

Master's Programme in Information and Service Management

# The Role of Data Management in Electronic Health Record Systems

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**Abstract**

The shift from paper-based records to electronic health records (EHRs) has enabled comprehensive patient profiles and improved decision-making for healthcare professionals and patients. However, the lack of standardisation between EHR systems creates challenges with data sharing, hindering the full potential of EHRs. This research examines how EHR adoption influences care delivery and the challenges associated with utilising patient medical records to their full potential, focusing on interoperability issues. By employing a qualitative approach that combines a literature review with interviews with Finnish healthcare professionals, this research identifies the benefits of EHRs, and the challenges associated with the lack of interoperability. This research reveals the substantial benefits of interoperable EHR systems for patients and care providers, offering practical recommendations for improved health data management.

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**Keywords** interoperability, Electronic Health Record, Care Delivery Organisation

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### **Tiivistelmä**

Siirtymä paperipohjaisista potilaskertomuksista sähköisiin on mahdollistanut kattavampien potilasprofiilien muodostamisen ja parantanut terveydenhuollon ammattilaisten sekä potilaiden päätöksentekoa. Erilaisten potilastietojärjestelmien standardoinnin puute luo kuitenkin haasteita tiedon jakamiselle näiden järjestelmien välillä, mikä rajoittaa sähköisten potilaskertomusten hyödyntämistä. Tämä tutkimus keskittyy sähköisten potilaskertomusten käyttöönoton vaikutukseen hoitojen toteuttamisessa sekä tutkii potilastietojen hyödyntämiseen liittyviä haasteita, erityisesti yhteentoimivuusongelmia. Tutkielmassa käytetään laadullista lähestymistapaa, joka yhdistää kirjallisuuskatsauksen haastatteluihin suomalaisten terveydenhuollon ammattilaisten kanssa. Tutkimuksessa tunnistetaan sähköisten potilaskertomusten hyödyt ja yhteentoimivuuteen liittyvät haasteet. Tutkimus osoittaa, että yhteentoimivat potilastietojärjestelmät tuovat merkittävää hyötyä sekä potilaille että hoitohenkilökunnalle. Yhteentoimivuusongelmat nousevat keskeiseksi haasteeksi sähköisten potilaskertomusten jakamisessa. Tutkimus tarjoaa suosituksia terveystietojen hallinnan parantamiseen.

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**Asiasanat** yhteentoimivuus, sähköinen potilaskertomus, terveydenhuollon palveluntuottaja

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## Abbreviations

|      |                                                                             |
|------|-----------------------------------------------------------------------------|
| AI   | artificial intelligence                                                     |
| AMA  | American Medical Association                                                |
| API  | application programming interface                                           |
| CDO  | care delivery organization                                                  |
| DFD  | data flow diagram                                                           |
| EHR  | electronic health record                                                    |
| EMR  | electronic medical record                                                   |
| ER   | entity relationship                                                         |
| EU   | European Union                                                              |
| FHIR | Fast Healthcare Interoperability Resources                                  |
| GDPR | General Data Protection Regulation                                          |
| GP   | general practitioners                                                       |
| HL7  | Health Level Seven International                                            |
| HTTP | Hypertext Transfer Protocol                                                 |
| JSON | JavaScript Object Notation                                                  |
| ONC  | The Office of the National Coordinator for Health Information<br>Tehcnology |
| REST | representational state transfer                                             |
| UML  | unified modelling language                                                  |
| XML  | Extensible Markup Language                                                  |

# 1 Introduction

## 1.1 Background and Motivation

Advancements in technology have improved the healthcare sector (Pool et al., 2020). The integration of new technology into healthcare systems has changed how healthcare professionals manage patient data. The shift from paper-based records to electronic health records (EHRs) has revolutionised care delivery by enabling the creation of more comprehensive patient profiles, ultimately enhancing decision-making capabilities for care providers through data transfer between care delivery organisations (CDOs) (Stephen & Frank, 2024). This shift to digital tools has not only streamlined administrative processes but has also enabled patients to take a more active role in their healthcare decisions (Machal, 2024), leading to a more informed and better care.

However, these EHR systems have often been built in isolation from each other without much coordination or standardisation, leading to a variety of implementations that differ in features, data formats, and other aspects. This lack of uniformity in EHR systems creates significant challenges for interoperability and data sharing between different EHR systems within or outside of the healthcare providers and institutions (Al-Karaki et al., 2019). It can ultimately hinder the effective utilisation of patient data, potentially compromising patient outcomes.

The existing literature acknowledges current issues and demonstrates that efforts are being made to find solutions and improvements to address these challenges (Hoghton et al., 2023; Stiell et al., 2003; Poppe et al., 2017; González-Castro et al., 2021). Researchers, policymakers, and healthcare organisations are actively working to enhance interoperability, standardise data formats, and promote coordinated implementations of EHR systems.

While the importance of interpretability has been recognised, its concrete benefits and impact on healthcare and the role of the patients are still somewhat unclear. Additionally, it is important to understand the legislative and other concrete challenges related to interoperability, as well as their possible solutions. This research aims to address this gap in knowledge by focusing on how EHRs and interoperable systems can enhance patient care. By examining these topics, this research seeks to provide a more comprehensive understanding of the value proposition of

interoperable EHR systems for patients, healthcare providers, and the healthcare system as a whole.

## **1.2 Research Questions, Objective and Scope**

This research aims to identify and address challenges and opportunities in health data management and technology adoption within the healthcare sector, contributing not only to academic understanding but also offering practical insights and recommendations for healthcare practitioners. Specifically, the research aims to investigate the current state of technology in Finnish healthcare sector, focusing on the widespread adoption of EHRs and their benefits in care delivery. Since Finland is a member of the European Union (EU), this research also considers the regulations and policies of EU that impact health data management in the region of EU. The research also analyses the challenges surrounding healthcare data management, including interoperability issues that prevent seamless information exchange between different EHR systems. By understanding the current state and existing issues, the research explores potential solutions to optimise data utilisation and unlock the full potential of technology to improve healthcare outcomes. The following two research questions are explored in this research:

- 1. How does the adoption of EHRs influence the care delivery?*
- 2. What hinders the effective use of patient medical records?*

## **1.3 Structure of the Thesis**

This research uses qualitative research approach, combining literature review with an empirical research review to understand the dynamics of data management in healthcare sector. The qualitative nature of this research allows for a better in-depth exploration (Hammarberg, Kirkman & De Lacey, 2016) of health data management, offering perspectives from both academic research and professionals within the field.

The first chapter introduces to the topic, highlighting the problem behind the research, justifies the motivation, outlines the specific objective that guide the research and defines the structure of the thesis. The second chapter delves deep into

the existing literature on technology in healthcare, focusing on the use of EHRs and the challenges and concerns as well as ethical and legal implications in healthcare data management. The chapter assesses the current state of knowledge and tries to establish a comprehensive understanding of the subject matter. After the second chapter, the research shifts focus to the reasoning behind the chosen research methodology. The third chapter provides a detailed approach to the empirical investigation. It justifies the methodology selection with the research objectives and highlights its necessity for the research. The fourth chapter provides the key findings from the empirical research. The interviews conducted with various stakeholders within the Finnish healthcare sector provide invaluable insights. The chapter highlights the key findings that help to guide discussions and strategic actions to improve healthcare data management practices in the healthcare system. The fifth chapter transforms the key findings into actionable recommendations for professionals in the healthcare sector. It addresses practical strategies to enhance data management, acknowledging the complexities uncovered in this research. This chapter also analyses the limitations of this research as well as provides recommendations for future research. The final chapter concludes the research.

## **2 Literature Review**

This chapter reviews existing literature and provides a conceptual framework for the research. This review explores the impact of EHRs on care delivery, challenges and concerns in healthcare data management, and ethical and legal implications. By critically analysing the existing literature, the research identifies gaps, challenges, and opportunities that form the structure basis for the empirical research. This chapter first introduces EHRs and explores how EHRs are redefining healthcare engagement. Following this, the chapter addresses issues such as data management and interoperability in healthcare. This exploration helps the research to examine the ethical considerations and legal frameworks in the context of collecting, using, and sharing healthcare data. Finally, the chapter focuses on the role of education in governing health data.

### **2.1 The Positive Impact of Electronic Health Records**

The integration of technology into healthcare systems has reshaped patient engagement and care delivery practices. This subchapter explores the impact of technology on patient engagement within the healthcare sector. The subchapter examines the evolution from paper-based records to electronic formats and explores the extensive benefits that EHR systems offer and the various factors influencing patient engagement in the digital healthcare era.

#### **2.1.1 Introduction to Electronic Health Records**

Then-President George W. Bush addressed his concern on the current state of United States healthcare sector in 2004: *“By computerising health records, we can avoid dangerous medical mistakes, reduce costs, and improve care”* (The White House, 2006b). The United States healthcare system relied on outdated, paper-based systems, which had uncertain value, high costs, variable quality, medical errors, lack of coordination, and administrative inefficiencies (The White House, 2006a). According to HealthIT.gov (2023), the official website of The Office of the National Coordinator for Health Information Technology (ONC), in 2008, only 9% of non-federal acute care hospitals in the United States used EHRs. However, as of 2021, 96% of non-federal acute care hospitals in the United States had adopted

EHR, which marked a significant increase in the use of EHRs (HealthIT.gov, 2023). The popularity has grown significantly in other parts of the world as well. Nowadays, healthcare information is mostly stored in electronic format and is no longer maintained in a paper form. The shift from paper-based records to EHRs addresses the concerns raised by President George W. Bush regarding the challenges as highlighted in this State of the Union Address in 2004.

When discussing about computerised medical records, it is important to understand the different definitions that exist. Electronic medical records (EMRs) are paper-based medical records in digital format, and they contain information about medical conditions, histories, checkup reports, medications, and treatments of a patient within a CDO (Garets & Davis, 2006). In the other hand, EHRs are a collection of EMRs and refer to a repository of patient data in a digital form (Anshari, 2019). It is worth noting that the CDOs own the EMRs, but the patient has the ownership of the EHR that has information about the episodes of care of different CDOs within a region or even a country (Garets & Davis, 2006). A complete EHR can only be established if the CDOs have established a solid exchange of data across different CDOs (Garets & Davis, 2006). Otherwise, the CDO can only create the medical history for the patient solely based on the EMRs that they have. Since EHRs act as an extensive repository of patient information spanning various CDOs and have the most impact on care delivery, this research focuses solely on them. Figure 1 provides a more comprehensive differentiation between EMR and EHR.

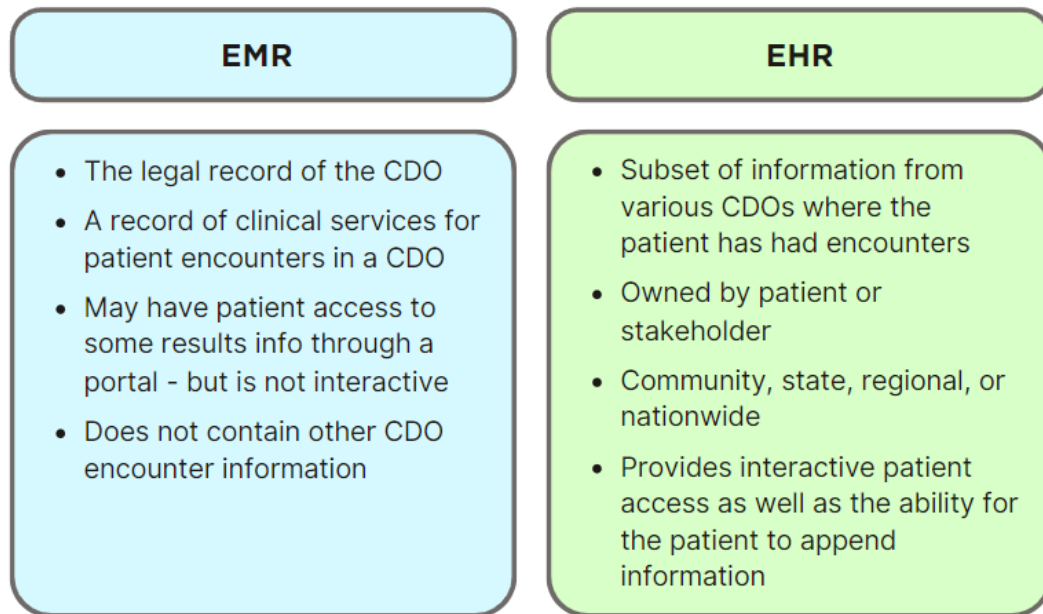


Figure 1. EMR vs EHR (Garets & Davis, 2006).

