktører til å bruke den, lager et økosystem. Det vil og gi kontinuerlig inntekt. Det er en hyggelig posisjon å være i. Ikke en revolusjonerende forretningsmodell.
I et selskap jeg jobbet for brukte EDI, vi var «disruptorer» i den bransjen, der vi er punktet som kobler sammen aktører, vi har i ganske lik forretningsmodell og posisjon.
Redusert kostnad for andre aktører, de slipper å ha direkte kostnad på utviklingen. Det å ha tilgang og å bli kjent med andre aktører vil ha verdi for forretningsutviklingen for kommersielle aktører. I teorien hvert fall.

9.3.12 Usability and Acceptability

9.3.12.1 HRE3

Det er jo 2 ting her. Én ting er på en måte, forskningen som går på systemforskaling, altså selve løsningen. En annen ting i forskningen som går på selve innbygger dataene, helsedataene. Så det er, og jeg er jo primært opptatt av det siste som helseforsker naturlig nok,

samtidig som vi er opptatt av på en måte at man ser et sånn. At man også bruker de endrer dette, for det kan du si noe om på en måte. Altså, det har jo med usability acceptability. Alle disse type mer logikkene som er det løsninger som fungerer, det ikke bruker man det, bruker man det ikke. Hvis man endrer sånn og sånn i løsninger. Det er flere og flere som svarer er like svarer. Det er masse sånne typer ting er jo som er som er på en måte personopplysninger på et annet nivå igjen da, men det er jo fortsatt. Enten innbygger data om helsen eller systemdata, som altså begge deler i kommunen sitter. Der er knyttet til en tjeneste da.

9.3.12.2 PHP1

Q: Hvilken funksjonalitet eller egenskaper tror du er viktig for en slik markedsplass eller datadeling plattform for å forenkle deltakelsen?

A: Den må være tydelig strukturert for at forskning eller helsetjenesten skal se på det som relevant. Så må de veldig lett se hvilke typer data dette er. Du må kunne tagge det altså hvis det er søvndata da, OK, den må være godt beskrevet hva den søvndataen er. Er det mennesker som har sovet hjemme, er det på institusjon, har de sovet her, hvor lenge har de sovet? Hvilke omgivelser, var det kontrollerte omgivelser, eller ikke kontrollerte? Sånn god info om dataene, sånn at den i det hele tatt skal kunne brukes, det er viktig. Hvem er det som er selger og leverandør av de ulike datasettene, selvfølgelig veldig viktig, fordi mange studenter har lyst til å tjene greie penger. Kanskje hadde de gitt fra seg data billigere enn det andre mennesker hadde gjort? så kan man tenke at OK, her kommer det en kynisk aktør inn, og sier at vi betaler 100 kroner til alle som går med denne klokka i dag. De blir en slags sånn Finn.no markedsplass hvor du kan «huke av» de ulike egenskapene som du er avhengig av, og så får du opp tilgjengelige datasett da kanskje? Tenker jeg.

9.3.13 Ongoing Projects and Initiatives

9.3.13.1 HRE4

Yeah. If we that the journal systems will give access to such data. But I mean if we leave the journal systems aside because that's like very sensitive personal data about diagnosis and so on. So, if that data is anonymized in some way, I can imagine it to be part of the of the marketplace. Otherwise, there's a lot of other data. So, if we if you take aside the

journal systems and think let's say about the registries, so cancer registry, or dept registry. I don't remember all the types of registries that you have in Norway. I address registry, I don't know, birth registry, all these things. So even if you just have some kind of anonymous or some kind of anonymized data from the journal systems and data from the registries and data from the smartphone apps where it will be prices, that is still a long way ahead. Because some data, I think data from the cancer registry are not so difficult to get them. They want research on this. I'm not talking about research on how to develop apps for it, but research on I don't know. Detecting early prevention phases, symptoms, managing throughout the diagnosis and all these things. Yeah, one project is called "Godt Begynt", where they going to track and research data from the day you have a kind of since you are child till when you grow up to kind of predict and help you to foresee in your diseases and so on based on the data that are collected.

[…]

Q: I want to ask you furhter on that and how open is this data that are gathered can and the researcher use this data to further research on their thesis and so on.

A: Yeah, I wouldn't know because the way that I get the research for my data. It's so first of all, I don't gather personal health data for the research, right? I am doing research mostly on digital infrastructures, which means that I get the research about, as you said, data flow, data sharing, how data are used in work practices, right, what's the technological and organizational interdependencies and these things. But I don't use personal health data in my research, so there is now I don't know if you have the time to look at it and when you're supposed to deliver, but in Norway there was a project called "Helseanalyseplattformen", which started 2018, and it was stopped December the previous year. So a couple of months ago, mostly because of legal issues. This plattform was supposed to be an official public sector platform, for example, like Helsenorge is for you to get insight into your personal data, Helseanalyseplattformen was supposed to be a platform for researchers who want to use health data for research. I'm not sure if it had also other purposes, but definitely research was the biggest reason why they wanted to do this. So it's part of a bigger project called "health data program" or something like that, where as of now, what do they have from that health data program? They have a portal called helsedata.no where you can go and access certain data from different registries, sources. So they have various sources of personal. Not just personal, so health data, sorry. And they have certain variables on like analysis that you can perform on these data and if you click on each of the kind of data collections or data products that they have. So you can you can see for each of the data products for which purpose you can use it, how much do you have to pay and these things. So this is a project which of course there's interest about this and this is important. But it was stopped for again. I don't want to obsess you with this legal stuff, but it was stopped for legal reasons. That was the main thing. There's this

I don't know if I should call it law or if it's a principle. It's a EU regulation called Schrems 2 and that means that if you are an EU country or an part of the EØS agreement, you you should not store data outside the EU.

