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Data Availability & Interoperability for Chronic Brain Disease Care in The Netherlands

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Abstract

The thesis addresses the pressing issue of inefficient health information exchange within the healthcare landscape, particularly concerning patients with chronic brain diseases. This challenge often results in inadequate communication between healthcare providers and impedes the delivery of effective patient care. To mitigate these obstacles, an innovative healthcare information exchange architecture is proposed, grounded in FAIR data principles. The system integrates metadata for healthcare data, ensuring accessibility and machine-actionability. A significant focus lies on preserving patient privacy through robust access control mechanisms, facilitated by distributed ledger technology. Automation of authentication and authorization processes streamlines manual tasks, enhancing efficiency while providing transparency and control to patients over their data. By maintaining healthcare information within the original facility and implementing transparent access tracking, the proposed system aims to improve efficiency, effectiveness, and patient-centricity in healthcare delivery for individuals with brain diseases. The feasibility of the proposed solution was assessed through practical testing of IT tools and methodologies, alongside soliciting stakeholder feedback. This comprehensive evaluation aimed to determine the solution's potential effectiveness in addressing identified challenges within healthcare information exchange. Overall, the thesis presents a comprehensive solution to the challenges of healthcare information exchange, offering potential enhancements in personalized care and data security within the healthcare landscape.

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1 Introduction

1.1 Problem statement

Technology plays a crucial role in facilitating healthcare providers by ensuring the availability of patient healthcare information. Often, healthcare providers face challenges in obtaining complete or accurate healthcare information, such as the list of prescribed medications, treatment plans, and medical history. This challenge becomes even more pronounced when dealing with individuals suffering from chronic brain diseases like dementia and acquired brain injury as they struggle to remember details and effectively communicate with healthcare providers (Oppermann et al., 2017). Consequently, the availability of comprehensive health information becomes even more critical in these cases to ensure the delivery of personalized patient-centric care. Furthermore, it is not only medical data that holds significance; healthcare providers must also consider the preferences and wishes of the patients. For instance, when a patient when a patient who suffers from dementia transitions to a care home after living independently for as long as possible, expressing their desires may not be easy. The wishes and preferences of elderly patients with chronic brain diseases can be intricate and may still evolve over time (Bail et al., 2023). Additionally, healthcare providers must have access to both internally and externally acquired health information. Therefore, all types of information must be made accessible to healthcare providers to enable the provision of personalized care. The current situation where healthcare providers are approaching patients not completely informed on the medical situation should be addressed.

Providing personalized care relies on the availability of almost real-time healthcare data across various healthcare facilities. This necessitates healthcare providers to make well-informed decisions based on a comprehensive understanding of a patient's health situation (Mukherjee, Cresswell, & Sheikh, 2021). To facilitate personalized care for patients with chronic brain diseases, it's crucial to accurately discern the preferences of both patients and their caregivers and healthcare providers. This group of individuals possesses the most accurate and comprehensive knowledge of the existing bottlenecks and issues. The objective of this research is to identify and analyze these bottlenecks and problems, in order to gain a clear understanding of areas where the current healthcare information exchange infrastructure can be further developed. This will ultimately assist healthcare providers, patients, and caregivers in delivering and receiving personalized care wherever it is required. To provide personalized care in diverse settings, leveraging patient-generated health data (PGHD) becomes indispensable for comprehending a patient's condition, particularly in scenarios where continuous monitoring within a single healthcare facility is not feasible (Abubakar Kawu et al., 2023).

The prevalence of chronic brain diseases, especially among elderly patients, will exert additional pressure on the Dutch healthcare system, as the demand for care is projected to increase in the future (Hilderink & Verschuuren, 2018). This aligns with the findings of the Rijksoverheid (2020), who has identified that the current organization, labor shortage, and rising costs render the Dutch care system unsustainable in the long run. The costs associated with the ageing population constitute a significant portion of these expenses. Specifically, elderly care is expected to account for 25 percent of the total care expenses, compared to the current 20 percent Rijksoverheid (2020). This represents a cost increase from 17 to 43 billion euros, placing immense strain on the affordability, quality, and accessibility of the Dutch healthcare system. Consequently, the rising costs, growing demand for care, and ageing population will necessitate a shift towards promoting self-reliance and enabling individuals to receive care in their own homes for as long as possible, while minimizing the time spent in hospitals (de Bes-van Staalduinen, Kin, Quak, van Rijn, & Schoone, 2020). The increasing number of healthcare practitioners involved in the care for patients with chronic brain diseases, coupled with the trend of people living longer in their own homes and a declining number of children available to provide care for the elderly, will further intensify the demand for caretakers (Hilderink & Verschuuren, 2018).

This emerging trend of increased self-reliance, greater responsibility for caregivers, and enhanced personal care within one's own home for an extended period of time aims to alleviate some of the burden on the elderly Dutch healthcare system. These future developments will have several implications. Firstly, there will be a greater variety of healthcare providers to assist individuals with chronic brain diseases in their own residences. Which will fracture the data even more. Additionally, as individuals transition to care facilities, their chronic brain diseases are likely to be more severe, which results in patients having less control over their data and may struggle to fill in any gaps within these healthcare information systems. Therefore, the realization of these future trends relies on the integration of new technologies, improved data accessibility, and enhanced exchange of healthcare information among the various healthcare professionals involved.

The importance of improving the availability and exchange of healthcare information is evident. Recent research has shown that enhancing the accessibility and utilization of healthcare data can lead to improved quality of care and potentially reduce the cost of Dutch healthcare (Rijksoverheid, 2020). To achieve this, it is crucial to enhance the control of patient and healthcare provider information, thereby increasing the availability of healthcare data. Patients with chronic brain diseases such as dementia and acquired brain injury (ABI) often interact with multiple healthcare providers. Therefore, it is essential to ensure that the exchange of healthcare information occurs efficiently and effectively. If healthcare providers do not have access to comprehensive health information about a patient, they will be unable to obtain a complete understanding of the patient's health status. This happens especially when a patient with for example dementia is not able to fill in the gaps in the system. Consequently, healthcare professionals will be unable to develop a personalized care plan or administer medical interventions without consulting other healthcare providers involved in the patient's care. The problem here is that consulting other healthcare providers is now a time-consuming and inefficient process.

Currently, there is a lack of an efficient method for sharing healthcare information, which is causing issues not only in the Netherlands but also in other countries worldwide. A recent study conducted in England has revealed that general practitioners are unaware of the conclusions reached by specialists during consultations with their patients in hospitals, unless they actively reach out to the hospital (Mukherjee et al., 2021). This lack of interoperability between health information exchange systems hinders effective collaboration between these two types of healthcare providers, as well as with other providers. Consequently, these challenges in exchanging healthcare information result in duplicated work among healthcare providers, an increase in medical examinations, heightened frustration among elderly individuals and care providers, and a disruption in the delivery of professional care (Guthrie et al., 2014).

Several reasons contribute to the current lack of an efficient data exchange system. Firstly, different healthcare providers utilize disparate data storage systems that are not compatible with each other. When a patient visits a general practitioner or a healthcare institution, it is likely that this institution uses an online environment to store and potentially make the healthcare data available to the patient. This will also be possible when another patient visits a different healthcare institution or a general practitioner's office. However, the system where this data is stored and made available will often differ. There are significant differences between the various information systems in primary and secondary healthcare (Lindenberg et al., 2022). This causes problems when the data needs to be exchanged with other facilities. This research should take into account these different heterogeneous healthcare information systems. Secondly, another problem with the current situation in healthcare is that there are still significant differences in the description and coding of healthcare data (Lindenberg et al., 2022). This means that the ontological representation used by healthcare professionals to represent certain healthcare entities needs to be harmonized. These standards are necessary to enable the exchange of healthcare information across different healthcare domains. The solution that will be proposed should account for these dissimilarities between the ontological representation of data points. Thirdly, primary health-care professionals, as well as patients, should be involved in the design and maintenance of digital solutions (Neves & Burgers, 2022). This is one of the reasons why current IT solutions don't succeed. The NHS National Programme for IT (NPfIT), one of the most ambitious projects undertaken in UK public sector, costing approximately £10 billion, collapsed due to the lack of end-user engagement and public trust in care (Mukherjee et al., 2021). Us, as IT people, have to first understand the problems and the train of thought of patients and stakeholders around the patient. That is why, for every solution to succeed, it is crucial to start with the elicitation of the requirements and wishes from the patients and stakeholders around the patient (Neves & Burgers, 2022). Additionally, the Dutch data protection law, known as the Algemene verordening gegevensbescherming (AVG), and the European General Data Protection Regulation (GDPR) impose restrictions on the transfer of personal healthcare data. These factors make it challenging to transfer healthcare information efficiently between providers using existing technologies, without further burdening them with administrative tasks.

A study conducted by the "Denktank (ont)regel de zorg" revealed that healthcare professionals currently already spend 40 percent of their time on administrative tasks and only 60 percent on providing care (Ministerie van Volksgezondheid, 2018). This highlights the inefficiency of the current data system, as healthcare professionals are dedicating a significant portion of their time to administrative duties.

A deficiency in an efficient system for exchanging data among healthcare providers, without disproportionately burdening them with administrative tasks, is not only a social issue but also a political concern. The Dutch government is actively seeking ways to enhance the exchange of health information. Consequently, on September 29th of the previous year, a Dutch law called the "Wetsvoorstel Elektronische gegevensuitwisseling in de zorg" (Wegiz) was approved. The Wegiz is part of the program for electronic information exchange in healthcare. The Ministry of Health, Welfare, and Sport (VWS) aims to support the digitization of healthcare (Nouwt, 2022). This law mandates the electronic sharing of healthcare information directly from one computer to another (Veereschild, 2022). Currently, the exchange of healthcare information between healthcare providers still sometimes occurs through letters or patients (sometimes accompanied by relatives or caregivers) being asked to provide information about their health situation at another healthcare facility.

The Wegiz law aims to reduce the administrative burden on healthcare specialists and limit avoidable mistakes due to a lack of information (Veereschild, 2022). The Wegiz law will contribute to ensuring that the appropriate healthcare data is available at the right time. Once the Wegiz law comes into effect, it will apply to all healthcare providers, including general practitioners, home care services, hospitals, psychiatric institutes, and IT suppliers (Lindenberg et al., 2022). In the future, the Wegiz law will be expanded to include rules and obligations regarding how the data should be transferred. This means that the Wegiz is the first step towards an interoperable healthcare infrastructure. Making electronic data sharing mandatory and adding obligations regarding standards in the future will be a step in the right direction. However, there are still challenges to be addressed when implementing the Wegiz law. Electronic data sharing is currently a lot of work for healthcare specialists due to the lack of system integration and the absence of widely accepted standards (Lindenberg et al., 2022). While it is now clear that healthcare information should be shared more efficiently, little is known on how to do it more efficiently.

Healthcare information and its accessibility are currently significant concerns in Europe. In 2020, the European Commission unveiled an ambitious initiative known as the European Health Data Space (EHDS). The objective of this initiative is to establish a comprehensive framework encompassing legal, governance, data quality, and interoperability aspects. The primary aim is to facilitate the access and reuse of health data, thereby enhancing healthcare delivery, research, and policy-making in the region (Shabani, 2022).

The EHDS looks at primary use and secondary use of healthcare data around Europe. For the primary use of healthcare data the eHealth Digital Service Infrastructure (eHDSI) was introduced. The eHDSI encourages the collaboration and exchange of healthcare information of individuals across EU member states (Schmitt, Cosgrove, Pajić, Papadopoulos, & Gille, 2023). The goal of this initiative is to give patients access to healthcare no matter where they are in the EU and building towards a connected digital health infrastructure. In order to accomplish these objectives, two electronic cross-border health services have been implemented. The first service of the eHDSI, enables European Union (EU) citizens to obtain their prescribed medication from any pharmacy in a participating EU country (Schmitt et al., 2023). This service utilizes electronic tools to acquire and transfer medicinal prescriptions among healthcare providers located in various member states across Europe.

The second service offered by the eHDSI aims to facilitate access to health information for patients when they visit a physician in a different EU country. This service involves the provision of digital patient summaries, which contain crucial health-related information such as allergies, diagnostic tests, medical history, procedures, and immunization records. The intention is to further enhance the content of these summaries in the future by incorporating medical images, laboratory test results, and hospital discharge reports. This initiative seeks to improve cross-border healthcare and ensure seamless access to comprehensive patient information across EU member states.

To identify the problem comprehensively, it is imperative to review existing research on the topic. Numerous studies have explored various components related to data sharing solutions. For instance, some tools and initiatives focus primarily on consent management. Notable examples include the Personalized Consent Flow (Rake et al., 2017) and Sync for Science (S4S) (Hulsen, 2020) initiatives. The Personalized Consent Flow offers individuals control over their personally collected health data, allowing them to choose the extent to which they share their data for research purposes (Rake et al., 2017). Similarly, the Sync for Science initiative facilitates individuals' access to personal healthcare data, enabling them to share this data with researchers to gain insights into human health and diseases worldwide (Hulsen, 2020). However, these tools primarily address data reuse and only partially contribute to the broader data sharing problem.

Furthermore, three other data sharing initiatives from various regions have been examined. The Connected Bradford initiative from the United Kingdom serves as a data linkage accelerator, providing insights into individuals' health across multiple dimensions (Sohal et al., 2022). In Sweden, a system lacking real-time data availability and featuring data movement instead of a single point of truth poses limitations. Additionally, the Gift-Cloud platform facilitates data sharing and reuse of medical imaging, enabling clinics to share imaging data with other organizations (Doel et al., 2017).

However, these solutions exhibit characteristics incompatible with the chronic brain diseases context, such as the absence of real-time data availability and data movement instead of a single point of truth. In Sweden, the National Health Information Exchange (HIE) platform acts as a point of connectivity for various healthcare applications and eHealth services, aiming to integrate disparate healthcare systems into a unified platform (Davoody, Koch, Krakau, & Hägglund, 2019). Nevertheless, the challenge lies in linking all healthcare systems to the HIE platform, rendering it suboptimal.

Presently, many Dutch healthcare facilities utilize the Siilo app for transferring healthcare information securely (Sollie & Timmers, 2019). However, this solution involves data transfer, which does not alleviate the administrative burden. Thus, despite existing initiatives, there remains a need for a comprehensive data sharing solution tailored to the specific requirements of Dutch chronic brain disease care.

In this study, initiatives were identified that align with the FAIR guidelines (Wilkinson et al., 2016). These guidelines, emphasizing data to be 'Findable', 'Accessible', 'Interoperable', and 'Reusable', establish a robust framework for depositing, discovering, sharing, and reusing data in contemporary data systems (Purnama Jati et al., 2022). It's important to note that while FAIR data encourages accessibility, it does not imply openness; rather, data can only be accessed under well-defined conditions to safeguard privacy (Purnama Jati et al., 2022). The FAIR principles represent an innovative approach to ensuring responsible access to health data, recognizing the importance of data security and the necessity for data sharing in informed decision-making processes, thereby facilitating the extraction of valuable insights from the data.

The FAIR guidelines primarily are primarily researched in the context of of enabling the reuse of healthcare information, yet they also offer significant potential in supporting personalized patient care through the exchange of health data. By allowing controlled access to diverse data sources while safeguarding privacy, the FAIR principles prove highly adept at facilitating the availability of healthcare information (Hulsen, 2020). FAIRification of health data facilitates seamless information sharing across various storage systems, enhancing interoperability and enabling different healthcare systems or institutions to utilize this information for personalized care provision (Dias et al., n.d.).

Given the sensitive nature of patient health data, handling such information requires utmost care and compliance with relevant regulations. In our context, the General Data Protection Regulation (GDPR) stands as the most significant legal framework. Enforced by the European Commission, the GDPR aims to strengthen and standardize the protection of personal data within the European Union (EU) (Eva et al., 2022).

Two notable initiatives, VODAN Africa and FAIRhealth, are exemplars of implementing FAIR principles in data sharing practices (Wilkinson et al., 2016). VODAN Africa focuses on facilitating access to COVID-19-related data across Africa, aiming to enable safe data access while contributing to the FAIRification of health data in the region (Purnama Jati et al., 2022). On the other hand, FAIRhealth combines medical data with data from CBS for analytical purposes, seeking to establish connections between lifestyle factors, type 2 diabetes, and health costs (Sun et al., 2018). However, it's essential to note that while these initiatives share common ground with our objectives, they operate in distinct contexts — VODAN Africa primarily focuses on Africa's health data landscape, while FAIRhealth concentrates on healthcare data reuse within the Netherlands.

To summarize, it is evident that the Dutch healthcare sector cannot sustain its current state. Multiple issues have been identified to support this conclusion. The aging population and the prevalence of chronic diseases, such as dementia, will lead to exponential increases in healthcare costs. Additionally, the shortage of healthcare professionals, the current organizational structure, and the high administrative burden on healthcare providers necessitate a change. As a result of higher costs and labor shortages, patients with chronic brain diseases are expected to live longer in their own homes and rely more on self-care. Consequently, this will further fragment healthcare information from patients with chronic brain diseases. Without addressing the inefficient global exchange of healthcare information, personalized care is not feasible, and costs will continue to escalate. To address these challenges, we must explore more efficient utilization of time and resources within the Dutch chronic brain disease care care system while improving the interoperability of healthcare information across different providers. To date, there is a noticeable gap in research regarding the exchange of sensitive healthcare information for patients with chronic brain diseases utilizing the FAIR guiding principles. This study endeavors to address this critical and intricate issue by offering solutions grounded in FAIR guidelines. Additionally, it will carefully consider the pertinent laws and regulations that impact this domain, ensuring compliance and ethical integrity throughout the proposed solutions.

1.2 Research gap

If we analyze the issues outlined in the care for patients with chronic brain diseases and its projected trajectory, it becomes apparent that we must seek a more efficient and streamlined approach to exchanging healthcare information, while also adhering to the relevant regulatory frameworks. Additionally, we need to find a way to enhance the accessibility of the data in order to provide personalized patient-centric care to vulnerable elderly patients, such as those with dementia. It is important to do this in a privacy preserving way due to the sensitivity of this data.

In order to enhance the efficiency and efficacy of healthcare data processing, it is imperative to prioritize the transformation of data into a machine-readable format. This will facilitate the optimization of healthcare specialists' workflow through the automation of presently manual tasks.

To achieve machine-readability, the FAIR guidelines and principles, introduced by Wilkinson et al. (2016), were introduced. This research will therefore investigate how the utilization of FAIR semantic data can address the aforementioned problems in the Dutch chronic brain disease care system, while still complying with the relevant regulatory frameworks. By doing so, we can propose a healthcare information exchange system that ensures the data is Findable, Accessible, Interoperable, and Reusable, while healthcare providers retain sovereignty over their patients records.

There has been limited research conducted on the use of FAIR semantic data for the processing and exchange of personal information. Therefore, our objective is to assess the feasibility of this use case and provide an innovative health information exchange architecture for the care for patients with chronic brain diseases by utilizing innovative techniques.

Therefore, the following research question was proposed:
How can the implementation of FAIR semantic data principles in the care of patients with chronic brain diseases contribute to establishing an infrastructure that that preserves the privacy and facilitates accessibility and interoperability?

1.3 Research objectives

The primary goal is to propose a federated information technology (IT) architecture that is in accordance with the preferences of stakeholders in the domain of chronic brain disease care and showcases the most efficient methodologies derived from our comprehensive research.

To accomplish this objective, several subsidiary objectives were identified:

- The primary objective entails identifying the health information requirements and needs of stakeholders involved in the care of patients afflicted with chronic brain diseases.
    - The first step here is to identify what healthcare information is currently missing according to healthcare providers in the field of chronic brain disease care.
    - The next objective is to speak to the chronic brain disease care stakeholders and comprehend the impediments that cause this information to be unavailable for healthcare practitioners in the chronic brain disease care.
    - It is also crucial here to determine and identify the specific healthcare information that is essential for their needs as a healthcare professional or caretaker of patients with chronic brain diseases.
- The second objective involves identifying and conceptualizing the pertinent tools and resources available for facilitating FAIR data production.
    - The first step entails exploring what the possibilities are of data production on sensitive patient and personal data of patients suffering from chronic brain diseases in a FAIR-data architecture.
    - The subsequent step is to utilize innovative tools and information technology techniques to ensure that the healthcare information, which holds utmost significance for our stakeholders, is easily Findable, readily Accessible, capable of seamless interoperability, and can be Reused effectively (FAIR).
- The third objective entails testing and implementing the proof of concept for FAIR data production.
    - Here, the feasibility of this technical architecture is tested and validated.

1.4 Research questions

Therefore, we ask:

The Research Question

How can the implementation of FAIR semantic data principles in the care of patients with chronic brain diseases contribute to establishing an infrastructure that that preserves the privacy and facilitates accessibility and interoperability?

The questions that we use to ultimately answer the research question:

- What are the specific health information requirements and needs of stakeholders involved in the care of individuals suffering from chronic brain diseases?
  - What information is currently missing among healthcare providers in the field of chronic brain disease care?
  - what are the impediments with regards to the availability of such information?
  - What kind of healthcare information is perceived as the most crucial to stakeholders in the care for patients with chronic brain diseases and should be available for them?
- What are the existing tools and resources designed to facilitate the production of FAIR data, and how can these be conceptualized to effectively support the generation of FAIR data?
  - What is the possibility of data production on sensitive patient and personal data in a FAIR-data architecture?
  - How should a healthcare information exchange architecture, based on the FAIR guidelines and principles, be constructed to allow healthcare stakeholders in the care for patients with chronic brain diseases to exchange healthcare information while preserving the privacy?
- How can a proof of concept for FAIR data production be effectively tested and implemented, ensuring adherence to FAIR principles and demonstrating practical feasibility in real-world settings?
  - What is the assessment of the feasibility of the proposed technical architecture?

1.5 The hypothesis

The implementation of FAIR semantic data principles in the chronic brain disease healthcare sector will lead to the establishment of an information infrastructure that not only ensures the provenance of data but also enhances accessibility and interoperability. Furthermore, this implementation will maintain the data sovereignty, allow for access-control under well-defined conditions, to preserve the privacy of patients with chronic brain diseases.

1.6 Conceptual framework

1.6.1 The FAIR Guiding Principles

Whenever we need to derive meaning from data, we can simply read the text and consider the provided context in textual format. However, if the data is presented in text form to a computer, it cannot fully understand and interpret the data. This occurs due to two primary issues within the current internet infrastructure. Firstly, the information is not inherently machine-readable, meaning it cannot establish connections without being coded into programming languages and uniform resource identifiers (URIs). Secondly, instances lack significance unless semantic connections are established. As a solution, the semantic web was introduced by Berners-Lee, Hendler, and Lassila (2001). The main goal was to develop the underlying technology that enables machines to better interpret data and establish standardized interoperable data formats that can be utilized across various services or platforms (Shadbolt, Berners-Lee, & Hall, 2006). To support this objective, several core formats were created to promote an improved approach to modeling, characterizing, and querying data (Kanza & Frey, 2019). This challenge prompted organizations and scientists to devise a method for enhancing data management, leading to the development and introduction of the FAIR data principles in 2016 (Wilkinson et al., 2016).

The FAIR Guiding Principles for data management and stewardship have been developed as part of a comprehensive framework with the goal of organizing, managing, and sharing data. These principles and guidelines, proposed by Wilkinson et al. (2016), aim to enhance the findability, accessibility, interoperability, and reusability of data. The fundamental concept underlying the FAIR methodology is to enable machines to process data. This means that computational systems should be able to independently locate, access, integrate, and utilize data without human intervention (Wilkinson et al., 2016). Therefore, it is crucial to store data in a FAIR manner. Another interpretation of FAIR is "federated AI ready," indicating that it can be used for federated analyses due to its machine readability (Mons, Schultes, Liu, & Jacobsen, 2020). This statement implies that the mentioned action results in the processing of data in a manner that ensures its compatibility with future advancements and allows machines to efficiently support us. In the following sections, we will explore the specific components of the FAIR principles.

Findability
The initial stage in achieving data FAIR compliance involves recognizing the necessity for data to be discoverable. This is why Wilkinson et al. (2016) introduced the concept of findability. To ensure data is findable, it is imperative to establish a well-documented process for indexing, organizing, and querying data. This can be achieved through the utilization of unambiguously readable metadata and traversable knowledge graphs, which are defined by a standardized ontology or vocabulary specification (Plug et al., 2022). To enhance data findability, it is crucial to assign a unique and persistent identifier to the data.

For data to be Findable Wilkinson et al. (2016) has identified four principles:

F1. (meta)data are assigned a globally unique and persistent identifier

F2. data are described with rich metadata (defined by R1 below)

F3. metadata clearly and explicitly include the identifier of the data it describes

F4. (meta)data are registered or indexed in a searchable resource

Accessibility
Once data has been indexed and integrated into a health information system to ensure the ease of locating the data, it becomes essential to make the data accessible under clearly defined conditions (Plug et al., 2022). These well-defined conditions involve methods of authorization and verification of credentials. The accessibility of data depends on the identity of the individual and the purpose for which they seek access to the data. Certain data sets may be made accessible or inaccessible based on the preferences of those seeking access. Typically, data access is facilitated through the utilization of an application programming interface (API) that handles queries appropriately (Plug et al., 2022). In summary, accessibility goals are achieved when data can be accessed in accordance with clearly defined and unambiguous authorization and authentication requirements.
For data to be Accessible Wilkinson et al. (2016) has identified four principles:

A1. (meta)data are retrievable by their identifier using a standardized communications protocol

A1.1. the protocol is open, free, and universally implementable

A1.2. the protocol allows for an authentication and authorization procedure, where necessary

A2. metadata are accessible, even when the data are no longer available

Interoperability
Interoperability refers to the manner in which data must be integrated and connected to other data. According to Wilkinson et al. (2016), interoperability entails the ability of data, as well as tools originating from non-collaborating resources, to seamlessly function together with minimal effort. To attain data interoperability, it is essential to utilize the ontology derived from the controlled vocabulary consistently across the entire use case or landscape where interoperability is desired (Plug et al., 2022). Furthermore, it is essential that the metadata includes distinct identifiers. In order to ensure interoperability of the data, it is necessary to standardize the knowledge obtained from the data and the metadata by employing templates. Once this process is completed, if the (meta)data can be interpreted and evaluated automatically, it becomes machine-actionable (Plug et al., 2022). It is crucial for the nodes within the derived knowledge graph to be extensively interconnected. In summary, data achieves interoperability when it is connected through semantic metadata and capable of being safely and automatically processed, stored, and explored by various entities (Plug et al., 2022).
For data to be Interoperable Wilkinson et al. (2016) has identified four principles:

I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.

I2. (meta)data use vocabularies that follow FAIR principles

I3. (meta)data include qualified references to other (meta)data

Reusability
Reusability is greatly influenced by data protection regulations, such as the General Data Protection Regulation (GDPR). In order for data to be reusable, it is essential to have proper data provenance. Good data provenance is attained when the origin of the data and the procedures that produced the data are clearly defined, accurately documented, and regularly updated (Plug et al., 2022). In order to maintain the integrity of data, it is imperative to thoroughly document all pertinent and interconnected metadata within a data management plan (DMP). A DMP serves to outline the process of accessing or generating data, as well as establish standards for managing, describing, and storing data (Plug et al., 2022). Additionally, a DMP is utilized to describe the system by which data is securely handled throughout the entire research process. To address the aspect of data reusability, it is important to consider data that possesses good provenance, enabling its reuse across various entities. The data needs to be described in the right way for it to be replicable in other environments (Wilkinson et al., 2016).

For data to be Reusable Wilkinson et al. (2016) has identified four principles:

R1. meta(data) are richly described with a plurality of accurate and relevant attributes

R1.1. (meta)data are released with a clear and accessible data usage license

R1.2. (meta)data are associated with detailed provenance

R1.3. (meta)data meet domain-relevant community standards

1.7 Ethical and legal considerations

1.7.1 Laws and regulations

Worldwide, there exist numerous concerns, laws, and regulations pertaining to the processing of data. In order to comprehend the methods by which data can be processed, it is imperative to grasp the concepts of data governance and regulatory frameworks that significantly impact this subject matter. The primary aim of these frameworks is to establish a standardized approach to handling data in accordance with the relevant laws and regulations (Plug et al., 2022).

Data governance

Data governance is a concept that pertains to the implementation of regulations and policies regarding the collection, handling, and storage of data. Additionally, it encompasses the authorization and management of data that is transferred between various countries (Plug et al., 2022). To provide further explanation, data governance ensures that data remains consistent and reliable, and is not misused. The importance of data governance is increasing as organizations encounter new regulations regarding data privacy and protection. For instance, data governance promotes conformance with regulations like the European Union's General Data Protection Regulation.

GDPR

On May 25, 2018 the General Data Protection Regulation (GDPR) came into effect. The GDPR makes the use of the concept "privacy by design" of crucial significance. The concept "Privacy by design" looks at data protection from the beginning of designing systems in which appropriate technical and infrastructure measures should be implemented (Dutta, Das, Dey, & Bhattacharya, 2020). This regulation aims to enhance and unify the safeguarding of personal information with the European Union (Eva et al., 2022). Whenever one is involved in handling data and adhering to regulations, there are various stakeholders, roles, concepts and definitions to consider. Failure to comply with the regulations outlined in the General Data Protection Regulation (GDPR) will lead to a penalty of either 20 million euros or a percentage (2 or 4 percent) of the worldwide revenue, whichever amount is greater (Dutta et al., 2020).

The data owner and data subject

The initial parties to consider are the data owner and the data subject. The data owner refers to an individual or entity that possesses full authority and legal rights to determine who can access and manage their data (Plug et al., 2022).

On the other hand, the data subject pertains to an individual whose data has been gathered. It is possible to identify this person, either directly or indirectly, through the specific data collected (Article 4(1), GDPR). To be specific, the data subject possesses specific privacy rights concerning their data. These rights include the right to be informed, the right of access, the right of rectification, the right to erasure, the right to restrict processing, the right to data portability, the right to object, and rights in relation to automated decision making and profiling (Eva et al., 2022).

Personal data

The data that is collected from the data subject has the potential to be classified as personal data. Personal data refers to any data, information, or knowledge that pertains to an individual and is considered the property of the data subject in accordance with the General Data Protection Regulation (Article 4(1), GDPR). If a specific entity or individual intends to handle personal data, they must adhere to the seven principles of data protection and accountability outlined in article 5.1–2 of the GDPR. These principles include lawfulness, fairness, and transparency; purpose limitation; data minimization; accuracy; storage limitation; integrity and confidentiality; and accountability. There are certain categories of personal data that are considered special and can only be processed and utilized by legally certified entities. These particular categories of personal data are therefore subjected to stringent regulations as outlined in Article 9(1–3) of the General Data Protection Regulation (GDPR).

The data controller and the data processor

There are two parties involved in handling the personal data generated by an individual, namely the data controller and the data subject. The data controller is granted the authority to oversee the personal data collected from the data subject. The conditions, purpose, and methods of storing and utilizing the personal data are determined by the data controller, as stated in Article 24(1–3) of the General Data Protection Regulation (GDPR). Typically, the data controller is the healthcare facility where the data is generated in the healthcare sector. This entity is also legally responsible for obtaining consent or permission from the data subject. Additionally, they are obligated to have a purpose statement and a data management plan in place when processing personal information.(Plug et al., 2022).

The data processor is accountable for the processing of data in a manner that conforms to the conditions, purpose, and methods established by the data controller for storing and utilizing personal data. Furthermore, it is the responsibility of a data processor to diligently carry out the processing of data while implementing adequate security measures. This includes ensuring the protection of personal data belonging to data subjects. An example of a data processor could be a data steward, whose primary responsibility is to handle the personal data collected from the data subject throughout the entire process on behalf of the data controller. (Article 28(3), GDPR). Sometimes, the entity responsible for managing and processing data, known as the data controller, is also the same entity that processes the data. This is often the case in situations involving small clinics. However, in most cases, the data controller is a specialized party, such as a cloud service provider. In these instances, the cloud service provider typically enters into a contractual agreement with the data controller, outlining the respective responsibilities, legal obligations, and non-disclosure requirements.(Plug et al., 2022).

Informed consent

Informed consent is utilized to grant the data controller authorization to manage the personal data collected from the data subject. Informed consent must be explicit, clear, and can only be provided voluntarily when the data subject is adequately informed about all the data processing activities (as defined in Article 4(11) of the General Data Protection Regulation). In accordance with the GDPR guidelines, informed consent can be retracted at any time. Additionally, the data subject has the right to request access to their personal data and to request its deletion (Plug et al., 2022).

The Data Privacy Impact Assessment

The data processor is responsible for implementing a data repository process that ensures the security of personal data stored in the entity they are accountable for. As part of their responsibilities, they are required to prepare a report known as the data protection impact assessment (DPIA) report, as stated in Article 35(1) of the General Data Protection Regulation (GDPR). This report includes an evaluation of potential security risks and the measures taken to mitigate these risks. The data protection assessment utilized in France by the National Commission on Informatics and Liberty (CNIL) is detailed in Appendix A. Through its regulatory oversight, the CNIL ensures adherence to data privacy laws governing the collection, storage, and utilization of personal data.

1.7.2 Ethical considerations

In this case study, interviews are utilized, making it crucial to comprehend and convey the rights of both the researcher and the participants. Prior to each interview, the interviewee is provided with an information letter and a permission letter. The permission letter explicitly states that the research will be recorded and participation is entirely voluntary. Additionally, the interviews are stored separately from any personal information.

There are also important rights to be mentioned regarding post-interview procedures. Once the research is completed, the recordings will be deleted. Furthermore, it is agreed that the interviewees will not be referred to by their names in the thesis. This measure ensures that interviewees cannot be identified directly or indirectly. Instead, their roles will be discussed in the thesis, considering the large number of individuals working in this field.

In formulating an architecture, it's crucial to recognize the sensitivity of handling data concerning vulnerable patients in a delicate environment. The data involved includes personal information of individuals with chronic brain diseases, possibly diagnosed with dementia, necessitating strict regulation and stringent security measures to ensure privacy-preserving health information exchange.