The shift from paper-based records to EHRs has brought significant improvements in various aspects of healthcare. One of the key advantages is the enhanced coordination and continuity of patient care (Campbell et al., 2020). EHR systems that allow the transfer of data between other EHR systems improve care continuity (Campbell et al., 2020) which can be beneficial in cases where the patient uses multiple different CDOs. Bonomi (2016) highlights that an EHR is not just a digital collection of health information but rather a dynamic platform that involves continuous engagement from patients and healthcare professionals. Thus, EHRs not only improve patient care but also enhance coordination and continuity by allowing data transfer between different EHR systems within or outside the CDO.

The data collected through EHRs can be reused for the primary use of care delivery of a patient or it can be secondarily used. The Finnish Ministry of Social Affairs and Health defines the secondary use of health data as the following: “*The secondary use of health and social data means that the customer and register data created during health and social service sector activities will be used for purposes other than the primary reason for which they were originally saved.*” (STM, 2019). This means that the data was primarily collected while providing care for the patient, but now it is intended to serve another purpose. The data can be used secondarily,



for example, in epidemiological research (Sidebottom et al., 2015) to create a better understanding of diseases and suitable treatments for them (Safran et al., 2007), ultimately improving care delivery. With the growing utilisation of EHRs, ensuring the quality of the data becomes important to enable an exchange of data between the CDOs.

The large volumes of data have increased the use of EHR data, but it is important to understand that the utility of these data sources is ultimately determined by their quality (Kahn et al., 2016). Aggregated and de-identified data from diverse patient populations can help healthcare providers to identify trends and patterns that can improve patient care (Kasoju et al., 2023). When medical data can be effectively reused across various EHR systems, it enables a more comprehensive understanding of health history of a patient (Upadhyay & Hu, 2022) and therefore offers a better outcome for the patient. However, the potential benefits of the data provided by EHRs hinge on the ability to access and analyse it effectively. The current lack of interoperability between EHR systems creates challenges. Inconsistent data structure and formats across different systems make it challenging to utilise data from multiple sources (Brooks, El-Gayar & Sarnikar, 2013). This fragmentation restricts the ability to utilise the full potential of EHR data for identifying trends, understanding patient populations, and ultimately, improving care delivery.

### **2.1.2 Redefining Healthcare Engagement**

Advancements in technology have changed the way we consume and manage data. These advancements have particularly revolutionised the healthcare sector by providing more efficient ways to handle patient data. Health-centric applications enable both healthcare professionals and individuals to read and update patient data. The current state of technology in healthcare reflects to a dynamic interplay between data management, patient engagement, and the widespread of EHRs.

The healthcare sector is adopting EHR systems widely. According to a study published by the European Commission (2019), EHRs were available in all analysed EU countries and 96% of general practitioners (GPs) used it in their work. These EHRs are essentially collections of patient health and healthcare data stored in the system database (Haas et. al., 2011). These computerised records keep medical staff

up to date on the patient medical records and facilitate safer and more efficient care delivery which ultimately contributes to improved patient outcomes (Menachemi & Collum, 2011). EHRs enable transformative changes in the quality of care that include effectiveness, efficiency, and patient safety (Menachemi & Collum, 2011). However, these benefits can only be realised if patients actively participate by contributing their health data and engaging to the care delivery process.

Information and technology alone are insufficient for maximising treatment efficacy; patients need the motivation to engage (McAlearney et al., 2016). Patient engagement is widely recognised as a critical component in enhancing clinical outcomes (Campbell et al., 2020). EHRs play an important role in this process as they serve as tools that empower individuals to actively participate in decisions and management of their health. Patient portals, as highlighted by Stewart et al. (2020), emerge as a particularly effective option within the EHR framework, providing secure access to health information of a patient, facilitating communication with healthcare providers, and offering functionalities such as appointment scheduling and prescription management.

Patient portals offer a secure gateway to health information and facilitate seamless communication between patients and healthcare providers (Dendere et al., 2019). Carini et al. (2021) highlighted that digitalisation offers various benefits for improving care delivery. Certain features, such as laboratory tests, imaging, medical notes, messaging with healthcare providers, and medication refills were seen as helpful and overall patients expressed satisfaction with digital tools (Carini et al., 2021). However, patients must be motivated to use these portals. Irizarry, Dabbs & Curran (2015) pointed out that personal factors, including age, ethnicity, level of education, health literacy, health status, and caregiving responsibilities significantly impact the utilisation of patient portals. Another study conducted by Irizarry et al. (2017) suggested that healthcare organisations should also consider offering customised strategies to address the needs of those individuals, who are unwilling to use information technology. They suggested that healthcare organisations should explore workflows that seamlessly incorporate patient portal information into phone discussions and in-person interactions with healthcare providers (Irizarry et al., 2017).

While patient portals and EHRs that provide data for the portals empower patients and improve healthcare delivery, there are still challenges to address. The lack of interoperability between EHR systems creates fragmented patient data (Li et al., 2022) within the portals, hindering a holistic view for informed decision-making by healthcare providers. Even with standardised systems, patient motivation is an important factor in improving patient outcomes (Walker et al., 2017) by getting necessary data to these systems. Factors like age, health literacy, and access to technology can significantly impact patient portal utilisation (Yoon et al., 2024). Therefore, ensuring both interoperability between systems and patient motivation to engage is essential for EHR systems to utilise the most relevant health information.

Having explored the impact of technology, particularly EHRs, on healthcare and the challenges of seamless data exchange, this chapter now delves deeper into the specific challenges and concerns surrounding the management of healthcare data. While technological advancements have undoubtedly improved the efficiency of handling patient information, the increased reliance on EHRs and patient portals introduces a set of challenges. As healthcare providers increasingly adopt new or existing EHR systems, the need to balance the transformative benefits with robust safeguards to protect sensitive health data increases.

## **2.2 Challenges and Concerns in Healthcare Data Management**

The adoption of EHRs has brought great benefits in healthcare delivery, efficiency, and patient outcomes. However, technological advancements have also created challenges regarding interoperability, privacy and security, and the ownership of data.

### **2.2.1 Importance of Interoperability**

Enhancing the safety and efficiency of care while facilitating better medical decisions is supported by the ability to access, analyse, and share comprehensive patient data (Garets & Davis, 2006). To understand what the EHR systems are for, it is important to understand the operational characteristics of these services and the specific requirements of the healthcare environment (Sha & Rahamathulla, 2020). It involves considering the diverse needs of various medical specialties and the

seamless integration of EHR functionalities into existing practices (Roland, Sanner & Aanestad, 2017). Interoperability is one of those functionalities and it has been a widely discussed challenge in the development of EHR systems (Hoghton et al., 2023). Interoperability defines the ability of various systems or software to communicate with one another, accurately share data, and effectively utilise the shared data in a consistent manner (Iroju et al., 2013). However, the fact that many of these systems span across different healthcare providers (Miller & Tucker, 2014) makes achieving seamless interoperability more challenging. The main idea of interoperability is shown below in Figure 2.

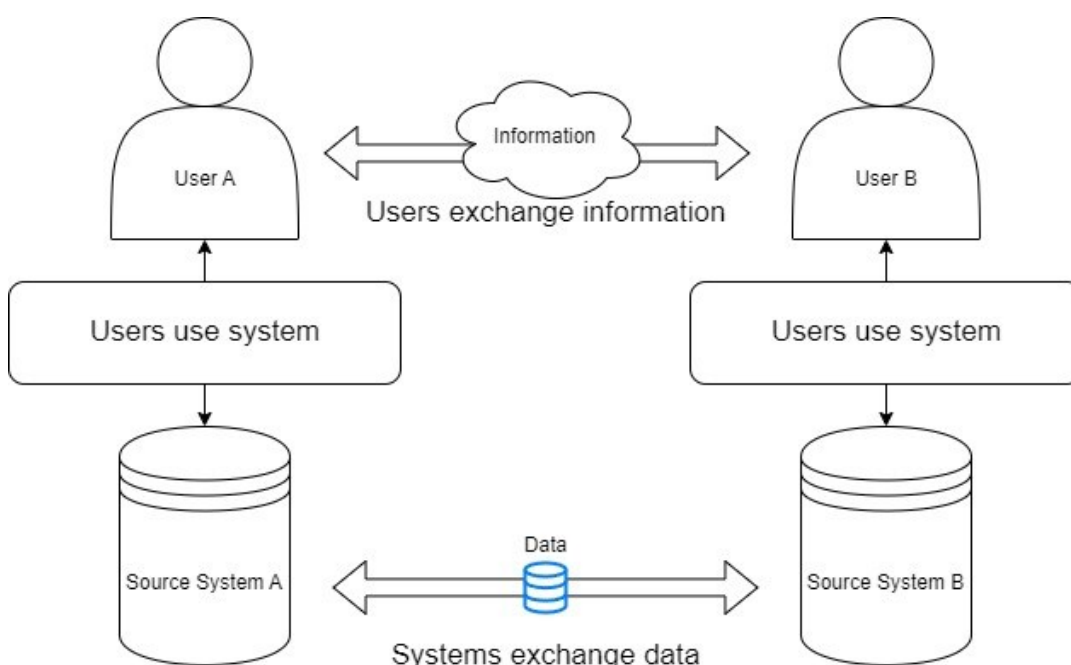


Figure 2. Illustration of interoperability (Iroju et al., 2013).

The urgent need to achieve interoperability is highlighted by the increasing demand for past patient medical information at the point of care, that is why interoperability should be considered a key requirement (Kobusinge et al., 2018). To optimise the effectiveness of these systems, ensuring seamless data flow from one system to another is essential. This facilitates the comprehensive retrieval of complete medical history of a patient, enabling healthcare professionals to provide the best possible care (Serbanati, 2020). In addition, the cost-effectiveness brought by unified systems can be significant. The lack of interoperability prevents access to

data which leads to increased costs due to the need to repeat tests and physician assessments (Stiell et al., 2003). The ability to share and re-use existing data reduces the cost of healthcare (Iroju et al., 2013). This streamlined approach not only optimises resource allocation but also minimises administrative overheads, resulting in more efficient and affordable healthcare services (Alexandrou & Mentzas, 2009).

Although, interoperability can be challenging to establish without a set of guidelines. Traditional design methodologies used in development such as unified modelling language (UML), entity relationship (ER) diagrams, and data flow diagrams (DFD) do not explicitly tackle interoperability challenges (Gaynor et al., 2014) but they are tools that facilitate communication and visualisation during the development process. However, standardised frameworks might offer a solution for overcoming challenges like interoperability. Standardisation ensures systems across countries adhere to common frameworks, facilitating interoperability and data exchange (Poppe et al., 2017). The Fast Healthcare Interoperability Resources (FHIR) framework offers a standardised approach for health data exchange, thereby enhancing the efficiency and affordability of healthcare services (Mandl et al., 2020).

FHIR was initially introduced in 2011 by the Standard Developing Organisation Health Level Seven International (HL7) and it is based on previous HL7 standards (Vorisek et al., 2021). It combines the benefits of the previous standards established on modern web technologies like representational state transfer (REST) architecture, application programming interface (API), Extensible Markup Language (XML), and JavaScript Object Notation (JSON) formats and authorisation tools like Open Authorization (Vorisek et al., 2021). FHIR was developed to help healthcare systems to achieve interoperability, which is acknowledged as a key requirement in the healthcare sector (Bender & Sartipi, 2013). FHIR is an attractive and growing standard in the medical sector and it has support from both the scientific community and large EHR providers for healthcare data exchange (González-Castro et al., 2021).

However, even though FHIR is seen as a great option to achieve interoperability, it is facing criticism. FHIR simplifies basic healthcare data creation but lacks clear instructions for organising these building blocks into more complex structures and supporting advanced workflows beyond basic operations, which may impact

interoperability (Bender & Sartipi, 2013). The standard also lacks mutually acceptable definitions for data elements, leading to diverse interpretations and potentially misinterpretations among CDOs (Rienstra, 2023). Additionally, FHIR adds some overhead to developers. Since FHIR uses simple Hypertext Transfer Protocol (HTTP) for retrieving data, it can become complex and time-consuming for large volumes of users, leading to increased delays in operations and becoming a huge issue for real-time applications (Sreejith & Senthil, 2023).

