






Establishing a Health Data Marketplace: A Framework for Success

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Abstract. This study outlines essential elements needed to develop a Health Data Marketplace (HDM) by building upon an existing data platform in Norway. A comprehensive framework is proposed that accounts for technical, legal, financial, and additional considerations. The results highlight the pivotal roles of key HDM actors - Marketplace Operators, Marketplace Users, and Legal Authorities - and emphasize critical enablers such as Data Standardization, Interoperability, Integration, Security, Trust, and Legal Frameworks. Such a marketplace has the potential to catalyze the effective, secure, and ethical use of health data, contributing to enhanced healthcare outcomes, research, and innovation.

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

1 Introduction

In Norway, reliable and good-quality health data are collected for patients. This is mainly attributable to the utilization of a singular, standardized personal identifier, which facilitates data combination and analysis [1–3]. Since 2017, the Norwegian eHealth Directorate 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 stimulate research and innovation, improve public health, and support economic growth [4, 5].

Several innovative initiatives have emerged in the Norwegian e-health landscape, including Helseanalyseplattformen (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 premises, the initiative stopped in December 2021 due to

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legal and technical challenges related to adequately protecting the data [6, 7]. In contrast, Helsedata.no, a part of the health data program focusing on healthcare infrastructure and services, has successfully been established. This platform hosts different types of data and facilitates data access for research, quality improvement in health services, medical development, and other health-related aims. While the platform primarily targets research, 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 data sources belong only to specific categories such as central health registries, national medical quality registries, national health surveys, biobanks, and socio-economic data, while a complex and strict access request process is limiting its potential [5].

The observed limitations within present-day health data exchange systems inspired us to delve deeper into their potential. To do this, we performed a literature review, focusing on Data Marketplaces (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 a Health Data Marketplace (HDM) successfully. The literature highlights the importance of thorough case studies on DMs and their providers [8] and suggests the need for more research into novel marketplace solutions that tackle issues within data ecosystems [9–13]. Research areas that need to be further developed include privacy of sensitive data in DMs [14, 15], standardized data formats, and interoperability [16]. Also, there additional research is needed on data governance frameworks and their influence on DM dynamics [17]. The current study aims to address these complex issues through an exploratory case study. The study uses the Egde Health Gateway (EHG) as a case. EHG is a platform for data flow between health information systems and actors in line with the Norwegian target architecture for data sharing in the health and care sector. EHG is continuously expanded adding new connections to health record systems and application providers. The objective is to identify components required to establish a secure, efficient, and collaborative platform for health data exchange. The study is guided by two primary research questions (RQs):

RQ1: “What are the essential components for successfully implementing a Health Data Marketplace in Norway?”.

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

The paper is organized as follows. Section 2 presents related literature. Section 3 presents the method employed. Section 4 presents the findings, and Sect. 5 provides a discussion along with implications and suggestions for future work.

2 Related Literature

This section presents key findings from our literature review. To facilitate structure, we have organized the content into four primary categories: Technology, Legal Hurdles, Financial, and Other Aspects in DMs. This literature is the background of our study.

Technology. IoT technology is vital for data gathering in and healthcare but there are challenges including scalability, data standardization, and AI integration [12]. Standardized protocols can improve wearable device data flows in healthcare [18]. Data sharing

requires adherence to FAIR (Findable, Accessible, Interoperable, Reusable) principles and stable end-to-end systems [16, 19]. Health data interoperability involves both technology and human activity aspects [20, 21]. Storage arrangements can vary, with some DMs using cloud storage and others decentralized storage [8, 9]. Blockchain can enhance data trading trust and transparency [22].

Legal Hurdles. More and Alber [23] discuss the balance between gaining insights and maintaining privacy in DMs. Regulations like GDPR have specific provisions for data collection and retention [23, 24]. For instance, prior research discussed GDPR and HIPAA's impact on wearable health devices [18]. Furthermore, research by Spiekermann [25] outlines challenges related to trust, security, and the lack of established regulatory frameworks for data trading.

Financial Aspects. Prior research has suggested business model archetypes for DMs, useful across industries [8, 9]. Teece [26] underscores the role of dynamic capabilities and organizational design in business models. Specifically for healthcare, prior research [16] calls for more open solutions in health sensor industry. Furthermore, researcher identified essential properties for traded data, including compliance with FAIR principles [27] and emphasizes the role of metadata in data quality and trading [28].