Lastly, it is essential to emphasize that no companies or institutes are involved in the proposed solutions presented in this thesis. The researcher is not financially supported by any stakeholders in this research or the healthcare industry. This research is conducted entirely independently.

1.8 Relevance

The significance of this thesis is apparent and can be categorized into both academic and societal importance.

1.8.1 Academic relevance

The academic significance of this thesis stems from the conclusion that it will be one of the initial studies conducted on utilizing FAIR semantic data and the personal health train to propose an architecture for exchanging sensitive healthcare information of patients with chronic brain diseases. Additionally, there is limited academic literature available on constructing an architecture that adheres to regulatory frameworks and caters to the requirements of the end users it aims to serve. This thesis can serve as a foundation for future academic research. Moreover, the proposed architecture can be applicable to other departments within the Dutch healthcare system or even on a global scale.

1.8.2 Societal relevance

The study of the current state and consequences of population ageing is a prominent area of research in contemporary times. Projections indicate a substantial rise in the number of individuals aged 75 and above in the Netherlands, with an estimated increase of 700,000 by the year 2040 (Hilderink & Verschuuren, 2018). This data underscores the ongoing trend of population ageing and its significant implications for the healthcare system in the Netherlands, as well as the prevalence of specific diseases among the elderly population.

Cognitive diseases are seen with an increasing frequency in the Dutch Healthcare. More people are being diagnosed with dementia on a daily basis, indicating a growing prevalence of this condition. In the Netherlands alone, there are currently approximately 290,000 individuals who are afflicted by this disease. However, this number is projected to escalate significantly, surpassing half a million by the year 2040 (*Factsheet cijfers en Feiten over dementie: Alzheimer Nederland*, 2021). This anticipated surge can be attributed to the aging population, as dementia is more commonly observed among older individuals. Over 80,000 individuals, who have been diagnosed with dementia, currently reside in care homes. The provision of care for these individuals with dementia incurs the highest costs at a national level (*Factsheet cijfers en Feiten over dementie: Alzheimer Nederland*, 2021). In addition to the substantial medical expenses, it also exerts immense pressure on the healthcare system in the Netherlands. It has been observed that individuals diagnosed with dementia require three times more care compared to a similar group of individuals without dementia. This increased demand for care poses significant challenges for the healthcare sector in effectively managing resources and providing adequate support to those affected by dementia. For example from 2015 to 2040 the people with dementia who are allowed to live in home care will rise from 76.000 to 165.000 people (Hilderink & Verschuuren, 2018). We currently don't have enough home care facilities and home care workers to make this possible.

Another cognitive disease that is being diagnosed with increasing frequency is acquired brain injury (ABI). In The Netherlands, approximately 130,000 individuals are affected by this condition annually, while an additional 650,000 people experience difficulties as a result of having ABI (hersenletsel.nl, 2022). These figures represent more than three percent of the total population residing in The Netherlands.

Elderly patients suffering from chronic brain diseases like dementia and ABI are often not just suffering from one disease. This phenomenon necessitates treatment from multiple healthcare professionals, thereby placing additional strain on the healthcare system. This additional strain is attributed to the fundamental requirement of individuals for increased care from multiple healthcare professionals. Moreover, the transfer of healthcare information from a patient to various healthcare professionals and facilities imposes additional pressure and administrative burden on the healthcare providers.

Technology has the potential to greatly impact public health and revolutionize healthcare. Technological applications, such as mobile apps, sensors, and alarm systems, hold promise in addressing future challenges in the care for patients with chronic brain diseases. These include providing care for individuals with dementia and supporting self-management in chronic conditions (Hilderink & Verschuuren, 2018).

However, the integration of technology in healthcare has been slower compared to other sectors (Hilderink & Verschuuren, 2018). This delay can be attributed to various factors, both within and outside of the healthcare sector, which pose challenges to the expansion of technology in healthcare. As patients, caretakers and family increasingly take charge of their own health, advancements in technology further empower them in this regard. Consequently, healthcare providers and patients need to acquire new skills to adapt to these changes, while also considering the needs of individuals who may face difficulties in utilizing technology.

The societal significance of this thesis is particularly evident in the ongoing challenges faced by the Dutch healthcare system in exchanging healthcare information in an effective, efficient, and secure manner. Currently, healthcare providers lack a comprehensive understanding of a patient's condition when making decisions, while vulnerable patients, such as those with dementia, are unable to provide additional information about their healthcare status and well-being.

To address these issues, the Dutch government approved a law called the "Wetsvoorstel Elektronische gegevensuitwisseling in de zorg" (Wegiz) on September 29th, 2022. The Wegiz law is part of a program aimed at digitizing healthcare(Nouwt, 2022). The wegiz mandates the electronic sharing of healthcare information directly between computers (Veereschild, 2022). By ensuring that the appropriate healthcare data is available when needed, the Wegiz law is necessary due to the existing problems with healthcare information exchange and the absence of an effective electronic solution. Additionally, healthcare providers are concerned about their administrative workload, making it crucial to propose a solution to this societal problem without further burdening them. The wegiz serves the purpose to reduce the administrative burden on healthcare specialists and minimize avoidable mistakes resulting from a lack of information. Furthermore, there is a societal concern regarding the sharing of personal healthcare information while complying with regulatory frameworks. This thesis aims to propose and validate a more effective, efficient, and secure framework for exchanging health information that addresses these societal problems.

1.9 Location

This thesis has been conducted for the masters program ICT in Business at Leiden University. The focus of this thesis is on the patients with chronic brain diseases in the Dutch healthcare sector. Specifically, the research aims to investigate the healthcare information exchange for caretakers, and healthcare providers of patients with dementia and acquired brain injury due to the fact that this vulnerable group is usually not able to fill in the gaps in the health information systems. The research methodology employed in this study is the case study research method, which involves gathering insights from stakeholders in the Dutch chronic brain disease care sector. Ultimately, a healthcare data exchange framework is proposed based on the findings. To validate the effectiveness of this framework, a proof of concept is conducted. This research was conducted from March 2023 until January 2024.

1.10 Research embedding

This research is associated with various other research endeavors and research groups. Firstly, it is linked to the PhD research of Ria Landa, who is investigating the SOCAV method's potential to enhance personalized care for patients with dementia, with a joint chapter discussing the impact of improved healthcare information availability on reducing administrative burdens.

Additionally, this research aligns with the work of my second supervisor, Dr. Dympna O'Sullivan at the Technical University of Dublin, focusing on innovative practices in dementia and elderly care.

Furthermore, this research is connected to the GAIC network, examining societal change and healthcare accessibility globally in light of demographic and technological shifts.

Lastly, this research has received support from the Leiden Institute of Advanced Computer Science (LIACS) and Leiden University Medical Centre (LUMC) course Data Science In Practice, where students Michael de Rooij, Michael de Koning, Nathalia Morales Rojas, Rick Schreuder, Tessa de Jong, and Wessel van Putten contributed to the Data Interoperability Architecture for Elderly Dementia Care in the Netherlands project, providing insights and techniques relevant to this research.

1.11 Research approach

In our research approach, we must consider the various paradigms that exist. A paradigm refers to the different ways in which we can think about and study the world. To put it more concretely, it encompasses how we acquire knowledge and how we utilize that knowledge. Paradigms are shared ideas within a specific field or community. They can be seen as the thinking patterns of researchers, and they can change if the existing ones are proven to be inaccurate or unsuitable. This is why they are significant, as they allow for the emergence of new and more precise frameworks that enable us to perceive the world under investigation in a different manner. However, this can also lead to controversy, as individuals tend to cling to their traditional research methods. This resistance to change is a common trait among researchers, as it is among the general population. Eventually, the evidence becomes so compelling that a paradigm shift becomes inevitable, although multiple paradigms can coexist simultaneously. For instance, one paradigm may be more suitable for addressing a specific research question, while another paradigm may be better suited for a different research question.

In the context of this thesis, the interpretivism paradigm is the most appropriate school of thought. Interpretivism holds the fundamental belief that social scientists should recognize that the world of interest is not easily perceivable, as it is constructed differently by each individual. Therefore, there is no singular truth; it is subjectively constructed by each person. In this thesis, we are particularly interested in patients with chronic brain diseases and their caregivers and healthcare professionals, as well as their interactions. We aim to understand their thoughts and perceptions of their world. To achieve this understanding, it is crucial for us to closely observe people's actions and behaviors and interpret them using our own knowledge. Thus, immersing ourselves in the research context is essential. We strive to interpret and comprehend everything that healthcare professionals and caretakers say, do, and how they behave. Our goal is to become insiders in their world and propose a solution from that perspective. This approach will result in a framework that incorporates multiple realities. To accomplish this, we must also acknowledge our own positionality as researchers, including factors such as our background, political preferences, gender, age, and ethnicity. By understanding these factors, we can behave in the most natural and objective way possible and effectively comprehend someone else's world.

1.12 Research design

In this study, a case study research design is utilized as we seek to achieve a thorough and nuanced comprehension of the perspectives and insights within the realm of caring for patients with chronic brain diseases. We have chosen this method in order to thoroughly comprehend the opinions regarding information exchange in healthcare. Specifically, this study is retrospective as it examines the progress of health information exchange thus far. Our focus is on data interoperability in the care for patients with chronic brain diseases, which serves as a representative case study for the entire healthcare sector in the Netherlands. This subject is considered an outlier due to the unique wishes and preferences within the chronic brain disease category. We believe that studying the care for patients with chronic brain diseases will provide valuable insights into the issues identified in the Dutch care sector's health information exchange. Therefore, we will use chronic brain disease care as a lens through which we examine the object.

To ensure a comprehensive analysis, this thesis employs a multiple case study approach, examining the thoughts and perceptions of individuals from various organizations in different or identical roles. This case study also involves nested elements, as it explores the experiences of employees within healthcare organizations that employ different health information exchange methods, as well as the caretakers who interact with these organizations. Lastly, this case study can be classified as a parallel case study, as all aspects are studied simultaneously without one study influencing the next.

To validate our case study, we will propose a health information exchange architecture specifically tailored for the chronic brain disease care sector. This proposed solution will be tested through a project. While the stakeholders in the chronic brain disease care sector will be the primary beneficiaries, the entire healthcare sector in the Netherlands could also benefit from this solution. However, it is important to note that the implementation of the General Data Protection Regulation (GDPR) may vary across EU countries, potentially rendering the proposed solution infeasible for other countries. Nevertheless, certain elements of this thesis could still be advantageous for them.

1.13 Perspective

The perspective adopted in this thesis is a combination of etic and emic approaches. The research begins with an emic perspective, aiming to gain an insider's understanding of the health information exchange in the care for patients with chronic brain diseases. This involves exploring the ideas, concepts, and challenges perceived by those directly involved. It is essential to comprehend these ideas, as well as the underlying logic, emotions, and motivations. This emic perspective allows for a comprehensive understanding of the diverse and complex nature of the healthcare information exchange in Dutch chronic brain disease care, including the nuances and user experiences.

To propose an IT architecture, test hypotheses, and validate results, an etic perspective is employed. As the respondents lack an IT background, it becomes necessary to utilize available resources and literature to propose IT solutions that align with their ideas. Once this is accomplished, it becomes crucial to validate the observations made and identify both similarities and dissimilarities.

1.14 Thesis outline

This thesis consists of the following chapters. Chapter 2 will delve into the theoretical framework. Chapter 3 will outline the research methodology employed to address the various research questions posed. The findings of the research will be presented in Chapter 4. Following this, Chapter 5 will analyze and interpret the results, highlighting any limitations encountered and suggesting avenues for future research in the discussion section. Finally, Chapter 6 will present the conclusions drawn from the research findings.

1.15 Timeline

The chronological sequence of events pertaining to this thesis is depicted in Figure 1.

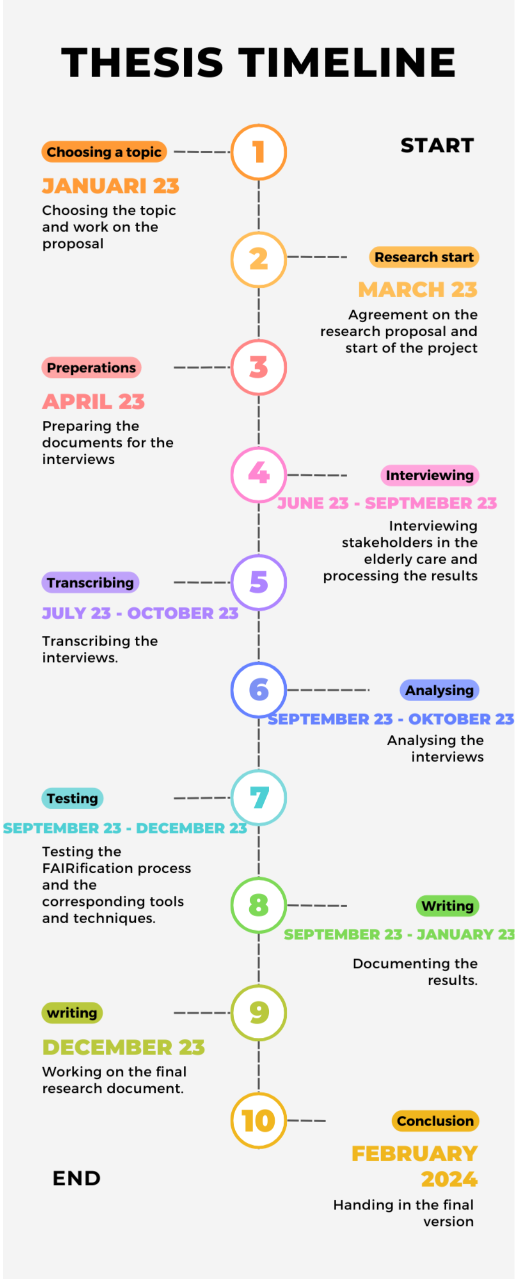


Figure 1: The timeline of this thesis.

2 Theoretical framework

Before delving into the discussion of results, it is imperative to lay the groundwork by addressing certain theoretical concepts pertinent to our analysis. This chapter serves to elucidate additional ideas essential for comprehending the potential of FAIR data and considerations crucial for implementing such a system. Additionally, we will delve into the exploration of distributed ledger technology, which will play a pivotal role in examining authentication and verification solutions within the context of this thesis. Through this exploration, we aim to provide a comprehensive understanding of the theoretical underpinnings that inform our subsequent discussions and analyses.

2.1 FAIR concepts and models

In this section we will describe some of the methods and techniques we have used to answer the research question and propose a healthcare information exchange architecture based on the FAIR principles.

2.1.1 The hourglass model

The hourglass model is a suitable framework for describing how different heterogeneous systems can make their data FAIR. This model incorporates the Fair guidelines discussed in the previous section. The fundamental idea behind this model is that multiple data collection systems can be utilized while still ensuring the ability to process, reuse, and share data (Stocker, Stokmans, & van Reisen, 2022). Upon closer examination, the hourglass model consists of three parts: the top, center, and bottom. In the top and bottom sections, there is freedom to operate. At the top, raw data can be collected using preferred tools, while at the bottom, the data can be analyzed using preferred tools. Through the FAIRification process, data is transformed to comply with the FAIR guidelines, minimizing the need for excessive protocols. This process is essential for making data FAIR. The bottom half of the hourglass represents FAIR orchestration, which involves taking action with the FAIR data, such as making it accessible through specific technologies. The hourglass model is depicted in Figure 2 below.

2.1.2 Data sovereignty

To keep a single point of truth, adhere to the regulatory framework and maintain the rights of the data owner, data controllers and processors it is crucial to maintain data sovereignty. We achieve data sovereignty when data is stored and stays at the place where it is produced, complete data ownership is guaranteed, data follows the local regulatory guidelines (Plug et al., 2022).

2.1.3 FAIR Data Point (FDP)

Whenever an entity or data repository conforms to the FAIR Guidelines and principles and adheres to the local regulatory framework, it can be referred to as a FAIR Data Point (FDP) (van Reisen et al., 2021). The adherence to the FAIR guidelines enables different FAIR Data Points to collaborate through the Internet of FAIR Data and Services (IFDS) (van Reisen et al., 2021). In order to facilitate communication between various FAIR Data Points, concepts such as the Personal Health train and Data visiting are implemented.

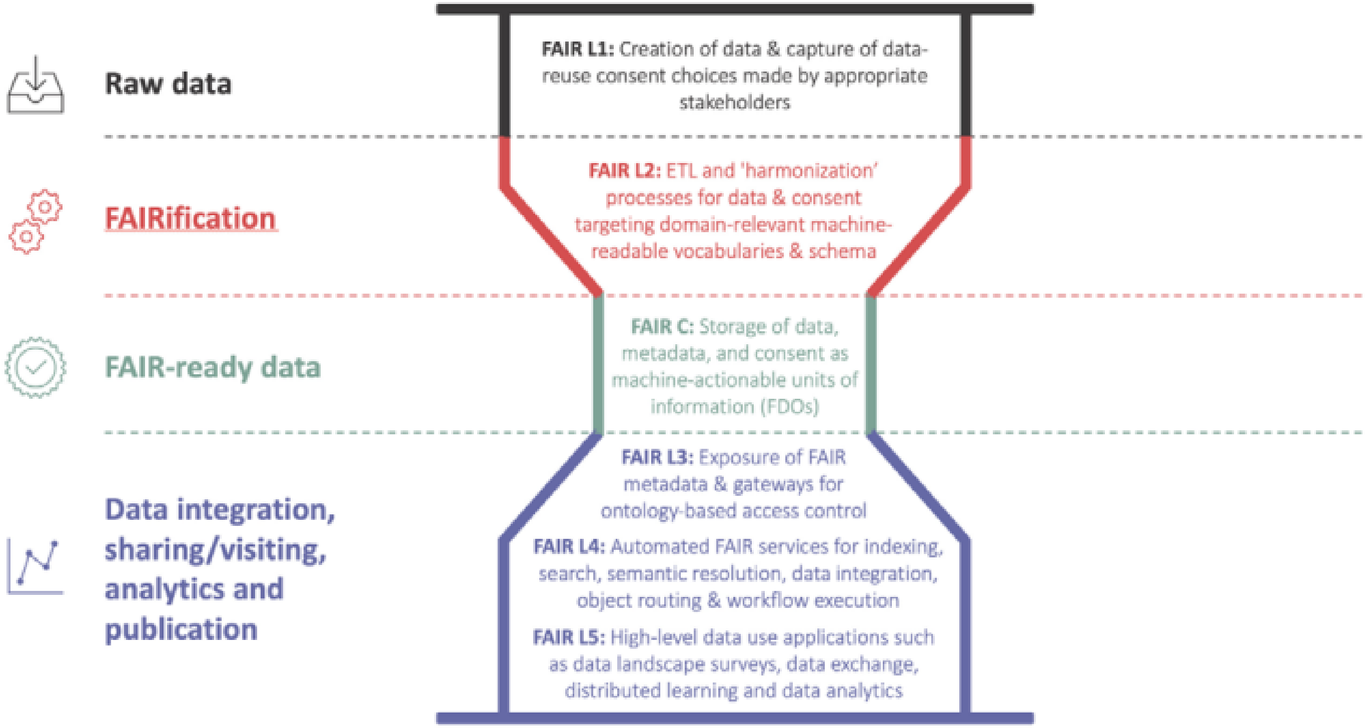


Figure 2: The hourglass model that describes the process of implementing and using FAIR data in your organization (Cardoso Silva Ferreira & van Reisen, 2023).

2.1.4 Federated analyses

Whenever we implement FAIR Data Points within the Internet of FAIR Data and Services (IFDS), it becomes feasible to exchange information among individuals while adhering to clearly defined access conditions. This can be achieved by adopting the concept of federated analysis. Federated analysis employs customized algorithms and generates outcomes that are either comparable or identical to those obtained through centralized analysis (Rootes-Murdy et al., 2021). By enabling individual-level analysis without the need to share samples or complete individual datasets, federated analysis facilitates compliance with the regulatory framework (Patel et al., 2019). Federated analysis can be done by using the Personal health train.

2.1.5 The personal health train (PHT)

The personal health train is closely associated with the FAIR guidelines that we have previously discussed. According to Ippel and van Soest (2019), the personal health train enables the sending of queries to various FAIR data points (FDPs) and receiving the results without the need to load the datasets onto your computer. This is achieved through the Internet of FAIR Data and Services (IFDS) by utilizing the concept of data visiting (van Reisen et al., 2021). Data visiting allows for the retrieval of aggregate analysis or statistics from an FDP (Plug et al., 2022). This initiative facilitates the transfer of analyses to the data rather than transferring the data to the analyses. The processing occurs entirely at the other FDP, with no exposure of underlying data. Additionally, the personal health train allows for easy addition of data to the original and up-to-date dataset since there is only one dataset. In the personal health train, there are "spoorwegen" (railways) that provide access to these stations, but only if authorized to travel there. The station, which serves as the data owner, is responsible for sending only the permitted data to the researcher. The train possesses a Digital Persistent Identifier (PID) that enables its identification (Beyan et al., 2020). It also contains all the necessary information to transfer code and the results of queries in an independent message. One of the advantages of this method is that even after the analyses, the data owner retains the ability to revoke the researcher's rights (Ippel & van Soest, 2019). Furthermore, the personal health train ensures the maintenance of data sovereignty.

The PHT was conceptualized due to a need for a way to maximize the interoperability of heterogeneous systems Beyan et al. (2020). The PHT gives data owners the power over the data. On the other side, there are also some problems to solve here. According to Beyan et al. (2020), the PHT is not always feasible. Especially for data that is deemed as sensitive and when data is not collected for research purposes. Patient data is in the first place not collected for research purposes which could make the implementation of the PHT more difficult for that use case.

2.1.6 Federated learning and AI

Federated learning, also referred to as decentralized learning, is a type of federated analysis that employs machine learning algorithms on federated data sets. In federated learning, models are trained on data without requiring data owners or subjects to share their data at any stage of the model training process (Rootes-Murdy et al., 2021). Subsequently, the outcomes of the machine learning algorithm can be applied to real-life problems and use cases. It is of utmost importance to align and develop the FAIR guidelines, principles, tools, and methods with the principles of federated learning in our consciousness (Mons, 2020).

This technique can also be used to train Artificial Intelligence (AI) models. This is why the potential to train on FAIRified federated sources has already interested the AI communities worldwide (van Reisen et al., 2021).

2.2 Distributed ledger technology for authorization and verification

The landscape of the web is undergoing a fundamental shift, transitioning from a platform primarily focused on publishing documents to one centered around the sharing of structured data (Acosta et al., 2019). A pivotal driver of this evolution is the widespread adoption of Linked Data principles by an increasing number of data providers. Concurrently, there has been a rise in the prominence of Distributed Ledger Technologies (DLTs) to support this trend.

DLTs, including blockchain technology, represent decentralized systems designed to facilitate secure and transparent storage and management of data (Mou et al., 2023). Transactions within these systems are recorded in blocks, each linked to the preceding block through cryptographic hash values. Once a block is created, its contents cannot be altered, ensuring data immutability. Through the utilization of cryptographic techniques and consensus algorithms, DLTs offer features such as data traceability and resistance to tampering (Zheng, Xie, Dai, Chen, & Wang, 2018).

Within the healthcare industry, DLTs hold significant promise for revolutionizing data interoperability by bolstering trust, security, and efficiency in data exchange and collaboration. The security and efficiency afforded by distributed ledgers present an opportunity to address the trust deficit inherent in data sharing, thereby supporting the validation and re-decentralization of the web, particularly within the context of Linked Data.

However, it's worth noting that while DLTs offer robust security mechanisms, they also encounter challenges. In this regard, leveraging the strengths of Linked Data and web technologies, such as interoperability, indexing, and querying, can help address some of the hurdles faced by DLTs, fostering a symbiotic relationship between the two domains (Acosta et al., 2019).

2.2.1 Smart contracts

DLTs offer a fundamental capability in the creation and execution of smart contracts (Mou et al., 2023). These contracts represent self-executing programs that encapsulate the terms of an agreement between involved parties. Once deployed on the blockchain, smart contracts possess the ability to autonomously enforce predetermined rules and conditions. They serve as a mechanism to facilitate, verify, and ensure compliance with the terms of a contract without requiring intermediaries.

The results or outcomes of smart contracts are securely stored within transactions on the blockchain. Similar to other transactions recorded on the blockchain, these smart contract transactions are immutable and traceable (Mou et al., 2023).

In the realm of healthcare information exchange systems, smart contracts emerge as a powerful tool for automating and enforcing various aspects such as data-sharing agreements and access control mechanisms. By leveraging smart contracts, these systems can significantly enhance their security, transparency, and overall efficiency.

2.2.2 Self-Sovereign Identity (SSI)

Ensuring a secure and dependable identity framework is paramount for accurately identifying users and delivering services effectively. Conventional centralized identity systems exhibit numerous security vulnerabilities and lack mechanisms for granting users control over their identities (Shuaib, Alam, Alam, & Nasir, 2021).

The concept of self-sovereign identity (SSI) has emerged as a solution to address these shortcomings by empowering users with control over their identity information in a secure manner (Shuaib et al., 2021). In any healthcare information system, safeguarding the privacy and security of user records is of utmost importance. The healthcare sector, in particular, faces significant challenges concerning patient information privacy and security. Self-sovereign identity solutions present a promising avenue for mitigating these threats and enhancing the overall security and confidentiality of healthcare data.

Self-sovereign identities afford individuals greater autonomy over their digital presence; however, this autonomy necessitates a heightened level of responsibility for establishing and upholding both privacy and trustworthiness. Unlike traditional identity systems where credentials are issued by third parties, in self-sovereign identity systems, individuals are accountable for ensuring the accuracy and reliability of their digital identities.

To establish trustworthiness, individuals must procure evidence from third parties to verify the information contained within their digital identities (Der, Jähnichen, & Sürmeli, 2017). Subsequently, individuals are required to furnish this evidence when necessary. For instance, the correctness of an address listed in a digital identity could be confirmed by referencing official records from a registration office. This decentralized approach empowers individuals to actively manage and validate their own digital identities, fostering a more resilient and trustworthy identity ecosystem.

Verifiable Credentials (VCs)

In the contemporary digital landscape, physical credentials such as passports, social security cards, and employee badges are universally recognized and owned. These credentials serve to authenticate individuals' identities, particularly in contexts like airport security checks before international travel. However, as society increasingly relies on digital platforms and tools for various activities, the need has arisen for digital counterparts to these physical credentials. Verifiable credentials are part of of the SSI and can be described as: digital credentials stored in digital wallets that can be used for identification, authentication, and authorization (Sedlmeir, Smethurst, Rieger, & Fridgen, 2021).

Verifiable credentials represent a significant advancement in identity management, offering a convenient, secure, and privacy-oriented alternative to traditional physical and digital credentialing systems (Sedlmeir et al., 2021). Unlike their physical counterparts, verifiable credentials can be easily stored and retrieved online, aligning with the shift towards digitalization in modern society. Moreover, they can seamlessly integrate with distributed ledger technologies (DLTs), enhancing their security and trustworthiness.

By leveraging verifiable credentials and digital wallets, individuals can navigate digital verification processes with ease and confidence. These digital solutions not only streamline identity management but also contribute to a more efficient and secure digital ecosystem.

How does this work?
Figure 3, coming from the Dutch Blockchain Coalition (van den Wall Bake, n.d.), illustrates the fundamental process of transferring verifiable credentials from an issuer to a verifier, also known as a Relying Party. Unlike traditional digital data transfer methods, where the verifier directly retrieves data from the issuer, in this scenario, the subject of the data, referred to as the Holder, verifies the data transfer.

The Holder initiates the process by requesting specific data from the Issuer, such as a driver's license, diploma, or doctor's prescription. The Issuer then cryptographically signs and seals the data before transmitting it to the Holder, who securely stores it in their digital wallet. Additionally, the Issuer may record a validity statement in a Verifiable Data Registry to confirm the authenticity of the data without disclosing its details. If needed, the Issuer can revoke the validity statement, such as in the case of revoking a driver's license after a traffic violation.

When the Holder engages in a transaction with another party, acting as the Verifier, such as renting a car, the Verifier requests the necessary data from the Holder, who presents it along with cryptographic proof of its accuracy. The Verifier can then verify the data's validity by checking the Verifiable Data Registry to ensure it has not been revoked.

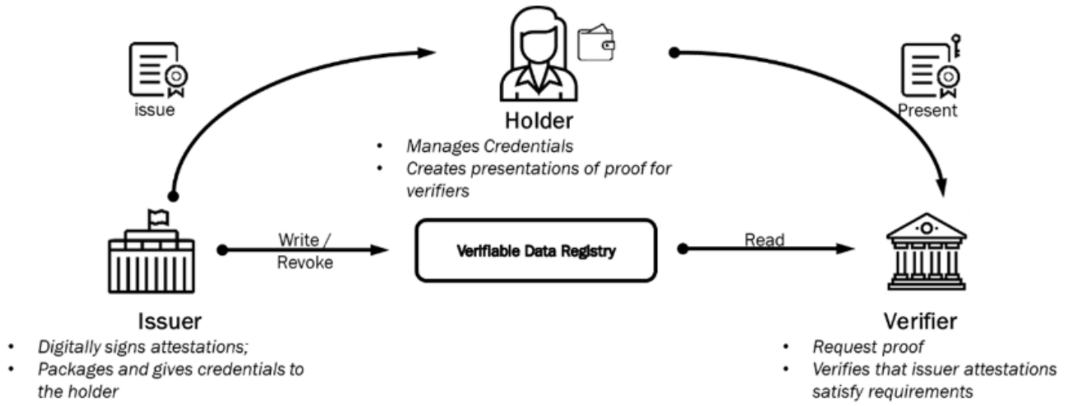


Figure 3: The figure shows a simplified diagram illustrating the distribution of verifiable credentials through the framework of Self-Sovereign Identity (SSI) (van den Wall Bake, n.d.).

3 Research methodology

The research question emanates from a desire to comprehend the preferences and needs of patients and stakeholders, particularly those associated with individuals with conditions such as dementia, and leverage this understanding to propose an IT infrastructure to support them. To address this research question via qualitative research, a case study approach was adopted. The methodology section is structured into seven parts. Initially, we elucidate how the interview process yielded data, delineating the tools and documents employed in this process. Subsequently, the following 3 sections expound on the methods utilized to gather the requisite data to address each specific research question.

3.1 Gathering data from the interviews

To propose a solution to the research question, we conducted 16 semi-structured interviews comprising open-ended questions, involving a total of 17 respondents. This cohort consisted of 9 healthcare specialists specializing in the care of patients with chronic brain diseases, and 8 caretakers of patients with the same backgrounds. Collaboration was established with two healthcare organizations for this research endeavor. Two healthcare organizations, Zinzia Care Group and WoonZorgcentra Haaglanden (WZH), collaborated with the researcher, facilitated by the University Knowledge Network Elderly Care Nijmegen (UKON) and the University Network for the Care Sector in Zuid-Holland (UNC-ZH), respectively. These partnerships aided in the identification of interviewees for the study. Interviewees were selected either by the collaborating healthcare organizations in consultation with the researcher, through endorsement by a healthcare specialist supporting the research, or via outreach methods such as flyers at healthcare facilities and LinkedIn posts.

The selection criteria prioritized individuals involved in the care of patients with chronic brain diseases like dementia, acquired brain injury, including those providing continuous care as well as those offering intermittent support. We aimed to engage with individuals from various facets of the care process, spanning from daily caregivers to those involved during sudden healthcare needs.

Interviews were conducted in environments chosen by the respondents, predominantly at their workplaces or homes, ensuring comfort and convenience. Anonymity was preserved throughout, as confirmed by the consent forms signed by participants before the interviews. Additionally, an information form accompanied the consent form, providing participants with details about the interview process and discussion topics. This facilitated informed participation and encouraged respondents to prepare by discussing the topic with colleagues, ensuring well-informed responses.

The researcher employed a topic list during interviews to cover all research questions systematically. While adhering to the listed topics, flexibility was maintained to explore additional relevant areas or address emerging information needs during the interviews.

After discussions between the researcher and the collaborating healthcare organizations, the information letter and consent form were adjusted to incorporate additional agreed-upon sections. Prior to the interviews, the interview process and the rights of the interviewees were thoroughly discussed at a prearranged time and location with each participant. Subsequently, interviews were recorded using a mobile phone and a laptop to ensure accurate documentation and sufficient audio quality.

Following the conclusion of the interviews, the transcription process commenced. Manual transcription, assisted by a transcription pedal, was employed to maintain quality assurance. A document folder containing incomplete transcription files and a separate folder containing audio files were organized. All files and filenames were anonymized and encrypted, accessible only through a secure file on the researcher's computer. These raw transcription files and audio recordings were utilized for transcription purposes.

Upon completion of transcription, a comprehensive review of the gathered data was undertaken to identify overarching concepts and understand the broader themes discussed in the interviews. Subsequently, the coding and labeling software, MAXQDA, was utilized for the coding and labeling process. Initially, open coding was conducted, involving the identification and highlighting of significant portions within the data, facilitated by the electronic capabilities of MAXQDA. Following open coding, the axial coding stage commenced, wherein connections between the identified open codes were established, allowing for the categorization of groups of codes into labels. Subsequently, selective coding was employed to select the main labels and their corresponding codes necessary to address the research question and sub-questions effectively. This process yielded 42 labels and 587 codes. These codes and labels were translated to English in order for them to be used for this research.

Throughout the coding and labeling process, the use of memos facilitated the identification of recurrent themes and categories across the 16 interviews. With the identification of these themes and topics, efforts were directed towards understanding their connections and determining how the data should be represented in the findings.

3.2 The specific health information requirements and needs of stakeholders involved in the care of individuals suffering from chronic brain diseases

In this section, we delved into the research methods employed to uncover the particular health information requirements and needs of stakeholders engaged in caring for individuals afflicted with chronic brain diseases.

3.2.1 The missing healthcare information according to the interviewees

The data required to address this sub-question was extracted from the interviews conducted with healthcare specialists and caretakers. Participants were specifically asked about the types of healthcare information they perceive as missing when providing care to patients with chronic brain diseases. Responses to this inquiry, along with relevant segments from the interviews, were categorized under the label "missing information" during the coding and labeling process.