The process of integrating and achieving interoperability of healthcare records is complicated and it involves technical, regulatory, and organisational challenges (Hoghton et al., 2023). Systems used for medical records within healthcare organisations have been developed independently, resulting in many diverse models for representing and recording patient information (Iroju et al., 2013). As a result, medical history of a patient is scattered between different systems, making it more difficult to capture the whole medical history for the patients (Roehrs, Costa & Righi, 2017). This highlights the need for interoperability to ensure a holistic view of the medical history of a patient across different healthcare systems. However, in addition to this kind of decentralised model of transferring data, a centralised system should also be considered for alternative solution to tackle interoperability issues. Holmgren & Ford (2018) discovered that care providers using more centralised systems were more likely to achieve interoperability.

The Finnish healthcare sector is utilising a centralised service called Kanta (Jormanainen & Reponen, 2020). Kanta is a set of digital services used in healthcare and social welfare in Finland and its main purpose is to improve the efficiency and effectiveness of healthcare and social welfare operations, including enhancing interoperability (Vehko et al., 2021). One of its many services is “Omakanta”, that allows patients to access their personal health records, such as electronic prescriptions, laboratory tests, and other medical records (Kivekäs, 2019). In a study conducted by Kivekäs et al., 2019, electronic health service significance was analysed, and the study revealed that long-term patient care and self-monitoring can be effectively supported virtually. It highlights the phenomenon that centralised EHR systems not only complement traditional care pathways but also aim to transform them (Kivekäs et al., 2019).

A study conducted by Varonen & Pirinen (2022) explored the challenges of Kanta services interoperability. The study revealed difficulties in aligning structured healthcare data of Finland with internationally existing structured data sets. Additionally, the abundance and incompatibility of EHR systems between CDOs seemed to pose challenges in data transferability (Varonen & Pirinen, 2022). Another study conducted by Lipiäinen, Gustafsson & Lavinto (2021) pointed out that the patient data that is not recorded in the Kanta services remains within the information data systems of the CDO. Other CDOs face challenges in utilising this collected data due to closed or incompatible patient data systems (Lipiäinen, Gustafsson & Lavinto, 2021). This highlights the ongoing need for standardised data formats and seamless information exchange to optimise patient care.

This subchapter explored the different aspects of achieving interoperability in healthcare. While existing approaches like FHIR and centralised services offer some opportunities, there is a significant gap in knowledge that hinders optimal implementation. These gaps include exploring alternative solutions for FHIR or enhancements that can handle its complexities in transferring data. Also, the interplay of centralised and decentralised systems for interoperability needs investigating and this research examines the best practices for data ownership, accessibility, and integration across EHR systems. This research aims to fill those gaps so that in the future, healthcare systems can have a better chance of achieving interoperability to be able to transfer patient data across EHR systems, ultimately improving patient care delivery.

The next subchapter discusses the ownership, security, and privacy aspects of data. It explores the concept of CDOs acting as data controllers for patient medical records and being responsible for implementing appropriate data protection protocols, enabling the safe transfer of data.

### **2.2.2 Data Ownership, Protection and Responsibility**

Data controllers are responsible for processing personal data, but they can grant access to data processors who hold and process data on behalf of the data controllers (EU, 2019). In this research, CDOs are considered as the data controllers. Figure 3 illustrates the process of authorising data processors to process personal data. In

this context, the EHRs are the personal data of CDOs and each CDO is held responsible for the right data protection protocols for processing EHRs. Although, there are existing laws that guide CDOs on how to practice data protection regarding EHRs but CDOs are still responsible for figuring out how to secure the data. It involves administrative safeguards such as comprehensive education, technical safeguards including encryption and firewalls, and physical safeguards like access control (Keshta & Odeh, 2021). On top of that, the different EHR systems with varying security protocols make it difficult to maintain a consistent level of data privacy (Fernández-Alemán et al., 2013). Because if a system lacks robust security protocols and a breach occurs, the integrity of the data may be compromised, leading to conflicts between the same data across different systems. This ultimately hinders interoperability because the data is no longer consistent.

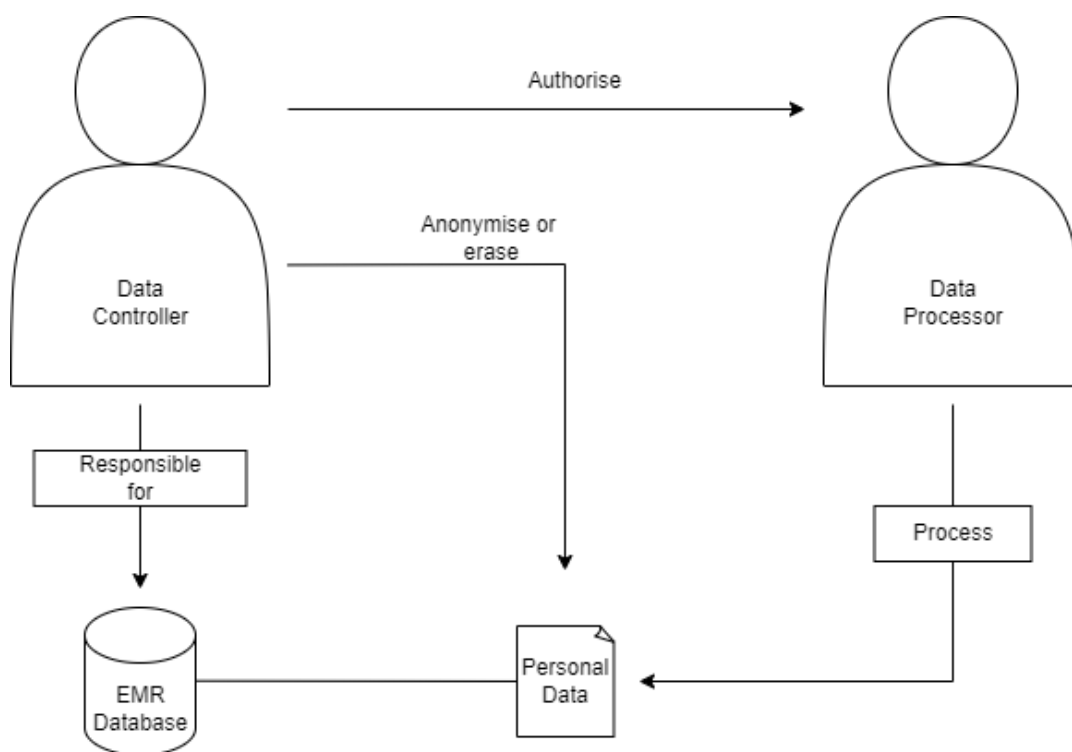


Figure 3. Data controller authorising data processor to process personal data (Olca & Can, 2022).

The framework for data protection of EU, the General Data Protection Regulation (GDPR), was designed to enable data processing of individuals and it has created various opportunities to benefit from existing data (Mayer-Schonberger &



Padova, 2015). Patients benefit greatly from data processing: for example, Determann (2019) pointed out that X-ray images can be shared from one doctor to another without the need to retake the same X-ray. In this example, CDOs could share the X-ray images with other CDOs and reduce radiation exposure to patients (Mendelson, Erickson & Choy, 2014). So, GDPR demonstrably benefits both citizens and organisations as it empowers citizens with control over their data and provides organisations with a framework for accessing necessary data and resources, eliminating the need to repeatedly collect existing information from the patient (Shah & Khan, 2020). However, without a secure and standardised way to transfer data between EHR systems, sharing patient data across different systems remains a challenge (Schmeelk et al., 2022). This hinders the core idea of seamless data exchange to improve the quality of care.

Data ownership determines who has the right to access, use, and control patient data (Hummel et al., 2020). Liddell, Simon & Lucassen (2021) suggested that researchers should move away from the metaphorical language of data "ownership" and focus on protecting individuals, valid data uses, and an effective data economy. However, data ownership is not merely a metaphorical language, but a legal and ethical concept (Janeček, 2018) that has real consequences for data controllers and processors. Data ownership implies to the existence and enforcement of data rights and obligations, such as the right to access, use, and control data, and the obligation to respect, protect, and share data (Hummel et al., 2020). This balance between rights and obligations forms the foundation of ethical and legal considerations in health data management that keeps data secure and accessible for legitimate purposes (Stoeger & Schmidhuber, 2020). These unclear ownership structures and fragmented access control mechanisms can potentially hinder the secure and standardised data exchange that is essential for seamless patient care across different healthcare providers.

While data protection regulations and frameworks like GDPR offer a foundation for responsible data management, there are still uncertainties on how to achieve truly seamless interoperability within these constraints. This research focuses on how can the CDOs find a middle ground that minimises the risk of breaches without hindering the interoperability and accessibility of data. This research goes beyond

the technical aspects of interoperability, focusing on the need for a more comprehensive standardisation of data formats, including ownership structures, access control mechanisms, and data governance frameworks. By addressing these uncertainties, this research aims to find ways to improve interoperability to unlock its full potential and achieve a balance between information accessibility and robust data protection.

The discussion of ethical and legal implications in health data management highlights the importance of data protection regulations. Achieving interoperability and ensuring data ownership and protection are crucial. However, the evolving technological advancements in healthcare pose ongoing challenges in keeping pace with the ethical and legal complications. The upcoming subchapters focuses on the ethical and legal implications of health data management as well as the important role of education in shaping health data governance. By examining the relationship between education and health data governance, this research tries to understand how well-informed stakeholders can contribute to ethical practices, enhance data transparency, and find a balance between accessibility and safeguarding sensitive information.

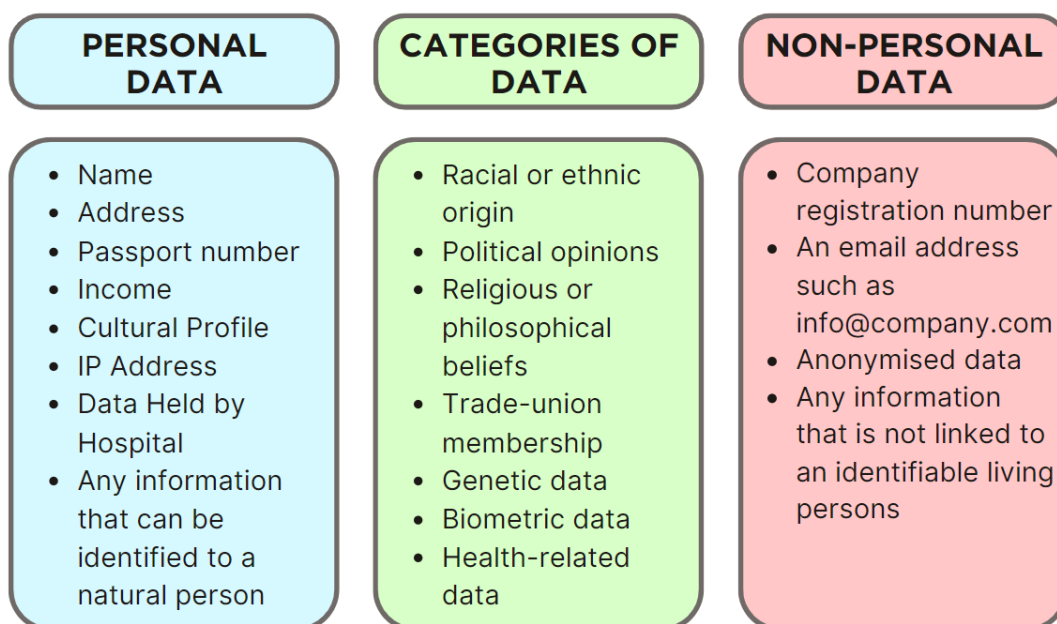
## **2.3 Ethical and Legal Implications of Health Data Management**

With the speed at which modern medicine is evolving, healthcare providers are constantly challenged to keep pace with the ethical, legal, and privacy implications of emerging technologies. As innovations reshape the healthcare sector, stakeholders must remain alert in addressing the ethical dilemmas and legal obstacles that these advancements bring. The rapid digitalisation of healthcare data raises concerns regarding patient privacy and data security, which needs proactive measures to safeguard sensitive information in an increasingly interconnected healthcare ecosystem (Tresp et al., 2016) as it ultimately affects the interoperability of EHR systems.