Other Aspects in Data Marketplaces. Prior research explored non-economic benefits like knowledge transfer in open DMs [29]. Trust issues are common challenges in DMs [15, 23]. Decentralization and blockchain can address these by establishing trust and preventing market monopolies. Chowdhury, Ferdous [15] propose a trust framework for health data sharing. Nguyen and Ali [14] recommend a reputation system for transparent and trusted transactions. These insights set the stage for our study.

3 Research Method

To address the RQs, we opted for semi-structured interviews [30, 31]. The interviews were conducted based on a guide developed from the literature review and following a purposive sampling strategy [32]. The data collection method enabled the exploration of unanticipated themes and tailoring to different participant's background and expertise [33, 34]. 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 following all Norwegian guidelines for research data [35]. We established a collaboration agreement with Egde, the developers of Egde Health Gateway (EHG), which provided us access to connections and resources within their ecosystem. As a result of this collaboration, we identified various interview participants that have roles as data providers, data users and consultants. Table 1 provides an overview of all study participants. The participants received the interview guide in advance and this allowed them to reflect on the questions before the interview. We recorded all interviews and transcribed them. The recordings enabled us to review the interviews multiple times, making them a more reliable data source.

Data analysis followed a systematic approach per Oates [31] and Miles, Huberman [36]. An inter-coder reliability approach was adopted to enhance the validity and reliability of the results [37]. Two authors individually coded the interview transcripts into

Table 1. Overview of study participants.

ID	Description	Category	Organization
HRE1	E-health Executive	Healthcare & Research	Egde Consulting
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 Consulting
TDS3	Data Consultant	Technology & Data	Egde Consulting
PMI1	Innovation Consultant	Project Management	Egde Consulting
PMI2	Project Manager	Project Management	Egde Consulting
PMI3	Innovation Consultant	Project Management	Egde Consulting
PHP1	C-Level Executive	Private Health Provider	Private Health Company
PHP2	C-Level Executive	Private Health Provider	Private Health Company

themes. We discerned patterns and trends in the data and synthesized the findings to respond to the RQs. We used NVivo to code the data into categories and grouped the codes into the themes identified in the literature.

4 Findings

4.1 Technical Findings

The operation of a Health Data Marketplace (HDM) hinges on the ability to address various technical aspects, including data standardization, integration, interoperability, and security. This section provides an overview of these findings.

Data Standardization and Interoperability. Both data standardization and interoperability were frequently discussed during the interviews. HRE1 highlighted the use of standardized data formats, like HL7's FHIR, noting that *"having intentional standardizations, the more people use it, the better it gets"*. PMI3 discussed the importance of terminology standards stating: *"...apart from how the data is structured and formatted. There is the whole terminology side of things..."*.

Integration and Collaboration. HRE1 mentioned the role of Egde Health Gateway (EHG) in enabling collaboration by providing an integration platform for secure sharing and interaction. PMI2 further noted: *"We see that customers communicate using the gateway [EHG], sharing services that can be complementary to each other."*

Data Storage and Access. Data sharing difficulties within healthcare were noted by PMI1, stating: *"There is quite a silo in this sector..."*. HRE4 identified an issue with how data are stored by vendors, stating: *"most of it (data) stored by the vendor that"*

provides digital home follow up services, and if you as a hospital specialist want to have an insight into the 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”.

Potential of Emerging Technologies. Interviewees often mentioned the potential of emerging technologies like artificial intelligence (AI), machine learning (ML), and blockchain. TDS2 noted: *“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, uncertainty surrounds the applicability of new technologies. PMI3 discussed AI and ML’s potential but showed skepticism regarding blockchain’s immediate relevance saying, *“I am not too sure where blockchain is going to come in right now, to all of this”.*

4.2 Legal Findings

Regulatory Compliance and Privacy. The interviews highlighted the pivotal role of the General Data Protection Regulation (GDPR) and privacy in operating an HDM. HRE1 stressed stricter privacy standards in the Nordics, saying, *“GDPR, laws, and privacy are the challenges that come to mind (...) We have strict rules that govern privacy in nordic countries.”* Referencing the well-rounded security framework provided by *“Normen,”* PMI3 termed it as *“probably the most comprehensive security framework for health data in Europe”.*

Ethical and Anonymization Challenges. Beyond mere legal compliance, participants drew attention to the considerable ethical issues coupled with the difficulties in anonymizing large population datasets. Consent was deemed crucial and also national ethical approvals as explained by HRE3 - *“...approval from the data owner at the service level... And you must have an overarching national ethical approval”.*

Balancing Innovation and Overcoming Legal Barriers. The balancing act between fostering innovation and sticking to regulatory compliance posed a significant challenge. HRE4 expressed this as *“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”.*

4.3 Financial Findings

Emerging Business Models and Collaboration. Interviewees often referred to the ongoing transition from traditional consultant services to subscription-based services, stimulating new business models. HRE1 noted, *“consultant services are being replaced by subscription-based services, with a connection fee.”* and TDS3 proposed a consumer-based service model where consumers pay for the data they use on the marketplace.