Subsequently, these identified instances of missing data were synthesized and visualized to enhance comprehension and provide a comprehensive overview of the existing gaps in healthcare information. This synthesis process involved summarizing the collected data points and presenting them in a structured format, allowing for a clearer understanding of the prevalent information deficiencies encountered by healthcare providers and caretakers in the context of caring for patients with complex medical conditions.

3.2.2 How healthcare information is currently shared and the impediments with regards to the availability of such information

During the interviews, the methodologies employed in sharing healthcare information were thoroughly explored and categorized under the label "Current ways of information exchange." This categorization encompassed an assessment of the existing practices, applications, and methods utilized for information exchange among healthcare providers within the same organization, as well as between different organizations, patients, and caretakers.

Having examined the current landscape of healthcare information exchange, attention was then directed towards identifying the impediments hindering the availability of such information. Through extensive discussions with interviewees, factors contributing to the absence or limited access to healthcare information were scrutinized. These impediments were systematically categorized during the coding and labeling process to facilitate a comprehensive understanding of the challenges encountered in information exchange within the healthcare domain. The labels utilized to explore these impediments include:

- Complications in healthcare
- The administrative burden
- Waiting for information
- The difference in quality between healthcare providers and institutions
- Problems with reporting systems
- A lack of information exchange
- Interpretation of medical files
- Time shortages
- Errors in medical files
- Findability of healthcare information

These different reasons for the unavailability of this healthcare information can therefore be outlined to answer this sub question.

3.2.3 The specific healthcare information that is most important for the healthcare providers to know about a patient with chronic brain diseases

In order to comprehensively understand the requisite healthcare information, it was imperative for this study to evaluate the essential data sought by healthcare stakeholders and caretakers in caring for patients afflicted with conditions such as dementia and acquired brain injury. This inquiry aimed to discern the primary healthcare data solicited by these professionals and caretakers, thereby facilitating an appreciation of the most frequently sought-after information. Such insights serve to augment the existing body of healthcare information, thereby addressing potential gaps therein.

This provided us with additional insights into the factors that healthcare providers and caregivers consider significant, shedding light on information that they may not have recognized as absent, but rather, may have been inaccessible due to insufficient data sharing. The discussion surrounding missing data can be daunting for participants, yet delving into this area enabled us to gain a more comprehensive understanding of the healthcare information necessary for effectively managing patients with the specified conditions.

These findings emerged during the transcription process of the interviews, wherein diligent efforts were made to identify and categorize the salient information articulated by participants. Subsequently, an Excel spreadsheet was systematically updated with each newly identified data point, facilitating the compilation of a comprehensive inventory detailing the critical healthcare information deemed vital by stakeholders.

3.3 Identifying and conceptualizing the pertinent tools and resources available for facilitating FAIR data production

In this section, we explored the research methods utilized to identify and conceptualize the relevant tools and resources available for facilitating FAIR data production.

3.3.1 The possibilities of data production on sensitive patient and personal data in a FAIR-data architecture

In order to explore the potential for generating FAIR data on sensitive subjects, an exploratory study was conducted to identify the necessary tools and concepts for exchanging such information. The objective is to evaluate the availability of tools supporting a FAIR-data architecture and to determine which tools and methods are most suitable for this specific scenario. To aid in this endeavor, three extra unstructured interviews were conducted to ascertain the specific tools that could be utilized to facilitate this purpose. These interviews were conducted without recording and served solely to obtain insights into the requirements for information sharing within a FAIR-data architecture, aligning with the FAIR data principles, and enhancing the exchange of healthcare information for patients afflicted with dementia, acquired brain injury, or multimorbidity.

3.3.2 How should a healthcare information exchange architecture, based on the FAIR guidelines and principles, be constructed to allow healthcare stakeholders in the care for patients with chronic brain diseases to exchange healthcare information while preserving the privacy?

Having identified various tools and methods for FAIRifying and sharing sensitive personal healthcare information of patients with chonic brain diseases, we proceed to select those that align most closely with our specific requirements and objectives. These selected tools and methods will form the foundation for constructing an IT architecture capable of facilitating effective healthcare information exchange. To address this aspect, the chosen IT architecture will be thoroughly elucidated and visually represented to provide a comprehensive response to this sub-question.

3.4 Testing and implementing the proof of concept for FAIR data production

In this section, we examined the research methods employed to test and implement the proof of concept for FAIR data production.

3.4.1 The assessment of the feasibility of this technical architecture

The feasibility of this architecture was assessed through a dedicated project aimed at testing the identified tools and methods for exchanging sensitive personal information. This project spanned approximately 2 months and involved a project group comprising the researcher and six master's students enrolled in the Data Science In Practice course. Their collective task was to evaluate the proposed FAIR healthcare information exchange tools. Prior to commencement, all members of the project group signed confidentiality agreements, ensuring the protection of interviewees' information, with no access granted to any personal or identifiable data. Throughout the project, the healthcare information deemed missing or of utmost importance by the interviewees was utilized to assess the efficacy of the tools and demonstrate the feasibility of healthcare information exchange with sensitive patient data. Additionally, this endeavor aimed to illustrate to the interviewees the potential benefits of employing FAIR data principles and how this specific architecture could facilitate seamless exchange and reception of healthcare information.

The IT architecture for healthcare information exchange undergoes further testing by elucidating its functionality to the interviewees and soliciting their feedback. The responses obtained from this interaction will be documented in this chapter, providing valuable insights into the potential utility of such an architecture in keeping the interviewees informed about patients' healthcare information as and when required.

4 Research findings

In this thesis, we endeavor to investigate more efficient time and resource utilization within the Dutch care system for patients with chronic brain diseases, concurrently enhancing the interoperability of healthcare information across diverse providers. The primary objective of this research is to propose viable solutions to the intricate challenge at hand, meticulously considering the preserving of the privacy of this sensitive personal and healthcare information.

To address this intricate issue effectively, it is imperative to identify the missing information in current healthcare information exchange amongst providers specializing in care for patients with chronic brain diseases. Subsequently, a comprehensive understanding of the obstacles impeding the availability of this crucial information for healthcare practitioners is essential. Our focus then shifts to mitigating the unavailability of data by exploring avenues for the production of sensitive patient and personal data within a FAIR (Findable, Accessible, Interoperable, Reusable) data architecture. The exploration of these possibilities is followed by the implementation of innovative tools and information technology techniques to actualize the aforementioned FAIR principles, ensuring that healthcare information of paramount importance to stakeholders is easily accessible. Finally, the technical architecture proposed will be subjected to feasibility tests.

The culmination of these efforts aims to provide answers to the overarching research question: How can the implementation of FAIR semantic data principles in the care of patients with chronic brain diseases contribute to establishing an infrastructure that that preserves the privacy and facilitates accessibility and interoperability?

In pursuit of answering this research question, we engaged in discussions with 17 stakeholders in the field of chronic brain disease care. These stakeholders are for example the hospitals and their employees, home care institutes and their employees, care homes and their employees and the patients and caretakers. The subsequent transcription of these interviews was meticulously executed, and the resultant transcripts underwent systematic coding and labeling. This chapter is structured to meticulously explore and present the findings derived from these interviews, aligning with and addressing the research questions.

4.1 The specific health information requirements and needs of stakeholders involved in the care of individuals suffering from chronic brain diseases

In this section, we investigate the specific health information requirements and needs of stakeholders involved in caring for individuals affected by chronic brain diseases. By addressing three key questions, we aim to gain a comprehensive understanding of the situation.

4.1.1 What information is currently missing among healthcare providers in the care for patients with chronic brain diseases?

4.1.1.1 Is healthcare information actually missing?

To ascertain the types of healthcare information that are occasionally or consistently absent, it is imperative to initially determine the current existence of missing data. In the context of healthcare information sharing, multiple stakeholders play crucial roles. An examination reveals that the exchange of health information among these stakeholders presently falls short of meeting the expectations expressed by the interviewees. A participant in the interviews articulated the issue as follows:

> *(#12, caretaker, online, with LS) Well, that disappoints us. Some time ago, she had to be admitted to the hospital again because something was wrong. I found it quite remarkable that information known to the general practitioner was not known in the hospital and also not by the physiotherapist, and vice versa. When she was discharged from the hospital, it took a very long time for the general practitioner to have any good news. That, I find particularly surprising. I think, guys, it's good that you give permission and that you're all critical about it. But if you've given permission, my expectation would be that the information is shared more easily so that the other, well, institution is aware of it and can take it into account when providing care. That disappointed us.*

This interviewee expresses disappointment in observing that, despite the provision of consent to share information, there is a notable delay, non-sharing, or unread status of the shared information. The interviewee underscores the criticality of efficiently sharing healthcare information from various facilities and stakeholders for everyday care practices. This sentiment is echoed by another interviewee affiliated with a care home, who characterizes the current scenario as follows:

> *(#2, Elderly care physician, face to face, with LS) Well, what I miss is also the, because you have the information flow from admission, right, so from home to here [the care home] and from the hospital to here [the care home]. But besides that, as long as someone is here [the care home], they, of course, have hospital contacts or follow-up appointments and that information may go wrong more often than when someone comes here for the first time. So, suppose someone has a follow-up appointment with a medical specialist or is referred to a medical specialist, the feedback from the hospital to us is not working well. For that, we have to actively inquire about information through the clinic: What was discussed? What has been done? What is the current plan? We may encounter more challenges with this than with information from admission.*

This underscores the challenge faced by care homes in acquiring healthcare information about their patients from other healthcare facilities. The interviewee emphasizes the necessity of this data to comprehend past discussions, actions taken, and the planned course of action for the future. In a separate interview with a caregiver of a dementia patient, the interviewee underscores the importance of the caregiver's presence during healthcare appointments:

> *(#9, Caretaker, face to face, with LS) No, we used to go as well because my mother went for regular check-ups at the hospital. Towards the end, my mother began to have the cognitive trouble, and my father would accompany her, but he wasn't very clear-headed either. So, one of the daughters would always go along to provide feedback on what had been agreed upon during that conversation. Otherwise, the doctor in the nursing home wouldn't get a clear picture, and neither would the caregiver.*

This highlights a deficiency in the exchange of information among healthcare facilities and the subsequent consequences for individuals with dementia and their caregivers. The challenges associated with information sharing are consistently recognized by a significant number of interviewees, underscoring the pressing need for an improved mechanism to share healthcare information. Such an enhancement is crucial not only to provide adequate support for vulnerable groups, such as patients with dementia, but also to streamline the workflow for healthcare practitioners.

4.1.1.2 What specific healthcare information is missing?

In the interviews, stakeholders were queried about the healthcare information they found lacking in relation to their patients with chronic brain diseases. The absent healthcare information identified by the interviewed stakeholders can be classified into two distinct categories. Firstly, there is a notable absence of medical data, and secondly, there is a recognized need for additional welfare-related data pertaining to their patients, who suffer from chronic brain diseases. The specific healthcare information that is reported to be lacking is detailed below.

Medical data

The interviewees unequivocally conveyed that there is presently a frequent unavailability of crucial medical data, ranging from occasional to frequent or constant lapses. They precisely identified the types of data that are commonly inaccessible. These healthcare information categories for patients with chronic brain diseases, particularly those with conditions like dementia, can be further classified into overarching subcategories.

Historical healthcare information

The interviewees articulated that, at times, medical data concerning their patients remains elusive. One aspect highlighted as missing is historical medical data. The interviewee explicates this deficiency in knowledge about a person's past medical history in the following excerpt from the interview:

> *(#2, Elderly care physician, face to face, with LS) But that is mainly the referral letter and not the older letters, so, for example, if they have been admitted to another hospital before, we don't receive those records. We only get the referral letter, for example, from the general practitioner saying the patient needs to be seen by you, and not the other 10 letters. We usually have to request those ourselves.*

The interviewee communicated that they do not routinely receive the medical records detailing a patient's past, necessitating explicit requests for access to incorporate the information into their care plans. This imperative to acquire comprehensive knowledge of the medical history of their patients is reaffirmed by the interviewee, who notes that, albeit occasionally provided in the form of a letter to the patient, the information is not consistently accessible. Furthermore, the interviewee expounds on the considerable effort required to obtain the medical history of their patients:

> *(#2, Elderly care physician, face to face, with LS) No, I think that would really make a significant difference because, currently, in the ideal world, someone who is admitted has all the papers from the hospital with them. However, it still happens that they don't have them with them, and we have to ask for them. Then, a medical secretary spends about three-quarters of an hour a day making those follow-up calls. This also applies to information from the general practitioner; we have to make a lot of follow-up calls. Even though we ask the general practitioner to send a kind of episode list, summarizing the medical history, there are still additional questions sometimes, as I mentioned earlier about the medication—what is it actually for? So, I spend about an hour each week making these follow-up calls for such information.*

The interviewee advocated for the ideal scenario where patients possess their complete healthcare information in the form of one or multiple letters. This approach, according to the interviewee, would enhance the accessibility of healthcare information for patients with chronic brain diseases, saving them the effort of contacting various healthcare providers for additional details. The interviewee provides a specific example where more information on the reasons behind a patient taking a particular medication would have been beneficial.

Current medication overview
Another category of healthcare information that stakeholders, who are caring for patients with chronic brain diseases, currently find lacking is a current medication overview. One of the interviewees articulates this issue as follows:

> *(#3, Elderly care nurse, online, with LS) Well, what I sometimes miss and I missed it for example last week, during my admission, I really missed a current medication overview. It wasn't included. I did receive packets of tablets and a sort of history of what the person was taking before the admission, but in the conversation, I heard, 'Yes, since my admission, I suddenly had very high blood pressure. I got new tablets for that.' I couldn't find that information in the handover. Sometimes it is, sometimes it isn't, it seems like it depends on who the current treatment provider is, and one may have more experience with it than the other.*

In this context, it is explained that the current medication overview is occasionally not entirely up-to-date or accessible. The example provided by this interviewee illustrates a situation where a patient had to supplement the information gap by indicating the presence of additional medications not listed. If the patient were unable to fill in this information gap, the situation could have had more severe consequences. The interviewee goes on to highlight that the accuracy of shared healthcare information is contingent upon who the other healthcare provider is and their level of experience.

Results of any additional examination
The interviewees expressed a desire for more comprehensive results from additional examinations conducted on the patients they are currently treating. The following excerpt from the interview elaborates on this aspect:

> *(#2, Elderly care physician, face to face, with LS) Sometimes the results of additional examinations are not entirely comprehensive in a letter; they can be somewhat concise. In those cases, we occasionally inquire for more information, such as additional details about a brain scan or information from the emergency department. If there has been any physical examination, for instance, if there were any abnormalities detected in the heart, we may request that additional information through the medical secretariat.*

Once more, the interviewee underscores that healthcare information arrives in the form of a letter. However, in this instance, the letter is deemed overly concise, prompting the healthcare provider to request additional information. The interviewee cites an example where the additional examination involves a brain scan, highlighting that the absence of comprehensive data from examinations is not exclusive to this particular type of assessment, as evidenced in other interviews.

The medical situation when a patient was living at home
For certain interviewees, a notable gap in information pertains to data from the period before the individuals were residing in a care home. The interviewee emphasizes this issue in the following segment of the interview:

> *(#2, Elderly care physician, face to face, with LS) So, we are always very curious about how things were actually at home. Often, people can tell us something about it themselves, or their family members who were present. But I think it would also help if we already knew from home care what kind of care was provided and how it was going. Was there already a cause for concern?*

The interviewee elucidates that there is a collective curiosity among healthcare providers he/she knows regarding the conditions preceding the arrival of patients at care homes. While acknowledging that the information gap can be filled by the patient or their family, the interviewee deems this solution suboptimal. Expressing a preference for a more comprehensive approach, they express a desire to acquire insights from home care providers regarding observations made while caring for the patient. However, it is not explicitly mentioned whether obtaining such information is currently feasible.

healthcare information that supports a patients well-being

Beyond medical data, care stakeholders, who are working with patients that suffer from chronic brain diseases, identified another category of information perceived as lacking in the interviews—healthcare information that supports a patient's well-being. The subsequent discussion will delve into the distinct types of well-being healthcare information currently absent when administering care to patients with chronic brain diseases, such as those with dementia.

Personal information and hobby's

During the interviews, the absence of personal information and hobbies emerged as significant and missing components, as underscored by numerous interviewees. A caretaker, for instance, highlighted that while it is occasionally feasible to input medical information into information systems, the same capability is not readily available for personal information and hobbies:

> *(#12, Caretaker, online, with LS) Hobbies are not something you can directly input, right? She enjoys crafting, that's good to know. I also know which magazines and things she likes because in all the apps, you have the option to indicate what's wrong, right? Which body part or, well, throw in some medical terms for the issues someone is experiencing, like high blood pressure or whatever else. You can include all of that, but not so much those personal aspects.*

This supports the finding that hobbies are not easily shared by caretakers and therefore missing in this specific information system. It also shows that medical data, like for example which body part hurts about a patient can sometimes be added to the system as a caretaker. This caretaker specifically talks about hobbies and what the patient likes to read. This finding, that softer personal information is not available, was supported by another interviewee. This interviewee talks about how it is not being exchanged by stressing the following:

> *(#9, Caretaker, face to face, with LS) No, but all those softer things, they are not transferred at all—like what kind of person your mother is or what she enjoys, and what one should avoid doing. I get the feeling that it's purely business—yes, the medical history, what medication she's on. You should be grateful if all of that is read and understood correctly.*

This interviewee talks about that the healthcare professionals working with his mother are not aware of the softer personal information due to a lack of transferring of these types of information. The finding from the other interview that is solely medical information that is being transferred is supported here. The interviewee also addresses that he thinks that transferring data is purely business and he does not feel that medical information is always read or understood correctly. Another interviewee feels like sometimes they don't miss this healthcare information at first, but later on in the care process they realize that something was missing. An interviewee described this as following:

> *(#16, Two care physicians, face to face, with LS) It happens, for example, around someone's death, when someone has passed away, you hear from the family, 'Hey, this person was really passionate about sailing,' I'm just giving an example, while you hadn't known that for the past ten years. Then you might think to yourself, 'Really, if we had known that, we could really have done something about it in the context of well-being.'*

The interviewee describes an example where they did not know the patient was in love with sailing during the ten year time the interviewee had cared for the patient. Therefore, the interviewee was fed up about the fact that they could have done something with this for the patient. To generalize the missing of this type of care information an interviewee added in the interview:

> *(#11, Dementia care physician, face to face, with LS) Well, I think that aligns a bit with what I just said. Yes, that life history is very important to me. But, as I mentioned earlier, it's often not known, so I approach someone a bit blank, and then you try to get to know them.*

This interviewee confirms the findings from the other interview about missing this personal data about someones life while also adding what this healthcare professional does to close the information gap.

Well-being information for daily activities
Another category of well-being information identified as missing by the interviewees is information about the patients' preferences in daily activities. An interviewee identified the most important types of this kind of well-being information:

> *(#10, Elderly care nurse, face to face, with LS) When someone comes out of the hospital, you don't have much of that information because the hospital doesn't specifically address daily cares, like what they eat in the morning, how they feel, and how they want to be assisted. But when someone comes from a care facility, you already somethimes have those standard details because they have used them there. However, in the conversation with the patient, we basically assume a blank page. My colleagues go into that conversation and strictly follow the questionnaire.*

This interviewee started by saying that whenever a patient comes from a hospital there is no information available about daily care. The information that is than specifically missing is what patients eat, how they are currently feeling, and how they want to be assisted. The interviewee does say that data could be available when someone comes from another healthcare facility then the hospital. This could be available due to the fact that they use these types of data in their daily care in other healthcare facilities. While well-being information could be available, this interviewee specifically says that they collect these types of data from the ground up with a new patient.

Well-being information on how to approach patients
The way you approach a patient can be of crucial importance for vulnerable patients with chronic brain diseases and can be specific to a patient. An interviewee that we spoke about this matter claimed that this information is missing when they start caring for someone:

> *(#2, Elderly care physician, face to face, with LS) Yes, I definitely think that's good, also in terms of the approach, how someone prefers to be approached by healthcare. That is also pleasant. See, now I collect that data myself upon admission.*

The way someone is approached is valued highly by this interviewee and therefore collected by the interviewee when he/she starts caring for a new patient.

A summarizing overview of what healthcare information is currently missing

In summary, a considerable amount of healthcare information remains absent in the care for patients with chronic brain diseases. Figure 4 offers a comprehensive and condensed overview of the identified missing healthcare information.

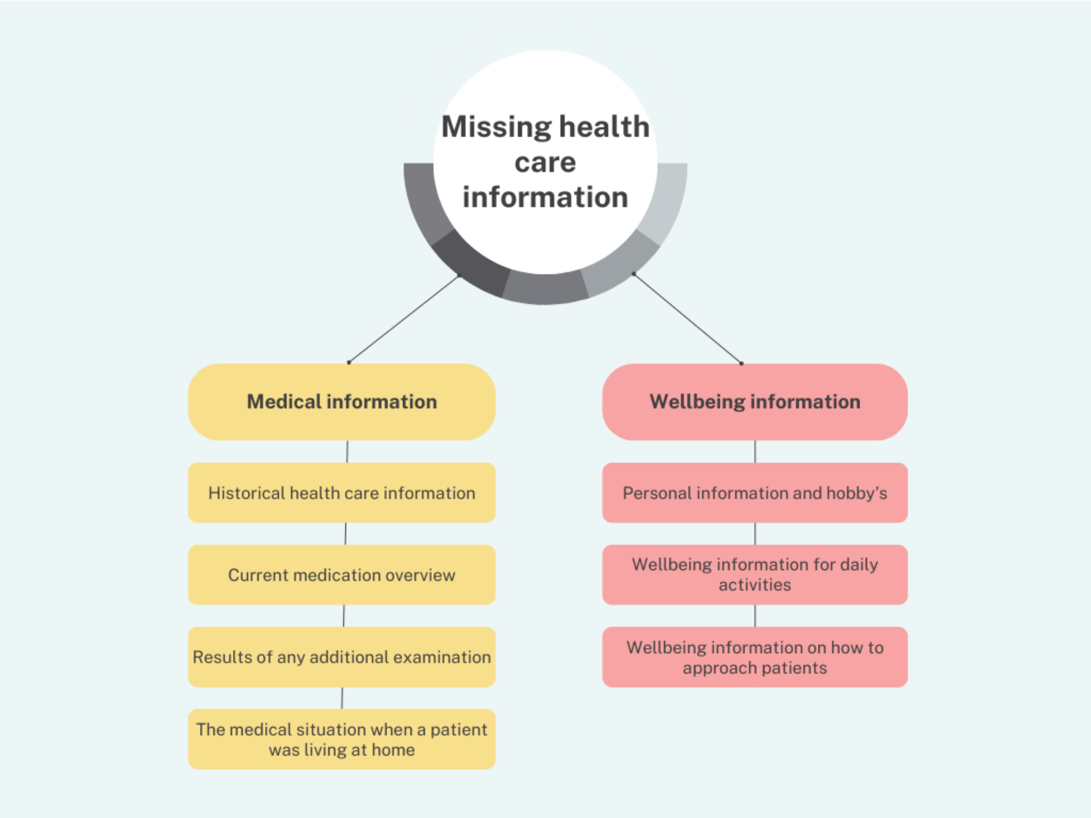


Figure 4: This graph shows an overview of the healthcare information of patients, with chronic brain diseases, that was deemed as missing in the interviews.

4.1.2 How is healthcare information currently shared according to the interviewees?

To acquire a deeper understanding of the current practices surrounding the sharing of healthcare information, particularly for patients with conditions like dementia, interviewees were asked about the methods they use to both share and receive such information. This inquiry serves as a crucial step in grasping the current state of affairs and pinpointing areas for potential enhancement in the exchange of health information for patients with chronic brain diseases, including those with dementia. The ensuing discussion is structured into three main sections, each with distinct objectives. Firstly, we aim to develop a comprehensive understanding of how information is exchanged between caretakers and healthcare facilities. Furthermore, we seek to examine how both homogeneous and heterogeneous healthcare facilities participate in the exchange of healthcare information. This categorization enables us to delineate and analyze the various approaches employed across different healthcare settings.

4.1.2.1 Information exchange between caretakers and healthcare facilities

The exchange of information between healthcare facilities and caretakers is of paramount importance for patients with dementia or other diseases, considering the increased reliance of these patients on their caretakers. During an interview conducted for this study, a caretaker shared valuable insights into the evolution of this information exchange process:

> *(#12, Caretaker, online, with LS) No, okay, well, I am quite assertive in the sense that when I go there, I always ask what happened today? And they take the time to go through it with you. In the past, I found it easier; they had notebooks on the ward with some notes that you could take note of. Nowadays, everyone has an app or a tablet or whatever, so it's not hanging at the bed in the hospital; you can't access the medical files directly. If it were somewhere in an app and I could access it, that would be great. Now, I just do it. I walk to the desk or at least to the area where the administration is, and I ask, 'Can you please tell me how, what, etc.?' They do it because I don't want to hear it only from my wife.*

In this interview, it is evident that the information exchange between a caretaker and a healthcare facility is at times entirely contingent on the information provided during the specific facility visit. The interviewee expresses a preference for a system reminiscent of a previous solution, involving a notebook located at the patients' medical bed, or the implementation of an app to facilitate access to patient information. The interviewee emphasizes the desire for a broader source of information beyond relying solely on medical details provided by their spouse or being dependent solely on healthcare professionals within the facility. This underscores the importance of establishing a more comprehensive and accessible system for caretakers to obtain relevant healthcare information about the patient. Notably, the interviewee underscores the desire for comprehensive information beyond solely medical details, emphasizing the importance of a more holistic approach.

Contrastingly, other interviewees discuss a shift toward involving caretakers in some parts of the medical files, aiming to provide them with detailed information about the patient's medical history. This highlights a diversity in practices and suggests ongoing efforts to enhance the involvement of caretakers in accessing pertinent healthcare information:

> *(#9, Caretaker, face to face, with LS) Well, during the time I worked there, the possibility for family members to read the dossier also emerged.*

This highlights that, at least on certain occasions, there is the possibility for caretakers to stay updated about the health of the patient. The practice of permitting caretakers to access and read the medical files of their patients within healthcare facilities has been expanded in some instances, with the added capability for caretakers to contribute information to the systems. The caretaker discussed this development during one of the interviews:

> *(#9, Caretaker, face to face, with LS) Yes, we spoke directly with the care team within the facility, made phone calls, and sometimes sent emails. We could also access a reporting system from Nedap, a specific system, where we could read reports and input things that they would then read—like 'pay attention to this,' or, well, very small practical details. We could also read about how the care was progressing or what challenges they were facing.*

The interviewee outlined the available avenues for sharing healthcare information with the healthcare facility. These options included sending emails, making phone calls, and actively contributing and accessing information within the medical files through the information system at the healthcare facility. The implementation of these functionalities was facilitated by an application named Nedap. The interviewee expressed that these tools provided a means for direct communication, enhancing the exchange of medical information between caretakers and healthcare professionals.

A summary of the healthcare information exchange possibilities between caretakers and healthcare facilities

To summarize, the communication between caretakers and healthcare facilities can occur through various channels:

- The information can be directly communicated in person.
- The information can be communicated in the form of a phone call.
- The patient can sometimes still communicate the information between the caretaker and healthcare facility.
- Accessing information from online medical files is another avenue for obtaining data, where caretakers may also contribute additional information to enrich the system.

4.1.2.2 Information exchange within healthcare organizations

The exchange of information between healthcare providers within healthcare organizations predominantly occurs through a unified system. In response to inquiries about information exchange practices, interviewees consistently mentioned the specific system they utilized, emphasizing their ability to access patient healthcare information collected within their respective organization. One interviewee emphasized the following regarding the information exchange within the same organization:

> *(#7, Case manager dementia, face to face, with LS) But there are also people living in the facility. And then you notice how nice it is to have those short lines, where you can just call when something is wrong. 'I haven't finalized it yet. I still need to apply for that indication, but could you start looking for a spot because it's not possible to stay at home anymore?' Then they already know the story, and because it's a closed system, they can all read in the dossier.*

This interviewee corroborates the observation that healthcare providers within the same organization have the capability to access patient information collected throughout the entire organizational network. In this instance, it facilitated the seamless transfer of a patient receiving treatment at home to a related healthcare facility within the same organization:

> *(#7, Case manager dementia, face to face, with LS) I work for an organization, and when you work for the organization, we all use the same system. Each client has a medical file, and in that medical file, the speech therapist and occupational therapist can all access it if they're from the same organization.*

This shows us how medical specialists can work together when the information exchange is available. Another interviewee also underscores the utility of employing a single system across the entire healthcare organization. This uniformity aids them in effective communication with colleagues specializing in different facets of the care process:

> *(#6, Chronic brain disease care physician, face to face, with LS) No, it's actually very handy. You have the dossier, so to speak. And you look into it, and then you immediately see, um, you have an overview of all your clients in a certain section. I always check each day which clients I have, and I always read about how their week has been. In principle, I see people once or twice a week, so I always check, 'Hey, how did it go?' That's important to me, and I can see in the dossier. These are basically the daily reports that I then see for a client. If there are really important things in there, I can always discuss it with the psychologist. For example, if I think, 'Hey, um, I see something here, and I don't trust it or find it remarkable,' then I can have a conversation about it. Or with the client themselves, if that's possible, for example. Yes.*

The interviewee provides an example of the information they can access about a patient and emphasizes the capability to discuss important information with colleagues, such as a psychologist, as needed. This collaborative approach enables them to contextualize problems, highlight important factors, and address any uncertainties in the care for patients with chronic brain diseases.

A summary of the healthcare information exchange possibilities within healthcare organisations
To summarize, the healthcare information communication within healthcare organisations can occur through various channels:

- The employees can read the online medical file due to the fact that they have access to the healthcare information system that is used in this organisation.
- The information can also be communicated in the form of a phone call or email if something is not clear from the system.

4.1.2.3 Information exchange between heterogeneous healthcare facilities

When healthcare specialists from one facility need to contact a healthcare specialist from another facility, the process is often more complex than simply accessing the healthcare information system used within their own organization. As a result, several steps may be involved in facilitating this exchange of information. This chapter aims to outline these steps, providing insight into the current complexity of information exchange for heterogeneous healthcare facilities. By delineating these steps, we can better understand the challenges and intricacies inherent in the current process of exchanging information across different healthcare settings.

Communication vocally through the patient, caretakers or family members
Indeed, the first possibility outlined in the previous chapter about information exchange between caretakers and healthcare facilities is applicable here as well. When healthcare specialists from two different facilities encounter gaps or discrepancies in the exchange of healthcare information, they may resort to seeking crucial medical information directly from the patient, caretaker, or a family member. This approach was reaffirmed by one of the interviewees:

> *(#2, Elderly care physician, face to face, with LS) Because, I think, it's already somewhat inventoried before admission by the Care Coordination department, also involving the family. And maybe it's more common if a handover comes from home care. I don't know, I'm not in control of that myself. But I do think it's nice. Yes, usually, people I talk to can tell it reasonably well themselves or their family can add to it.*

This step of seeking healthcare information directly from the patient or individuals close to the patient may not always be feasible, particularly in cases involving patients with dementia or acquired brain injury. These patients may struggle to recall medical information accurately, or they may have difficulty communicating due to cognitive impairments. Additionally, caretakers may not always be present during medical appointments, further complicating the process of obtaining relevant information. These challenges underscore the need for alternative strategies to ensure comprehensive and accurate exchange of healthcare information, particularly for patients with dementia.

Exchanging healthcare information with a physical or online letter when the patient has an appointment in a heterogeneous healthcare facility

Another option for conveying healthcare information is to provide the patient with medical information in the form of a letter upon their departure from a healthcare facility. This letter can then be carried by the patient to subsequent healthcare specialists involved in their care process, thereby furnishing them with essential healthcare information. This process was elucidated in the interviews by one of the participants:

> *(#3, Elderly care nurse, online, with LS) And when someone, let's say, arrives on the day they are supposed to, they often have a very large envelope with them. So, you're already talking about letters, and they often have a nursing handover in there with information for the patient, like, 'Hey, you've experienced this, and this is what we're going to do.' It often includes medication, usually in those nice packaged bags, all pre-packaged for one day as a bridging solution, so that we receive the prescriptions the next day, which are then created and delivered by the pharmacy to us, so we can then continue providing them.*

This illustrates that heterogeneous healthcare facilities, in certain cases, utilize the method of providing patients with a letter containing critical medical information for communication. The interviewee specifically discussed the exchange of information from the hospital to the care home. However, this process can pose challenges, particularly when dealing with patients with conditions such as dementia, as these letters are more prone to being misplaced or forgotten when patients visit medical specialists.