### **2.3.1 Laws Protect Data**

In 2018, GDPR replaced the old Data Protection Directive 95/46/EC, and it now serves as a foundation for organisations that manage the personal data of EU citizens (Chico, 2018). Personal data can include information about a person such as

their name or address, as well as sensitive information about a special category of personal data that requires heightened protection (European Parliament, 2016). Figure 4 shows the differences between personal data, special categories of personal data and non-personal data in the context of GDPR. As GDPR serves as a foundational regulation for data protection, there can also be additional laws such as national laws that add an additional layer of reassurance for the right use of health data. For example, in Finland, there is a secondary law that rules out the secondary use of social and health information, and the law has been in force since 2019 (STM, 2023). The law aims to ensure efficient and secure handling of personal data in social and healthcare operations, integrating them with relevant authorities while safeguarding individual rights and privacy (Finlex, 2019). The secondary use of data refers to utilising medical data for purposes beyond its original collection, including using the data for statistics, information management, research, or product development (Niemelä, Lähteenmäki & Pajula, 2021). Interoperability has a tremendous impact on the secondary use of data since it facilitates the secure and standardised exchange of medical data. This allows for the data to be readily available for research, statistics, and other secondary purposes outlined above.



*Figure 4. Differences between personal data, special categories of personal data and non-personal data (European Parliament, 2016).*

While the notion of introducing an additional layer of protection may appear beneficial, it comes with drawbacks. According to a report by Aejmelaesus, Pitkänen & Matinheikki (2023) the secondary law has significantly increased the costs and delays associated with research and development work in the social and healthcare sector. In another study conducted by Reito et al. (2022), it was discovered that secondary law introduces specific challenges and concerns in healthcare data protection, including financial burdens and hindrances to traditional research approaches. The law might interfere with interoperability leading to data not being able to transfer seamlessly.

These country specific laws might also hinder technological innovation and that is why general legal frameworks like GDPR, might be a better option. In a study conducted by Pajula et al. (2021), the team of researchers investigated the impacts and potentialities of secondary law of Finland. They found out that there is a significant potential in the secondary use of health data since it would save resources and would support international export (Pajula et al., 2021). However, the slowness of permit processes and data services, and the domestic and international interpretation of legislation may decrease overall interest in utilising data within the scope of secondary law and thus impede technological development in Finland (Pajula et al. 2021).

While strict data protection laws aim to ensure the patient privacy, there is a tension between accessibility and security. Healthcare professionals require access to accurate and comprehensive patient data to make informed decisions (Adane, Gizachew & Kendie, 2019). Having robust privacy protection is important and it means establishing clear ownership protocols, documentation standards, and privacy guidelines to govern the shared information (Worobiec et al., 2023). Leaving a meaningful audit trail of every operation conducted on health information data is an integral component of this security framework (Adler-Milstein et al., 2020). This transparency fosters accountability and aids in monitoring data use. The great challenge is achieving this balance, ensuring accessibility for patient care while protecting sensitive health information.

The GDPR serves as a cornerstone for data protection within the EU. It provides a foundation for organisations handling personal health information.

However, it and other legislations might create tension with the need for seamless interoperability in EHR systems. Some EU countries have established stricter national data protection laws on top of GDPR which might hinder the use of data. This research examines the impact of the secondary use of data in Finland on interoperability and contributes to a future where legislation and interoperability can provide an optimal solution for care delivery.

### **2.3.2 Ethical Use of Data**

Ethical use of data touches individuals, healthcare professionals, and society as a whole. Health data, encompassing sensitive information about wellbeing, diagnosis, and treatment of individuals require careful handling to protect privacy, maintain trust and to ensure equitable access. The ethical use of health data is not just a legal obligation but a duty respecting autonomy, dignity, and the right to privacy (Hayes & Kuyumdzhieva, 2021). The responsible and ethical utilisation of data becomes increasingly critical, as technology advances in the healthcare sector and introduces innovations such as artificial intelligence (AI) (Jeyaraman et al., 2023).

Withholding health information from individuals raises questions about transparency and the autonomy of individuals in managing their well-being (Ewuoso, Hall & Dierickx, 2021). Withholding information from patients, especially from competent patients, violates ethical principles, including autonomy, beneficence, and nonmaleficence, and such an act can be seen as not only a violation of the fiduciary role of a doctor, but is also indefensible both legally and ethically (Edwin, 2008). The patient, or an individual responsible for the patient, is responsible for making the treatment decision based on the information the person may have at that moment. The American Medical Association (AMA) Code of Ethics (2012) at Opinion 8.08 states the following “*Physicians should sensitively and respectfully disclose all relevant medical information to patients. The physician’s obligation is to present the medical facts accurately to the patient or to the individual responsible for the patient’s care and to make recommendations for management in accordance with good medical practice.*”.

As patients increasingly share the decision-making with healthcare professionals, all relevant information should be available for the patient in a form that they

can understand and use while deciding on their health (Bostick et al., 2006). Incompatibilities between EHR systems can make it difficult, or even impossible for CDOs to access complete medical history of a patient in the first place and thus prevent them from disclosing any relevant information that could affect the decision-making. Forde, Redin, and Vandik (2005) analysed 31 case reports from 1996 to 2002 brought to the Clinical Ethics Committee of the National Hospital of Norway and found that withholding information was the most common ethical dilemma discussed in these cases.

There are legal frameworks and national legislation guiding ethical data use. However, there are conflicts between the use of data and patient care which might put the individuals at risk such as strict data protection protocols or access rights to data that can restrict access to relevant information in case of an emergency. In those situations, healthcare professionals must delicately balance between patient interests and data protection (Costa et al., 2012). Healthcare professionals may use health information of a patient to provide better care by customising treatments, improving diagnoses, and finding new cures (Determann, 2019). Just like patients, healthcare professionals make decisions based on the existing information and that is why providing comprehensive health data from the patient is important to them as well. However, policymakers appear to be more concerned about how health information can harm patients if used against them, rather than focusing on how it can benefit the patient (Determann, 2019).

The ethical use of patient data presents a complex challenge. It requires striking a balance between patient privacy and autonomy, and the need for seamless access to data. This research explores solutions that ensure patient privacy while enabling transparent access to relevant information. Ensuring ethical handling of data requires well-informed healthcare professionals who can utilise existing data appropriately and responsibly. This research also explores the role of education in responsible data governance practices. By addressing these factors, this research aims to contribute to a better outcome where interoperability empowers ethical and responsible data utilisation within the healthcare sector.

As this subchapter has explored the ethical and legal aspects of health data management, protecting data is essential as healthcare systems advance. These two

subchapters discussed the impact of data protection laws, such as the GDPR, and country-specific regulations on the use of health data. The next subchapter focuses on education, which has an important role in shaping health data governance. Education influences how healthcare professionals, policymakers, and society engage with and utilise health information (AlMubarak, 2022). The next chapter examines the relationship between education and health data governance, exploring how well-informed stakeholders can contribute to ethical practices, data transparency, and the balance between accessibility and safeguarding sensitive information.

### **2.3.3 The Role of Education in Health Data Governance**

As stated earlier, managing health-related data can be challenging, and it requires education (Hovenga & Grain, 2013). The evolving nature of healthcare data and legislation, coupled with the increasing reliance on digital technologies highlights the importance of well informed and skilled workforce in governing sensitive health data. Education should be offered to any healthcare professional, data manager, or any other stakeholder who is responsible for the right use of the health data of a patient to develop an understanding of the benefits and risks of the used data (Saf-ran et al., 2007). Education can be concentrated on compliance and regulations, data security and privacy, interoperability, ethical implications, data quality and integrity, continuous adaptation, or any other subject that touches the context of health data governance.

Effective staff training ensures that employees are well-informed about the latest regulations and compliance requirements, reducing the risk of breaches (Waly, Tassabehji & Kamala, 2012). Internal data breaches happen far more frequently than external hacks and therefore comprehensive training is crucial to prevent GDPR sanctions and financial losses (Yuan & Li, 2019) not to mention the damage to the reliability of the healthcare sector. That is why it is essential that all users receive continuous trainings on security protocols and proper utilisation of EHRs (Jannetti, 2014). The training equips staff with the necessary skills to effectively use these systems (Dobrow et al., 2019) identify potential vulnerabilities in the system, take appropriate preventive measures, and safeguard sensitive patient information effectively (Arain, Tarraf & Ahmad, 2019). By ensuring staff receive ongoing training

on security protocols and better utilisation of EHRs, CDOs can minimise the risk of data breaches and regulatory non-compliance. The trainings can also equip staff with the skills needed to effectively collect, analyse, and utilise patient data. This may ultimately lead to more comprehensive medical records, providing a clearer picture of the health of each patient.

A fundamental aspect of health data governance is compliance with legal frameworks and regulations. Healthcare professionals should be aware of the evolving laws that regulate the collection, storage, and sharing of health data (Theodos & Sittig, 2020). A study by Rosca et al. (2020) emphasised the need to keep healthcare staff and patients informed about data protection and patient rights. They found a correlation between the level of education and knowledge of data protection and the rights of patient protection. Through proper staff training, patients can have confidence that their personal data is safe and being managed appropriately (Nass, Levit & Gostin, 2019). Data leaks involving private information of patients, such as medical conditions and identity, directly impact the personal lives of the patients (Thapa & Camtepe, 2021). Patients may choose not to share important information or seek medical help if they lack confidence in the security of their personal data (Arain, Tarraf & Ahmad, 2019). A security breach not only jeopardises the trust of an individual in healthcare systems but also undermines the integrity of the entire healthcare sector. When patients have confidence that their data is secure and are empowered to participate in their care through information sharing, it can contribute to more comprehensive medical records within EHR systems.

Education programs should also emphasise the significance of maintaining data quality and integrity. The inappropriate use of EHR functionalities can lead to medical errors, compromised patient care, fraud, and abuse if the systems are being used without proper education (Vimalachandran et al. 2016). Regular training sessions, workshops, and access to updated educational resources should be provided to ensure that healthcare professionals remain proficient in utilising health data. Healthcare professionals must learn the best practices for data validation, accuracy checks, and overall data quality assurance (Gliklich, Dreyer & Leavy, 2014). When the staff understands the importance of data accuracy and standardisation, CDOs can leverage EHR systems to their full potential. It allows the creation of more

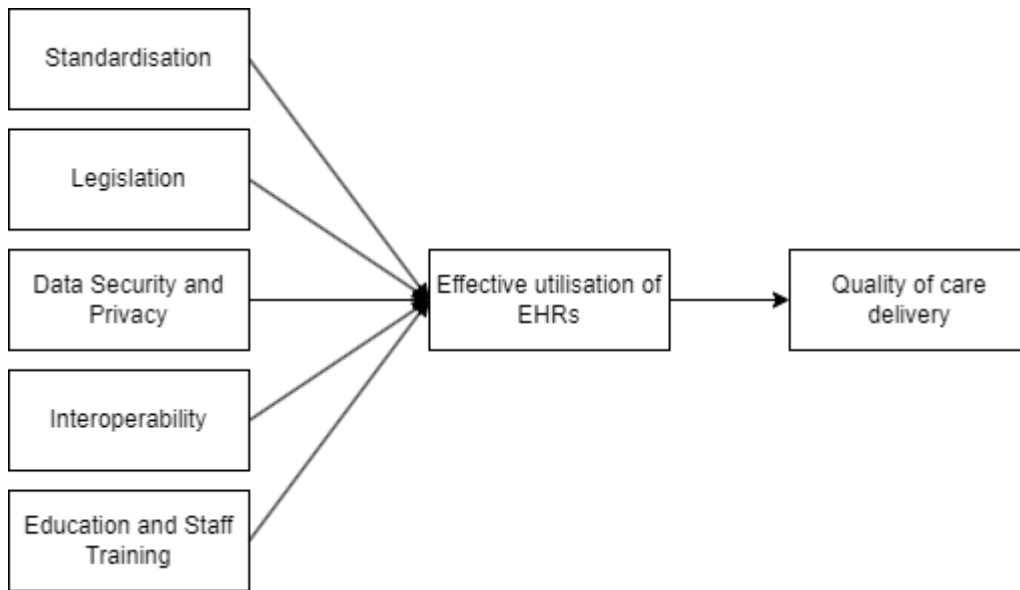


comprehensive and interoperable patient records, facilitating the seamless data exchange across different CDOs.