Data Marketplaces as a Source of Financial Benefits. Participants pointed out potential financial gains through DMs. HRE1 saw opportunities for entrepreneurs, stating, *“EHG, allows entrepreneurs to bypass the complexities of setting up different integrations with data providers.”* PHP1 shared similar views, highlighting that HDMs could fill data gaps in organizations, thereby offering ready-made solutions for customers.

Financing and Financial Incentives. Participants pointed to important financial aspects. HRE2 emphasized the role of data storage costs, saying, “*We pay quite a large sum to (data storage provider)*”. PHP1 stressed the need for a just and transparent pricing model: “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”.

4.4 Other Findings

Trust Between Stakeholders. The critical role of trust among stakeholders was a dominant theme during the interviews. HRE2 highlighted the importance of trust in relation to the quality assurance of collected health data, stating. HRE4 cautioned about the difficulty of restoring faith following a breach of trust, “*Even one scandal can make it very difficult to regain trust subsequently*”.

Usability and Acceptability. The usability and acceptability of data solutions were brought up in several interviews. For instance, PHP1 stated: “*Data solutions must be transparent and user-friendly, offering clear data type descriptions ... Awareness of the data providers and price variations is critical*”.

Ongoing Projects and Initiatives. Various ongoing projects and initiatives related to HDMs were highlighted by the interviewees. For instance, Agder County efforts to improve mental health and reduce social inequality among children and young people were relayed by HRE3. Additionally, collaborations among partners like Kristiansand municipality, Siemens Healthineers, Fundable, and Zyberia were touched upon by PMI2, who works on EHG.

4.5 Synthesis – Proposed Set of Components

The investigation of the potential development of an HDM in Norway led to the identification of several key components, each of which can play a vital role.

Data Standardization, Interoperability, and Integration (DSII). This 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 standardization ensure that data can be combined and used across various systems and institutions.

Data Security, Trust, and Legal Frameworks (DSTLF). The dual challenges of maintaining data security while also fostering trust between various stakeholders are encapsulated in this component. Building trust between stakeholders requires clear, consistent, and enforceable legal frameworks that protect data rights while facilitating cooperation and data sharing. Ensuring regulatory compliance is crucial.

Anonymization, Ethical, and Legal Considerations (AELC). Anonymizing personal health data is an ethical necessity, not just a legal requirement. Striking a balance between utilizing health data for benefit and protecting individuals’ privacy is vital.

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

Exploration of Emerging Technologies (EET). This component 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 (BMDS). This component emphasizes the significance of having viable and sustainable business models. A collaborative approach is essential to drive innovation and ensure sustainability.

Financial Benefits and Incentives (FBI). 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 (CIS). This 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 innovation.

Usability and Acceptability of Data Solutions (UADS). A user-friendly, transparent, and acceptable system is essential for ensuring the efficient utilization of health data, thereby driving the marketplace's success.

A consolidated HDM framework including all components is provided in Fig. 1. The role of each component, as described above, aligns with its placement within this framework, demonstrating its influence and primary domain within the HDM.

5 Discussion

The synthesis of the literature and the empirical insights in our framework contribute to the existing body of knowledge on Data Marketplaces (DMs). The proposed framework aligns with past studies emphasizing the critical importance of privacy in handling sensitive data within DMs [14, 15]. The framework, focusing on secure data handling, anonymity, and compliance with regulations like GDPR, supports this. 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 interoperability across health systems may pose challenges. Further research is required to in actual operational contexts.