Additionally, the interviewee highlighted the issue of patients receiving only a day's worth of medication upon admission to the facility. This finding was corroborated by a medical specialist who received medical information from home care:

> *(#5, Elderly care physician, face to face, with LS) Some patients do bring paper files like, 'This is what home care does daily. This is our plan.' I've seen a daily plan overview on paper, but nothing electronic, so it's usually in paper form. They would have a little folder for that.*

This interviewee discusses the exchange of information from home care specialists to the care home, emphasizing the notable absence of electronic information received from home care. In instances where a patient with dementia receives medical treatment in a hospital and subsequently returns to the previous care setting, such as home care or a care home, it is crucial for healthcare specialists to communicate effectively with those providing ongoing care. This ensures continuity of care and informed decision-making. In one of the interviews, the process of information exchange from a hospital to an external organization was explained:

> *(#5, Elderly care physician, face to face, with LS) Yes, we always have a standard discharge letter, and it's either a discharge letter to the general practitioner. They always receive one as a standard, and a discharge letter to the place where a patient is going, not to their home because, in principle, a patient doesn't need a letter. But if it's a care institution, then a letter goes to the Elderly care physician, and it basically states what*

> *they have done, what complications there were, and that the patient has been admitted until a certain date with this medical history. This is what we've done. These are the medications administered. And yes, it's an online letter. Normally, it only goes to the general practitioner, unless another specialist wants it, but usually only to the general practitioner.*

This interviewee elucidates that there exists a standard discharge letter that is electronically communicated to the general practitioner or elderly care physician, who often functions as a general practitioner in the care home setting. This letter typically contains information about the events that transpired during the hospital stay, including any complications that arose. However, it's worth noting that the finding regarding hospitals primarily communicating their letters and findings electronically was not universally agreed upon in the interviews conducted. Another interviewee emphasized that the hospitals they have frequent contact with often communicate through letters:

> *(#16, Two care physicians, face to face, with LS) But actually, most of the exchange is still done on paper, especially from the hospital.*

This finding, particularly regarding hospitals primarily exchanging information via paper letters, contradicts the information provided in the previously mentioned interview. It indicates that there are various methods employed by different hospitals for exchanging healthcare information. Furthermore, the interviews also shed light on the exchange of information from care homes to hospitals. One interviewee explains the process of exchanging some of the medical information they have collected:

> *(#9, Caretaker, face to face, with LS) Yes, when someone was sent to the hospital, a printout of the dossier had to be made with a current medication overview. That was then sent along with something about a statement of whether or not people wanted to be resuscitated. But that was just a paper printout, something to give to the ambulance.*

This care home provides a printout to the ambulance regarding a patient, thereby making relevant healthcare information accessible to medical specialists working in ambulances. This illustrates the practice of transferring healthcare information in a visible format for immediate use by emergency medical personnel. Additionally, healthcare organizations have the capability to transfer certain healthcare information on paper while transferring other information electronically. One of the interviewees elaborated on this by explaining that they use both paper letters and electronic communication interchangeably:

> *(#2, Elderly care physician, face to face, with LS) If someone has to go back to the hospital, we often arrange for their admission because something has gone wrong. We can make a referral through ZorgDomein, and in that, we include all the information, providing a current medication overview on paper to send with them in the ambulance.*

This interviewee underscores the diverse methods employed for sharing healthcare information when a patient requires treatment elsewhere.

Exchanging healthcare information from the medical history from a patient to a heterogeneous healthcare facility

When a patient, with a chronic brain disease, is already at another healthcare facility and their current medical specialist requires information from a past healthcare facility, a distinct process unfolds. This is necessitated by the inability to directly provide medical information to the patient or transport it via ambulance, as well as potential challenges in the patient's ability to communicate due to cognitive illness or other factors. In such cases, the process typically begins with the current healthcare facility contacting the other facility for the required information. This communication can occur via various means such as phone, email, or other channels. Once contact is established, the information sharing process commences, culminating in the transfer of relevant medical data. This process highlights the importance of effective communication and collaboration between healthcare facilities to ensure comprehensive care for the patient, particularly in situations where timely access to past medical information is crucial for ongoing treatment. The process for contacting a healthcare specialist from another healthcare facility and sharing healthcare information has been described as the following:

> *(#5, Elderly care physician, face to face, with LS) Well, we always have to contact the on-duty resident doctor, so the one who is not yet a specialist. So, in principle, we call the on-duty resident doctor and say, 'This patient is here. I want the details. Can you email or fax them to me, one of the two?'*

This interviewee simplifies the necessary steps for facilitating healthcare information exchange. Firstly, contact is made with the other healthcare facility, typically via phone. Next, both parties identify the patient involved. Lastly, a method for sharing the healthcare information is agreed upon. In this case, the interviewee prefers using email or fax for distribution.

Regarding the use of emails for distributing medical information between healthcare facilities, it's worth noting that many facilities utilize secure mailing systems. These systems ensure that emails can only be accessed in a secure environment. One interviewee mentioned a hospital where some medical specialists exclusively shared information using such a secure environment.

> *(#7, Case manager dementia, face to face, with LS) Because the hospital sends everything securely, which is very good. You ask the neurologist, 'Can I have the latest letter for Mr. Jansen, or should the family request that?' Yes, I always have to ask for permission, of course, from the family or the client, that I can take a look. But people don't make a big deal about it. They usually agree and sign for it. The general practitioner sends it securely by email. The neurologist also sends it securely, but the neurologist has to send it back to the general practitioner, of course.*

This indicates that numerous healthcare facilities have the capability to send emails securely. In response to the necessity for securely transmitting healthcare information, several Dutch initiatives have been introduced, enabling the secure and electronic exchange of healthcare information through dedicated applications. An interviewee expressed their confidence in securely sending healthcare information and posing questions to other healthcare specialists using such platforms:

> *(#7, Case manager dementia, face to face, with LS) We have the Siilo app, which I use a lot because it's also secure, and that's pleasant. Because, yes, when I call or talk to the general practitioner, you first get a secretary who says, 'I'll ask the question to the general practitioner.' Then the general practitioner gives the answer to the secretary, but that's not always convenient. It's already a bit muddled by then, of course. So now I often use it. We have that one general practitioner's practice; then I send a message to the general practitioner, 'This is what's going on; can you think along for a moment?' And then she can respond at her convenience, either by providing an answer when she has a moment or by calling.*

The interviewee mentioned the Siilo app as a tool that facilitates secure communication and information exchange among medical specialists. Siilo enables direct communication and sharing of medical information in a secure manner. However, the Siilo app was not the only tool highlighted in the interviews for secure information and document exchange. Other tools or platforms were also mentioned, indicating a range of options available to healthcare professionals for secure communication and data sharing:

> *(#9, Caretaker, face to face, with LS) But where I work now, we use a secure workspace called mSave, and we send each other data in a secure workspace. We also use ZorgMail, but of course, there are various systems for that.*

The interviewee discusses two distinct systems utilized within their healthcare organization. The first system, mSave, facilitates the secure exchange of healthcare information among professionals within a designated workspace. The second system, Zorgmail, enables healthcare professionals to securely transmit care information via email. These applications have been adopted in healthcare settings largely due to the absence of interoperability among healthcare information systems across organizations. Additionally, another system mentioned by an interviewee is VIPLive:

> *(#7, Case manager dementia, face to face, with LS) And those caregivers, of course, all work with a closed files. And now, with the general practitioners, we use Viplive. I don't know if you're familiar with it. It's a system where the general practitioner reports, and I, of course, have only one general practitioner's practice to deal with, so I can enter my findings in their system. When I've been with a client, I can share my story about what's currently happening.*

The interviewee discusses the VIPLive application, which enables users to add information to the medical files of general practitioners. This functionality facilitates the sharing of information about mutual patients and promotes collaboration among healthcare professionals.

A summary of the healthcare information exchange possibilities between heterogeneous healthcare facilities/ organisations

In summary, communication among diverse healthcare facilities or organizations can take place through a variety of channels:

- The healthcare information can be conveyed directly in person to the caretaker or patient, who can then transmit it in person to the other healthcare facility or organization.
- The healthcare information can be exchanged through a physical or online letter when the patient has an appointment in a heterogeneous healthcare facility.
- The healthcare information can be exchanged through a physical or online letter between the heterogeneous healthcare facility.
- The healthcare information can be exchanged through a (secure) e-mail between the heterogeneous healthcare facility.
- The healthcare information can be exchanged through a fax between the heterogeneous healthcare facility.

Summarizing how the healthcare information exchange is currently working

Figure 5 illustrates the current functioning of the healthcare information exchange system for patient data of individuals with chronic brain diseases, based on insights gathered from interviews. It outlines the existing tools and methods employed in this process.

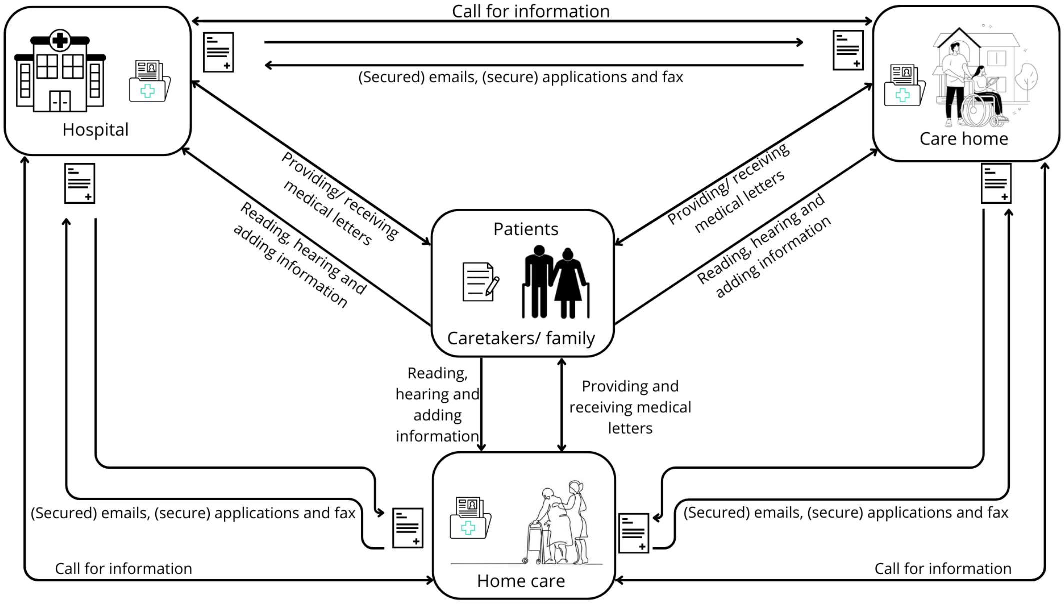


Figure 5: This graph shows an overview of the healthcare information exchange from the descriptions in the interviews.

4.1.3 What are the impediments with regards to the availability of such information?

Various impediments contribute to the challenges surrounding the availability of healthcare information of patients with chronic brain diseases. Firstly, the recording systems vary across different healthcare facilities, resulting in discrepancies in how and what healthcare information is registered. Consequently, medical data that is accessible at one facility or department may not be available elsewhere. Additionally, the lack of interoperability between different systems prevents the automatic exchange of healthcare information. As a result, healthcare professionals are compelled to manually exchange information, exacerbating the challenges associated with information exchange, particularly amidst perceived time constraints and high workloads.

In this chapter, we will delve into the impediments surrounding the availability of healthcare information through interviews with stakeholders involved in the care of patients with chronic brain diseases. Our aim is to identify the most significant challenges and understand how these obstacles are perceived by those directly involved in patient care. Through this exploration, we seek to gain insight into the root causes of these issues and explore potential avenues for improvement in healthcare information availability within this context.

4.1.3.1 Problems with recording systems for the availability of healthcare information within healthcare organizations

One of the obstacles impacting the availability of healthcare information is the perceived issues with healthcare information systems. As elucidated by one of the interviewees, there are instances where healthcare information is indeed available, but its interpretation proves challenging:

> *(#7, Case manager dementia, face to face, with LS) That's also important when you're looking at each other's records. Because if someone writes, I don't know, 'it went well today.' Well, what do you mean by that then?*

This highlights the critical importance of the manner in which information is reported, as it significantly influences how others interpret it. Healthcare professionals rely on this information to provide the best possible care to the patient, necessitating a comprehensive understanding of the patient's current condition as well as their medical history. This interviewee provided an illustrative example of this scenario, where a patient was labeled as "aggressive":

> *(#7, Case manager dementia, face to face, with LS) Someone acts aggressively, then I become aggressive myself, what do you mean? Someone says something unexpected or does something unexpected, but that's not, what's happening? You have to describe what you see. And then I think if someone is waving their hands, do they want to hit you or are they distraught? I can't take it anymore, then you also start waving your hands. So if someone writes something, it's going to have that kind of flow, so you have to be very careful with the language you use.*

This example serves as a poignant illustration of how individuals can be misinterpreted when daily care recordings lack precision. Merely noting a patient's aggressiveness fails to provide a comprehensive understanding of the situation. Consequently, when such information is shared, for instance with the care home where the patient will reside, it may inaccurately portray the patient as a danger to others due to their perceived aggressiveness. However, the interviewee does not believe that the patient was genuinely aggressive and advocates for adjustments in care based on a more nuanced understanding. This underscores the significance of careful word choice in reporting. Another interviewee emphasizes that it's not just how information is documented in medical files, but also what is documented. This importance was underscored by one of the interviewees:

> *(#6, Chronic brain disease care physician, face to face, with LS) Everything is reported in our system, right? Even bowel movements. Yeah, so sometimes I think when I see a client who, for example, can't do much anymore. I have, for example, a client with reduced consciousness, and I only read about the bowel movements, and then I think there must be more than just bowel movements. Yes, I want to know if he's awake and for how long he's been awake and if he's really alert when awake. How about saturation and heart rate? Those are important things for me too.*

This interviewee identifies a significant issue wherein they miss vital information from patients due to a lack of reporting by colleagues. This discrepancy suggests that individuals have varying perceptions of what constitutes important patient health information, highlighting the necessity for a more standardized reporting process. Additionally, there is a challenge with recording systems and associated processes—they must remain up-to-date whenever new healthcare information, whether collected within the facility or shared from external sources, is obtained. The interviewee further explained that this can result in instances where data is missing from patients' medical files:

> *(#8, Former elderly care manager, face to face, with LS) Yeah, well, the problem sometimes was indeed that such a GP dossier wasn't always kept up to date, so it concerned the medical history. So if not all medical history was in the GP information system, sometimes a family would say, 'Oh yeah, but then she also had surgery, and then that happened, and then that happened.' You wouldn't see that reflected in the medical information of the GP system.*

The interviewee highlights the current limitations in fully relying on medical files, stemming from the frequent addition of crucial medical interventions and information by the patient's family. This underscores the significant human intervention required to maintain the currency of medical files, thereby impacting the availability of healthcare information necessary for healthcare specialists to provide personalized, patient-centric care.

Furthermore, an implication of the current reporting process is that family and caretakers may have access to read along. This awareness leads healthcare specialists to exercise caution in reporting all aspects of the patient's health. This concern was emphasized in the subsequent part of the interview:

> *(#16, Two care physicians, face to face, with LS) Even more, it's as if it happens that professionals adapt to the fact that they know that a critical family member is reading along, so they don't write things down. I do that too, you know. A medical file is a tool for professionals to exchange information with each other, and it's not a means to inform family members. You have other means for that.*

The interviewee acknowledged that they occasionally alter their reporting behavior when aware that a critical family member is reviewing the reported information. This adjustment can lead to gaps in healthcare information and adversely affect its availability. Furthermore, the healthcare provider expressed the opinion that healthcare information reporting systems should primarily serve to make vital healthcare information accessible among healthcare professionals, rather than being utilized as a tool to inform caretakers and family members.

4.1.3.2 Data can be recorded but may be not easily findable

Through the insights shared by the interviewees, we've gained an understanding of the implications associated with the healthcare information recording systems utilized within their respective organizations and beyond. It's apparent that while data may be recorded, it isn't always efficiently organized or readily accessible, hindering its availability for future use. This poses challenges in utilizing recorded healthcare information effectively, as highlighted by one of the interviewees:

> *(#5, Elderly care physician, face to face, with LS) I think most things are available, but it just needs to be better organized so that when you need to search quickly during a shift, you can find it all at once.*

This interviewee corroborated the notion that data must not only be findable but also quickly accessible, as healthcare providers often need to access it swiftly before caring for the patient. In shedding light on the recording processes within their healthcare organization, the interviewee elaborated in the following segment of the interview:

> *(#5, Elderly care physician, face to face, with LS) Yes, it should officially be organized under different headings, but it's not like that in reality. So it's mainly about what the nurse has written? That's separate. What have the doctors written? That's also separate, but it's quite mixed up, making it sometimes very difficult. Sometimes I'm really spending half an hour just to eventually get the patient's medical history in order, to find out what they've been through. Because you get such a huge block of text for each day, as every day when the care team or nurse is with a patient, they make an overview, which is very good, but it means you lose track.*

The interviewee articulates the necessity for data to be more easily accessible to facilitate its utilization in the care process. They elaborate by explaining that the current organization of data, written separately and in blocks of text, makes it challenging to locate specific information efficiently. This organizational structure can result in significant time investment, with the interviewee noting that they sometimes require up to 30 minutes of searching to compile a patient's medical history—a task that is untenable for every patient encounter.

Another interviewee shares a similar sentiment, particularly in relation to receiving information from the general practitioner. They also express frustration over the cumbersome nature of locating pertinent information within the healthcare records.

> *(#4, Elderly care physician, online, with LS) It's sometimes a bit of searching, yes, it's sometimes searching, and it's sometimes also, you have your own file but people*

> *come from the GP, and then you have, for example, the whole GP file, sometimes 250 pages if not more or less. Like I just said, if it's a PDF that is readable, where you can sometimes press Control F and find something, which it's much faster than having to go through all those pages to see if there's something I want to know. So yes, that, that is a big difference.*

This interviewee encounters challenges in locating necessary medical information when they receive extensive medical files from the general practitioner. These files, sometimes spanning up to 250 pages, often lack the functionality of basic search tools like Control + F, further complicating the information retrieval process. This difficulty in accessing pertinent information is particularly problematic given the interviewee's daily workload, which involves caring for multiple patients.

These examples underscore how the availability of healthcare information hinges greatly on its findability. If information is not easily locatable or quickly accessible, it is perceived as unavailable and consequently underutilized in the care process.

4.1.3.3 Different healthcare information systems are causing problems with the availability and sharing of healthcare information

The interviewees also note that it's not only information collected within a healthcare facility that may be unavailable; there are also challenges arising from the lack of interoperability between different healthcare information systems. This interoperability gap results in health information from other facilities not being directly accessible, further complicating the process of obtaining comprehensive patient data. One interviewee captured this sentiment, remarking:

> *(#3, Elderly care nurse, online, with LS) One uses Ysis, others use Portavita, and others use another system. So many different institutions, so many systems that exist, and I think, I think that's where a very large part of the [problem lies], in the intercommunication of all these different systems that are on the market.*

The interviewee elaborated on a pivotal aspect within the healthcare domain, elucidating that nearly every healthcare organization operates with a distinct healthcare information system. This diversity poses a significant obstacle, hindering the effectiveness of current technological solutions and methodologies aimed at facilitating the sharing of healthcare information among providers involved in a patient's care journey. This observation was further substantiated by the interviewee, who underscored the contrasting outcomes arising from uniform versus disparate utilization of healthcare information systems:

> *(#3, Elderly care nurse, online, with LS) If someone. Look, suppose I leave and another caregiver comes in, then that's kind of the basis they can continue from, so to speak. So the data that's in my medical files, of course, I also give a handover to that person, but suppose that person then moves to another care institution? Yeah, then I don't know if the data goes with them. That, I actually don't know. That depends on whether my other employer has certain home care organizations of the same organization that work in the same system, so if someone is familiar with home care. Then we already know something about that person, but there are also other organizations. There are, of course,*

> *so many home care organizations that work with a different system, and if someone comes from there, well, then we actually know nothing about that person, even though there is, of course, a lot known.*

This observation underscores the ease with which a caregiver within the same organization, utilizing the same system, can access medical records pertaining to a particular patient. However, the scenario drastically changes when a caregiver affiliated with a different healthcare organization seeks access to the same patient's healthcare files due to the patient's relocation. This stark contrast elucidates the formidable challenge inherent in seamlessly exchanging healthcare information among disparate healthcare providers operating within distinct healthcare information systems. This challenge extends beyond healthcare organizations, encumbering caretakers and patients' families alike, as articulated in the subsequent excerpt from an interview with one of the caretakers:

> *(#12, Caretaker, online, with LS) What I find difficult is that there are 3 or 4 apps or websites where I have to log in for delivery institution 1, 2, 3, 4 and then I think Hello, can't we log in somewhere with DigiD, just like how you're logged in to my government, and I can easily navigate?*

The aforementioned caretaker grapples with the myriad healthcare information systems required to access information from various healthcare providers regarding the patient under their care. Expressing a preference for a streamlined solution, the caretaker envisions a scenario wherein they could log in using a unified authentication system, such as DigiD, and seamlessly navigate through a consolidated interface to access pertinent data from different healthcare providers. These instances serve to elucidate the inadequacies of the current technological landscape in facilitating the exchange of healthcare information across disparate systems. It is evident that the existing systems only cater to interoperability within a singular healthcare information system, thereby exacerbating the challenges associated with cross-system healthcare information exchange.

4.1.3.4 The current technologies used to share healthcare information sometimes fail

The implementation of technologically advanced tools for sharing healthcare information between these different healthcare information should ideally instill confidence and trust among healthcare workers in these technological advancements. However, this is not always the case. One interviewee highlighted occurrences where the secure emailing tool utilized by their healthcare facility did not consistently deliver crucial healthcare information:

> *(#16, Two care physicians, face to face, with LS) We then write the letter, and the medical secretary sends it via secure email to the general practitioner, and sometimes it's still questionable if it arrives because sometimes it doesn't. And then it has to be resent. So yes, it's just very inconvenient for the general practitioner as well.*

In this explanation, the interviewee elucidates that certain healthcare information fails to reach the general practitioner, necessitating additional time and effort from both healthcare providers when such information is overlooked. Moreover, there are instances where the general practitioner is unaware that information is being sent, resulting in the omission and subsequent unavailability of crucial healthcare information within the care process.

4.1.3.5 To much reliance on an inefficient fallback system

The information exchange system endeavors to innovate by incorporating tools like secured emailing. However, these innovative solutions don't always function as intended, necessitating the utilization of a fallback system. Unfortunately, this fallback system is currently characterized by inefficiency and does little to enhance the availability of healthcare information. This challenge was elucidated in one of the interviews:

> *(#3, Elderly care nurse, online, with LS) But actually, I've never had a situation where I couldn't do my job because of the current state of the system. It's often just a phone call or a quick email like: "Hey, do you have some extra information?" and then either it's over the phone or through email.*

The interviewee underscores that while it's never impossible to work through obtaining data, they also acknowledge that when technological solutions falter, less efficient and secure methods for requesting and sending information become necessary.

4.1.3.6 healthcare information has to be registered two times which takes time and effort

Even in cases where healthcare information exchange proves successful, various impediments persist, impacting the availability of this information both immediately and over the long term. The manner in which information is collected upon receipt significantly influences its availability not only in the present but also in the future. This comes from the fact that in the existing healthcare information exchange system, the processing of healthcare information occurs on both ends: where it is initially collected and where it is subsequently received. This dual-sided process holds immense significance for ensuring the availability of healthcare information. One interviewee elucidated the intricacies of this process:

> *(#4, Elderly care physician, online, with LS) Yes, I definitely think so, because for example, just with a specialist letter, if it could be securely sent digitally and loaded directly into the file, it would already save them from having to process it, make a PDF, and load it in, and still, of course, sometimes they have to extract and process data, but there are quite a few steps they have to take just to get it in there.*

The interviewee delineates the intricate process involved in integrating specialist letters into their own information system. Upon receipt of a specialist letter, several steps ensue before it is fully incorporated. Depending on the content, they may either save the entire letter or extract specific data for loading into their system. This process can be notably time-consuming, with further delays incurred when dealing with paper-based documentation, as emphasized by one of the interviewees:

> *(#4, Elderly care physician, online, with LS) Yes, it's strange that from the hospital we receive lists but we get them on paper. Then we have to enter everything separately. Sometimes the pharmacy does it for us, but it's not automated.*

This interviewee elaborates on the workflow when dealing with paper-based documentation at the healthcare facility. They describe a meticulous process wherein each piece of information is entered separately into the system. While this approach demands more time upfront, it enhances future findability. Contrastingly, simply scanning documents and appending them to a file accelerates the process but compromises the ability to search for specific information later on. Another interviewee corroborated this practice, underscoring the trade-off between efficiency and findability in handling paper-based documents.

> *(#3, Elderly care nurse, online, with LS) So, we receive a lot of things on paper, which we then have to input again.*

The process of entering data twice—once upon initial collection within the facility and again upon receiving healthcare information—proves to be a time-consuming endeavor, appearing inherently inefficient. This inefficiency poses a significant challenge to the availability of healthcare information, as its utility hinges on its findability. The reliability of this findability is not assured and is heavily contingent on the methods employed during data entry, including what information is included or omitted. Consequently, while healthcare information may be exchanged at a certain juncture, its subsequent availability and discoverability within the receiving health facility become uncertain due to the nuances of processing techniques.

4.1.3.7 What information is available at other healthcare facilities is not visible

Within the current healthcare information system, it proves challenging for healthcare providers to grasp the medical history of their patients. Specific information regarding past medical events available at other healthcare facilities remains hidden from view, leaving specialists unaware of potential gaps in their knowledge. Consequently, it becomes unclear which data to request from another healthcare facility, leading to either requesting everything—a task often infeasible or inefficient—or risking missing pertinent information. One of the interviewees, employed at a care home, shed light on how this limitation renders data inaccessible to them:

> *(#5, Elderly care physician, face to face, with LS) Because yeah, we don't have a system where if I type in a name and date of birth, we can see, 'Oh, they've been there,' so at that moment, you can't do anything.*

This interviewee expressed a desire for a comprehensive search system that would enable them to efficiently locate specific patient information and track their medical history across various healthcare facilities. Another interviewee echoed this sentiment, recognizing the extent of information that can be overlooked due to a lack of visibility of what healthcare information is available:

> *(#16, Two care physicians, face to face, with LS) And a lot of information sometimes just passes me by. If something happens in the hospital, they send all these letters to the GP, and I don't even know what's going on or what the situation is. It's very inefficient and it takes a lot of time. And if you're also not sure if you missed something, well, then you don't do it [asking for the information].*

This example illustrates a scenario where healthcare information is shared with the general practitioner but not with the care home. The interviewee expresses frustration over the lack of awareness regarding their patient's status, highlighting the inefficiency of a system requiring the care home to independently request data from the GP. Moreover, when data is not shared, there is no means to discern what healthcare information is available. The interviewee emphasized that without knowledge of existing information, there's no incentive to request it. These closed systems, where visibility into collected healthcare information is restricted, contribute to inefficiencies in healthcare information exchange and impede the availability of vital patient data.

4.1.3.8 healthcare information is currently still not always send electronically

This leads us to the subsequent obstacles concerning the availability of healthcare information. Despite advancements in technology, electronic communication and exchange of healthcare information between facilities are not yet ubiquitous. Many healthcare facilities still rely on traditional paper-based methods for exchanging information. The arrival of information in the form of a paper-based letter significantly affects the availability of healthcare information. One interviewee articulated the following perspective on this matter:

> *(#4, Elderly care physician, online, with LS) it's all on paper, the information transfer, and that's actually quite inefficient, I think.*

The interviewee expressed a sentiment of reliance solely on paper-based methods for healthcare information exchange, deeming this approach inefficient. This perspective resonated with another interviewee, indicating a shared experience among healthcare facilities wherein information exchange predominantly occurs via traditional paper-based channels:

> *(#16, Two care physicians, face to face, with LS) But actually, here it's mainly exchanged on paper, especially from the hospital.*

This excerpt from one of the interviews underscores the prevalence of paper-based methods in healthcare information exchange. In another interview it was highlighted that it's not only medical files but also consent forms from patients or caretakers that are commonly exchanged via paper between healthcare facilities. The intricacies of this process were elucidated by one of the interviewees:

> *(#16, Two care physicians, face to face, with LS) Well, it depends, because it also happens sometimes that the hospital wants the patient's permission to send that data. So then I have to go to the patient with a paper note to get it signed, and then I send that to the hospital and then the hospital can send the data back to me.*

This illustrates the considerable time investment required to obtain consent on paper and subsequently share it with another healthcare facility. Such a process appears inherently inefficient. However, the exchange of healthcare information via paper has become deeply ingrained as a conventional mode of communication between healthcare facilities. Another interviewee characterized the scenario where individuals bring their medical letters with them to the healthcare facility upon arrival as the ideal situation:

> *(#2, Elderly care physician, face to face, with LS) In that ideal world, as it is now, someone who is admitted brings all the papers from the hospital. It also happens sometimes that they don't have it with them.*

The interviewee initially envisions an ideal scenario where individuals bring all their medical information from previous hospital visits with them to the healthcare facility. However, they also highlight an inherent inefficiency in this system, namely when patients forget to bring one or more medical letters. This deficiency not only hampers the availability of healthcare information in the short term but also poses long-term challenges if the information is not properly entered, or not entered at all, into the facility's information system.

The subsequent impediment pertains to the registration of healthcare information, both at the collecting healthcare facility and at the facility where the information is exchanged. The inefficiencies in this process are largely attributed to the prevalent use of paper-based healthcare information exchange methods.

4.1.3.9 Sharing healthcare information is done manually

The efficacy of the current healthcare information exchange system relies heavily on human intervention to transmit data, thus introducing various constraints to the system. This section delves into the limitations that hinder the availability of healthcare information. As one interviewee remarked:

> *(#16, Two care physicians, face to face, with LS) Yes, and how smoothly things go, that's actually more dependent on the individual than the system taking care of it. So ideally, you would want the system to make it just as easy regardless of the person. Now, it often depends on the willingness of a medical assistant or how much time the GP sets aside on Friday afternoon. It's much more dependent on that than on the system, because the system is inefficient. That's basically it.*

The interviewee elucidates how one's ability to receive healthcare data is contingent upon the willingness and availability of other healthcare practitioners. This underscores the extent to which the current healthcare information exchange system relies on human involvement. The fact that these individuals are balancing other responsibilities alongside transmitting healthcare information contributes to delays and inefficiencies within the system. Waiting for individuals to send information can be particularly frustrating, especially when promptly applying for a patient's indication:

> *(#7, Case manager dementia, face to face, with LS) For example, if you need to apply for an indication, like the WLZ indication, then you have to request a care indication from the CZ, the Central Body. They want data from that client, but you have to gather it from everywhere, from the GP or the neurologist, and if you want to quickly apply for an indication because it's necessary and they take a long time to send it, then it's annoying because you can't proceed. And of course, everyone also has their closing time, like it's 5 o'clock in the afternoon, then the computer shuts down and people go home. I understand that, but there's a person behind it, where sometimes there's a critical situation and you need to be faster.*

The interviewee highlights the challenges inherent in requesting an indication within the current healthcare information exchange system. To compile the necessary patient information, one must gather data from multiple sources, each of which relies on manual transmission by individuals. This process is time-consuming, particularly when requests are made late on a Friday afternoon, with little likelihood of receiving any information before the weekend. This underscores the inefficiencies pervasive in the current healthcare information exchange system. Another interviewee further emphasized these difficulties:

> *(#6, Chronic brain disease care physician, face to face, with LS) I think it's mainly about the exchange, because when I then call the polyclinic assistants, there is something noted in that person's file that I can work with. But then it doesn't automatically come to us.*

The interviewee concurs that the inefficiency of the healthcare information exchange system is at the crux of the problem. They recognize the existence of crucial medical information that could facilitate patient care, yet lament its failure to be transferred automatically. Furthermore, given the demanding nature of healthcare work, where professionals are often stretched thin with numerous responsibilities, it is understandable that much-needed information may fall through the cracks and remain unexchanged.

4.1.3.10 healthcare information is not being shared

One of the simplest explanations for the lack of availability of healthcare information is the failure to share it. Within the current healthcare information exchange system, there is a requirement for individuals from different healthcare facilities to actively share pertinent information with one another. Consequently, there are instances where this crucial information is not exchanged. While the specific reasons behind this phenomenon will be explored in detail in a subsequent chapter, it suffices to say that healthcare information may not be shared for various reasons. One of the interviewees corroborated the finding that certain information is not shared as expected:

> *(#14, Caretaker, face to face, with LS) And when you go to a pharmacy [...] there's something that needs to be asked. And then, you always have to mention, also, I don't understand why that isn't standard information, but he's receiving tube feeding.*

The caretaker consistently emphasizes the necessity of informing medical professionals about the patient's tube feeding regimen. This is crucial because certain medications cannot be administered through the tube. However, despite its importance, this information is not consistently shared with the pharmacy by the healthcare organization responsible for the patient. Additionally, another interviewee noted the variability among general practitioners in sharing vital healthcare information, with some being more diligent in their communication practices than others:

> *(#16, Two care physicians, face to face, with LS) And we always ask the general practitioner for the medical history of each patient. Not every general practitioner sends it, but many do, and that provides additional information.*

This illustrates how the availability of healthcare information can vary, with some pieces of information being shared while others are not. In this particular instance, the interviewee highlights the inconsistency in sharing the patient's medical history. The medical history is crucial for informed decision-making by caregivers, yet its sharing is sporadic. One interviewee revealed that there is no communication whatsoever with the district nurse unless there is something out of the ordinary observed:

> *(#2, Elderly care physician, face to face, with LS) No, unless we encounter issues and think, 'Hmm, it would be nice to speak with that district nurse about how things were done before.' Then we actively seek contact. But there is actually no data exchange. Not beforehand.*

This scenario underscores that information held by the district nurse may not automatically be relayed to a care home unless there is a specific reason prompting inquiry, such as an anomaly. For patients with chronic brain diseases, the district nurse may possess critical information that the patient cannot communicate in a later stadium in the care home setting. This lack of communication between these two healthcare providers is a general issue, but for vulnerable patients, it can have detrimental consequences. It highlights the need for improved communication channels to ensure that essential healthcare information is shared effectively, especially for those who are most vulnerable.

4.1.3.11 Difference in how well information is shared between different healthcare facilities and healthcare professionals

As per the insights provided by the interviewees, a significant variance exists not only in the reception of healthcare information but also in its timeliness and completeness. Several factors contribute to this divergence, including the originating facility, specific department, and even the healthcare specialist involved in the information dissemination process. One interviewee shed light on the disparities in healthcare information sharing practices across different facilities:

> *(#16, Two care physicians, face to face, with LS) Well, that varies from, yeah, if I start with the hospitals, the information there also varies per hospital. Well, with the AMC, we have good agreements.[...] Then we get a whole book of information. From some hospitals, there's no information transfer at all. Then we have to call them to ask: Hey, are we getting a letter? It really takes a lot of time before you reach someone who can say something about it.*

This observation underscores the critical influence of inter-facility collaboration on the comprehensiveness of healthcare information exchange within the current system. It highlights a suboptimal scenario where the efficacy of information exchange hinges on the quality of cooperation between facilities, indicating a deficiency in established standards. Another interviewee corroborated these findings, noting similar discrepancies, albeit within different departments of the same healthcare facility. When queried about the specific healthcare information they are missing, this interviewee responded:

> *(#4, Elderly care physician, online, with LS) Well then, my first question is from which department does it come, because if it's from geriatrics, then I know we'll receive a very comprehensive letter, which also includes a bit of well-being, because that was another part of your question, but I find that important. Where a bit of well-being could also be described, but where especially a very broad view of the patients is taken. If someone has been to the surgery or orthopedics, you'll get a letter, jokingly I would say, two lines.*

This observation underscores the multifaceted nature of factors influencing the potential omissions in healthcare provider knowledge, as evidenced by the source department of healthcare information in this instance. Such variability complicates the reliable and systematic utilization of healthcare information for patient-centric personalized care, a practice contingent upon the accessibility and consistency of healthcare data.