This subchapter indicated that CDOs must develop comprehensive educational programs that equip their staff with the necessary knowledge on data security, privacy, interoperability, and ethical considerations. Patients gain better trust when they understand that they are in the hands of well-informed stakeholders. This research examines the role of education in fostering public confidence. By promoting continuous learning among healthcare professionals CDOs can ensure they possess the latest knowledge and skills for handling sensitive patient data effectively. By addressing these gaps in knowledge, this research aims to empower well-informed healthcare professionals by fostering a culture of responsible data governance and building trust within the healthcare system.

## **2.4 Conceptual Framework**

*“Conceptual frameworks represent ways of thinking about a problem or a study, or ways of representing how complex things work. They can come from theories, models, or best practices.”* (Bordage, 2009). A conceptual framework was selected to clearly define the key concepts, and relationships of health data management. The conceptual framework for this research is presented in Figure 5. The model is based on the existing literature, and it has five key areas: standardisation, legislation, data security and privacy, interoperability, and education and staff training. These areas are seen as the building blocks that ultimately impact two crucial outcomes: effective utilisation of EHRs and quality of care delivery.



*Figure 5. Conceptual framework.*

This conceptual framework serves as the roadmap for understanding how these various factors influence the effective use of EHRs and ultimately the quality of care provided. Standardisation acts as the foundation, ensuring consistent data collection and exchange across CDOs. Legal frameworks established by legislation creates the guidelines that protect patient privacy and govern data access. Legislation reflects to data security and privacy measures that foster trust and ethical handling of sensitive information. Interoperability acts as the bridge, enabling seamless communication and data sharing between different EHR systems thus providing a holistic view of the medical history of a patient. Finally, education and staff training empower the workforce by quipping them with the knowledge and skills to leverage the full potential of EHRs for improved patient care and outcomes.

This conceptual framework guides the research process in several ways. The five key areas proposed in the framework serve as a foundation for categorising and analysing the collected data. This approach examines the data through the lens of each framework element to understand how it influences the outcomes. The framework also provides a valuable lens for understanding the research findings. Results are analysed to the proposed relationships between the framework elements and the two crucial outcomes: effective utilisation of EHRs and quality of care. This enables the identification of patterns, trends, and potential areas where the framework

might require further refinement based on the research findings. By applying the conceptual framework throughout the research process, this research aims to identify best practices and develop effective strategies for optimising health data management.

### **3 Research Methodology**

This part of the research focuses on the selected research methods used to explore the role of data management in EHR systems. The chosen method for this research is qualitative research, with a specific focus on semi-structured individual in-depth interviews. This approach is selected because it provides detailed and comprehensive information about experiences and perspectives of individuals (DiCicco-Bloom & Crabtree, 2006).

#### **3.1 Qualitative Research**

Qualitative research enables understanding of perceptions, experiences, or events from a personal perspective (Tenny, Brannan & Brannan, 2022). Unlike quantitative methods that rely on counting and measuring, qualitative research focuses on the narratives and the depth of insight that cannot be easily quantified (Hammarberg, Kirkman & De Lacey, 2016). This selected method, for gathering empirical data, was chosen because it allows to gain a better understanding of complex issues that are common in the healthcare sector. Individual interviews were selected over group interviews because they let the interviewer a deep dive into personal and social matters, whereas group interviews provide a broader range of experiences but prevent the interviewer from gaining the same level of individual depth (DiCicco-Bloom & Clabtree, 2006). This approach provides a flexible framework that allows for a detailed exploration of experiences and viewpoints of interviewees. The nature of semi-structured interviews enables the interviewer to follow up on interesting insights, ask probing questions, and adapt the interview based on emerging themes (Mashuri et al., 2022).

#### **3.2 Empirical Data Collection**

The interviewees were selected from different areas of expertise to gather a better understanding of the matter. The target was to get different profiles with different backgrounds such as technical persons, specialists from the field of medicine, and someone with a legal background. This research gathered empirical data by conducting a series of six semi-structured interviews (see Table 1).

*Table 1. The interviewees.*

| <b>Number</b> | <b>Title</b>            | <b>Area of expertise</b>                                 | <b>Experience</b> |
|---------------|-------------------------|----------------------------------------------------------|-------------------|
| Interviewee 1 | Product Owner           | Healthcare product owner                                 | 19 years          |
| Interviewee 2 | Software Architect      | Software development in the social and healthcare sector | 5 years           |
| Interviewee 3 | Solution Consultant     | Technical product owner in healthcare sector             | 6 years           |
| Interviewee 4 | ICT & Privacy Lawyer    | Corporate lawyer                                         | 11 years          |
| Interviewee 5 | Chief Medical Officer   | Specialist in general medicine                           | 14 years          |
| Interviewee 6 | Quality Chief Physician | Quality improvement and digitalisation                   | 20 years          |

60-minute interviews were conducted through Microsoft Teams -meetings and all of them were recorded with the permission of the interviewee. These recordings enable to pay attention to the subtle details in the interactions between the interviewee and the interviewer which helps to verify the accuracy and comprehensiveness of the collected data (Barriball & While, 1994). By recording the interviews, the interviewer can fully concentrate on the interviewing process without the need of taking notes separately. The asked questions were not provided for the interviewees beforehand as the answers wanted to be authentic and without having any biased responses. The nature of the questions was more open-ended because they often offered more probing (Adams, 2015). It means that the questions give the interviewer a chance to ask additional questions if a new topic arises during the interview process (Young et al., 2018). Questions were thought thoroughly that they would provide answers to the initial research questions. They were designed to be specific to each experience and expertise of the interviewee. A complete set of interview questions is included in Appendix A of this research.

Once the interviews were conducted, a thematic analysis approach was employed. Thematic analysis is often applied in qualitative research to find and analyse recurring patterns and themes occurring in the interviews (Vaismoradi, Turunen & Bondas, 2013). This process involved transcription, initial coding, developing

themes, and data saturation. The transcription part was done by the automatic transcription feature offered by Microsoft Teams during the interviews. However, to verify the validity of the transcripts, they were checked against the recordings, and necessary corrections were made. The transcripts were then coded to identify initial codes representing significant concepts, ideas, and experiences mentioned by the interviewees. These codes were then reviewed, refined, and grouped into themes and subthemes that captured the essence of the perspectives of the interviewees on the research subject. Examples of this process are presented in Table 2. This analysis process continued until it reached data saturation. Data saturation is the point where new significant themes are not emerging from the interviews anymore (Braun & Clarke, 2019). This stage of the analysis ensures a comprehensive understanding of the experience of the interviewees. Through this thematic approach, the research aimed to get rich insights from the interview data and present a holistic understanding of the perspectives of the interviewees on the research topic.

*Table 2. Example of generated codes and themes.*

| <b>Theme</b>            | <b>Subtheme</b>                                   | <b>Quotation</b>                                                                                                                                                                                                                                             |
|-------------------------|---------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Data sharing and access | Importance of easy access to patient information. | “The problem is not that the data is not available or there is no data. The issue lies in the usability of data. Information is not beneficial if you cannot find it.”                                                                                       |
|                         | Ethical considerations around data access.        | “Ethical dilemmas arise in the use of (patient) data when privacy regulations are applied to patient care and healthcare operations. In such situations, balancing patient benefit and privacy requires careful consideration and often legislative review.” |

|                                     |                                                                                       |                                                                                                                                                                                                                                                                                                                                                                                      |
|-------------------------------------|---------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Data protection and security        | Balancing data security with the need for accessibility, and innovation and research. | “GDPR sets rules for the use of personal data, but it does not prohibit the use of the data for scientific purposes. However, the secondary use of patient data act significantly hinders development and innovation activities, especially software development.”                                                                                                                   |
|                                     | The importance of well-educated staff.                                                | “The practical training of the doctors is quite short, so the goal is just to get to work as quickly as possible and then they might have used it (the EHR system) incorrectly for a few months.”                                                                                                                                                                                    |
| Impact of interoperable EHR systems | Improved continuity of care.                                                          | “Information availability improves continuity of care. Patients are currently receiving safer and more effective care because we (the healthcare sector) have access to EHRs.”                                                                                                                                                                                                       |
|                                     | Challenges in sharing EHRs between different systems.                                 | “For example, a patient might have undergone a laboratory test at a certain CDO and needs to use another CDO for follow-up care. However, if one of the systems used by these CDOs lacks interoperability, the test may need to be retaken by the new CDO. This might be due to the fact that most of the CDOs have created these EHR systems alone without any standardised model.” |

The informed consent of each interviewee was obtained through email before the interviews by accepting to be part of the research. Additionally, the consent of recording these interviews was asked again at the beginning of each interview. The interviewees were informed of the purpose of the research, how the data would be used, and the right of the interviewees to withdraw at any point. The interviewees were assured of anonymity in the final reported research. The nature of the questions was tailored to avoid soliciting overly sensitive information. The focus of the questions remained on professional experiences and general perspectives on health data management. By following these protocols, the interviews aimed to gather valuable insights while safeguarding the privacy and confidentiality of the interviewees. The anonymised data is being used solely for this research and is not being shared in a way that could identify any individual participant.



## **4 Findings**

In this chapter, the research summarises the interviews with key people related to this research. These interviews provide valuable insights into various aspects of how EHRs influence the Finnish healthcare sector and what hinders their effective use. Hearing from experts, including healthcare practitioners, technical personnel, and a legal professional, who share their perspectives on health information availability and reuse, interoperability, ethical dilemmas and legislation, data protection and security measures, and patient experience. By exploring common themes and individual experiences, this thorough examination sets the stage for informed discussions and recommendations. This chapter is divided into subchapters based on the topics covered in the interviews.

### **4.1 Health Information Availability and Reuse**

Based on the existing literature there is no doubt that EHRs have revolutionised the healthcare sector. Each interviewee agreed that these electronic health records have helped the healthcare sector compared to the old paper-based versions. These EHRs have made it easier for both the healthcare professionals and the patients to access relevant health information. These records have made it possible for healthcare professionals to respond quickly and facilitate effective information sharing, resulting in positive consequences, especially during epidemics.

The interviews emphasised the importance of making relevant patient health information easily accessible to healthcare professionals. Seamless access to relevant health data was highlighted as a crucial factor when making informed decisions on health matters. Some of the interviewees stated that at this moment, even though there could be an integration that enables interoperability between systems, the data is not in a format that benefits the health professional or the patient. They stated that sometimes it can be hard to find relevant information of the patient from a mass of data accumulated over the years. A common problem was also that the systems were not consistent and clear enough, making them unintuitive to use. The interviewees stressed the need for simple and user-friendly platforms. The information must be easy to find. Some of the interviewees stated that the systems should

provide a more user-focused approach that is easy and intuitive to use. This limits the effectiveness of data sharing in the context of improving patient care.

*There should be some kind of a dashboard, where the essential information from the history of a patient would automatically appear for the doctor at that moment.*

-Interviewee 5

*The problem is not that the data is not available or there is no data. The issue lies in the usability of data. Information is not beneficial if you cannot find it.*

-Interviewee 6

Another crucial aspect discussed was the imperative need for reusing existing data. In the context of healthcare, data reuse involves leveraging existing medical records, including diagnostic images and examination results. CDOs attend to re-take images or examinations while it can be unnecessary in most cases. Repeating the same medical test or imaging procedure is not only wasteful in terms of resources but may also fail to serve the best interests of a patient. In fact, it could even be harmful to the health of a patient in certain situations. However, during the interview, one participant emphasised that CDOs should not overly prioritise resource conservation. Instead, they should carefully consider the circumstances. While using previously collected data can be advantageous, there are situations where caution is necessary. For example, new symptoms may have emerged, and the old examinations or images might not show these new occurrences, making the old data irrelevant. Therefore, healthcare professionals must exercise discretion when deciding whether to rely on existing data or choose to take new examinations or images. However, as mentioned, numerous situations exist where existing medical records could have been reused, highlighting the need for seamless data exchange between systems to optimise patient care.

*Repeating laboratory tests incurs significant costs nationwide, as patients often undergo the same tests due to various medical protocols or physician discretion, leading to redundancies and unnecessary resource utilisation.*

- Interviewee 5

*The most expensive patient in healthcare is the untreated or inadequately treated patient, because as a general rule in medicine, the earlier and the better the treatment, the lower the overall costs. So, trying to save on medical examinations can sometimes be a human tragedy and, in addition, terribly expensive.*

-Interviewee 6

## **4.2 Interoperability and Sharing Data**

Another major topic was interoperability, the ability to share data between systems. Interoperability was seen as an essential point to create an integration between different EHR systems. As mentioned in the previous subchapter, interoperability was not only seen as important to create connection between systems but to offer a way to transfer data in a format that would benefit the healthcare professionals and the patients the most. In these interviews, every participant mentioned that the data should be able to transfer between the EHR systems. These EHR systems contain vast amounts of data collected over the years, even decades. This data can include static information and summaries that might not seamlessly transfer between centralised registries like Kanta and other systems. It may lead to incomplete or inconsistent patient records, causing the doctor to potentially repeat unnecessary tests that have already been conducted on the patient, thus resulting in additional costs and a waste of resources.