9.3.13.2 HRE3

Q: Ja, det var kjempebra. Kunne måtte si litt kort åssen, dette er godt begynt. Prosjektet startet. Hva var liksom motivasjonen fra starten.
A: Motivasjonen fra Start av egentlig at man altså, Helsedirektoratet, lyst ut midler. Til altså regionene fylkene sånn at Agder fylkeskommune på vegne av flere kommuner søkte en god del midler. Fra Helsedirektoratet for å utvikle bedre kunnskaps, altså mer kunnskapsbaserte tiltak for å bedre barn og unges psykiske helse og utjevne forskjeller i altså sosial ulikhet og helse.
Også var vi på en måte på prosessen, og vi var veldig raskt og tydelig på det at hvis vi skal si noe om sosial ulikhet og helse, vi skal si noe om psykisk helse og utviklingen av det på samfunnsnivået skal si noe om hvordan de tiltakene, de ressursene vi faktisk bruker. Hvordan det du treffer eller ikke treffer, så må vi ha på en måte indikatorer som sier noe om, ja, men hvordan. Hvordan står det til med barns helse? Så utgangspunktet var egentlig ideen om at vi måtte ha en rigg for å evaluere, og så var det sånn at midlene der gikk ikke.Var ikke på en måte rigger. De var rigga til tiltak, utviklingen i seg selv og ikke til evalueringen av tiltak, så dermed så søkte vi ekstra mye.
Det var egentlig Kristiansand kommune som tok initiativ med oss flere som partnere for å på en måte rigge en type system fra det som og også koble oss på helsestasjons og skolehelsetjenesten. Så de første 3 årene så hadde vi prosjektvirksomhet på den måten, og så vi ganske fort at spørreskjema på talen som ble brukt. Den hadde jo da ikke noe integrasjon med. Med journalsystemene som er litt gammeldagse i tjenesten sånn at det ble på en måte 2 separate system og en god del sånn tungvinte prosesser og mange klikk for helsesykepleierne da.

9.3.13.3 PMI2

Q: Hva er CRANE for noe?
A: Det er EU prosjekt knyttet til helse i et livsløp. Der man kan dele alle sine data, med ulike aktører, behandlere, AI og alt mulig. Kan identifisere risiko, behandling osv.
Q: Ja okei, så utnytte mest data best mulig?
A: Ja det går ganske langt i å være forebyggende, så det er nesten man samler data fra da man har blitt født. Dette bli brukt til å veilede personen videre innen helse osv.

Den går ganske høy den Cranen, det liksom for å finne diagnose nå. Økosystemet er jo mye større. Vi jobber med blant annet Kristiansand kommune, og 3 – 4 andre partnere, Siemens healtineer, Fundable, Zyberia. Det er så mye gøy som skjer innen dette.

9.4 Implementation Guide for Platform Operators

The following steps provide a detailed roadmap for Platform Operators to implement the proposed health data marketplace framework, considering the specific components of Egde Health Gateway (EHG), Egde Health Cloud (EHC), and Health Data Marketplace (HDM).

Step 1: Requirement Gathering and Analysis Engage with all stakeholders to understand their needs and expectations. This includes healthcare systems, data users, and data providers interacting with the EHG, EHC, and HDM. Define the functional and non-functional requirements, considering the specific standards and protocols supported by EHG (like HL7 FHIR, HL7v2, CDA, ebXML, or KITH, and APIs - REST or SOAP).

Step 2: Architectural Design Design the system architecture to detail the integration of EHG with the HDM. The architecture should account for the necessary data exchanges, data storage in EHC, and user interaction with the HDM. Create clear data flow diagrams, outlining how data will be fetched from the EHC via EHG and provided to users through the HDM.

Step 3: Development Develop the HDM to work in conjunction with the EHG. Ensure the platform is capable of handling standardized data formats and is compatible with the EHG's supported APIs and electronic message exchange protocols. Develop the HDM to manage transactional aspects of data exchange, such as consent management and potential payment processing.

Step 4: Security and Compliance Ensure robust security measures are in place, leveraging the EHG's existing authentication system (Egde IAM component). Implement data encryption at rest and in transit and maintain strong user authentication and authorization processes. In addition, verify that the system complies with all relevant health data regulations, particularly those specific to Norway, given the location of the private Egde Cloud.

Step 5: Integration Establish seamless integration between EHG and HDM. Ensure data can be fetched securely from the EHC through the EHG and presented to users via the HDM. Confirm that the EHG correctly interprets data requests from the HDM, pulls the relevant data from the EHC, and returns it to the HDM in a secure and standardized format.

Step 6: Testing Conduct rigorous functional and non-functional testing. Validate the proper functioning of the EHG and HDM integration, data fetching from the EHC, and the user interface of the HDM. Perform extensive security testing to identify potential vulnerabilities.

Step 7: Deployment Initiate deployment of the integrated system in a controlled environment, ideally starting with a small-scale pilot program. Ensure that the deployment process considers the potential for hybrid cloud configurations, leveraging both the private Egde Cloud and public cloud solutions if necessary.

Step 8: Training and Support Provide comprehensive training to all users on how to interact with the HDM, including how to submit and access data. Offer ongoing support to address any issues or concerns that arise during the use of the system.

Step 9: Monitor, Evaluate, and Improve After deployment, continuously monitor the system's performance and solicit user feedback. Implement regular system updates to address identified issues or areas for improvement, ensuring the platform continues to meet user needs and regulatory requirements.