4.1.3.12 A lack of time to share healthcare information and administer correctly due to the already high administrative load

The interviewees extensively discussed their perception of a burdensome administrative workload. While acknowledging the critical importance of healthcare information administration, they expressed a desire to ensure that such tasks do not encroach upon their time spent directly with patients. One interviewee articulated dissatisfaction with the current balance achieved in this regard:

> *(#5, Elderly care physician, face to face, with LS) No, it's true, you spend a lot of time on administration. I spend three times more time on administration than I actually spend with a patient. Also, typing afterwards and searching for everything beforehand.*

The interviewee conveyed discontent regarding the current equilibrium between their clinical responsibilities and administrative tasks. Specifically, the interviewee expressed dissatisfaction with the administrative duties involving processing healthcare information digitally and searching for relevant data. This sentiment was echoed by another interviewee, who shared similar frustrations with administrative burdens. The following excerpt from the interview elaborates on this shared experience:

> *(#3, Elderly care nurse, online, with LS) I had an intake interview last week, my shift is eight hours. I spent one and a half hours working on typing up the intake interview, one and a half hours of my workday, one and a half hours that I actually want to be there for the people. Am I sitting behind a computer to type up a report of what that person could do and what her expectations are? Yes, that's up to us as nurses to do? Yes.*

The interviewee articulates a strong inclination to dedicate more time to patient care and less to administrative tasks. However, the pervasive high administrative load bears consequences for both the exchange and availability of healthcare information. Among the myriad administrative duties, sharing and requesting healthcare information stand out. The quality of shared information hinges significantly on the caliber of information administration and its associated processes. Hence, it is conceivable that when healthcare practitioners express discontent with the energy and time invested in administrative tasks, the overall quality of information may diminish, thereby affecting its availability.

4.1.3.13 The healthcare information is not available, because it takes the healthcare organization a long time to share

Healthcare professionals are currently overwhelmed with their workload. The requirement for manual transmission of healthcare information from one facility to another adds to this burden. Consequently, due to the busy schedules of healthcare organization employees, there can be significant delays in the sharing of healthcare information. This often results in the receiving healthcare organization having to wait for important information they need urgently. One of the interviewees recounted an instance where there was a need for a medication sheet for the next day, but it was not received initially:

> *(#3, Elderly care nurse, online, with LS) I have to give an example from my old job. There, for instance, we often needed a current medication list, and we had to request it ourselves from the pharmacy. We'd call the pharmacy and say, 'Hey, I need a new medication list for this person, because the signing sheet we have is full, it goes up to today, and from tomorrow, we need to start signing on a new sheet.' That was still done on paper back then, with paper signing sheets, so we'd ask them to fax a new list. Yeah, well, you'd call in the morning around eleven, and then by the afternoon, around two or half past two, you still wouldn't have the list. And then you'd have to call them again, like, 'Hello, I called you this morning. Maybe you should do something now, because otherwise, we won't be able to sign the medication for these people tomorrow morning, as we start at seven and you start at half past eight.'*

This illustrates an example where a caregiver urgently required a piece of healthcare information but initially couldn't obtain it. The timely receipt of this information was crucial because without it, the caregiver would be legally unable to administer medicine to the patient. The specific medications and dosages required would remain unclear. In this instance, there was an acute need for the healthcare information to be shared promptly. In other scenarios, the receiving healthcare facility may desire the information urgently, even if there isn't an immediate deadline or acute need for it to be shared. An example of this was shared by one of the interviewees:

> *(#7, Case manager dementia, face to face, with LS) But sometimes, that takes too long, because although the neurologist sees all these clients at the clinic, they don't send the data on the same day. Sometimes it can take a few months, and then the practice assistant says, 'I haven't received anything yet.' Well, then I'll just go get it from the neurologist myself, so sometimes you're searching for information.*

In this scenario, a busy neurologist juggles a high volume of clients each day, necessitating the sharing of information for each one. However, this process can consume more time than available in a typical workday. Consequently, some information isn't immediately shared. The cycle repeats the next day, compounding the challenge as the neurologist faces another full day of patient consultations. It's easy to envision how healthcare information might slip through the cracks amidst such a demanding schedule. The interviewee elaborates on how months can pass without the necessary healthcare information being made available. Subsequently, they must follow up with repeated calls to request the information, resulting in a significant delay between the initial inquiry and receiving the information. Another interviewee encountered a similar issue when a patient transitioned to a care home setting:

> *(#4, Elderly care physician, online, with LS) When they come to live here, we request their entire medical file, so we have all the information. But it takes a long time to get that. You're immediately responsible for their care, so ideally, you want to have it as soon as possible, but sometimes there's quite some time in between; we're talking weeks.*

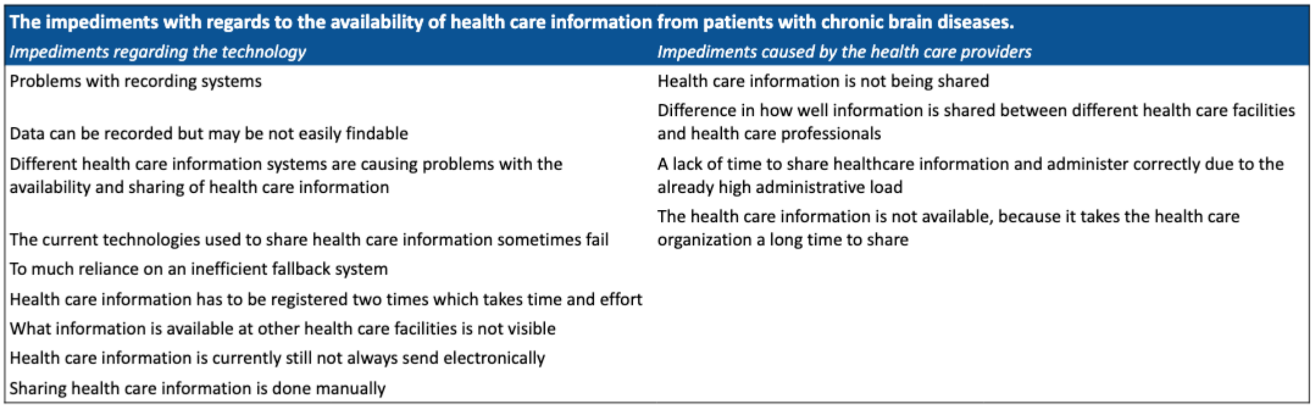
This interviewee highlights the challenge of waiting for weeks to receive the healthcare information of a patient upon their arrival at the care home. This delay is concerning because caregivers must begin providing care immediately upon the patient's arrival. The absence of pertinent healthcare information for an extended period can lead to significant consequences. Another interviewee attributes some of the delays to the implementation of new privacy laws, which necessitate obtaining consent from the patient or caretaker before sharing information. Despite acknowledging this factor, the interviewee contends that the sharing of healthcare information should ideally occur within a maximum of two days:

> *(#4, Elderly care physician, online, with LS) Since the new privacy laws, you have to sign the consent form, so a statement needs to be signed. That goes to the secretariat. They process it and send it to the GP. Then they have to process it, and theoretically, it could take two working days. However, in practice, it sometimes takes weeks, and you have to ask several times, 'Can you send it, can you send it?' So, yeah, there's an issue there.*

The primary reason for the delay in sharing healthcare information, as identified by the interviewee, is the reluctance or inability of the other healthcare organization to send it promptly. While the busy schedules of healthcare specialists may contribute to this delay, it underscores the inefficiency of the current system. There is a clear need for a more streamlined and automated method of sharing healthcare information, eliminating the requirement for manual intervention in the process.

4.1.3.14 A complete summarizing overview of the impediments with regards to the availability of patient information from patients with chronic brain diseases

In summary, Table 6 provides a comprehensive overview of the impediments hindering the availability of healthcare information for patients with chronic brain diseases.



The impediments with regards to the availability of health care information from patients with chronic brain diseases.

Impediments regarding the technology	*Impediments caused by the health care providers*
Problems with recording systems	Health care information is not being shared
Data can be recorded but may be not easily findable	Difference in how well information is shared between different health care facilities and health care professionals
Different health care information systems are causing problems with the availability and sharing of health care information	A lack of time to share healthcare information and administer correctly due to the already high administrative load
The current technologies used to share health care information sometimes fail	The health care information is not available, because it takes the health care organization a long time to share
To much reliance on an inefficient fallback system	
Health care information has to be registered two times which takes time and effort	
What information is available at other health care facilities is not visible	
Health care information is currently still not always send electronically	
Sharing health care information is done manually	

Figure 6: This table shows an overview of the impediments with regards to the availability of patient information from patients with chronic brain diseases

4.1.4 Why it is crucial to have the healthcare information available

In caregiving for vulnerable patients with chronic brain diseases, access to healthcare information is paramount. This accessibility serves multiple crucial purposes: aiding caretakers and healthcare specialists in providing personalized, person-centric care, eliminating the need to repeatedly request the same information, mitigating preventable errors, facilitating optimal medical decision-making, and reducing reliance on patients, family, or caretakers for pertinent healthcare details. Moreover, the availability of healthcare information empowers patients to maintain independence, prevents over-reliance on caregivers, and potentially fosters opportunities for continued learning. These essential roles of healthcare information availability will be explored further in this chapter.

4.1.4.1 Caring for patients with chronic brain diseases

It is imperative to understand certain behaviors and beliefs exhibited by individuals with chronic brain diseases such as dementia, as they can significantly impact their medical well-being and potentially mitigate cognitive decline. Utilizing healthcare information provided by daily caregivers is essential for assessing an individual's overall health, especially when they may no longer be able to effectively communicate their feelings. This information not only benefits other caregivers but also aids medical specialists when the individual requires hospitalization. Therefore, this knowledge can profoundly impact the lives of those with dementia, and its unavailability can lead to serious consequences. One interviewee emphasized the importance of recognizing changes in behavior and promptly communicating them to experts:

> *(#11, Dementia care physician, face to face, with LS) What particularly struck the care team that day [that the behaviour changed and] and later found out that she had a urinary tract infection. Often, you see that with the elderly, there's something physical going on. An infection or something else, which can suddenly cause their behavior to change drastically. So those kinds of things, because we focus a lot on that behavior, it's noticeable when there's suddenly a lot of difference.*

This underscores the critical importance of effective communication and access to healthcare information when caring for individuals with dementia. Without proper exchange of health information, potentially severe conditions such as urinary tract infections can go undetected, leading to significant health complications. Additionally, understanding a patient's background and personal history is essential for providing tailored care to individuals with dementia, as they may no longer be able to communicate these details themselves. One interviewee highlighted the potential challenges that arise when such information is unavailable, emphasizing the need for comprehensive healthcare communication systems in dementia care:

> *(#7, Case manager dementia, face to face, with LS) A brain disease is very complex. It manifests differently in everyone. Some people can articulate it very well, saying what they feel, what bothers them, or how they prefer things to be done. But some people can't do that at all. They retreat into themselves or become angry, and then you have to find another way. That's also why I turn to sports. For some people, it's through movement, like going for a walk or doing sports, that you build a connection. And eventually, you can also have a difficult conversation about when things aren't going well. So, the foundation is very important. Yes, indeed.*

The ability of individuals with dementia to express their feelings, preferences, and needs is often limited, yet this information is vital for providing effective care. Therefore, it is imperative that any data regarding their emotions or preferences, especially if they can still communicate them, be documented and shared among caregivers and healthcare facilities involved in their care. As the dementia progresses, this information becomes even more critical for those providing care. Additionally, the example provided by the interviewee underscores the significance of personal details, such as favorite music genres, in enhancing the quality of care and building rapport with patients. One interviewee emphasized the importance of having access to such personal information for caregivers:

> *(#6, Chronic brain disease care physician, face to face, with LS) These individuals often react based on emotions, and when they feel unsafe, they shut down. They can't handle things anymore. But music opens them up again, bringing back memories. When you say, 'Here, take this headphone,' suddenly they can do more because they feel safe, and music helps. I've seen videos where people couldn't connect with someone, but then they put on headphones with music they connect with, and suddenly, they answer questions. That's when I think, 'This is why I do it.' Before, they were closed off, just lost in their own world. That's what's fascinating. And when you manage to break through that lack of contact, that's when you think, 'This is truly amazing, and it's what makes it all worth it.'*

This example vividly illustrates the contrast between a patient with dementia opening up and withdrawing. It underscores the significance of possessing insights from the patient's past, which could have been documented and shared among caregivers in earlier stages but are now inaccessible without someone close who knows these details. Additionally, understanding the patient's perception of time is crucial for providing effective care and fostering mutual understanding, as highlighted by one interviewee.

> *(#10, Elderly care nurse, face to face, with LS) Especially with people with dementia, right? They kind of go back in time, so it's very helpful to know which time period they think they're in now. And what was happening at that time, you know, what was important to them back then?*

Understanding the patient's perception of their current time period holds value not only for daily caregivers but also for specialists during appointments. It provides insights that aid in tailoring approaches to the patient's needs and facilitating better communication and understanding between caregivers and specialists.

4.1.4.2 People with chronic brain diseases can deteriorate rapidly

Ensuring that we have comprehensive and current information from the patients with for example dementia is paramount, as their health can deteriorate rapidly if any crucial details are missing. This underscores the critical importance of establishing an effective healthcare information exchange system, as emphasized by one of the interviewees.

> *(#7, Case manager dementia, face to face, with LS) But I also find it comforting to know because I don't visit people every week. With some people, if they have a partner, often that partner calls when something is wrong. Some people are stable, and you visit them once every six months, while others you visit every three months. But with people who are not doing well, you really have to visit them every week or every few weeks. If you're not paying attention and someone isn't eating well, especially if there's no home care involved yet, and they're living all alone, they can deteriorate in no time.*

Indeed, in cases where multiple parties are involved, such as when a patient receives home care and requires coordination with their general practitioner or dementia care specialist, an inefficient healthcare information exchange system can have serious consequences. Without seamless access to the patient's complete health information across all involved parties, there's a risk that critical details may be overlooked, leading to potential deterioration in the patient's condition. For instance, if the home care team refers the patient to the general practitioner without the latter having access to relevant healthcare information collected by the former, there's a chance that the patient's condition may not be properly assessed, potentially resulting in suboptimal decisions regarding their care. Given the inability of vulnerable patients to communicate such nuances themselves, it becomes imperative to ensure that comprehensive health information is readily available to all relevant healthcare providers involved in the patient's care.

4.1.4.3 To deliver personalized, patient-centric care to people with chronic brain diseases

Providing patient-centric care poses inherent challenges, especially when catering to individuals with chronic brain diseases. The difficulty arises from their limited ability to communicate preferences and feelings effectively. Thus, it becomes essential for healthcare providers to access previously collected data containing their medical preferences and personal information. Despite the patients' current inability to articulate such details, this historical data can significantly influence their overall well-being and healthcare outcomes.

The importance of having medical preferences of patients with chronic brain diseases available

The medical preferences of patients hold significant importance for daily caregivers. Lack of access to this information can pose considerable challenges, as caregivers may struggle to discern the patient's wishes and restrictions. This insight was conveyed by one of the interviewees:

> *(#1, Caretaker, face to face, with LS) Also, the things we discussed, like for example, when they sent a temporary worker who then did strange things, what are those things they didn't do right? So, the way of washing, the way of lifting. You can also be a caregiver, but you have to know what the patient can and cannot do. So, you understand,*

> *you can put someone there who has been in care for 40 years, but that doesn't mean they can wash someone they don't know well.*

This interviewee emphasizes that delivering effective patient-centric care relies not only on healthcare professionals' experience but also on understanding the patient's wishes. However, getting to know the patient can be challenging, as previously mentioned. Therefore, it is vital that information about the patient is readily available and exchanged among caregivers when needed. The interviewee also discusses the repercussions of not having access to this information:

> *(#1, Caretaker, face to face, with LS) I notice, I just notice with washing, so when I wash her, you never hear complaints, never groaning, never pain, nothing, because I know exactly what I have to do, but when someone else comes, and I regularly experience this, then I hear awww. they don't do this on purpose, but then they raise the arm slightly too high. I know exactly what I can do, and then you have to be able to sense those kinds of things, and then you have to slowly grow into it, right? It's also normal that someone has to learn that when they come.*

The caretaker elucidated that when they provide care to the patient, the patient is entirely comfortable, whereas when an unfamiliar caregiver attends to them, the patient feels uneasy. The caretaker attributes this discomfort to the necessity for everyone to learn and become acquainted with the patient. However, having access to the patient's preferences would be more advantageous. This access could mitigate patient discomfort and facilitate caregiver transitions in situations where healthcare organizations face staffing shortages.

The importance of having personal information of patients with chronic brain diseases available

In this thesis, numerous healthcare professionals and caretakers have shared compelling narratives about the transformative effects of having access to healthcare information for patients. We can empathize with the significance of pursuing activities we cherish or being mindful of past traumatic experiences. For individuals without chronic brain diseases, conveying such information is typically feasible, but for vulnerable patients, articulating these details can be immensely challenging, if not impossible. The availability of this information can profoundly impact an individual's life, well-being, and healthcare journey. To underscore the critical importance of having this information accessible, we have curated examples from the interviews. One interviewee shared a tragic yet pivotal example:

> *(#7, Case manager dementia, face to face, with LS) I have a lady, and she is so, she is so fierce in her behavior. She almost comes right up to you, and I think well, what's going to happen now? But she doesn't do anything, but she's very fierce. well, it turns out afterwards after a very long time that she, she has a son from her marriage, but that's from a rape. That's so important to know, so that woman has been living with it all her life. But it was never talked about, but she is very mean about that son. Then I think, what's that about? What did that son do? Because then you see what happens and now I know, yes, and there is also not talked about but now you understand a lot more, why she is so incredibly angry at the pharmacy that does it wrong and everyone does everything wrong, so when you come there, then you think well, how should I move so*

> *that I don't disturb her? [...] but if you know the background. Where it comes from. Then you also see that she is not an angry malicious woman, but she is a woman who is just very damaged. And I think if you know backgrounds, then you also look differently at that person. Then you don't think what a difficult person, then you think, imagine being in her shoes and having all this on your plate. And then you are also never understood because nobody knows that background and I actually think a doctor who knows those things, then you should, not everyone needs to know that, but those who are really close, they should know some things about children lost or wars or really the heavy things people have experienced, because then you can take that into account that when you come, that you don't trigger that.*

This example from one of the interviewees underscores the significance of accessing information from a patient's past. In the case discussed, a patient with dementia exhibits aggressive behavior. Understanding the patient's personal history, as shared by caregivers, enables a more personalized approach to care. This insight allows caregivers to comprehend the patient's perspective and tailor their actions accordingly, avoiding actions that may exacerbate the situation due to a lack of understanding. However, it is evident from this interview segment that accessing such pertinent information through current healthcare information exchange channels can be challenging. The interviewee recounts encountering this information after a prolonged period, highlighting the inefficiencies in information dissemination. Another interviewee corroborated this observation, emphasizing the importance of doctors being aware of significant events in a patient's life, despite their tragic nature:

> *(#8, Former elderly care manager, face to face, with LS) I have another example and that was a lady who always got so angry and very restless in the evenings. And then they had to undress her with 5 nurses and lay her in bed, because she just didn't want to take off her clothes. She just wanted to go to bed with clothes on. [...] And at some point someone came who had also cared for her in the past from home care and said, yes, but she was a midwife before. She always went to bed with her clothes on because she had to get up at any moment to go to a birth, so you really can't get that out of her anymore, because she now thinks again that she is a midwife. [...] and if you don't know that, you'll keep busy. That costs a lot of time and energy for nurses that they don't have, while if you connect more to what is going on at that moment in the life of a person with dementia and in the mental situation, then you can anticipate much better, I think.*

This example illustrates a situation where a patient's behavior caused challenges for both the patient and the nurses providing care. The patient exhibited agitation and restlessness in the evenings, requiring the assistance of multiple nurses to prepare for sleep. However, this routine was unsustainable for the nurses, who also had other patients to attend to and administrative tasks to complete.

Later, a caregiver discovered that the patient, a former midwife, had always slept fully clothed due to her previous profession, during which she needed to be ready to assist with deliveries at any time. Despite suffering from severe dementia, the patient retained this belief and behavior. Once this information became known to healthcare professionals, they could adapt the care plan accordingly, eliminating the need to undress the patient before bed.

This example underscores the importance of healthcare providers sharing significant patient-related information and ensuring its availability for future reference, especially when the patient is no longer able to communicate such details. Effective communication and documentation facilitate better understanding between caregivers and patients, leading to improved care outcomes.

One of the interviewees shared an instance where leveraging a patient's hobbies and personal memories facilitated better patient-centered care and enhanced the patient's overall happiness:

> *(#11, Dementia care physician, face to face, with LS) I have a gentleman, who is actually quite far along in his dementia. He hardly speaks anymore, but he walks a lot. He has an urge to walk, only to walk around the corridor a bit in his own world. With a very committed, somewhat younger woman, and I spoke to her, and she said, well, until recently, until that man was admitted, I still played table tennis with him in the garden. And yes, that's not possible anymore, so well, I bought a net and set it up over the table, and I didn't use it right away, but first indeed what I just told you, made some contact first, and first played some tennis, just with a balloon, and well, that sometimes went a bit difficult, but he did respond to that, and then indeed at the sight of table tennis. Well, not really at the sight yet, but when pointing to the net. And well, he still walked around the table or in the room a bit. But actually, as soon as I started playing myself and he heard the tapping of the ball. And he saw that ball near him. Yes, he immediately stood in the right posture and hit the ball back almost like a professional, but I myself thought, Oh, wait, I have to polish up my own skills to hit back the ball.*

This example illustrates the importance of having access to information about a patient's past experiences and preferences. In this particular case, the wife of the patient shared that her husband had a fondness for playing table tennis. The healthcare provider utilized this knowledge to engage the patient in playing table tennis, despite the patient's inability to speak due to dementia. Remarkably, the patient was able to participate in this activity, showcasing the significant impact of leveraging such healthcare information. Furthermore, this instance even led the healthcare provider to reflect on their own table tennis skills, adding a touch of humor to the situation. Another interviewee also emphasized the power of utilizing a patient's background, hobbies, or passions to enhance their care and overall well-being:

> *(#10, Elderly care nurse, face to face, with LS) We had a resident. Who was an artist before and unfortunately couldn't communicate with us anymore. Who was unfortunately too far in the dementia process, but you could show him paintings or something. And he liked that then or another resident who used to be completely into billiards and We have a kind of Chinese billiards on the facility, so we go the day care coaches will then play Chinese billiards with that gentleman and he really likes it.*

These insights demonstrate that patients with chronic brain diseases can derive enjoyment and benefit from engaging in activities they once loved, even if their condition has progressed to a point where they may not actively participate or lack someone to communicate their preferences. Access to this information, even in advanced stages of dementia, can enable patients to continue learning and experiencing new things, as highlighted by one of the interviewees:

> *(#6, Chronic brain disease care physician, face to face, with LS) Yeah, yeah, I have uh I have with one client and This was a woman who has dementia. And actually quite in a fairly advanced stage that you couldn't really have a conversation anymore. But I have uh through what I knew from her past been able to teach something new. So I actually continued on something I knew and as a result, she learned something new, so that's cognitive. And in the meantime, it was like when I went to pick her up, she started singing too when I went to pick her up. That people had something like hey [how is that possible].*

This example illustrates how valuable insights from a patient's past can be in providing personalized care. By learning about the patient's connection to the church, the caregiver was able to incorporate elements of church music into a new song, creating a meaningful experience for the patient. The caregiver's initiative to sing this song during interactions with the patient, despite not knowing it previously, demonstrates the impact of leveraging such information to enhance the patient's well-being. This unexpected and positive outcome surprised other healthcare providers in the facility, highlighting the transformative potential of utilizing personal background information in care delivery.

4.1.4.4 It enables patients to avoid unnecessary dependence on others

In caring for patients, particularly those with chronic brain diseases, it's common to assume they are unable to do anything independently. While this inclination may stem from a well-meaning place, it's crucial to recognize that these individuals are still capable of performing tasks without constant assistance. One interviewee discusses strategies for maintaining the activity levels of such patients:

> *(#7, Case manager dementia, face to face, with LS) Active living at home means everyone participates. Home care won't take over, but they'll assess what the client needs to do on their own, what they want. They can't put on their socks themselves anymore, but what's needed? Do they need an aid or training on how to do it, and even people with dementia can still learn. They just need a period where someone watches them and encourages them, saying they're doing well. And you see what challenges they face. Maybe they need to sit in a different chair to reach their feet better. So, it's great that all these people work together, all for the benefit of. Because the group of people with dementia is tripling, so you can't admit all of them to a nursing home. They all want to stay home as long as possible, but then you need to ensure they can help themselves as long as possible.*

The interviewee highlights the assessment process undertaken by home care providers to determine what tasks patients can still perform and potentially learn. Even individuals with dementia, the interviewee emphasizes, are capable of learning. Sometimes, they may require assistance or training to accomplish certain tasks independently. By observing them and providing optimal conditions, such as using a chair instead of the bed to put on socks, patients can enhance their ability to perform daily activities. This focus on independence is not only beneficial for the patients themselves but also essential due to the increasing prevalence of dementia. With the rising number of cases, not all patients can be accommodated in nursing homes, making it crucial for them to maintain their independence for as long as possible. Moreover, the desire for autonomy is shared by the patients themselves:

> *(#7, Case manager dementia, face to face, with LS) And people want that too because if you're sitting there in the morning waiting for home care to come put your socks on and you've been awake since 7 a.m., and they only come at 12 a.m., you spend your whole morning waiting. People won't start reading the newspaper or a book or go out because they're just waiting, so then they become dependent on others, and that's not good. People find it very nice, and some are used to the care of others, so they sometimes have to switch but there are also people who are just starting with care and say, 'Oh no, I'd like to learn myself because then I can go where I want.' And that's the beautiful thing, seeing people happier when they can still do things themselves. Then they get compliments like, 'You still do all that yourself? You're so old, and you can still do it?' Well, then they become very proud. And of course, there's not enough manpower, so that's also a factor, so sometimes it's born out of necessity.*

The interviewee emphasizes that patients share the desire for independence, as relying entirely on caregivers can lead to prolonged waiting times and a loss of autonomy. For instance, if home care is scheduled for 12 a.m, but the patient wakes up at 7 a.m, they may wait five hours before receiving assistance, restricting their ability to start their day. Overdependence on care can be detrimental to patients, both in terms of their physical well-being and their sense of pride. Encouraging patients to perform tasks independently not only reduces their reliance on care but also allows them to manage their schedules and experience a sense of accomplishment. This approach is essential due to the shortage of manpower in care facilities. The interviewee further elaborates on strategies to promote patient independence:

> *(#7, Case manager dementia, face to face, with LS) I've always learned that you care with your hands behind your back, so you can help when needed. You don't let someone fall, but if they're still busy tying their shoelace, you don't say, 'Shall I quickly do it?' Yes, no, I can do it three times as fast, but that's not the point. You'd make someone dependent.*

The interviewee's approach to patient care is evident in their emphasis on encouraging independence. They advocate for allowing individuals to attempt tasks on their own, intervening only when essential, rather than merely expediting the process. The interviewee draws a parallel, likening tasks that seem basic to us to running a marathon for patients with conditions such as dementia. This comparison underscores the significant challenges patients face in performing seemingly simple activities and underscores the importance of providing patient-centered care:

> *(#7, Case manager dementia, face to face, with LS) We run a lap, and I can still do it, but if you can't anymore and you try something that's very difficult. But then you deserve a medal. That's really true. People need to be encouraged because it's easier to say, "Yes, I can't, I can't." And yes, that's also part of dementia. Some want to do everything themselves and push everyone away, but others become very apathetic and wait for things to be arranged for them. That's part of the disease, and then you have to come up with something again to get these people moving.*

This excerpt from the interview sheds light on the significant challenges individuals with dementia face when performing basic tasks and emphasizes the sense of accomplishment associated with completing them independently. The interviewee observes that preferences regarding independence vary among patients, with some desiring autonomy while others prefer assistance for every task. They attribute these preferences to the natural progression of the disease. For those who prefer assistance, specialists play a vital role in facilitating movement and independence. These specialists, known as occupational therapists, employ various techniques to support patients in regaining mobility and autonomy, thereby enhancing their quality of life:

> *(#7, Case manager dementia, face to face, with LS) Edomah, those are special occupational therapists who assess what someone needs to still be able to make their own cup of coffee. Do they need picto's or arrows on the coffee maker, so that someone can do it themselves but with a checklist? If someone can still read well. A checklist is also sometimes seen in the bathroom, listing what you need to do to get dressed in the morning, like 'Don't forget this' or 'Don't forget that.' So, they figure out what someone needs to remain independent.*

In this segment of the interview, the discussion centers on edomah therapists, specialized occupational therapists who assist patients in regaining independence. These therapists employ various strategies to help patients perform tasks on their own. They utilize tools such as pictograms, arrows for direction, and checklists to aid patients in completing tasks independently. Pictograms, in particular, are instrumental as they provide visual cues outlining the steps required to accomplish a task. These interventions are especially beneficial for individuals with cognitive impairments who may struggle to remember specific actions.

Why is it crucial to have healthcare information available when helping patients not becoming to dependent on care?

The significance of having accessible healthcare information while assisting patients to avoid dependency on care stems from the necessity for all healthcare providers to understand the patient's capabilities, ongoing learning process, and utilization of tools for specific actions. These details are essential for daily caregivers to determine the appropriate level of assistance required for various tasks. Healthcare specialists in hospitals and general practitioners are cognizant of the patient's abilities, which enhances the care process, informs medical decisions, and potentially slows the decline in cognitive health.

4.1.4.5 To prevent mistakes with medicine and dosages

Patients with conditions such as dementia, acquired brain injury, or multimorbidity require precise management of their medication regimen, including timing, dosages, and administration methods. Ensuring access to comprehensive healthcare information regarding medication is paramount for their well-being. However, as highlighted by one interviewee, there are instances where this process falls short, leading to potential risks in medication management:

> *(#1, Caretaker, face to face, with LS) But I had it all set up so that I could read everything, so I could see, for example, that they had given the pills incorrectly, you know. Then I can go to the office [healthcare facility] and ask what's going on and I want to know what's going on and how that can happen, you know, because that shouldn't happen too often. Things like that, that can't happen.*

The caretaker had access to all the reports documented in the healthcare information system by the care home. Through this access, they identified an error in the medication administered to the patient. Such errors pose significant risks and should be avoided at all costs. Ensuring that healthcare specialists in care homes have access to comprehensive medication information is essential in preventing such mistakes. Similar issues can also arise in pharmacies when vital medical information about medications is not readily available. One of the interviewees provided insights into this incident:

> *(#14, Caretaker, face to face, with LS) Yes, so the pharmacy arrives and they prepare the medications..., if they happen to not have the prescribed medication but something similar, then the patient receives that, but they're not allowed to go through the feeding tube, so they don't know that the patient has a feeding tube. I find that very strange.*

This incident underscores the significant risks of medication errors that arise when crucial healthcare information is unavailable to or overlooked by healthcare specialists. Patients with conditions such as dementia or brain injury cannot compensate for gaps in their healthcare information. They depend on the accessibility of this information or the support of those around them. Consequently, there is an urgent need to explore more efficient methods of exchanging healthcare information to mitigate the occurrence of such errors.

4.1.4.6 To support the decision making of healthcare specialists

In the dynamic healthcare scenarios faced by patients with conditions like dementia, acquired brain injury, and multimorbidity, it's imperative to have immediate access to their complete medical records. The urgency stems from the fact that these patients' health statuses can change rapidly, necessitating swift and informed decision-making by healthcare providers. An interviewee underscored the significance of this access by pointing out instances where valuable resources were squandered due to delays or deficiencies in accessing comprehensive medical information:

> *(#9, Caretaker, face to face, with LS) Well, you see, the caregivers who take care of my mother daily, they have a lot of know-how. At one point, we had to visit the orthopedic surgeon because her hip was worn out. My mother had it in her head that she would still get a new hip because she had so much pain in that hip. But we were thinking, is that*

> *still worthwhile? With her Parkinson's, would she be able to rehabilitate anyway? That kind of information, I thought, well, the orthopedic surgeon, they only see her that one time in that hospital, and then she's nicely dressed up, looking well-groomed, and she can speak well. But they don't see how she's lying in bed the next day, unable to move, and the effects of Parkinson's. So yeah, to make decisions like getting a new hip, you actually need the input of the caregivers who take care of her daily.*

The interviewee emphasized the wealth of knowledge and insights that daily caregivers possess about the patient, underscoring their invaluable contribution to the patient's care continuum. This reservoir of information can significantly aid healthcare specialists in making informed decisions regarding medical interventions or formulating tailored treatment plans for specific conditions. For instance, the interviewee illustrated a scenario where an orthopedic surgeon could have leveraged this information to reconsider performing a hip replacement procedure for the patient. Without access to insights from daily caregivers, healthcare specialists face greater complexity in determining the optimal course of action for patient care.