*If medical information does not transfer between systems, it will lead to unnecessary expenses. For example, a patient might have undergone a laboratory test at a certain CDO and need to use another CDO for follow-up care. However, if one of the systems used by these CDOs lacks interoperability, the test may need to be retaken by the new CDO. This might be due to the fact that most of the CDOs have created these EHR systems alone without any standardised model.*

- Interviewee 1

*Very often, patients are treated with incomplete information, and we (healthcare professionals) try to compensate for this by asking as many questions as possible each time. No matter how many questions we ask, there will always be gaps in our knowledge.*

- Interviewee 3

The lack of interoperability prevents the seamless exchange of health information of the patients and ultimately decreases the quality of care. These interviews stressed the need for either having integrations between the systems or having a centralised service like Kanta where these systems could utilise patient data. Each interviewee mentioned the Kanta service which provides health information of patients to CDOs. As mentioned in the literature review, Kanta serves as a healthcare information system, which enables centralised electronic archiving of patient records and the long-term retention of data (Kanta, 2024). Even though Kanta serves as sort of a centralised system for storing the medical history of a patient, it was found out that it can be hard to navigate through the long list of patient medical history data. Kanta was seen as a good start, but it lacks features, and it needs to be improved. Additionally, Kanta is not meant to replace existing systems developed by the CDOs and all data might not transfer to Kanta from CDOs.

*The idea (of Kanta) is that different healthcare providers store patient data in a centralised register, and when the patient moves to another service provider (CDO), the data is transferred with the consent or permission of the patient. However, it is important to note that centralised register (Kanta) does not*

*necessarily contain all the information related to operative care and in some cases, transferring data directly between systems can be more efficient than routing it through a centralised registry.*

-Interviewee 4

*Kanta should offer comprehensive APIs that CDOs can use to create a complete picture of the medical history of a patient. This would make it easier for patients to switch to a different CDO.*

-Interviewee 6

Centralised services for sharing medical information streamlines the exchange of healthcare data by offering a centralised platform. This system effectively eliminates duplicate records, ensuring that all medical information is accurate and efficiently managed. Interviewees agreed that by consolidating information in one accessible location, healthcare providers can easily access patient records, reducing the risk of errors and enhancing the quality of care. Centralised nature of Kanta promotes collaboration among CDOs, leading to more coordinated and effective treatment plans and thus improving the quality of care.

*If you were to grant permission for another party to access your information, that data would not be duplicated. You could read the existing data through integration X and would not have to store the data yourself.*

-Interviewee 2

*Laboratory and imaging data should be stored in the same data pool (centralised registry like Kanta) so that the data is not stored in its own system but is instead available for shared use. There could be broader shared systems so that the data is then available (for any CDO).*

-Interviewee 5

However, there are still barriers that hinder interoperability to achieve the smooth transfer of data. A significant challenge identified in the interviews was that

each CDO has built their own systems in isolation, often tailored to their specific needs without any standardised model. These different systems can lead to compatibility issues and inconsistencies in data handling practices. Additionally, the cost of implementing comprehensive data transfer solutions across different platforms can be an obstacle. Figuring out who pays for these costs makes things more complicated and creates a big challenge for making steps forward to seamless interoperability between these systems.

*Those (centralised EHR systems) have pretty hefty price tags being thrown around when they (developers) announce, 'We can do this, but it'll cost you this much'.*

-Interviewee 5

The social and healthcare reform aimed to address various challenges within the healthcare system in Finland, one of which was the fragmentation of healthcare data. One of the interviewees pointed out that the reformation made data more unified but the data in different systems still resulted in a lack of an overall picture of the patient. Additionally, another important factor related to this was that Kanta does not replace the existing EHR systems. This means that centralised data banks like Kanta must be improved in a way that they would serve all existing EHR systems the same way, making them more valuable.

*Even though the social and healthcare reform improves data consistency, information in different systems still results in a lack of an overall picture of the customer (patient).*

-Interviewee 3

*In healthcare patient information systems (systems that contain EHR data), a significant amount of data is collected, and some of it may be static or aggregated, which may not directly transfer between the centralised registry (Kanta) and other systems.*

-Interviewee 4

The initial state of Kanta was seen as a good starting point or something to consider as the foundation of the centralised service for patient medical data. Since different CDOs have different needs for the data, the service would need to offer customisation based on the need of the EHR systems, meaning that the data remains the same, but the service would offer different ways to utilise the existing data. The seamless transfer of data enables effective treatment coordination, fosters collaboration among healthcare providers, and ultimately improves patient outcomes. Access and availability to data were seen to improve the continuity of care so that patients experience a more seamless healthcare journey, with fewer gaps and redundancies in their treatment plans.

*Information availability improves continuity of care. Patients are currently receiving safer and more effective care because we (the healthcare sector) have access to EHRs.*

-Interviewee 6

*The importance of seamlessly sharing information is fundamental so that individuals will receive appropriate care at the right time. This is perhaps the most important factor in improving patient care.*

-Interviewee 3

As discussions on healthcare data integration progressed, interoperability became one of the most critical concerns. The interviews highlighted the need for seamless data transfer between EHR systems. Challenges arose due to diverse data types, potentially compromising patient care. Despite obstacles, the role of Kanta as a centralised data service was emphasised. Enhancements and comprehensive APIs are essential for the smooth exchange of data and better patient outcomes. Next, this research focuses on another topic that arose from these interviews, ethical dilemmas and legislative considerations that underpin the use of healthcare data.

### 4.3 Ethical Dilemmas and Legislation

From the ethical point of view, the interviews uncovered various considerations that highlight the problems related to ethics and technology in the healthcare sector. The interviewees emphasised the importance of ethical principles guiding the collection, use, and sharing of health information. Patient autonomy and privacy rights were common topics of the interviews. The interviewees expressed concerns about balancing the need for access to health data with the imperative of safeguarding patient confidentiality.

One major ethical dilemma highlighted in the interviews was the challenge of determining the right scope of access to health information of patients. While the interviewees emphasised the importance of access to relevant data for effective decision-making, concerns were raised about the potential misuse or unauthorised access to sensitive medical information. The right balance between allowing access to important health information and keeping patient privacy safe is a key ethical concern in managing health data.

*All this (health) information is inherently sensitive; it belongs only to certain individuals. Specifically, it should be carefully considered, for example, when handling the health data of the citizen in various systems.*

-Interviewee 2

*Ethical dilemmas arise in the use of (patient) data when privacy regulations are applied to patient care and healthcare operations. In such situations, balancing patient benefits and privacy requires careful consideration and often legislative review.*

-Interviewee 4

These ethical considerations extended to the development and use of health technologies, particularly in data-driven applications. Interviewees emphasised the ethical responsibility of stakeholders, like software developers, that are responsible for building these systems to ensure the accuracy, reliability, and transparency of these applications. Legislation guides the development process, which sometimes



makes the development easier, but at the same time complicates things. In EU countries, GDPR and country-specific laws define guidelines for the right use of data. However, the ambiguity of GDPR was seen as a problem and its interpretation may lead to caution in sharing health information, leading to restriction of data. Another problem was the unnecessary strictness of additional laws like secondary law. These additional laws were also perceived as overly strict, with policymakers seemingly focused on creating them for the “worst-case scenario” rather than considering the best use cases.

*In Finland, there is a traditional phenomenon where we always lean towards worst-case scenarios and cater to the smallest minority, just to be safe. So, I believe that most citizens have the idea that it would be good if (patient medical) information were visible (despite the strict visibility laws).*

-Interviewee 6

*The legislation prevents the use of patient data for purposes that would clearly be in the best interest of the patient.*

-Interviewee 4

*Healthcare professionals must always justify why they are looking at patient information. This is somewhat burdensome for professionals, but on the other hand, it also ensures that they do not really look at the patient information for no reason. However, this also leads to the fact that they may leave out some information that would have been good to look at, but because they would have to justify it, they think about whether the justification is good enough.*

-Interviewee 3

Legislation was seen as ambiguous and raised concerns about how the restrictiveness of the legislation might hinder development and research. Some of the interviewees discussed the challenges regarding the secondary use of patient data in research and development. GDPR and country-specific laws add administrative bureaucracy and additional expenses to these processes. Researchers must obtain

expensive licenses for research data, which slows down the research and limits resources. Therefore, clearer, and more flexible legislation regarding the availability and accessibility of patient medical data is needed to balance the privacy concerns with research progress. Streamlining these processes and providing clearer guidelines would not only help researchers but also ensure that patient data is utilised effectively and responsibly. This could ultimately benefit both healthcare professionals and patient outcomes as more research is conducted, leading to possible breakthroughs in treatment and prevention methods.

*The (Finnish) secondary law has made it very difficult to use health information. It has killed research-oriented small-scale research because the research doctor must apply for the data from Findata, and it costs several thousand euros which not everyone has laying around.*

-Interviewee 6

*GDPR sets rules for the use of personal data, but it does not prohibit the use of the data for scientific purposes. However, the secondary use of patient data act significantly hinders development and innovation activities, especially software development.*

-Interviewee 4

These interviews proved that the legislative framework guides the development and use of patient health data. While legislation such as GDPR and country-specific laws provide guidelines for the right use of data, concerns have been raised regarding their restrictiveness and ambiguity. This pose challenges for stakeholders and impacts research and development efforts. The following subchapter examines what kind of role data protection and security measures have in this environment.

#### **4.4 Data Protection and Security Measures**

In the complex environment of managing sensitive data, prioritising robust measures for data protection and security becomes essential. These safeguards not only ensure patient privacy but also uphold the integrity of the data. The interviews

revealed different viewpoints and difficulties related to data protection and security within the Finnish healthcare sector. As mentioned in the previous subchapter, a recurring theme was to find a balance between accessibility and privacy concerning patient health data. While there is demand for easy access to EHRs to facilitate informed decision-making, there are equally strong concerns regarding the privacy and security of managing sensitive medical data. Interviewees stressed the importance of user-friendly platforms that prioritise data privacy without compromising accessibility. They emphasised the need for systems that are intuitive and efficient that allows healthcare professionals to access information swiftly while ensuring patient confidentiality.

Technical security measures emerged as critical components of healthcare data protection. They ensure that sensitive data remains secure and confidential during transmission and storage. Interviewees recommended centralised access control, encryption, physical security measures, and robust authentication methods to ensure that sensitive information can only be accessed by those who are authorised to access these records. These safeguards prevent unauthorised access, data breaches, and malicious activities. The interviewees emphasised the importance of implementing comprehensive security protocols that encompass both digital and physical aspects of data protection. Monitoring and regular auditing were also mentioned to detect and respond to potential security threats promptly. Implementing these measures helps healthcare organisations comply with data privacy regulations which is a critical factor for participating in data exchange within interoperable EHR systems.

*Centralised data storage should grant authorised users access to the data, while also keeping a record of who accessed the data, when, and for what purpose.*

-Interviewee 2

*Many systems rely on the principle that every activity is logged and that there must always be a medical reason for viewing the data.*

-Interviewee 3

However, there were some problems related to data privacy and protection. Many healthcare organisations are using cloud-based services to store and process patient data. However, these services pose a risk to data privacy, as they are often subject to the laws of the country in which they are located. This can make it difficult for healthcare organisations to ensure that their data is protected by GDPR and other data privacy regulations. These data privacy concerns can discourage CDOs from sharing data through EHR systems, fearing non-compliance with stricter local regulations like GDPR.

*There have been challenges in data protection related to health technology applications when using the services of large cloud service providers, such as Microsoft and Amazon. This is due to legal ambiguities, especially in applications from small vendors. Affiliations with the United States can cause problems.*

-Interviewee 4

The need for continuous improvement in data protection and security measures was also highlighted. This includes regular updates to technical safeguards, commitment to addressing emerging challenges in data management as well as ongoing training and education for staff. These measures were seen as essential for ensuring compliance with regulations and maintaining a high level of data security awareness among employees. However, one of the interviewees pointed out that doctors are often too busy and do not have time to attend the training or education programs. Unfortunately, neglecting staff training can significantly impact the awareness of threats among these individuals.