Building on recent studies [17], our study also underscores the critical role of data governance frameworks for DMs. Our approach to data governance mainly focuses on data standardization, security, and compliance with regulations. Furthermore, the

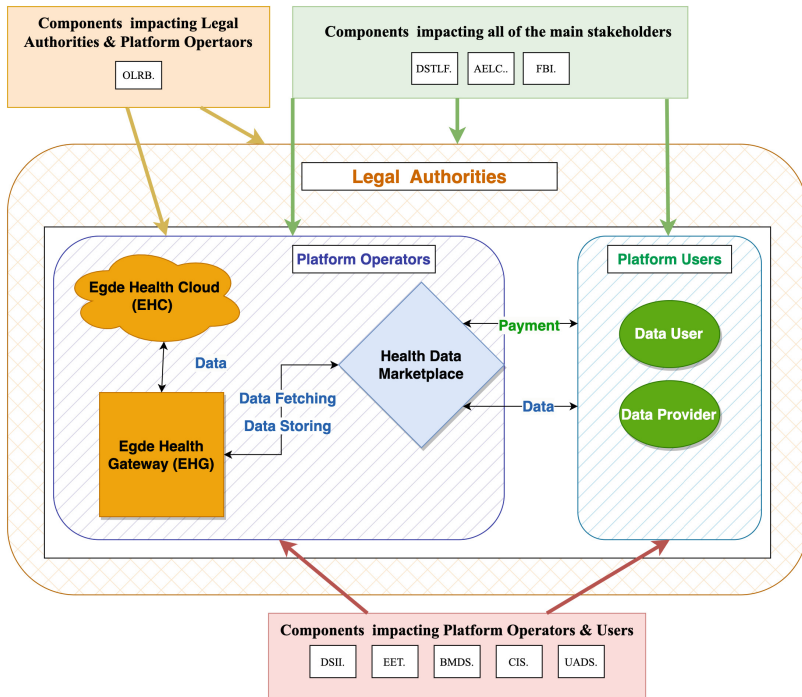


Fig. 1. Consolidated Framework

framework aligns with prior research on health data that points to the importance of arrangements for data quality assurance, data access (easing search and retrieval), and data crediting-rewarding (enabling tracing, attribution, and rewarding of data contributions) [38]. 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 [39]. Lastly, our research provides a novel view on democratizing health data by enabling various stakeholders, including citizens, to donate, sell and acquire data.

Implementing the framework can enhance data sharing and reduce data acquisition costs through 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 also promotes sustainability by mitigating the need for repetitive data collection, leading to more efficient resource usage. Furthermore, the 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.

Despite the rigorous approach adopted in this study, its limitations must be acknowledged. 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. A notable future research direction would be addressing this study's methodological limitations by broadening stakeholder perspectives. Interviewing more stakeholders, including patients about their willingness to donate or sell health data can contribute to developing a more comprehensive understanding. Furthermore, as the regulatory landscape for health data continues to evolve, future research could explore the implications of these changes on marketplace dynamics. A more detailed economic analysis of the HDM ecosystem could also be valuable as pricing mechanisms and business models certainly require further research.

6 Conclusion

In addressing the first RQ *“What are the essential components for successfully implementing a Health Data Marketplace in Norway?”* our study identified several vital components, including Data Standardization, Interoperability, Integration (DSII), Data Security, Trust, Legal Frameworks (DSTLF), Anonymization, Ethical, 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).

In this context, we seek to highlight the roles of the identified components. Data Standardization, Interoperability, and Integration can ensure effective data exchange, and Data Security, Trust, Legal Frameworks can help in fostering trust while ensuring data security. Further, Anonymization, Ethical, Legal Considerations can balance privacy and public benefit, and by Overcoming Legal and Regulatory Barriers can ensure compliance with technological advancements. The Exploration of Emerging Technologies ensures that emerging tech, such as AI and blockchain, is part of new platform development, and through Business Model Development and Sustainability enables devising sustainable business models to drive innovation. Financial Benefits and Incentives can encourage data sharing and managing platforms' financial viability, Collaboration and Innovative Solutions can help promoting resource pooling and shared ownership, and finally, Usability and Acceptability of Data Solutions can help ensuring user-friendly and accepted data solutions.

Further, in addressing the second RQ: *“How can a Health Data Marketplace be established using an existing data platform?”*, our study outlined how the Egde Health Gateway (EHG) could extend its functionalities to accommodate a Health Data Marketplace. Leveraging on the EHG's infrastructure and addressing our identified key components, we propose a framework where the technical requirements of DSII, the regulatory aspects per OLRB, emerging technologies as per EET, financial benefits and incentives (FBI) aligned with business models, and usability and acceptability of data solutions (UADS), among others, are addressed.

By effectively surmounting the challenges identified and leveraging opportunities, we believe our work can contribute towards an ethical, secure, and efficient use of health

data, consequently leading to improved healthcare outcomes, enhanced research, and stimulated innovation in Norway and beyond.

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