4.1.4.7 Eliminating the need to repeatedly request the same information

The repetition of inquiries regarding patients' health status reflects a notable inefficiency in the current healthcare information exchange system. Caretakers, who served as interviewees, observed a recurring pattern wherein healthcare specialists repeatedly requested the same information about the patients' health. This redundancy not only indicates a lack of access to comprehensive healthcare information among specialists but also suggests a systemic flaw in information dissemination. Despite patients' prior consent to share their health data across different healthcare providers, this redundancy persists, causing frustration among caretakers and unnecessary burden on healthcare specialists. One of the caretakers affirmed the observation that healthcare specialists are often without complete access to vital healthcare information about their patients:

> *(#14, Caretaker, face to face, with LS) We're actually continuously telling the same story. They see the broad outlines of what happened, so they already come in like, "Wow, that's bad," but you still have to explain the story.*

This illustrates the repetitive nature of having to recount the same medical history and background by caretakers on multiple occasions. Similarly, another caretaker expressed concern about the lack of coordination in healthcare information across different facilities. They observed that healthcare specialists often lacked awareness of the patient's medical history from other facilities, leading to the same information being requested repeatedly. The interviewee elaborated on their perception of this issue in the subsequent part of the interview:

> *(#12, Caretaker, online, with LS) A while ago, she had to be admitted to the hospital again because there was something wrong. And then I found it remarkable. Two-way that things known to the general practitioner were not known in the hospital and vice versa when she was discharged from the hospital, it took a long time for the general practitioner to receive a positive message too. That, I find remarkable. Then I think, guys, it's good that we give permission and that you're all critical about it. But if you've given permission, then my expectation would also be that it's shared more easily. So that the other, well, institution also knows about it and can take it into account in the care. That disappointed us.*

The interviewee highlighted a significant lack of communication between the general practitioner and the hospital medical specialist, despite their shared responsibility for a substantial portion of the patient's healthcare. Despite obtaining informed consent from the patient and caretaker for the exchange of healthcare information, an efficient communication channel was still absent. Consequently, healthcare specialists often resorted to consulting the patient for this information, leading to suboptimal and error-prone outcomes. The caretaker expressed discomfort with the need to repeatedly provide healthcare and personal information, a sentiment echoed in other interviews conducted:

> *(#7, Case manager dementia, face to face, with LS) That's also if I come back to the Wmo, the Wmo that if you go to a day care center or you want household help, then the Wmo comes for a kitchen table conversation. And then they ask for your date of birth again. You have to tell your whole story again, what disease do you have? But you already told all that to the district nurse the week before. Sometimes that just runs parallel and then we say, yes, that's terrible for those people. You've just told everything and especially if you have memory problems, you have to think every time, what was my date of birth again? What was the name of that street? Who was my doctor? So you've just coughed it all up with the help of your family and then another caregiver comes who wants to know it all again, while I think it's probably already noted somewhere.*

This individual discussed the process involved when someone from the Wet maatschappelijke ondersteuning (Wmo) visits your home to assess your need for assistance or eligibility for day care services. During these visits, individuals are subjected to a series of questions aimed at determining their eligibility, the extent of assistance they require, and how it aligns with their personal circumstances. Remarkably, these questions often cover information that the patient has previously provided, creating a redundant and uncomfortable situation for patients, families, and caregivers. This redundancy is particularly burdensome for patients with brain diseases. The interviewee expressed a desire for improvement in this area, indicating a need for better coordination and sharing of healthcare information among multiple providers to alleviate such discomfort for vulnerable patients:

> *(#12, Caretaker, online, with LS) No, well, you're reminding me of something now. I hope that later on we'll be better able to document things properly and now record them. What we also sometimes encounter, Is there this or that [disease in the family]? So then I think damn it. I think it's been mentioned a few times at various hospitals and institutions. You have to repeat every time what it was like with your father and mother. Your sister, your brother, who knows what or your uncle or aunt had this. Then I think, just record it somewhere.*

The interviewee expressed a desire for improved accessibility and organization of healthcare information for future use by healthcare specialists. Specifically, they highlighted the challenge of sharing information about hereditary diseases within the family, which caregivers may not always be fully informed about. This lack of knowledge can make it uncomfortable when such information is requested from them. To address this issue, one interviewee devised their own practical solution, which they elaborated on in the subsequent part of the interview:

> *(#12, Caretaker, online, with LS) Over the years, we've prepared ourselves to say that if we have to go somewhere, we still make a summary ourselves. We still add to that and then we take it with us. a to try to tell b I take it with me so that it can be handed over to the relevant institution, doctor, whether digitally or on paper. And this is practically shaped by us, so to speak, because we also keep having trouble with it. You have to repeat it 25 times, and so on.*

The solution devised by the interviewee, acting as both patient and caretaker, involves meticulously documenting both medical and personal information about the patient. This information serves a dual purpose: facilitating comprehensive communication of healthcare details and providing medical specialists with a complete understanding of the patient's medical situation. The interviewee shared that they implemented this approach due to the ongoing challenge of repeatedly explaining the same information and the frustration it caused. This finding underscores the importance of ensuring the availability of healthcare information in the future and highlights the inadequacies of the current healthcare information exchange system.

4.1.4.8 To prevent a reliance on patients, families and caretakers for medical information

Patients with chronic diseases such as dementia heavily rely on the support of those around them to manage their healthcare needs. Currently, it is these individuals who facilitate the exchange of healthcare information between various specialists involved in the patient's care. As discussed previously, ensuring that healthcare specialists have access to comprehensive patient information is paramount for making well-informed decisions. Family members, caretakers, and other involved individuals are frequently consulted for this purpose. However, this reliance on external sources of information poses challenges, as not all patients have such support networks, and errors in communication may occur. This necessity for external sources of medical information is highlighted in the following excerpt from the interview:

> *(#3, Elderly care nurse, online, with LS) And if family members, if you have a person with dementia and they still have a spouse or daughter who can provide that information, then that works nicely because that's actually your communication tool, and they stay in contact with the physiotherapist and say the speech therapist and has told us this. But there are many people who don't have that. They sometimes have children, but they live too far away, so they're not always there when the caregivers provide care.*

This interviewee underscores the current reliance on individuals around the patient to serve as the primary conduit for healthcare communication. They express concern about how healthcare practitioners, particularly those caring for individuals with dementia who lack close involvement from others, obtain essential medical information. This sentiment was echoed by other interviewees, indicating a shared recognition of this challenge within the healthcare system:

> *(#2, Elderly care physician, face to face, with LS) So you have to be lucky that a somewhat clever daughter or someone else has accompanied the patient to the hospital admission or appointment. Because you can't always expect that from those people. Because they only hear half of it. Yeah, they can't help it either.*

This observation highlights the significant reliance of caregivers on information provided by individuals close to the patient, such as family members, as demonstrated in this instance with the daughter. Another interviewee echoed similar sentiments, further emphasizing the dependency on such sources of information due to a perceived lack of accessibility to electronic healthcare information exchange:

> *(#5, Elderly care physician, face to face, with LS) If the patient is conscious, you ask if they are known elsewhere, if possible. If they are alone or unconscious but have a family member present, you ask the family member. But if they don't have anyone with them, then you can't do much at that moment. Because we don't have a system where if I type in a name and date of birth, we see, 'Oh, they've been there,' so you can't do anything at that moment.*

The insights shared by this interviewee underscore the necessity for a system wherein users can input a patient identifier and access relevant information based on their clearance levels. Without such a system in place, caregivers are currently unable to take any action supported by verified medical information. Regrettably, as mentioned by one of the interviewees, this sometimes forces caregivers to make decisions in the absence of crucial medical data:

> *(#5, Elderly care physician, face to face, with LS) Unfortunately, it does happen, not super often. Usually, there is a person or a neighbor involved, someone who is somewhat engaged. But there have been occasions where someone truly had no one in the system, and then we had to make a decision ourselves. Because during the shift, you can't just call a doctor in the middle of the night and say, 'This is the situation,' so you have to make a decision yourself at that moment, and preferably, you do this with the patient's children. But that's not always possible.*

The interviewee emphasizes the challenge faced when patients lack someone to assist them, leading to decisions made without adequate information—a situation with potentially serious consequences. However, the interviewee notes a recourse: contacting the general practitioner on the next weekday to obtain necessary information, thereby addressing the immediate issue.

The interviewee recounts a situation where the patient, initially capable of communicating their own healthcare information, was in the early stages of a disease. In this instance, the interviewee, acting as the mother's caretaker, found it somewhat easier due to the mother's medical background:

> *(#9, Caretaker, face to face, with LS) Yes, and furthermore, I think it ultimately turned out fine because my mother could also tell a lot herself, but imagine if you have someone who is very introverted or has dementia and can't express themselves well anymore. Then you are very grateful to have caregivers. They pick that up.*

This interviewee emphasizes the significance of having someone capable of communicating healthcare information within the current options for healthcare information exchange. This individual could be the patient themselves, a caretaker, or a family member. However, as the interview progresses, the interviewee notes that when the mother developed dementia and her cognitive clarity declined, it became necessary for someone to accompany her to medical appointments.

> *(#9, Caretaker, face to face, with LS) No, we always went too, because my mother regularly went for check-ups at the hospital, and towards the end, my mother wasn't very clear-headed, and my father went with her, but he wasn't very clear-headed either. So one of the daughters always went along to provide feedback on what was agreed upon in that conversation. Because otherwise, the doctor in the nursing home didn't get a clear picture, and neither did the caregiver.*

This further underscores the deficiencies of the existing healthcare information exchange system, underscoring the critical need for individuals who can accompany patients to medical appointments and effectively communicate the findings and outcomes discussed during those appointments.

4.1.4.9 Summarizing why it is crucial to have healthcare information available from patients with chronic brain diseases

In summary, the following list describes why it is crucial to efficiently exchange and have the healthcare information available of patients with chronic brain diseases:

- To provide general care for patients with chronic brain diseases.
- To provide personalized care for patients with chronic brain diseases.
- To prevent the rapid deterioration of patients with chronic brain diseases.
- It enables patients to avoid unnecessary dependence on others.
- To prevent mistakes with medicine and dosages.
- To support the decision making of healthcare specialists.
- To Eliminate the need to repeatedly request the same information.
- To prevent a reliance on patients, families and caretakers for medical information.

4.1.5 What kind of healthcare information is perceived as the most crucial to stakeholders in the care for patients with chronic brain diseases and should be available for them?

During the interviews, respondents were queried regarding the essential healthcare information required for their patients. As detailed in preceding chapters, these respondents comprised healthcare providers and caregivers responsible for patients with conditions such as dementia and acquired brain injury. Given the diversity within this respondent group, their responses reflected their distinct needs, contributing to a comprehensive understanding of the critical healthcare information necessary for the varied care received by these patients. The amalgamation of responses to this inquiry, coupled with the currently missing healthcare information, delineates the crucial healthcare data vital in the care process for patients, particularly those with dementia, as per the perspectives of our respondents. Specific types of crucial healthcare information are cataloged in Appendix B. The comprehensive list of vital healthcare information is condensed into three primary categories and nine subcategories, visually represented in Figure 7.

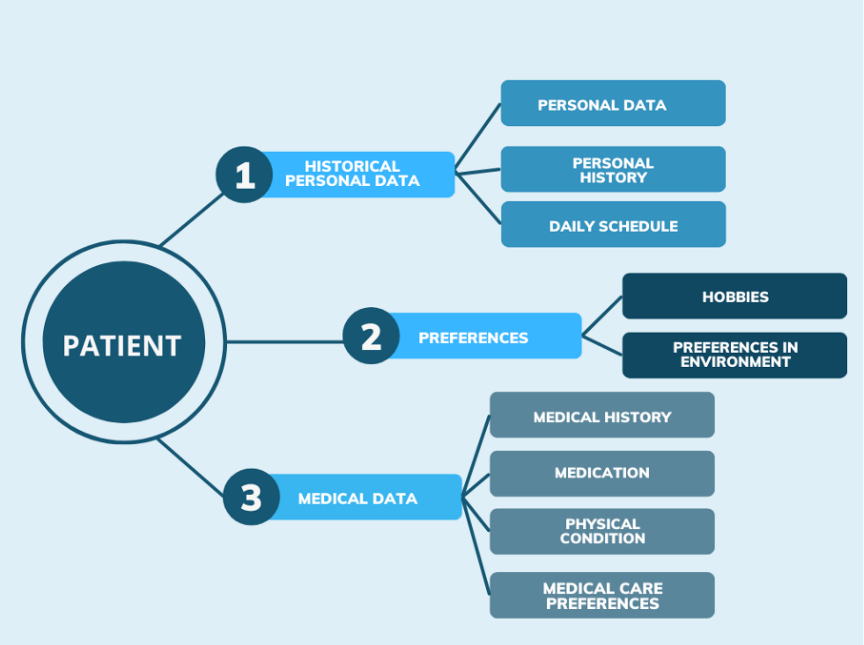


Figure 7: This graph shows an overview of the categories of healthcare information according to the interviewees of this research.

The primary categories encompass historical personal data, patient preferences, and medical data concerning the patient. Historical personal data comprises three subcategories: personal data, personal history, and daily schedules/routines. Patient preferences are delineated into two categories: hobbies and environmental preferences. Medical data is further subdivided into medical history, medication, physical condition, and preferences regarding medical care. All these categories encompass healthcare information essential for caretakers and healthcare professionals to deliver personalized and accurate care, thereby fostering comfort for patients, such as those with dementia, and their caregivers during the caregiving process.

4.2 Identifying and conceptualizing the pertinent tools and resources available for facilitating FAIR data production

In this section, we explored the results from identifying and conceptualizing the relevant tools and resources available for facilitating FAIR data production.

4.2.1 The possibilities of data production on sensitive patient and personal data in a FAIR-data architecture

In this chapter, we delve into an exploration of pathways aimed at rendering healthcare information FAIR, coupled with an examination of strategies facilitating secure and efficient access to this information for healthcare providers operating within diverse organizational contexts. This inquiry is motivated by the recognition that sensitive and personal healthcare data cannot be freely disseminated and typically requires explicit informed consent from patients for leaving the healthcare facility (Mons, 2020). Consequently, access to such sensitive healthcare information is strictly regulated, often permitted only in controlled environments and in a limited capacity. To align with these requirements within our specific use case, it is imperative that we implement measures to ensure the FAIRness of the data.

Central to this endeavor is the preservation of security and privacy, a task we undertake through the utilization of Distributed Ledger Technology (DLT). Through this examination, we aim to elucidate how DLT can serve as a foundational framework for safeguarding sensitive healthcare data, thereby facilitating seamless access while upholding stringent security protocols.

4.2.1.1 Producing FAIR healthcare information

To undertake the essential steps toward incorporating FAIR data principles within the healthcare sector, we adopt the established hourglass model, as depicted in Figure 2.

The hourglass model commences with the initial processing of raw information, preparing it for FAIRification in subsequent stages. In this study, we employ a comprehensive list of vital healthcare information, meticulously identified through interviews conducted as part of our research. This exhaustive list is available for reference in Appendix B, providing a detailed compilation of data points deemed critical for the care of patients with chronic brain diseases.

Producing Findable healthcare information

To transform this list of healthcare information into a FAIR-compliant format, a series of steps must be undertaken. Primarily, we must address the "Findable" aspect of FAIR, denoted by the "F." Achieving findability for healthcare information necessitates a departure from centralized, data warehousing approaches, which may not be conducive or practical in this context (Mons, 2020). Therefore, to ensure that healthcare information is discoverable for specialists and caregivers of patients with chronic brain diseases, it is imperative to establish a well-documented pathway for indexing this data (Plug et al., 2022). Moreover, organizing and querying the data require the implementation of unambiguously readable metadata and traversable knowledge graphs, guided by standards-driven ontology specifications. Throughout this process, assigning globally unique and persistent identifiers to both the data and metadata emerges as a critical consideration. This ensures not only efficient discoverability but also facilitates seamless integration and retrieval of relevant healthcare information.

To enhance the findability of healthcare information, leveraging tools such as the Stanford University CEDAR Workbench for Open Science and Bioportal proves invaluable. These platforms self-identify as FAIR-compliant, providing robust solutions for organizing, annotating, and sharing healthcare data. By utilizing these resources, we can streamline the process of making healthcare information readily discoverable for healthcare specialists and caregivers.

Producing Accessible healthcare information

Following the establishment of findability for healthcare information, the next imperative is to ensure its accessibility. Accessibility entails ensuring that both the data and metadata are retrievable by their identifiers using standardized communication protocols citepwilkinson2016fair. This necessitates the implementation of a well-specified method for performing repository queries, facilitating seamless access to the desired information (Plug et al., 2022). To operationalize these queries effectively, we rely on application programming interfaces (APIs), which serve as as tools for retrieving healthcare information from healthcare repositories. APIs can be used to streamline the process of accessing healthcare information, enabling healthcare specialists and caregivers to retrieve relevant data efficiently and effectively. Also, this allows data sovereignty, where the data stays where it is collected and only the results from the queries are returned.

Handling data queries under well-defined access and control conditions is paramount to safeguarding the privacy and security of sensitive healthcare information. To achieve this, we employ Distributed Ledger Technology (DLT) for automated authorization and credential verification. Verifiable credentials, owned by patients, caretakers, and healthcare providers, serve as the basis for authentication, while smart contracts facilitate the automatic validation of these credentials and grant access clearances based on predefined criteria.

The utilization of DLT, specifically blockchain technology, ensures that access to specific healthcare information is granted only to authorized individuals. Through the blockchain gateway protocol, registered user identity certificates and signatures are required for authentication and authorization of gateway client access permissions, as highlighted by Mou et al. (2023). This stringent authentication process guarantees the preservation of privacy for sensitive personal data, thereby instilling confidence in the security of healthcare information exchange.

Before advancing towards the goal of achieving interoperability in healthcare information exchange and enabling the deployment of the Personal Health Train concept, it is imperative that the implementation of FAIR Guidelines aligns with local laws and regulations Purnama Jati et al. (2022). This alignment can be ensured through the execution of a Data Privacy Impact Assessment (DPIA). A French DPIA, which offers comprehensive insights into the privacy implications of data processing activities, is provided in Appendix A. By conducting such assessments, we can identify the potential risks and implications associated with the implementation of FAIR Guidelines, thereby fostering compliance with legal and regulatory frameworks governing healthcare data management.

Producing Interoperable healthcare information

Health information exchange systems achieve interoperability when they seamlessly connect and operate, enabling secure, automated processes for data processing, storage, and analysis across diverse healthcare facilities (Plug et al., 2022). This facilitates the exchange of healthcare information among various healthcare information systems, as the machines communicate effectively using standardized protocols.

To achieve machine interoperability in healthcare information, it is crucial to ensure that both the data and metadata are associated with vocabularies adhering to the FAIR guiding principles. This involves linking healthcare information to relevant vocabularies available in Bioportal or creating custom vocabularies when necessary. By doing so, the data becomes linkable and gains quality references to other metadata. In the context of knowledge graph representation, this linkage ensures that nodes within the graph are interconnected, facilitating comprehensive data integration and analysis (Plug et al., 2022).

The prerequisite for achieving machine interoperability in healthcare information underscores the necessity for the ontology, derived from the central controlled vocabulary, to be resolvable by all individuals and healthcare organizations. This ensures accessibility and usability across diverse contexts and entities within the healthcare domain. Furthermore, it is essential that the unique identifiers associated with the metadata remain truly unique, preventing any potential conflicts or ambiguities during data exchange and integration processes. (Plug et al., 2022).

Producing Reusable healthcare information

We can say that healthcare information is reusable when the data and metadata is kept in good provenance (Plug et al., 2022). Therefore, it is necessary to document the metadata so it can be used for for replication or future reuse at different healthcare facilities around the Netherlands. This can be done by deploying metadata in a place which also follows the FAIR guiding principles. Therefore the metadata of this research is deployed on Bioportal and also on an open repository on Github.

Using the FAIRified data to exchange healthcare information while maintaining data sovereignty

Implementing FAIRification procedures enables the exchange of healthcare information while upholding data sovereignty. By ensuring data sovereignty within the proposed solution and upholding the rights of data owners, controllers, and processors, compliance with laws and regulations can be achieved. This closely follows the roles and rules described in chapter 1.7 about the GDPR. Through adherence to these legal frameworks, data can be accessed using the Personal Health Train, as detailed in chapter 2.1.5. This approach allows healthcare facilities to access data from one another, provided that authorization and verification steps have been completed. Consequently, healthcare information can be accessed without necessitating any action from employees at the hosting healthcare organization.

4.2.2 How should a healthcare information exchange architecture, based on the FAIR guidelines and principles, be constructed to allow the healthcare information of patients with chronic brain diseases to be visited?

In this chapter, we leverage the requirements and methodologies outlined for exchanging healthcare information of patients with chronic diseases while upholding data sovereignty, as discussed in Chapter 4.2.1. This chapter is structured into three distinct sections. Initially, we examine the FAIRification process and introduce the proposed tools for achieving interoperability. Subsequently, we explore how this IT architecture safeguards the privacy of sensitive healthcare information. Finally, we delve into ensuring the availability of FAIRified healthcare information for healthcare providers across different facilities, utilizing data visiting once the authorization and authentication processes are complete. The finalized healthcare architecture is detailed in Appendix **??**.

4.2.2.1 FAIRifying the healthcare information at each healthcare facility

In this section, we will elucidate the process of FAIRifying healthcare information within the proposed architecture for healthcare information exchange. The part of the proposed architecture that FAIRifies the healthcare information is displayed in 8

Harmonizing information systems with CEDAR
The FAIRification process commences within the healthcare information system of the targeted healthcare facility. This system, utilized by healthcare providers for documenting the healthcare information of patients with chronic brain diseases, serves as the starting point. Integration with the CEDAR template, established at the Stanford University CEDAR Workbench for Open Science, is pivotal. This web-based platform, comprising open-source tools and REST APIs, plays a crucial role in the proposed IT architecture. It facilitates the creation of a metadata template tailored to the incoming healthcare data, ensuring the generation of machine-actionable health data enriched with high-quality metadata Gonçalves et al. (2017).

Central to this process is the enrichment of metadata with ontologies, which are housed within the online repository known as BioPortal. BioPortal serves as a repository for biomedical ontologies and provides access to these ontologies through web services (Noy et al., 2009). This enrichment can leverage existing ontologies available in BioPortal or involve the creation of custom ontologies when necessary to suit the data at hand.

The challenge with BioPortal ontologies lies in their limited establishment for interoperability. While they offer flexibility in cases where a specific vocabulary is absent, they are less effective compared to established ontology tools like OBO Foundry, which prioritize standardization and interoperability. For this purpose, a dual approach is adopted. BioPortal offers flexibility, while specialized domain vocabularies like OBO Foundry provide enhanced standardization. Hence, a combination of standardized vocabularies is utilized where available, supplemented by flexible options from BioPortal in cases where specific ontologies are lacking in existing repositories.

Deploying your own vocabulary in BioPortal

Creating your own ontology begins with utilizing an Excel template provided in Appendix C, referred to as the vocabulary file. This template must be populated in accordance with the specific data you intend to FAIRify. Once completed, the next step involves leveraging the web-based tool SKOS play to convert the filled-in Excel template into a turtle (ttl) file, utilizing the Simple Knowledge Organization System (SKOS) language. It is imperative to test the conversion process to ensure accuracy.

The final step entails deploying this turtle file within BioPortal, thereby making the ontology accessible for integration with the metadata of healthcare information. This systematic approach facilitates the creation and integration of custom ontologies tailored to the specific requirements of the healthcare information being FAIRified.

Enriching metadata with ontologies from BioPortal

With the inclusion of ontologies in BioPortal corresponding to each data field from our CEDAR template, the next step involves enriching each field within the template with the respective ontology. This strategic integration enables the utilization of the CEDAR template to generate healthcare data accompanied by high-quality metadata. By associating each field with its corresponding ontology, we enhance the depth and specificity of the metadata, contributing to the overall FAIRification of healthcare information within the proposed architecture.

Allegrograph

The healthcare information originating from the healthcare information system undergoes redirection to the CEDAR template. Subsequently, the CEDAR template facilitates the generation of a Resource Description Framework (RDF). RDF serves as a data structure designed to represent knowledge, implementing a machine-interoperable language for encoding semantic graphs. Within this semantic graph, nodes represent universal resource identifiers (URI), enabling seamless querying of metadata across different healthcare facilities and facilitating data access.

RDF formats are typically stored in a triple store, and for our healthcare information exchange architecture, we have selected Allegrograph as our triple store solution. Allegrograph stands out as a multi-model platform, accommodating Vector, Document, and Graph data models. This platform serves as an entity-event knowledge graph, enabling efficient querying of triples and consequently, healthcare information retrieval. The complete FAIRification process is displayed in figure 8 and shows all the methods and tools we have used in this section.

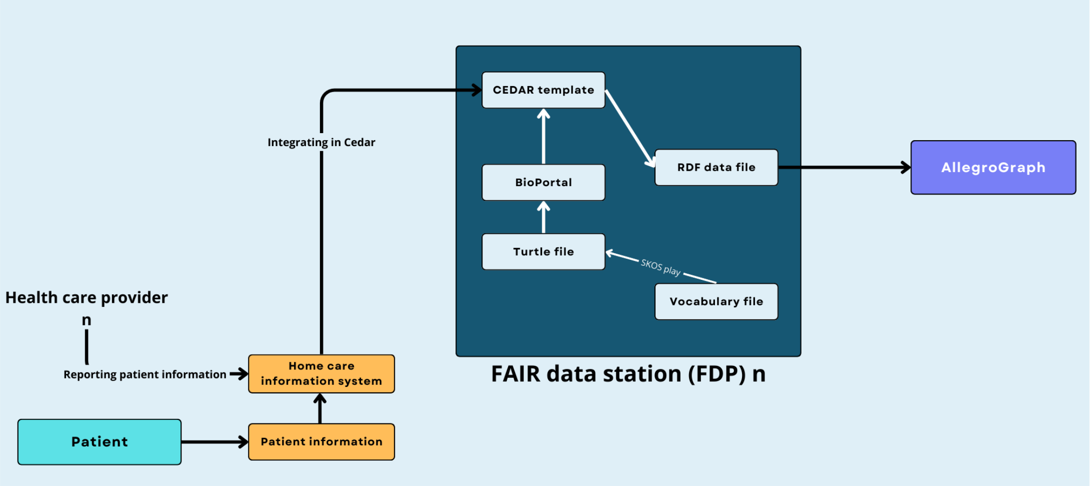


Figure 8: This figure illustrates the process of making healthcare information FAIR

4.2.2.2 Preserving the privacy of the patients

The effectiveness of the healthcare information exchange architecture hinges significantly on the preservation of privacy for patients with chronic brain diseases. As such, it is imperative that appropriate authorization and authentication measures are implemented, ensuring the maintenance of data sovereignty throughout the process. Illustrated in Figure 9, this critical aspect of the proposed architecture entails the following steps to ensure robust privacy protection.

Maintaining data sovereignty to preserve privacy

The proposed healthcare information exchange architecture adheres to the principle of leaving the healthcare information at its original collection point. Access to the data is granted solely upon meeting the authentication and verification criteria, ensuring that only the results of the query can be viewed. This approach serves to uphold the data sovereignty of the sensitive healthcare information, safeguarding patient privacy and confidentiality.

What data has been requested with the query

The initial step involves an automatic review of the query to identify the specific information requested from another healthcare facility. This process provides the system with an overview of the data that will be displayed upon successful transmission of the query to the triple store at the receiving facility. Once this overview is established, the requested type of information is forwarded to the smart contracts integrated within the distributed ledger technology. These smart contracts autonomously assess whether a transaction can proceed based on predetermined criteria, ensuring that only authorized access is granted to the requested healthcare information.

Informed consent

One crucial step in the architecture involves obtaining informed consent from the patient before sharing their healthcare information across different healthcare facilities. To respect patient autonomy, we aim to empower patients to selectively withhold information that they deem unnecessary or sensitive for sharing among healthcare organizations, provided it is not essential for their health. Integration of informed consent into the system serves as a fundamental requirement for authorizing the viewing of healthcare information retrieved by specific queries. Smart contracts within the architecture automatically verify whether informed consent has been provided, ensuring that access to the healthcare information is granted only when this condition is met.

Verifiable credentials (VCs)

The final component entails the authorization requirement, which is enforced through the use of verifiable credentials. Verifiable credentials, a key component of Self-Sovereign Identity within Distributed Ledger Technology, play a pivotal role in authentication processes. Healthcare providers' verifiable credentials are securely stored and retrieved online, enabling them to undergo digital verification to validate their identity. Authentication of healthcare providers typically requires presenting a valid passport and BIG number, a unique identifier that grants healthcare providers the authority to use their protected healthcare title and reassure patients of their legitimacy.

These digital solutions not only streamline identity management but also enhance the efficiency and security of the digital ecosystem, ensuring that only authorized individuals gain access to healthcare information within the exchange architecture.

Authorized and authenticated queries

Once all the prerequisites stipulated by the smart contracts have been satisfied and informed consent has been obtained to view the specified healthcare information, the query is deemed acceptable. At this stage, the query transitions into an authorized and authenticated state, granting permission to automatically retrieve the requested healthcare information from the corresponding healthcare facility. This ensures that only authorized healthcare professionals can access the designated healthcare data, thereby upholding privacy and security measures within the exchange architecture.

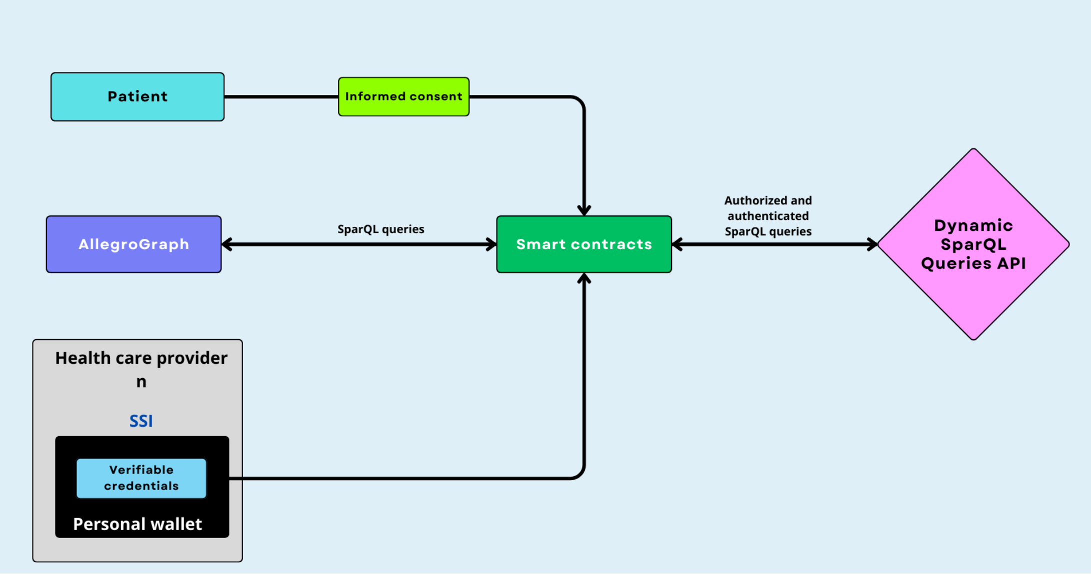


Figure 9: This figure illustrates the authorization and authentication process that we use to preserve the privacy of patients.

4.2.2.3 Visiting the healthcare information of your patients at different healthcare facilities

In accessing healthcare information of a patient from other healthcare facilities, the Personal Health Train ideology is employed. This ideology operates on the principle of data visiting, wherein a query is transmitted to the Dynamic SparQL Queries API hosted by the triple store, Allegrograph, within this architecture. SparQL, being a query language for the semantic web, facilitates this process. However, before automated querying of the triple store at another facility can occur, the access control requirements outlined in Chapter 4.2.2.2 must be satisfied. These requirements are integral for ensuring a secure and authorized visitation of healthcare information.

Once these prerequisites are met, the SparQL query can be utilized to access the requested healthcare information securely. This approach fosters a controlled and privacy-preserving environment, allowing healthcare professionals to access the necessary healthcare data. The entire process is illustrated in Figure 10, providing a visual representation of the data visiting process within the architecture.
To view healthcare information of on of your patients from other healthcare facilities, the Personal Health Train ideology is used. This is a data visting ideology where a query is send to the Dynamic SparQL Queries API from the triple store, which is in this architecture Allegrograph. SparQL is a query language for the semantic web. Before we can automatically query the triple store at onother facility, the access control requirements from chapter 4.2.2.2 have to be met. This allows for a secure and authorized visiting of healthcare information. If these requirements are met, then the SparQL query can be used to visit the healthcare information that we have requested. This allows for a controlled and privacy preserving enviroenment where we can see the healthcare information that we need as a healthcare professional. This process is displayed in figure 10.

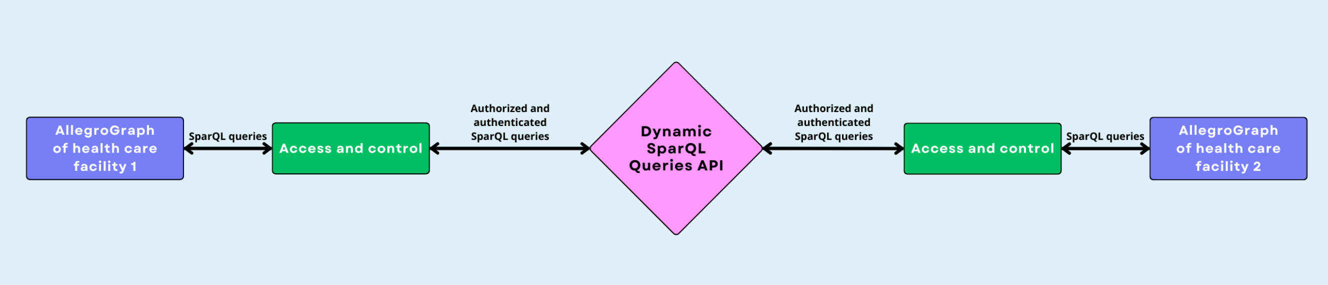


Figure 10: This figure illustrates how the actual communication of healthcare information will happen with the proposed healthcare information exchange architecture.

4.2.2.4 The complete healthcare information exchange architecture

These three components form the foundation of the complete healthcare information exchange architecture tailored specifically for exchanging healthcare information of patients with chronic brain diseases across various healthcare facilities. The complete healthcare information exchange architecture can be found in figure 11.