*The practical training of the doctors is quite short, so the goal is just to get to work as quickly as possible and then they might have used it (the EHR system) incorrectly for a few months. There is a challenge in finding time because during information system training, they are not doing their actual work.*

-Interviewee 5

The interviews also stressed the need for adopting a proactive approach to cybersecurity, including risk assessments, vulnerability scans, and incident response planning. The role of innovation and collaboration was brought up as they drive progress in data protection practices and knowledge-sharing initiatives. Stakeholders can adapt to new occurring threats and regulatory requirements when they prioritise continuous improvement. This way they can ensure that healthcare data remains secure and accessible for the benefit of the patients and providers. Being proactive means anticipating future problems, needs, or changes and acting appropriately. Proactive cybersecurity measures involve identifying and patching vulnerabilities, preventing data breaches, and regularly evaluating security posture. By standing ahead of cyber threats, organisations can safeguard sensitive patient data and ensure that the integrity of the data remains.

*It (patient data privacy) starts with education, it starts with competence. It stems from culture, it stems from leadership, and it stems from processes and operational models, so it has many facets. Data protection and privacy and incredibly important in healthcare. Trust is an essential prerequisite for a good doctor-patient relationship.*

-Interviewee 6

*We would install all critical updates and otherwise maintain and monitor any known vulnerabilities. That is how I would say that a good strategy could be. There should also be a system that can be used to identify if a new vulnerability arises from a dependency that is used somewhere in the organisation, and if it requires any action.*

-Interviewee 2

It is evident that there is a need for continuous improvements in data protection and security measures. Regular updates and staff training are necessary for better data protection. Challenges, such as time constraints for medical staff training, impact awareness of security threats. A proactive approach is crucial to stay ahead of evolving threats. After all, patient data privacy is not just about technical

safeguards, it is rooted in education, culture, leadership, and trust. This forms the foundation for strong doctor-patient relationship within the healthcare ecosystem. Robust data protection and security measures are essential for achieving seamless exchange of patient data. Standardising security protocols and fostering a culture of information security across CDOs empowers a secure and trusted environment for data exchange. Next, the research explores the aspect of patient engagement in this context.

#### **4.5 Enhancing Patient Experience**

The healthcare sector has shifted from a paternalistic approach to a more collaborative model. Healthcare professionals now develop treatment plans in collaboration with patients, emphasising on patient involvement brought up from these interviews. This shift empowers patients and fosters the ownership over their health. Additionally, collaborative care can improve treatment outcomes by incorporating the perspective and preferences of a patient. Patient involvement can enrich data within EHR systems, creating a more comprehensive picture of the health of the patient. This data can then be shared between other CDOs.

*Patients are becoming more involved. When we talk about the “good old days”, we used to talk about a paternalistic approach in medicine, where the doctor prescribes medication or diagnoses. We still use the term ‘prescription’, but we’re moving towards a shared decision-making process where the patient and the doctor, through joint discussion and consideration, define what this (the care delivery) is all about.*

-Interviewee 6

The interviewees stressed the need for creating systems that serve the patient. The main idea is to focus on what patients need and want, considering them as the key stakeholders in this process. Additionally, some of the interviewees recognised a problem that these EHR systems might act as gatekeepers withholding important information from the patients or from the healthcare professionals who are providing care for the patients.

*These systems should avoid the role of gatekeeper and allow people to access relevant data. These systems should also give the citizens the ability to enter their own data by themselves (in some cases) to reduce the data being incorrect.*

-Interviewee 1

These systems should be built in a way that the relevant data can be found easily, and users could navigate them effortlessly. Patient engagement was recognised for fostering commitment and strengthening the active involvement of the patient in managing their health. One of the interviewees suggested that patients should be offered interpretable results, such as visualisations that could empower patients and facilitate informed decision-making alongside healthcare professional. As healthcare practices evolve, this emphasis on patient empowerment has become increasingly crucial. This approach aligns with the change from traditional practices where patients are informed partners in their own care. Now they have an opportunity to receive and update information about their health seamlessly through patient portals.

*Here is an everyday example: when you can see your cholesterol levels, you can see they have changed over time. It will help us to understand what we are treating, what the goals are, and to strive for those goals ourselves. Simply put, knowledge is empowering.*

-Interviewee 6

As stated earlier, the healthcare sector has shifted away from some of the traditional practices. Healthcare professionals are now increasingly focused on orchestrating healthcare services rather than functioning as sole providers. In the past, patients typically relied on a single doctor who had comprehensive knowledge of their medical history. However, the interviews confirmed that nowadays patients often seek care from different healthcare providers. Whether the patient is traveling, within the scope of public occupational healthcare, under occupational health services, or for any other reason using a different CDO than they usually use, the person

might have multiple care providers. The medical information of the patient gets scattered between the different CDOs. This new trend only emphasises the need for orchestrating healthcare services rather than being the sole provider. This requires interoperability between the EHR systems to empower collaboration and coordination among healthcare providers to ensure holistic patient care and informed decision-making.

*The centralised system should have an interface that allows previous data to be retrieved for any application. In other words, if you have been a customer of a CDO X for 10 years and then switch to CDO Y, the app of the CDO Y would be able to retrieve the data through the interface. The idea is that the next application should be able to retrieve the data from Kanta through the interface. We do not need to build a huge jungle of interfaces, but I think Kanta is a good integrator for this purpose.*

-Interviewee 6

These interviews gave valuable insights regarding EHRs and their influence on Finnish healthcare sector. Balancing the concerns raised in the interviews with the potential benefits is crucial to understand the issue. The next chapter combines the analysed literature with the key findings from the empirical data.



## **5 Discussion**

This chapter concludes the findings and insights of the research. By combining the analysed literature with the key findings, this chapter aims to create a comprehensive solution for the initial research questions of the research: 1) How does the adoption of EHRs influence care delivery? and 2) What hinders the effective use of patient medical records? The objective of this research was to investigate the impact of EHRs on healthcare delivery, analyse the challenges associated with healthcare data management, specifically focusing on the lack of interoperability between different EHR systems, and to explore potential solutions for optimising data utilisation in healthcare.

### **5.1 Theoretical Implications**

The existing literature indicates that EHRs have been adopted widely in the US and in the EU (HealthIT.gov, 2023; European Commission, 2019). The shift from paper-based records to electronic format has been shown to have a substantial positive impact on the healthcare sector. Studies highlight how EHRs have allowed healthcare providers to access patients' complete medical histories and enable quicker access to these records (Serbanati, 2020). The interviews also acknowledged the importance of EHRs and the availability of healthcare data overall. These interviews highlighted the fact that leveraging existing data can enhance decision-making and resource allocation by providing CDOs with a more comprehensive view of the medical history of a patient.

#### **5.1.1 The Challenge of Interoperability and Data Availability**

Despite the potential of EHRs, both literature (Li et al., 2022; Miller & Tucker, 2014; Kobusinge et al., 2018) and the interviews revealed challenges with seamless data exchange. The lack of interoperability between different EHR systems was seen as a major issue. The main reason for the lack of interoperability was the fact that each CDO has built their own EHR systems independently in isolation without any standardised model. This has led to compatibility issues and inconsistencies in data handling which complicates the seamless transfer of data. Interoperability was recognised as a crucial factor because it enables access to past patient medical information

at the point of care (Kobusinge et al., 2018). By eliminating the need for patients to repeat tests and physician assessments, CDOs can reduce the cost of healthcare (Stiell et al., 2003). Additionally, the interviews emphasised that medical information availability improves continuity of care. When healthcare professionals have access to EHRs of patients, they can deliver safer and more effective care.

The literature identified two approaches for sharing EHRs: a centralised model where a central service provides information to all EHR systems, and a decentralised model where EHR systems directly share data with each other. The CDOs using the centralised option were more likely to achieve interoperability (Holmgren & Ford, 2018). Interviews also leaned towards the centralised approach as it would eliminate duplicate records and empower data protection by storing patient information in one secure location, eliminating the issue of data scattered across multiple systems. Kanta was seen as a good option for transferring data in a centralised way, but it lacks some essential features necessary for optimal functionality. First, the service might not contain all the patient information as some of it may be static and not transferred to Kanta, preventing other CDOs to utilise this collected data (Lipiäinen, Gustafsson & Lavinto, 2021). Secondly, the absence of comprehensive APIs is seen as an obstacle to get relevant information swiftly. It forces users to navigate through a long list of patient medical history data accumulated over the years.

### **5.1.2 The Legislative Burden, Ethical Considerations and Data Privacy**

Strict legislation emerged as a significant barrier to utilise patient data for secondary purposes. Interviews highlighted the need to strike a balance between patient privacy and data access. While legislation like GDPR has an important role in safeguarding confidentiality, overly strict interpretation or additional regulations can create unnecessary burdens. Studies by Aejmelaeus, Pitkänen & Matinheikki (2023) and Reito et al. (2022) revealed that law for secondary use of patient data increases costs and delays associated with research and development. Interviews recognised the same issue and suggested that overly strict legislation hinders research due to associated costs and lengthy waiting times, leading to potentially decline in research.

Reusing patient data, rather than using it for secondary purposes, presents a challenge in defining appropriate level of access. The inherently sensitive nature of this data creates an ethical dilemma for CDOs balancing patient benefit with privacy. The GDPR offers CDOs a framework for accessing necessary data and resources (Shah & Khan, 2020). It governs how personal data, including patient data, is processed (Mayer-Schonberger & Padova, 2015). Interviews agreed that GDPR sets the rules for the use of personal data but also mentioned that its restrictiveness might compromise patient care. Healthcare professionals must always justify why they are looking at certain patient information. This emphasis on justification and responsible use might discourage healthcare professionals due to permission-related anxieties, hindering access to potentially beneficial data.

The tension between optimal data access for informed decision-making calls for robust data protection. Interviews highlighted the need for technical safeguards like encryption and access controls as well as more holistic approach. This includes fostering a culture of information security within healthcare organisations and prioritising ongoing education for staff. These trainings equip staff with the necessary skills to effectively use the EHR systems (Dobrow et al., 2019) to identify potential vulnerabilities in these systems, take appropriate preventive measures and safeguarding sensitive patient information effectively (Arain, Tarraf & Ahmad, 2019). Thus, data protection does not only safeguard patient information, but it also impacts directly patient care and outcomes.

### **5.1.3 Patient Engagement and Education**

Finally, this research underscores the growing importance of patient engagement in healthcare data sharing. The interviews reminded about the shift from the paternalistic approach to a collaborative model, where patients are increasingly viewed as partners in their care. This collaborative approach empowers them and fosters a sense of ownership over their health data. Patient engagement is widely recognised as a critical component in enhancing clinical outcomes (Campbell et al., 2020). Patient involvement in treatment planning and data collection can enrich EHRs by providing a more comprehensive picture of their health. This enriched data can then

be shared securely between CDOs to improve care coordination and more informed decision-making.

A well-informed staff is essential for informed decision-making. Effective staff trainings ensure staff stay up to date on the latest regulations and compliance requirements (Waly, Tassabehji & Kamala, 2012). These trainings also equip them with necessary skills to effectively utilise EHR systems in secure manner (Dobrow et al., 2019). Interviews highlighted the need for ongoing trainings but revealed challenges with time constraints. Some healthcare professionals might not have time to attend these trainings or may attend trainings minimally, leading to potential misuse of EHR systems over time. Neglecting these trainings can significantly impact the use of these systems and potentially compromises patient care.

## **5.2 Practical Implications**

This research also provides practical considerations and actions that demonstrate what the results are in terms of actions. This chapter focuses on overcoming the challenges discussed in this research.

This research reaffirms the significant benefits of EHRs for healthcare delivery. They provide a comprehensive view of patient medical history, enabling quicker access to records and enhancing decision-making for healthcare professionals. CDOs should prioritise initiatives that encourage the continued adoption of EHRs across healthcare organisations. This includes equipping healthcare professionals with the ability to effectively utilise EHR systems with ongoing training programs. These training programs help staff stay up to date on the latest regulations, data security practices, and optimal data utilisation techniques.

Another driver towards gaining the full potential of EHRs is the need for standardised data entry protocols. These protocols help to maintain data quality and consistency within EHR systems. Without standardised protocols, data can be entered inconsistently, leading to errors and ambiguities between different EHR systems. For example, different abbreviations or terminology for medications or diagnoses can create confusion or prevent data from transferring between systems due to inconsistent data format. Standardised protocols ensure consistent formatting and

terminology and facilitates seamless data exchange and improves overall quality of data.

FHIR was suggested as one of the solutions to overcome issues related to lack of interoperability to adapt a common standard for data exchange. It enables seamless data exchange regardless of the EHR system used. However, it is important to understand both the capabilities and limitations of FHIR. The standards benefit from the existing web technologies and tools that help systems to achieve interoperability. For example, a healthcare provider using a non-FHIR compliant EHR system could potentially utilise a software translator to convert their data into a FHIR format before sharing it with another CDO. This approach leverages the benefits of FHIR for data exchange while acknowledging that not all EHR systems may be readily compatible. However, since FHIR does not support complex structures and advanced workflows beyond basic operations, the use of its usability must be weighed. In these situations, additional tools or standards may be required alongside FHIR to ensure comprehensive data exchange.

In addition to standardised data formats, centralised data platforms, like Kanta, offer a promising solution. These centralised services provide a central repository for patient data and facilitate secure data retrieval across various EHR systems. Maintaining data in one repository can be easier to maintain and manage, reducing amount of work and prevent ambiguous data between different systems (Sipic, 2023). While a standardised data formats and centralised data platforms facilitate effective data exchange, it is important to understand that they may not address all aspects of semantic interoperability. That is why these features need further development and research that requires funding from different healthcare organisations and potentially from the government. Interoperability requires resources and CDOs must focus on the common long-term strategy and forget about the short-term benefits.

Finally, the research emphasised the need to balance data access with robust data privacy measures. Prioritising technical safeguards such as encryption and access control is essential for protecting sensitive information. However, these measures alone are insufficient, thus fostering a culture of data privacy among healthcare professionals through staff trainings and clear guidelines ensures

responsible data handling practices. This builds trust and maintains patient privacy at the same time and more importantly reduces the risk of internal data misuse which were seen to happen more frequently than external breaches.

### **5.3 Limitations of the Research**

This research gathered empirical data through semi-structured interviews with healthcare professionals including healthcare practitioners, technical personnel, and a legal professional. However, limitations affect any research project, and this research is no exception. These limitations mainly arise from the empirical data collection but also extend to the literature review.

The primary limitation of the empirical data collection was the difficulty of recruiting participants with diverse expertise from different organisations. Due to the busy schedules of the healthcare professionals, arranging interviews was challenging. Many of those who were contacted were unresponsive. A bigger number of interviewees with varying backgrounds and experiences could have brought a richer and more nuanced understanding of the issue. Additionally, the empirical part of the research focused on the perspectives of healthcare professionals solely. Including the perspectives of patients could have provided a more comprehensive understanding of the challenges mentioned in the research. However, it was challenging to gather enough relevant patients to participate in the research and obtain a reasonable sample size for meaningful analysis of their perspectives.

As for the theoretical part of the research, the focus on a specific geographical region presents a limitation. The research mainly focused on the healthcare sector in Finland and the EU, excluding the rest of the world. Limiting the scope in this way can restrict the generalisability of the findings to other healthcare systems with different practices and regulations. Additionally, the research did not concentrate on other national legislation of countries on the topic. This could have provided valuable insights into how legal frameworks influence EHR implementation and data management across borders.

## **5.4 Recommendations for Future Research**

The result of this research highlights the need for further research on the effective utilisation of EHR data in healthcare. The purpose of this research was to investigate the adoption of EHRs and their influence on patient care delivery and to detect obstacles that hinder the effective use of these records. Because of the limit of this scope, there are plenty of areas that can be studied in the future.

Since this research primarily focused on the CDO perspective, prioritising patients could be done by incorporating their viewpoints and experiences into future research efforts. This would provide a more holistic understanding of EHR data utilisation and its impact on healthcare delivery for all stakeholders involved. The research could focus on how patients perceive the benefits and drawbacks of EHR data access, understand their concerns regarding data privacy, and explore their preferred methods for interacting and utilising their health information within EHR systems.

Another area of focus could be the existing EHR systems. The research could analyse existing solutions where interoperability has been achieved to understand the key factors that contributed to the success. On the contrary, the same research could also examine systems that suffer from the lack of interoperability and try to identify the specific technical or organisational barriers that hinder seamless data exchange. This holistic approach would provide valuable insights for optimising EHR systems.

## 6 Conclusions

This research investigated the impact of EHRs on healthcare delivery and identified challenges hindering the effective use of these patient medical records. While EHRs were found to offer significant benefits like improved access to patient data and better-informed decision-making, the lack of interoperability between different systems emerged as a major obstacle.

The core challenge identified was the absence of standardised data models across healthcare organisations. This fragmented nature of EHR systems, where each CDO has built its own systems in isolation, leads to compatibility issues and hinders the seamless exchange of patient data. The research explored both centralised and decentralised approaches to achieving interoperability. While existing solutions like the Kanta service offer a starting point, it requires further development. Centralised services, as highlighted in the interviews and supported by the literature, appear to be a more promising approach. However, these solutions need to overcome compatibility issues that have been built up from independent EHR system development. Comprehensive APIs are crucial to ensure CDOs can access relevant information quickly without the need of going through vast amounts of data accumulated over the years.

Optimising data utilisation through standardised data formats and improved data integration solutions were seen as important factors. This not only streamlines healthcare delivery processes but also benefits patients. By avoiding unnecessary tests through optimised resource allocation and enabling more informed treatment decisions based on comprehensive medical profiles, these improvements can significantly enhance the quality of care delivered.

The research concludes that interoperability between different EHR systems allows CDOs to gain the full potential of EHRs. It requires both technical and strategic measures. While acknowledging the value of existing solutions like Kanta, further development, and investment in a centralised approach with robust APIs and standardised data formats are needed. This not only helps the CDOs to streamline workflow and improve data quality, but also helps them to deliver more efficient and effective care. By fostering a more integrated data environment, the healthcare



sector can finally unlock the true potential of EHRs, leading to a future of improved care delivery and better patient outcomes for all.

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## Appendix A: Interview Questions

The interviews were conducted in Finnish and the questions were tailored for each interviewee based on their role. However, some questions remained the same for everyone. The questions are listed first in Finnish, followed by their **English** translation:

1. Antaisitko yleiskuvan roolistasi ja kokemuksestasi terveydenhuollon alalla?  
**Could you give an overview of your role and experience in the healthcare sector?**
2. Mitkä ovat mielestäsi merkittävimmät edut sovelluksista terveyteen liittyvien tietojen hallinnassa ja jakamisessa? **What do you think are the most significant benefits of applications in managing and sharing health-related data?**
3. Oletko havainnut aukkoja tai alueita, jotka vaatisivat enemmän huomiota terveydenhuollon sovellusten tietosuojassa tai tietojenkäsittelyssä? **Have you noticed any gaps or areas that would require more attention in the privacy or data processing of healthcare applications?**
4. Ketkä käyttävät tämänkaltaisia sovelluksia ja mihin tarkoitukseen? **Who uses these kinds of applications and for what purpose?**
5. Oletko kohdannut eettisiä ”dilemmoja” terveyteen liittyvien sovellusten käytön yhteydessä? **Have you encountered ethical "dilemmas" in the use of health-related applications?**
6. Mitä haasteita tai huomioita tulee esiin pääsyoikeuksia määriteltäessä käyttäjille? Onko pääsyoikeuksien hallinta vaikeaa tai monimutkaista? **What challenges or considerations arise when defining access rights for users? Is access rights management difficult or complex?**
7. Vaihteleeeko tietosuoja alueiden välillä? Esim. pieni vs. iso alue? **Does privacy vary between regions? For example, small vs. large area?**
8. Tuleeko mieleen osa-alueita tai näkökulmia, joita tässä tutkimuksessa olisi hyvä huomioida? **Are there any areas or perspectives that you think should be considered in this study?**

9. Miten tietosuojaa tulisi määritellä terveydenhuollon sovelluksissa? Huomioiden tiedon saatavuuden ja hallinnan? **How should privacy be defined in healthcare applications? Considering data availability and management?**
10. Näetkö, että tietosuojan hallinnointi on vaikeaa terveydenhuollon sovelluksissa? Jos on niin miten tai miksi? **Do you see privacy management as difficult in healthcare applications? If so, how, or why?**
11. Miten käyttäjän pääsyä tietoihin hallinnoidaan? **How is user access to data managed?**
12. Minkälaisia teknisiä turvatoimia olisi hyvä toteuttaa terveystietojen suojaamiseksi? **What kind of technical security measures should be implemented to protect health data?**
13. Kuinka sovelluksen olisi hyvä varmistaa, että vain tarvittavat tiedot ja oikeudet jaetaan käyttäjille? **How should the application ensure that only the necessary data and rights are shared with users?**
14. Miten sovellus hallinnoi päivityksiä ja varmistaa tietoturvan pysymisen ajan tasalla? **How does the application manage updates and ensure that security remains up to date?**
15. Koetko, että nykyinen systeemi (terveydenhuolto) ”holhoaa” kansalaisia suojelemaan heitä ”salaamalla” omaa terveyttään koskevilta tiedoilta? Esim. kaikki tieto ei ole saatavilla. **Do you feel that the current system (healthcare) "patronises" citizens to protect them by "concealing" their own health information? For example, not all information is available.**
16. Eroaako tietosuojan näkemys sidosryhmien välillä, jos eroaa niin miten? **Does the view of privacy differ between stakeholders? If so, how?**
17. Miten olemassa olevat lait vaikuttavat terveysteknologian sovellusten kehittämiseen ja käyttöön? **How do existing laws affect the development and adoption of health technology applications?**
18. Koetko, että lait edistävät vai hidastavat kehitystä? Varsinkin sensitiivisten tietojen jakamisen kannalta. **Do you feel that laws promote or hinder development? Especially in terms of sharing sensitive data.**

19. Onko jotakin yleistä haastetta (säädös/laki), jonka kanssa kehittäjät yleensä kohtaavat ongelmia? **Is there a common challenge (regulation/law) that developers generally encounter problems with?**
20. Kuka on vastuussa sovelluksen tietosuojasta? **Who is responsible for the privacy of the application?**
21. Näetkö eettisiä dilemmoja tietojen jakamiseen eri käyttäjäryhmien kesken? **Do you see ethical dilemmas in sharing data between different user groups?**
22. Mikä on mielipiteesi omakannasta ja keskitetystä terveystietorekisteristä? **What is your opinion on the patient portal and centralised health data register?**
23. Miten elektroniset terveystiedot ovat muuttaneet terveydenhuollon toimintaa? **How have electronic health records changed the way healthcare works?**
24. Miten arvioisit tilannetta potilaan koko lääketieteellisen historian hakemisessa eri hoitotoimittajien välillä? Onko sitä vai onko se olematon? Esim. Omakanta. **How would you assess the situation of retrieving a patient's entire medical history between different care providers? Is it there or is it non-existent? For example, Omakanta.**
25. Miten potilaiden sitoutuminen on muuttunut elektronisten terveystietojen käytön myötä? **How has patient engagement changed with the use of electronic health records?**
26. Miten potilastietojen uudelleenkäyttö tai toisiokäyttö on vaikuttanut väestön terveydenhallintaan ja lääketieteelliseen tutkimukseen? **How has the re-use or secondary use of patient data affected population health management and medical research?**
27. Osaatko sanoa kärsiikö teidän ohjelmistonne tiedon jaon puutteesta? Esim. tiedot eivät siirry järjestelmästä X järjestelmään Y (järjestelmien yhteen toimivuus). Jos kärsii, niin pystyttekö avata tätä hieman? **Can you say if your software suffers from a lack of data sharing? For example, data does not transfer from system X to system Y (system interoperability). If it does, can you explain it a bit?**

28. Koetko, että Suomessa tai Euroopassa on liian tiukat tietoturva toimenpiteet, jotka rajoittavat potilastietojen saatavuutta? **Do you feel that Finland or Europe has too strict security measures that restrict the availability of patient data?**
29. Minkälainen rooli koulutuksella on terveystietojen laadun ja eheyden ylläpitämisessä? **What role does education play in maintaining the quality and integrity of health data?**
30. Miten elektroniset potilastiedot parantavat potilaiden hoidon jatkuvuutta? **How do electronic health records improve the continuity of care for patients?**