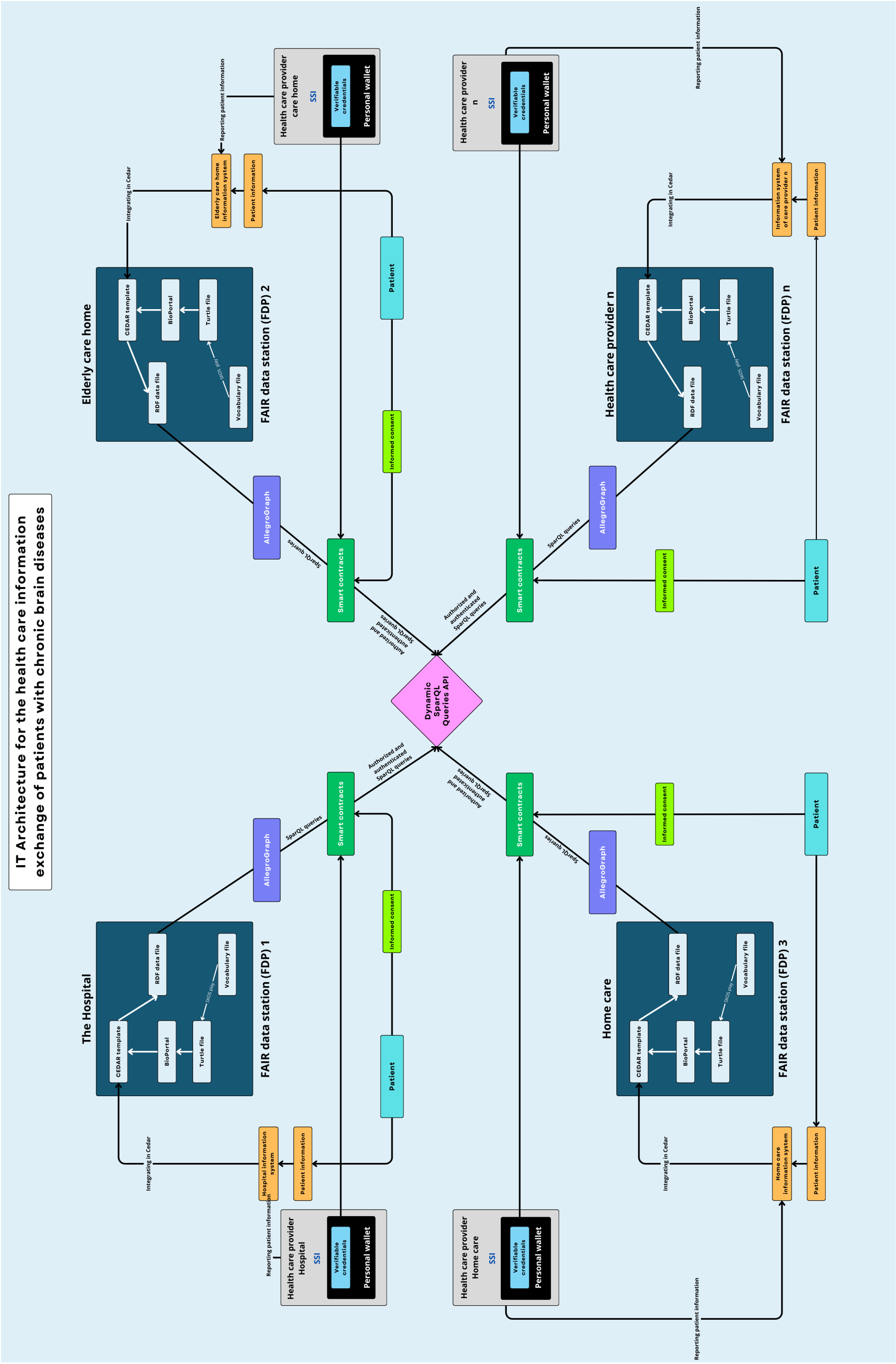


Figure 11: The complete proposed IT architecture for the exchange of healthcare information for patients with chronic brain diseases.

4.3 Testing and implementing the proof of concept for FAIR data production

4.3.1 The assessment of the feasibility of the proposed healthcare information exchange architecture

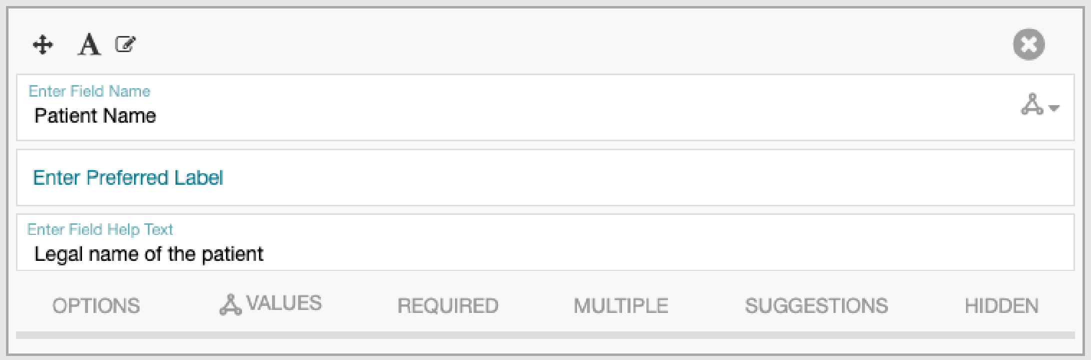
This chapter is structured into two main sections. Initially, we delve into an examination of the tools and methods delineated within the proposed healthcare information exchange architecture, assessing their efficacy and practical applicability for the exchange of healthcare information of patients with chronic brain diseases. Implementation of these tools and methods was undertaken through a collaborative group project involving six master's students from the ICT in Business program as part of their Data Science in Practice course. The subsequent portion of this chapter comprises insights garnered from the interviewees regarding the functionality of the system and its potential benefits for them.

4.3.1.1 The technical assessment of the feasibility of the proposed architecture

To assess the feasibility of the architecture, our initial plan was to commence with the compilation of the most vital information, augmented by the missing data delineated in Figure 4. The objective is to develop an ontology tailored to patients with chronic brain diseases, intended for utilization by healthcare practitioners. To accomplish this, it is imperative to ensure the list undergoes FAIRification to render it machine actionable. This process aims to enable computers to undertake tasks typically performed by healthcare specialists or medical secretaries within healthcare facilities, enhancing the findability of healthcare information and facilitating smoother information exchange.

The FAIRification process

The process of FAIRifying the compiled list of data points involved several sequential steps. Initially, the data points extracted from the table in Appendix B were integrated into a new CEDAR template. This facilitated the creation of machine-actionable data supplemented with metadata. While inputting the data into the CEDAR application, careful consideration was given to selecting the appropriate field type for each data instance. These field types included numerical, textual, datetime, or email fields, ensuring alignment with the expected format for both the template fillers and the CEDAR system itself. An illustrative example of such a field is depicted in Figure 12.



Enter Field Name
Patient Name

Enter Preferred Label

Enter Field Help Text
Legal name of the patient

Figure 12: This figure illustrates the process of loading data into the CEDAR template.

This figure provides details about a data instance, including the field name, accompanying help text clarifying the required input, and the corresponding field type. The field type is denoted by the letter A in the header, indicating that it represents a text field.

Once all the data instances from Appendix B have been incorporated into the CEDAR template, we proceed to follow the flow diagram depicted in Figure 13. This process aids in establishing connections between all the fields and the ontology in BioPortal.

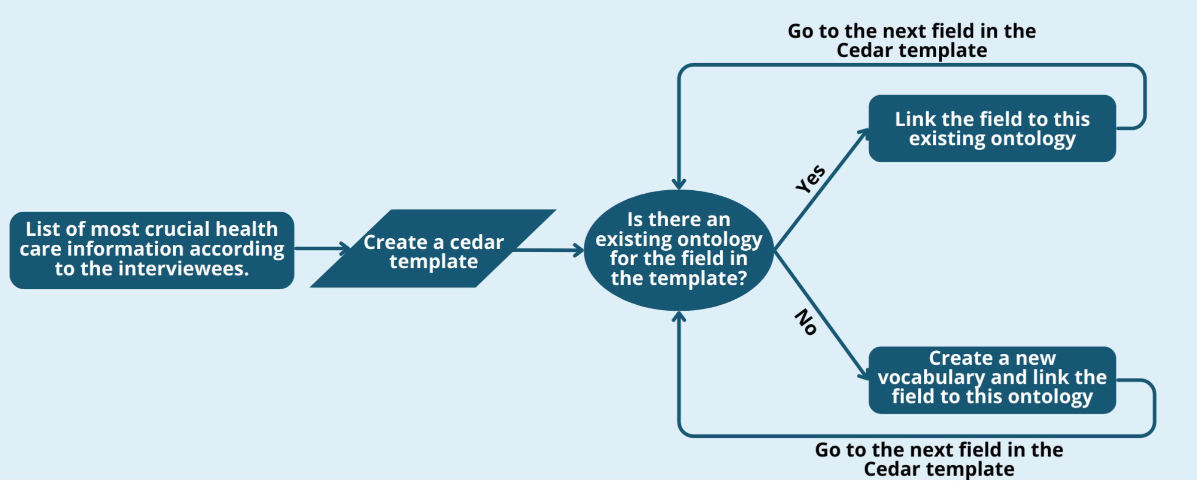


Figure 13: This figure delineates the necessary steps for constructing a CEDAR template and associating the fields with the respective vocabularies.

Linking to an existing ontology

The initial steps, involving the identification of the most crucial healthcare information from the interviews, have been elaborated upon in preceding chapters. Subsequently, it is imperative to establish connections between all fields and data instances in CEDAR with an existing ontology in BioPortal, whenever feasible, to facilitate future accessibility. By linking the data field in CEDAR directly to a definition available in BioPortal, approximately half of the 83 data points/fields collected could be associated with an existing BioPortal ontology.

Linking data to a non-existing ontology

For the data points that could not initially be linked, a new vocabulary was generated and uploaded to BioPortal. Within this vocabulary, we defined the remaining data points. The vocabulary creation process commenced with the utilization of an Excel template provided by the Leiden Institute of Advanced Computer Science, as detailed in Appendix C. Subsequently, the Excel template was completed with the requisite information pertinent to our specific use case and the data points not linked to an existing ontology in BioPortal. This Excel file, filled with our data, is available in Appendix D. The Excel template was then transformed into a machine-readable format, specifically a turtle (.ttl) file, facilitated by SKOS Play, an online application supporting SKOS (Simple Knowledge Organization System). Following the conversion, the newly generated turtle file underwent testing on SKOS Play to identify and rectify any potential errors or inconsistencies. The refined vocabulary was subsequently uploaded to an ontology on BioPortal, facilitating the sharing and accessing of structured information. As a result, the remaining half of the 83 data points/fields were linked to the ontology uploaded to BioPortal. This process of creating a new vocabulary and linking it to the fields in the CEDAR template is depicted in figure 14.

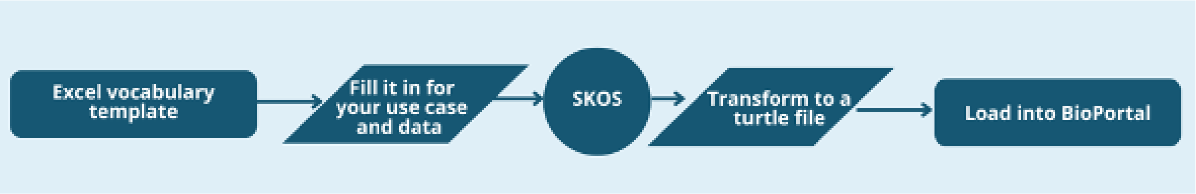


Figure 14: This figure illustrates the sequential steps required for constructing a new ontology and subsequently loading it into BioPortal.

The finalised CEDAR template

Once all fields were successfully linked to an existing vocabulary, the CEDAR template reached completion. This advancement enabled the population of the template to generate machine-actionable data. Filling in the form generated by the CEDAR template facilitates this process. The first section of this form is displayed in Appendix E.

Visualizing and querying the data using Allegrograph

Once the form has been populated, it becomes possible to obtain a Resource Description Framework (RDF) file containing the data in triple store format. Subsequently, this RDF file is loaded into Allegrograph utilizing its efficient parser. Allegrograph serves as a graph database specifically designed to efficiently store RDF data and facilitate complex queries using the SPARQL language. These queries enable access to specific data or subsets from the data. Furthermore, AllegroGraph provides visualization capabilities for the RDF data or query results, facilitating a comprehensive analysis of relationships and patterns within the dataset. Querying the data allows for access to patient data without the need to transfer it from the healthcare facility. An illustrative example showcasing patient data visualized and accessed through Allegrograph is presented in Figure 15. Figure 15 depicts the result of querying the retrieved RDF for CEDAR using SPARQL. The central node displays a unique identifier directly linked to various classes. The directed links establish relationships between the central identifier and other classes. This setup facilitates easy and efficient querying, particularly when retrieving data for a single patient from a larger dataset. This allows for personalized retrieval of healthcare information which can contribute to the availability of healthcare information and therefore more personalized care.

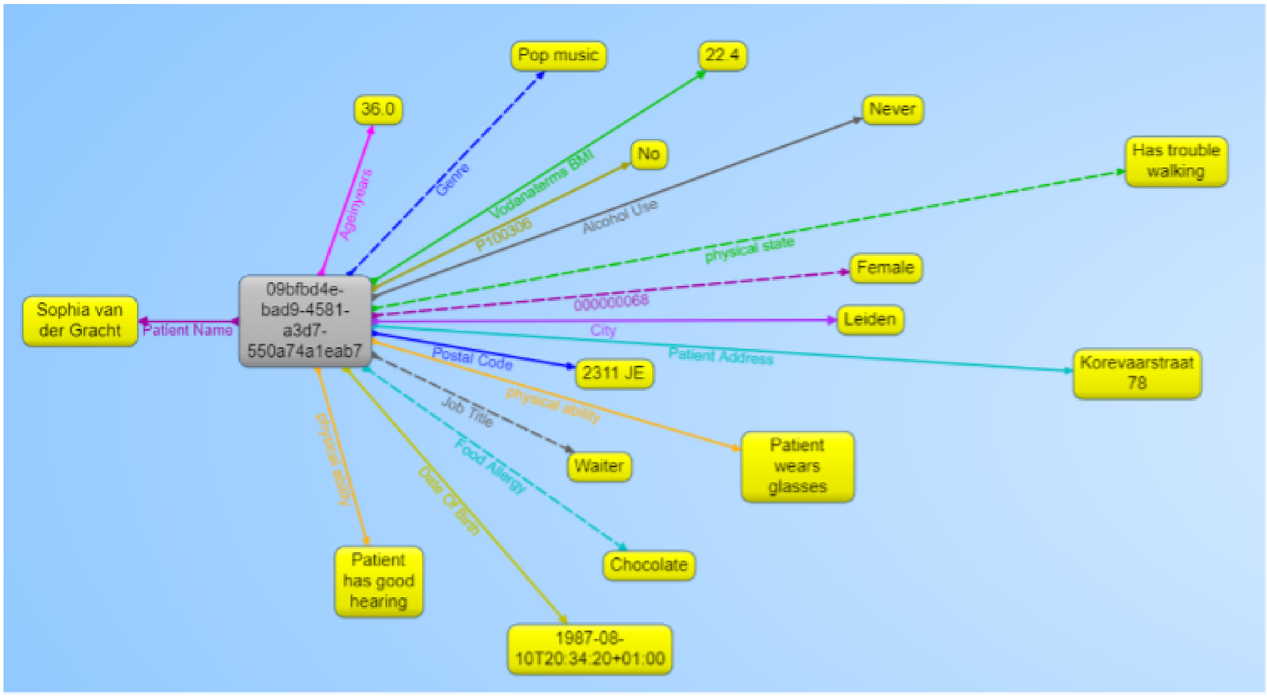


Figure 15: This figure shows shows an example of how RDF patient data can be visualized in Allegrograph.

4.3.1.2 The responses to the proposed solution from the interviewees

This section will explore the responses provided by the interviewees upon explanation of the proposed solution and architecture. The interviewees were briefed on how the health information exchange could potentially change, with minimal information provided on the technical solutions behind it. This approach was adopted as the interviewees lacked an IT background. Reactions from healthcare specialists and caregivers of patients with chronic brain diseases, such as those with dementia, varied across several categories. While many expressed positive feedback, some also harbored reservations. Additionally, interviewees identified certain limitations to the proposed solution and offered suggestions for improvement, occasionally pertaining to the proposed solution and sometimes addressing unrelated aspects.

Positive remarks from the interviewees

We will explore the positive reactions elicited from the interviewees towards the proposed solution. Firstly, we will discuss the general positive feedback received. Following this, we will examine the positive reactions regarding how it can enhance information exchange within healthcare facilities. Subsequently, we will delve into its potential to improve information exchange between healthcare facilities. The interviewees also expressed enthusiasm regarding the fact that the proposed solution does not involve data movement and maintains data where it is collected. Additionally, they highlighted the necessity for an easier and faster method to understand patients on both medical and personal levels. Finally, positive feedback was received on how this research contributes to leveling the playing field and providing healthcare specialists with a comprehensive view of the medical situation.

General positive remarks

The overall sentiment conveyed by the interviewees regarding the proposed solution and its impact on healthcare information exchange was positive. One of the interviewees expressed delight that this topic is being researched, emphasizing the importance of both the research topic and the implementation of a solution derived from this research:

> *(#11, Dementia care physician, face to face, with LS) No, yeah, I think it's just great to hear that you're working on that and that, so I think it's very valuable, actually, because I think a lot of time is lost in searching and those kinds of handovers, and especially in these times, yes, with indeed the shortage of people working in healthcare, and while the care burden is only increasing in the coming years, I think that could be very valuable if something could be improved there. So, yeah, I'm especially very curious.*

This illustrates the significant demand among healthcare specialists for such a solution, affirming the problems identified in this research for both the present and foreseeable future. It is evident from the interviews that the fundamental concept behind the proposed solution for healthcare information exchange would greatly satisfy many individuals. One interviewee emphasizes the following regarding this aspect:

> *(#16, Two care physicians, face to face, with LS) Yes, I think just the basic idea, as you say, if that is feasible from all angles, such an underlying search system. I think that would make a lot of people happy. Yes, I would certainly be happy with it.*

This interviewee emphasizes uncertainty regarding the current feasibility of the proposed solution, noting that if it were indeed feasible, it would bring satisfaction to them and many others working with patients with chronic brain diseases. This sentiment resonates with another interviewee who also expressed enthusiasm about the proposed solution:

> *(#6, Chronic brain disease care physician, face to face, with LS) Yes, yes, yes, it would be fantastic. I'm getting more and more excited. Yes, it would really save a tremendous amount of time. That's absolutely true. It would really save a lot.*

The interviewee expresses excitement regarding the potential time-saving benefits of the proposed solution for individuals working in healthcare. This underscores the necessity for change within healthcare to alleviate pressure on healthcare specialists. Similarly, another interviewee spoke positively about the proposed solution and highlighted the ongoing discourse within medical journals about improvements to healthcare information exchange:

> *(#7, Case manager dementia, face to face, with LS) Yes, they would still be able to provide quality care by essentially removing some administrative tasks and adding more time for care. That would be the most idealistic scenario. And if you follow medical journals a bit, everyone is really struggling with this. So all doctors would be very satisfied if you could develop something that at least makes this process smoother or faster.*

This interviewee expressed hope that the proposed solution would alleviate some of the time healthcare specialists spend on administrative tasks, thus enabling them to dedicate more time to patient care. Additionally, the interviewee highlighted the widespread recognition within medical journals of the need for a solution to healthcare information exchange, indicating that the proposed solution could generate excitement among many doctors. This underscores both the acknowledgment of the problem by interviewees and the medical community, as well as the significant demand for IT solutions to address this perceived issue. Lastly, one of the shorter positive responses from an interviewee was:

> *(#13, Caretaker, face to face, with LS) That would be really great if something like that could happen, yes.*

This illustrates the overarching sentiment regarding the proposed solution, reflecting both the emotional response and the demand from healthcare specialists and caretakers for an enhanced method of sharing healthcare information.

Positive remarks about how it could improve the information exchange within healthcare facilities. The proposed solution aims to enhance the findability of data, thereby facilitating the retrieval of healthcare information for medical specialists with the appropriate access clearances. According to one of the interviewees, this can contribute to the efficiency of healthcare information exchange within a healthcare facility:

> *(#14, Caretaker, face to face, with LS) Well, I think it's very important, even for the doctors among themselves in the hospital. That would already be a big thing.*

This indicates that there is room for improvement in healthcare information exchange even within healthcare facilities, suggesting that the proposed solution could enhance the communication of healthcare information among doctors in a hospital, for instance. One interviewee, who serves as a caretaker for his wife, provided an example of how an enhanced information exchange and simplified exploration of patient data could assist the healthcare facility in addressing nutrition preferences:

> *(#12, Caretaker, online, with LS) But then, even in the hospital, it was like, well, she has this food allergy, for example, she can't drink milk, but soy is fine. That was also a search in the hospital. Then I think, guys, hello, we already informed you about this a while ago. And then the kitchen has to order again, so you're in a situation where if they don't know in advance, there's nothing available on the ward. Then she doesn't get proper nutrition, so to speak. And if they had an app, for example, to check from the dossier, and you request it, and you have certified data, which is reliable, then they can work with that again. So I think it would help from all sides.*

This demonstrates the potential for a more efficient method of finding and sharing information within healthcare facilities, which could help circumvent and prevent certain problems. Moreover, the proposed solution could streamline the automation of tasks, such as automatically ordering soy milk for a lactose-intolerant individual upon their arrival at the healthcare facility.

Positive remarks about how it could improve the information exchange between healthcare facilities The interviewees also provided feedback on how the proposed solution could enhance information exchange between healthcare facilities. One interviewee expressed satisfaction with this observation, noting that the solution could assist in addressing this issue:

> *(#2, Elderly care physician, face to face, with LS) No, I think that would really make a significant difference because, currently, in the ideal world, someone who is admitted has all the papers from the hospital with them. However, it still happens that they don't have them with them, and we have to ask for them.*

The interviewee expressed concern about the occasional absence of necessary patient letters, resulting in healthcare providers assuming responsibility for obtaining the relevant healthcare information. The proposed solution could alleviate this burden from patients and streamline the exchange of healthcare information between different healthcare providers and caretakers. This observation was echoed by another interviewee who emphasized how it could enhance their communication with the general practitioner:

> *(#9, Caretaker, face to face, with LS) But I do notice, because where I work now, we often need medical records from the general practitioner. Yeah, you have to ask for them repeatedly because there's no time. Neither the general practitioner nor the general practitioner's assistant has time, so this, yeah, this would really be nice. I think it's good if you get specific information through that. Somewhat similar to when I call a clinic now. I assume it's a bit faster then.*

This demonstrates the areas in which this interviewee perceives value in the proposed solution within their daily responsibilities: it saves time for both themselves and for those who are responsible for sharing information with them. Additionally, this interviewee corroborates our finding that healthcare specialists face time constraints and are frequently awaiting information. This is a key area where our proposed solution could provide assistance. Our interviewees also highlighted that the current process of requesting and receiving data takes too long. One interviewee specifically discussed how this affects admissions:

> *(#4, Elderly care physician, online, with LS) Yeah, well, I think, if you, if you're talking about where perhaps most of the information exchange happens from our perspective, it may be different from another perspective. Where most of the information exchange occurs would be, for example, during admissions. If you're talking about data that is always available, say if you want to query things, we often need to know things in hospitals, if hospitals all have machine-readable data, so to speak, and you can look it up in a kind of Google search, then many organizations would be helped with admissions, if you want to help someone understand how things were with the cardiologist, you can also inquire immediately and get an answer instead of it taking weeks.*

This interviewee discusses the lengthy timeframe, spanning weeks, between requesting and receiving data when a patient is admitted to their healthcare facility. They perceive this delay as problematic and recognize how the proposed solution could expedite this process, fostering innovation in healthcare information exchange and communication among healthcare facilities and organizations.

This aligns precisely with the goal of the proposed solution.

Positive remarks about leaving the data where it is collected
An integral aspect of our proposed solution is the avoidance of physical or electronic transfer of data from one computer to another. Instead, the data is queried to provide results for any question regarding one or multiple patients. This ensures that there is a single point of truth for all data, and whenever the same question arises, the system can be queried again for the information by sending another query. This was one of the points that elicited positive reactions from the interviewees:

> *(#6, Chronic brain disease care physician, face to face, with LS) And yeah, I find what you're working on quite interesting. And um, yeah, I really think this... I really think it would save a lot. That it could be much more efficient. And also exactly what you said, not having to email and send data back and forth all the time, but just being able to look into the system. Just a section, if you have access. Yeah, like an access pass. And you leave it where it belongs.*

This indicates that the interviewee is enthusiastic about this aspect of the proposed solution and recognizes a notable increase in efficiency whenever such a solution is implemented. This sentiment was affirmed by the interviewee:

> *(#6, Chronic brain disease care physician, face to face, with LS) I think especially indeed with that sending of information, that's where a huge problem lies. Yeah, I really think indeed if you can leave your data where it is collected that there is just a lot to gain.*

This interviewee acknowledges the issue of sending information to each other and the fragmentation of medical records. They agree with the proposed solution, believing that it could effectively address and resolve this specific problem.

Positive remarks about better knowing the patient on a medical and personal level
While it aids in information exchange between facilities when a patient transitions from one facility to another, it can also facilitate access to the patient's medical history at other facilities when the healthcare specialist responsible for the patient changes, and there is limited time to familiarize oneself with each patient on a personal level:

> *(#15, Caretaker, face to face, with LS) And those nurses who rush in and out, sometimes they don't have time to get to know all the people personally. So how nice is it when they encounter something, that with one click on the computer, they can get the piece of information they're lacking.*

When nurses lack time to establish a personal connection with a patient, the proposed solution can expedite information retrieval and enable personalized care in a shorter time frame. This feature of the proposed solution was recognized by the interviewee and viewed positively. Personalized care necessitates not only understanding a patient's medical condition, such as dementia, but also forming a personal connection. This may be challenging, especially in advanced stages of dementia. Therefore, it is crucial to exchange not only medical data but also personal information, referred to as "softer data" in this research, more efficiently. One interviewee expressed satisfaction that softer personal data was also included in the proposed solution:

> *(#2, Elderly care physician, face to face, with LS) No, I don't think so. No, I also think it's nice that you're not just looking at the hard medical data, but also more at the soft data. Yes, yes, we're not always so focused on that. Or we encounter it less, I think. We're less frustrated by it because we don't expect it to be available. But it would indeed be nice if it could be retrieved more easily.*

This research proposes a solution where not only medical data but also softer personal data is more readily available for healthcare specialists and caretakers. While medical specialists may not always anticipate the availability of such data, this interview highlights their recognition of its value. Another interviewee confirmed this perspective when discussing the various branches of information that each person possesses. It is evident that caretakers and healthcare specialists desire comprehensive access to these information branches and aim to leverage IT tools to enhance the care they provide to patients. The interviewee emphasized that while this is an IT solution, it ultimately aids and personalizes human-to-human interaction:

> *(#7, Case manager dementia, face to face, with LS) It seems like a technical story, right, with a computer and information in the computer, but it's actually about the person. Who is that person with all those branches, and ultimately, when you have that information, you get a better picture of the person, and that benefits the care.*

This demonstrates a hesitancy towards IT solutions in healthcare, yet also reveals a hopeful outlook regarding the potential for these IT solutions to support healthcare specialists and personalize healthcare, particularly for vulnerable patients such as those with dementia.

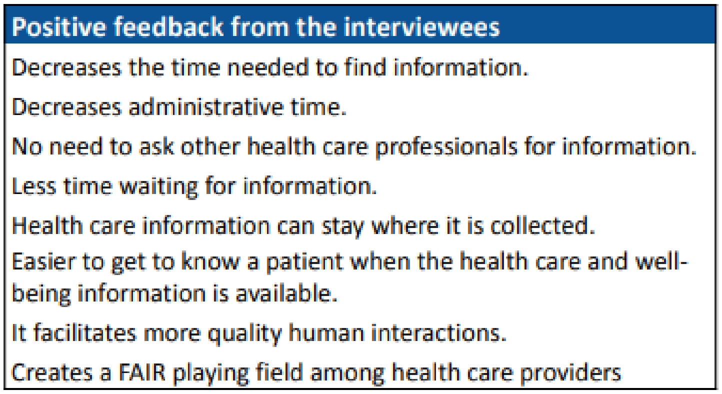
Positive remarks about getting a fair and complete idea of the medical situation
Whenever a medical letter is created by one healthcare facility for another, there is discretion in selecting what to include and what to omit. In some instances, certain details may be intentionally or inadvertently omitted from these letters. One of the interviewees emphasized that the proposed solution has the potential to ensure that all relevant information is available when access clearances are met:

> *(#16, Two care physicians, face to face, with LS) I can see the complete picture then, the honest representation because now it still happens. You don't have hard evidence for it. It's a bit of speculation what you do, but sometimes you feel that not everything is fully disclosed. To be able to discharge someone from the hospital as quickly as possible, that's not really commendable if it really happens that way, of course we can't say, but it does happen occasionally and in that regard, that system might create a more fair playing field.*

It is evident from this discussion that there is a requirement for a comprehensive understanding of healthcare information, and the absence of certain details could have ramifications. This interviewee particularly emphasizes how the proposed solution could promote fairness by ensuring equal access to information. The interviewee even suggests that in some instances, hospitals may prioritize discharging patients quickly, leading to omissions in medical transfer letters, thereby creating challenges for staff at other healthcare facilities.

A summary of the positive feedback from the interviewees

The positive feedback of stakeholders towards the proposed healthcare information exchange architecture is condensed in figure 16.



Positive feedback from the interviewees
Decreases the time needed to find information.
Decreases administrative time.
No need to ask other health care professionals for information.
Less time waiting for information.
Health care information can stay where it is collected.
Easier to get to know a patient when the health care and well-being information is available.
It facilitates more quality human interactions.
Creates a FAIR playing field among health care providers

Figure 16: This figure shows an overview of the positive feedback of stakeholders towards the proposed healthcare information exchange architecture.

Interviewees who still had some reservations

Not all reactions were entirely positive; some interviewees expressed satisfaction with the proposed idea but still harbored some reservations. This is a natural consequence when proposing any kind of change and must be taken very seriously.

The security

One of the interviewees expressed concerns regarding how security could be maintained. Security measures are crucial to safeguard healthcare information from unauthorized access. The interviewee emphasized the following points regarding this topic:

> *(#16, Two care physicians, face to face, with LS) So yeah, there are certainly very good aspects to the idea. But also, well, everything you open up becomes on the other hand less closed, and that can be a problem.*

The interviewee discussed how simplifying access to and exchange of healthcare information between facilities could potentially compromise the privacy of such information. This underscores the importance of security in this particular use case, given the sensitivity of the data involved.

Increase in administrative load

Another concern raised by an interviewee is the potential increase in workload, particularly the administrative burden associated with implementing and maintaining the proposed solution.

> *(#3, Elderly care nurse, online, with LS) Yes, that's why I mentioned the administrative burden. You wonder, what additional tasks will come with it? I can understand that you need to invest time and effort to start something. But then, how do you maintain it? Who will do what? It's also a matter of task allocation, but then, is there enough funding for it? Do I need to hire someone for that? In my previous job, we had to do our own scheduling, but in my current job, we have planners, people who are hired for that. It relieves an incredible administrative burden, but the organization needs to allocate funds for it.*

This interviewee is concerned not only about the potential increase in administrative workload but also about the possibility that the solution may only be accessible to healthcare facilities with sufficient resources to hire personnel for its implementation and maintenance. This reservation was echoed by another interviewee, who focused solely on the impact of increased administrative burden. This concern was further elaborated on in the subsequent part of the interview:

> *(#5, Elderly care physician, face to face, with LS) Wouldn't you increase that even more? It has often been in the news: the high administrative burden in healthcare. Isn't it then adding even more burden to all those disciplines that are already too busy, because they already have to fill in so many things also for the insurer and such?*

The interviewee highlights that individuals working in healthcare are already overwhelmed with their existing responsibilities and cannot accommodate any additional workload. Therefore, adding extra administrative burden to their daily tasks would not be feasible.

Human interaction is just as important as IT innovations.

Two interviewees expressed concern regarding how IT solutions may overlook the human aspect that is essential in healthcare. One interviewee feels that there is an excessive reliance on computerization, which may not always be beneficial:

> *(#15, Caretaker, face to face, with LS) Yes, that's true. It's super important. I also feel that in today's time, everything is computerized, all through the app. It's not the same as personal interaction. You only truly understand how it should be when you can look someone in the eye, you know?*

This interviewee acknowledges the importance of the proposed solution for the care of patients with chronic brain disease but also emphasizes that it can never fully replace personal interaction. They highlight the significance of interpersonal cues, such as eye contact, which provide valuable information and should not be disregarded in IT innovation, particularly in contexts involving human interaction. A similar sentiment was echoed by another interviewee, who also expressed optimism about the proposed solution while underscoring the indispensable role of human involvement for the success of any solution:

> *(#3, Elderly care nurse, online, with LS) And then I hope that systems like yours will continue to help us further. That's always the case. It can always be better, it can always be more efficient, as long as it doesn't come at the expense of people and caregivers, no, that's what I consider most important.*

Both of these interviewees articulated these points as factors to consider during the research process. Despite their reservations, they maintained high hopes for and belief in the potential of the proposed solution.

Unnecessary solution for some healthcare professionals
One of the interviewees expressed concern about whether the proposed solution would effectively assist every healthcare specialist involved in the care processes of patients with chronic brain diseases, such as those with dementia:

> *(#10, Elderly care nurse, face to face, with LS) A treating physician, yes, they... I don't think they necessarily need to be relieved, because then we're happy to think along [as nurses], and that can be fairly brief.*

This interviewee holds the view that a treating physician may not require such a solution, as they can rely on nurses to answer any questions they have about a patient. However, this perspective was contradicted by another interviewee who believed that nurses would not derive benefits from the proposed solution:

> *(#3, Elderly care nurse, online, with LS) I think the system, I think it's a good concept. However, I don't think it adds much for nurses because that information, well, we request it from the doctor. The doctor has access to it. [...] But if you, let me disrespectfully call it a helper, an extension of, I am an extension of the doctor, then I can't think of a situation where I would actively use this system. I don't need to inquire whether this gentleman has a history of high blood pressure or anything like that because then I ask a elderly care physician if this gentleman is familiar with it. Do you have any information or have you received a handover on this? That's a bit... Well, that's entirely from my role. Maybe another nurse sees it differently. But that's how I see it. [...] I don't see the added value of such a system, but maybe a practitioner thinks differently. I think so. As a practitioner, I would find it very useful if I had easy access to what my predecessors or my medical colleagues or paramedical colleagues have done for this person; I would find that very handy.*

This interviewee conveyed skepticism regarding whether a nurse would directly benefit from the proposed healthcare information exchange system. The interviewee is of the opinion that any questions they have can be directed to an elderly care physician. However, the interviewee acknowledged that the proposed solution could be highly beneficial for practitioners.

A summary of the reservations from the interviewees.

The reservations of stakeholders towards the proposed healthcare information exchange architecture are condensed in figure 17.

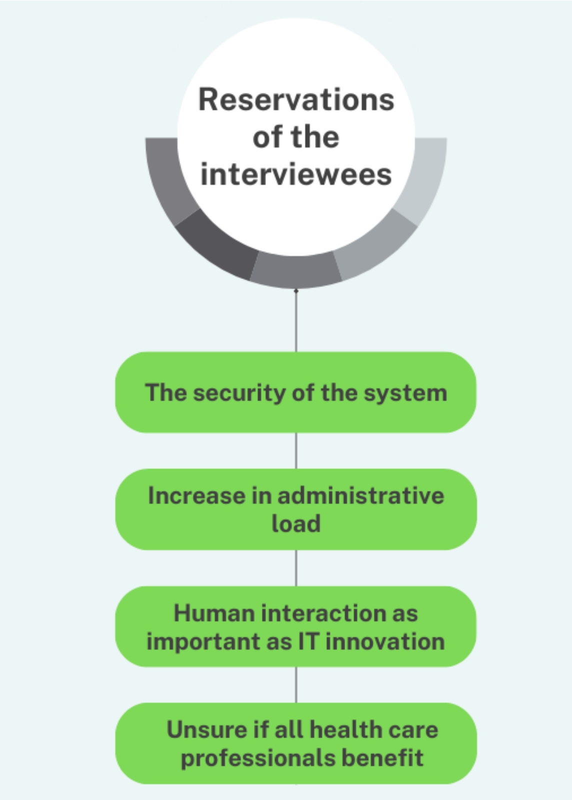


Figure 17: This figure shows an overview of the reservations of stakeholders towards the proposed healthcare information exchange architecture.

Limitations or advice from the interviewees

There were also some limitations and pieces of advice that the interviewees shared about the use case, which can be helpful to consider for implementing the proposed solution in real life. These insights are crucial to address before, during, and after implementation to enhance the chances of success. Therefore, these remarks should be documented and utilized for future research and implementation.

The resources available at smaller health facilities

Bigger healthcare facilities may possess more resources than smaller ones, including financial resources, medical specialists, supporting staff, and IT specialists. It is essential to consider this disparity when designing and conceptualizing a proposed solution, as it should cater to both smaller and larger healthcare facilities. One of the interviewees commented on this aspect as follows:

> *(#3, Elderly care nurse, online, with LS) Now I'm curious. We're talking about larger institutions here, which often have some money. But now, here at my health center, there's a small physiotherapy practice. Yes, and there are two physiotherapists who have a practice there, and for such a system to be purchased, I don't think those guys have the money, but they do have a patient base from half the neighborhood here, with people who already go to the hospital or to an institution, or who still receive outpatient physiotherapy. How will you ensure that everyone can use such a system? That's a lot for a small dietitian practice, a small podiatrist, and all those small healthcare entrepreneurs who simply don't have the funds to make such an investment. How do you deal with that?*

This interviewee emphasized the importance of ensuring that the proposed solution does not exclusively benefit healthcare facilities with ample resources. Specifically, the interviewee highlighted financial considerations, noting that smaller institutions like a small physiotherapy practice may have limited funds available to invest in such a solution. It is crucial to acknowledge this disparity in available resources when implementing the proposed solution.

Some specialists should see different information from others

One of the interviewees emphasized the importance of maintaining distinctions in the access levels of healthcare specialists. Currently, healthcare specialists have the ability to send or not send information, but the mechanism for determining access to specific information within the proposed solution remained unclear to this interviewee. As a result, concerns about privacy were raised by the healthcare specialist:

> *(#16, Two care physicians, face to face, with LS) And I also wrote down a piece about security, who will determine who can access which information. For example, imagine I'm a physiotherapist, then it's good to know if I know that someone, for example, has orthostatic hypotension, a drop in blood pressure when moving. That's good to know. But if it's in the dossier that, for example, I don't know, a man has erectile dysfunction or has some issues in the genital area, that's not at all relevant for that physiotherapist.*

The interviewee highlights the importance of distinguishing between different types of information. While certain information may be appropriate for access by physiotherapists, more sensitive details, such as erectile dysfunction, should remain private. Consequently, the interviewee urges the researcher to carefully consider these distinctions before implementing the proposed solution. This concern is echoed by another interviewee in the following part of that interview:

> *(#3, Elderly care nurse, online, with LS) Who is going to check the boxes like 'Okay, you can access this information, that information, and that information'?*

Determining access permissions and defining which information is accessible to different healthcare specialists is one of the critical aspects of implementing the proposed solution. This decision impacts the confidentiality and privacy of patient data, making it essential to establish clear protocols and guidelines for access control.

Keep it simple
An interviewee emphasized the importance of simplicity in IT solutions, suggesting that the best solutions are often simple approaches to complex problems. This underscores the need to prioritize simplicity in both research and implementation processes to ensure usability and maximize benefits for users:

> *(#15, Caretaker, face to face, with LS) And I think, then you have to, that's your job to keep it simple because obviously there aren't [always] such smart people. I notice it myself, fortunately I can still do some, but I would like to do much more, but it just doesn't come in anymore. But of course, I have peers who don't use apps, who don't have a mobile phone, who can't email, so then we're lagging behind a lot. Now that would probably catch up again because you are from the new generation and nowadays they start using those devices at one and a half.*

The interviewee emphasized the importance of simplicity in the proposed solution, particularly in the context of patients that suffer from chronic brain diseases. Given that these individuals may need to grant permission for data sharing, or in cases of severe dementia, their caregivers or family members may make such decisions on their behalf. Importantly, the end-users of the proposed solution, including healthcare professionals, may not possess extensive IT backgrounds. Thus, it is crucial to ensure that the solution remains straightforward and user-friendly to prevent it from becoming overly complex.

Connectivity or system failure issues

The interviewee, a caretaker with an IT background, raised a concern regarding the continuity of access to healthcare information once the connectivity or system is established. They emphasized the need to ensure uninterrupted access to health information even in the event of system failures or connectivity issues:

> *(#12, Caretaker, online, with LS) What I sometimes encounter from my own IT background is that you always have to arrange for help when the cloud is temporarily unavailable for whatever reason. You can ask a nice question, but you won't get an answer, so how do you solve that? Depending on the situation you're in, you want to have a fallback in case something goes wrong. But those are more technical setup issues that come up later, have less to do with healthcare, but it is something to pay attention to later on.*

The interviewee offers an example from their experience working with a cloud system, emphasizing the importance of having a fallback system in place. They suggest that a similar approach should be taken in our use case, ensuring that healthcare information exchange remains possible even in the event of technical issues. These considerations highlight the technical aspects that need to be addressed when implementing such a system.

A summary of the advice and limitations

The limitations and advice provided by stakeholders in the healthcare information exchange of patients with chronic brain diseases are condensed in figure 18.

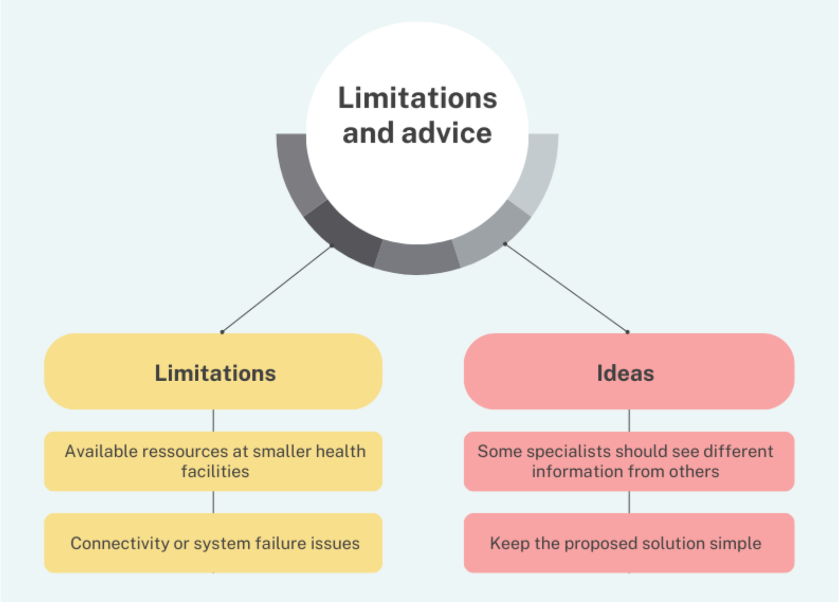


Figure 18: This figure shows an overview of the limitations and advice provided by stakeholders in the healthcare information exchange of patients with chronic brain diseases.

Ideas from the interviewees

Some interviewees presented ideas aimed at addressing short-term healthcare challenges prior to the implementation of the proposed solution, while others suggested ideas that complement or build upon the proposed solution. These ideas offer valuable insights for enhancing efficiency and effectiveness within healthcare and improving healthcare information exchange. Detailed descriptions of the proposed ideas can be found in this chapter.

Involving the family more

One of the interviewees emphasized the importance of strong collaboration among caregivers, patients, and healthcare specialists. This sentiment was elaborated upon during the interview:

> *(#14, Caretaker, face to face, with LS) Involve the family if the family is willing, or friends or acquaintances who might be able to pitch in. I always tell them, 'If it's busy, give me a call, I'll be there in half an hour. I can provide care, even if it's not scheduled for me to be there in the morning. Just to make it easier for my husband, so he doesn't have to feel rushed when taking his medications. They're short-staffed, so I make sure I'm there because then they don't have to do it, and I know he'll just relax, get washed, dressed, and sit in the chair comfortably when I help him.'*

This insight underscores the significant role that individuals surrounding the patient can play in enhancing the care process within healthcare facilities. The interviewee emphasized the value of allocating sufficient time for each patient and its impact on patient well-being. Additionally, the interviewee noted that while not all patients may have a support system, it underscores the importance of involving willing and able family members or caretakers in the care process.

Training for caregivers

Training plays a crucial role in enhancing various aspects of any situation. One interviewee raised a question regarding the availability of training programs for caregivers aimed at supporting the care received by the patient:

> *(#15, Caretaker, face to face, with LS) I have no idea if family caregivers receive a few hours of training. I have no idea, but that would be wise.*

This initiative could enhance collaboration between healthcare providers and caretakers, facilitating joint efforts to ensure the patient receives optimal and personalized care. Moreover, it could alleviate some of the burdens faced by healthcare specialists. This concept aligns well with the previous suggestion to involve individuals around the patient more actively in their healthcare journey.

The power of smart planning

Planning is a crucial in improving efficiency. This interviewee emphasized the significance of having a well-structured and clear plan in place, particularly in situations where healthcare providers are too busy to exchange information or document patient interactions effectively:

> *(#15, Caretaker, face to face, with LS) Yeah, that's something, you know, I'm not an expert, but I figure with my simple understanding, how important it is to have good planning.*

The statement was made in acknowledgment of the existing barriers hindering efficient exchange of healthcare information. The interviewee expressed belief in the potential for significant improvements in this aspect of healthcare delivery.

Creating a tool which transfers speech to text for documenting healthcare information

An idea proposed by one of the interviewees was to employ a tool or application that converts speech to text, aimed at reducing the administrative burden in healthcare:

> *(#9, Caretaker, face to face, with LS) Perhaps recording it or something on your phone, and then it goes directly into the file, something like that?*

This tool could be particularly beneficial for healthcare specialists who may not be proficient with computers, potentially saving time for all involved parties. It could complement the proposed solution by reducing the administrative workload and expediting the exchange of healthcare information.

Personalized visualization of data

After the implementation of the proposed solution, handling patient data becomes more manageable as it becomes machine actionable. Consequently, we can more readily visualize and present crucial information to healthcare specialists. During one of the interviews, this aspect was explored, and the interviewee shared some ideas regarding it:

> *(#12, Caretaker, online, with LS) No, maybe from a professional perspective, I see it more as visualization of the data. So, you throw in data points, fill up the bin, you have a whole list. For me right now, say if I were to go there, I would find it comforting to see what happened with my wife chronologically side by side, just like in a booklet where you can flip a page per day. I can imagine that the same data would need to be categorized for a doctor or specialist. They have less need for details, so they'd say, 'Did something happen today or not?' So, they figuratively speaking, have no interest in all those well-being pieces, to put it a bit bluntly.*

The interviewee expressed the desire for a chronological overview of his wife's medical history. Additionally, they emphasized that what might be important to them could be irrelevant to others. For instance, a doctor may not necessarily need a detailed account of every event but rather focus on abnormalities or critical findings. Personalized dashboards could address this by tailoring information according to individual needs, a feature achievable through the proposed solution.

Involving ambulances in a proposed solution

One of the interviewees emphasized the importance of including healthcare specialists working in ambulances in discussions about healthcare information exchange. They noted that these professionals require crucial patient information during transfers, as unforeseen circumstances can arise en route. Thus, integrating them into the proposed solution was deemed essential:

> *(#5, Elderly care physician, face to face, with LS) Maybe also consider linking with ambulances. Yes, take that into account, because sometimes, well, we wanted to refer a patient, but they didn't have any systems at all for the patient, so look into that, the connection between the healthcare institution and the ambulance, and then, on the way to the hospital, they also need a system. Yes, because the ambulance is external to the hospital. It's not like this ambulance only serves Erasmus [medical center].*

The interviewee pointed out that ambulance services operate independently from the healthcare facilities they serve, relying solely on the information provided by the transferring facility. This lack of direct integration leaves ambulance healthcare workers vulnerable to missing critical patient data, particularly in unforeseen situations. Consequently, the interviewee emphasized the importance of involving ambulance healthcare workers in the proposed solution to address this vulnerability.

A summary of the ideas of the interviewees

The concepts intended to tackle short-term healthcare challenges preceding the implementation of the proposed solution, as well as ideas that supplement or expand upon the proposed solution, are succinctly outlined in the following list:

- Involving the family more to relieve the healthcare professionals and strengthen the collaboration between the family and healthcare professionals.
- Provide caregivers with training sessions that help them with caring for the patient.
- Serious consideration must be given to the planning of healthcare and all associated aspects to enhance overall care quality, including the exchange of healthcare information.
- Use role-specific visualization methods to display the healthcare information in accordance with the wishes of different stakeholders.
- Involve the ambulance department in the proposed solution.

5 Discussion

5.1 The issue and what we have researched

The central issue we sought to address revolves around the unavailability of crucial healthcare data for providers, stemming from inadequate information exchange between disparate healthcare facilities and the inherent complexities of current healthcare information systems. This issue is particularly pronounced in the case of patients grappling with chronic brain diseases such as dementia, as their impaired communication abilities make it challenging for them to convey their medical needs and experiences effectively. Consequently, ensuring the accessibility of their medical information in a privacy preserving manner becomes paramount.

In light of this challenge, the focus of our research is to enhance the availability of healthcare information within individual healthcare facilities and facilitate seamless exchange between different facilities. By doing so, we aim to empower patients with chronic brain diseases to receive the patient-centric, personalized care they rightfully deserve. Our efforts are geared towards bridging the gaps in information exchange and leveraging advancements in healthcare technology to optimize patient care outcomes while preserving the privacy of this sensitive information. Through this endeavor, we aspire to contribute to the advancement of healthcare practices and ultimately enhance the quality of life for individuals facing complex medical conditions. This led to the following research question:

How can the implementation of FAIR semantic data principles in the care of patients with chronic brain diseases contribute to establishing an infrastructure that ensures the provenance of data and facilitates accessibility, while remaining compliant with GDPR regulations?

5.2 The key findings

In this chapter, we delve into the key findings of our research, which provide valuable insights into the management and exchange of healthcare information, particularly concerning patients with chronic brain diseases.

Firstly, we meticulously examined the healthcare information that tends to be absent when caring for patients with cognitive conditions. Through interviews and analysis, we identified specific types of medical and well-being data that caregivers often find lacking in their patient records.

Subsequently, we investigated the current methods and tools utilized by healthcare providers for sharing medical information amongst themselves. This preliminary exploration was essential for understanding the existing practices before delving into the obstacles hindering the availability of healthcare information. These impediments, as we discovered, often lead to inaccessibility of crucial data stored within individual healthcare systems and across various facilities, thereby impeding the delivery of personalized patient-centric care for individuals with cognitive diseases.

Having established the significance of ensuring the availability of healthcare information, we proceeded to compile a comprehensive list of the most vital data elements required for effective care continuity in patients with cognitive conditions. This compilation, informed by both the identified gaps in healthcare information and essential data for patient care, served as the foundation for our subsequent analyses and technological interventions.

With this curated list as our guide, we explored technical strategies to enhance the accessibility, interoperability, and privacy of healthcare information through the FAIRification process. We conceptualized an IT architecture tailored to FAIRify the identified healthcare information and enable secure, privacy-preserving exchange among healthcare practitioners from diverse facilities.

Following the conceptualization of the architecture, we conducted feasibility testing to validate its practicality. Central to this testing was the examination of an IT framework where sensitive patient data remains localized but can be securely accessed by authorized healthcare professionals from other facilities. This approach aimed to ensure data accessibility under well-defined access controls while prioritizing patient privacy.

Overall, our research journey encompassed a comprehensive examination of the healthcare information landscape, culminating in the development and testing of innovative IT solutions tailored to address the unique challenges faced in managing and exchanging data for patients with chronic brain diseases. Through these efforts, we aim to pave the way for improved care delivery and enhanced patient outcomes in this critical healthcare domain.

5.3 How these findings can be interpreted

In this chapter, we will interpret the findings from chapter 4. We will do this by interpreting the findings from all the chapters separately.

5.3.1 The missing healthcare information

In Chapter 4.1.1, it was deduced that there existed a deficiency in healthcare information critical for providing patient-centric personalized care. This conclusion emerged from insights gathered through interviews conducted with both patients and caretakers, who expressed concerns regarding the availability of healthcare information. The following conclusions were drawn from these findings: healthcare providers often find themselves lacking essential information regarding patients' medical history, even when they have referred them to other medical specialists. This discrepancy aligns with the expectation that healthcare information is not consistently shared among providers. Additionally, patients echoed the sentiment that they must fill gaps in healthcare information systems by proactively communicating crucial details about their health, particularly challenging for those with chronic brain diseases. These findings underscored the urgency of our research and underscored the inefficiencies within the current healthcare information exchange system.

The specific healthcare information found to be missing was somewhat unexpected for us as researchers. While it was anticipated that well-being information might be less available due to its perceived lower priority compared to medical data, the frequency of missing historical healthcare information and current medication overviews came as a surprise. These omissions are concerning, as they represent vital healthcare information crucial for making informed medical decisions and avoiding potential short-term consequences. The recurrent absence of both well-being and medical information heightened the urgency of our research objectives beyond initial expectations.

The combination of missing well-being and medical information is particularly critical for patients with chronic brain diseases, who rely on comprehensive care plans tailored to their individual needs. This comprehensive data not only facilitates personalized care but also equips healthcare providers with the necessary information to minimize errors and ensure the best possible outcomes for patients.

5.3.2 What the impediments are to why this healthcare information is currently missing.

This chapter delves into the challenges surrounding the availability of healthcare information. In summary, table 19 provides a comprehensive overview of the impediments hindering the availability of healthcare information for patients with chronic brain diseases. Some of these obstacles were anticipated based on existing literature. For instance, it was expected that a significant hindrance to information availability stemmed from the lack of interoperability among different healthcare information systems. The divergence in systems across various healthcare facilities and the absence of collaborative efforts among software developers exacerbate this issue. Additionally, our research revealed unexpected challenges within healthcare information systems themselves. This finding came as a surprise, as prior literature primarily attributed information unavailability solely to problems in healthcare information exchange.

Specifically, we identified issues such as difficulty in locating data and potential misinterpretations among colleagues when accessing healthcare information systems. Our proposed solution aims to address these challenges by streamlining data retrieval processes within individual facilities and facilitating seamless communication between healthcare providers. Furthermore, we propose implementing training programs and courses focused on effective healthcare information management to mitigate the risk of misinterpretation among colleagues. These interventions are integral to improving the overall accessibility and usability of healthcare information systems, enhancing efficiency and efficacy in healthcare delivery.

Furthermore, there were identified issues with existing technological solutions designed for exchanging healthcare information. These tools necessitate the administration of healthcare information twice: once upon collection at the sending healthcare facility and again upon receipt at the receiving facility. Moreover, perceived limitations include instances where healthcare information fails to reach its intended destination, leading to reliance on inefficient fallback systems such as phone calls to request information. However, these methods compromise security and privacy, underscoring the importance of avoiding the transmission of sensitive healthcare information via low-security means like letters.

Additionally, a noteworthy observation that emerged from our research, though not explicitly discussed in existing literature, pertains to the challenge faced by healthcare providers in manually requesting information. Often, providers are unaware of the available healthcare information, hindering their ability to make informed requests. Consequently, vital information crucial for patients with chronic brain diseases may be overlooked. For instance, healthcare providers may neglect to inquire about a patient's hobbies, assuming it to be irrelevant, even though such details could contribute to comprehensive care.

Moreover, the high workload experienced in healthcare settings further exacerbates these challenges. Healthcare professionals may experience delays in accessing healthcare information due to heavy workloads, or crucial information may be overlooked altogether. In summary, the lack of availability of healthcare information stems from both deficiencies within information systems at healthcare facilities and the actions of healthcare professionals themselves, who are responsible for sharing this information.

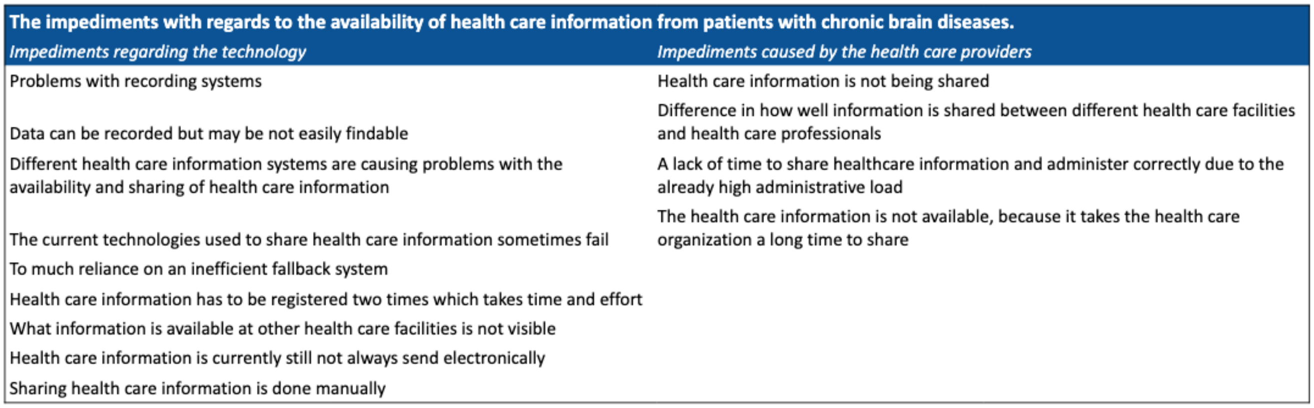
Addressing this issue requires a proposed solution that minimizes the burden on healthcare professionals while simultaneously bolstering healthcare information systems to enhance overall efficiency and facilitate improved healthcare information exchange.

Moreover, we have identified the critical importance of ensuring the availability of healthcare information, particularly for supporting the care of patients with chronic brain diseases. Due to their diminished ability to communicate feelings and preferences, the exchange of health information becomes paramount in detecting potentially severe conditions early, thereby averting significant health complications. Monitoring healthcare information is especially crucial for this patient group.

Furthermore, the inclusion of well-being preferences, often overlooked in current practices, holds significant implications for the overall health and well-being of patients in the later stages of dementia. Our interviews revealed instances where patients exhibited remarkable behaviors when exposed to hobbies or preferences from their past, highlighting the profound impact such information can have on their quality of life.

Additionally, the rapid deterioration observed in patients with chronic brain diseases underscores the importance of timely access to healthcare information. Identifying changes in a patient's condition promptly enables healthcare providers to intervene effectively, potentially mitigating adverse outcomes and enhancing patient independence.

Moreover, the availability of comprehensive healthcare information not only supports healthcare decision-making but also facilitates personalized, patient-centric care while minimizing preventable errors. However, reliance solely on patients and caretakers for information imposes undue strain on them and risks repeated inquiries about the patient's health status. To alleviate this burden, it is imperative to streamline information retrieval processes and minimize unnecessary disruptions to patients and caretakers.



The impediments with regards to the availability of health care information from patients with chronic brain diseases.

Impediments regarding the technology	*Impediments caused by the health care providers*
Problems with recording systems	Health care information is not being shared
Data can be recorded but may be not easily findable	Difference in how well information is shared between different health care facilities and health care professionals
Different health care information systems are causing problems with the availability and sharing of health care information	A lack of time to share healthcare information and administer correctly due to the already high administrative load
The current technologies used to share health care information sometimes fail	The health care information is not available, because it takes the health care organization a long time to share
To much reliance on an inefficient fallback system	
Health care information has to be registered two times which takes time and effort	
What information is available at other health care facilities is not visible	
Health care information is currently still not always send electronically	
Sharing health care information is done manually	

Figure 19: This table shows an overview of the impediments with regards to the availability of patient information from patients with chronic brain diseases

5.3.3 The healthcare information that is perceived as the most important

The healthcare information identified as most crucial was categorized into three primary categories: Historical personal data, preferences, and medical data. These categories formed the cornerstone of the proof of concept, wherein we undertook the FAIRification process to ensure accessibility and interoperability. It became evident that these categories were indispensable for providing comprehensive healthcare information to providers caring for patients with chronic brain diseases.

This finding underscores the pressing need for improved accessibility and exchange of healthcare information. The overwhelming importance placed on these categories by healthcare providers highlights the urgency for developing a more efficient information exchange system. It is evident that there exists a significant gap that must be addressed to fulfill the needs of healthcare providers and ensure optimal care for patients with chronic brain diseases.

5.3.4 The possibilities for data production on sensitive patient and personal data in a FAIR-data architecture

In this chapter, we delved deeper into the FAIR guiding principles, focusing on the four essential aspects of FAIRifying data: ensuring data is Findable (F), Accessible (A), Interoperable, and Reusable.

Our proposal suggests adopting the hourglass model for integrating FAIR healthcare information across various healthcare organizations. This approach allows each organization the flexibility to maintain their own data collection methods and systems, as well as the freedom to utilize derived information as per their requirements. This approach is crucial, as implementing an entirely new information system across all healthcare facilities in the Netherlands is neither financially feasible nor resource-efficient. By FAIRifying the healthcare information originating from different systems, organizations can leverage their preferred systems or those already in use.

Moreover, the FAIRification process outlined is applicable to all healthcare organizations in the Netherlands, irrespective of their existing systems or scale. Additionally, decentralized solutions are proposed to ensure data sovereignty and prevent the centralization of healthcare information.

This will help preserving the privacy of the patients and adhere to current rules and regulations. The utilization of distributed ledger technology enhances security and provides control over data access. However, there is a need for further research and development of open-source tools to fully implement these techniques and technologies, a prospect that warrants exploration and deployment in the future.

Furthermore, enabling healthcare information to be machine actionable facilitates automatic access to such information, eliminating the need for manual sharing by healthcare professionals. This is a significant advantage of providing data with high-quality metadata and linking it to open ontologies. By doing so, the administrative burden on healthcare providers is reduced as they no longer need to spend extensive time searching for healthcare information. Consequently, they can allocate more time to patient care, offering data-driven personalized healthcare, which is particularly beneficial for patients with chronic brain diseases.

5.3.5 The healthcare information exchange architecture for the healthcare information of patients with chronic brain diseases

In this chapter, we outlined the methods and solutions for proposing a more efficient healthcare information exchange system tailored for patient information of individuals with chronic brain diseases, with a primary focus on those with dementia. These tools will form the basis for proposing an IT architecture aimed at enhancing the availability of healthcare information within and beyond healthcare facilities by facilitating efficient exchange.

A crucial aspect of the proposed FAIRification and healthcare exchange architecture is their open-source nature, which serves to minimize implementation costs while ensuring accessibility to a wide range of healthcare organizations, regardless of their resources and workforce.

Moreover, the FAIRification process embedded within the architecture not only enhances healthcare information exchange but also optimizes the findability and availability of information within individual healthcare facilities. Thus, deploying the solution in even a single healthcare facility can already yield significant benefits.

However, a limitation highlighted in the previous chapter pertains to the lack of functional tools for utilizing distributed ledger technology for the authentication and authorization of healthcare practitioners using the healthcare information exchange solution. Yet, promising research by Mou et al. (2023) demonstrates the potential for practical implementation, which could revolutionize online authentication and verification processes.

Another limitation of the proposed solution is its current reliance on internet connectivity for operation. While this presents a challenge, efforts should be directed towards addressing this limitation in future iterations. In the interim, existing, albeit less efficient methods for healthcare information exchange can serve as fallback options until the proposed solution becomes fully functional.

In summary, the proposed healthcare information exchange architecture presents an innovative approach to enhancing the availability of healthcare information, irrespective of its point of origin, while safeguarding the privacy of sensitive data. This is achieved through the utilization of cost-effective tools and methods that afford healthcare organizations the flexibility to operate and utilize the acquired knowledge as they see fit. By empowering healthcare providers to leverage the system according to their needs and preferences, the architecture ensures that its benefits are maximized and not imposed upon those who may not find value in its usage.

5.3.6 Assessing the feasibility of the architecture

In this chapter, we conducted an assessment of the feasibility of significant components within the proposed healthcare information exchange architecture. Our focus was on FAIRifying the most crucial healthcare information identified by practitioners, alongside testing the querying capabilities of the triple store. This endeavor proved successful, demonstrating how queries sent to the triple store can efficiently render healthcare information accessible for providers caring for patients with chronic brain diseases. Importantly, we found that FAIRification could be achieved without incurring any costs for the tools and methods employed.

Furthermore, we sought feedback on the proposed healthcare information exchange solution from the interviewees, yielding valuable insights. All participants expressed appreciation for the potential value of the solution. Their positive responses corroborated our literature findings, indicating a collective hope for increased accessibility and reduced administrative burden. They welcomed the prospect of time-saving features and recognized the potential for enhanced patient care. Notably, the assurance of data sovereignty resonated well with them, underscoring their concerns regarding privacy preservation.

Additionally, our discussions confirmed the desire among healthcare professionals to develop deeper personal connections with patients. This reaffirmed our decision to incorporate well-being information into our research focus. Furthermore, there was a clear consensus on the importance of obtaining a comprehensive understanding of the patient, both personally and medically. Integrating these aspects can facilitate the delivery of personalized, patient-centric care.

Some interviewees expressed reservations regarding the proposed solution, particularly regarding concerns about potential breaches of security and an increase in administrative burden. However, these concerns were addressed within the proposed solution through stringent authentication and authorization measures, ensuring control over access to information and data sovereignty.

Another concern raised was the potential for increased administrative workload for healthcare professionals. It's important to clarify that the proposed solution is designed to alleviate administrative burdens. Proper utilization of the solution is expected to reduce time spent gathering and searching for healthcare information. At worst, if not used correctly, it would maintain the existing administrative workload rather than exacerbating it.

Additionally, some interviewees emphasized the importance of maintaining human interaction in healthcare and not overly relying on IT solutions. I wholeheartedly agree with this sentiment, and it's essential to highlight that the proposed tool aims to enhance, rather than replace, human interaction. By facilitating more quality time with patients and enabling easier connection on a personal level, the tool complements human-centered care. Moreover, having access to patient preferences, especially for those with chronic brain diseases, can contribute to patient comfort and positively impact human interaction.

a minority of interviewees questioned the extent to which the proposed solution would benefit them compared to other healthcare providers. However, it's my belief that improved access to healthcare information can benefit all healthcare providers by enhancing their understanding of patients and enabling personalized care delivery. Thus, while certain roles may perceive more immediate benefits, the overarching goal is to support all healthcare professionals in delivering quality care.

Some interviewees emphasized the importance of keeping the proposed solution user-friendly, especially for those who may not be technologically proficient. Simplicity in design was suggested to ensure accessibility for all users. Additionally, there was a consensus among interviewees regarding the need to regulate access to specific healthcare information based on the roles of healthcare practitioners. Further research is required to determine the mechanisms for controlling access and defining appropriate information visibility criteria.

Several suggestions were proposed by interviewees to enhance the design of the healthcare information exchange architecture and address existing challenges in caring for patients with chronic brain diseases. One approach involves leveraging the support of family members or caregivers in the care process, engaging them whenever possible to provide assistance. Smart planning was recommended as a means to optimize scheduling, allowing for efficient utilization of available resources and involvement of relevant stakeholders when needed. Moreover, providing training courses for family caregivers could empower them to contribute effectively to patient care, potentially enabling care to be provided in the patient's home environment.

Another idea raised was to integrate ambulances into the proposed solution, which could significantly improve the coordination of care for patients with chronic brain diseases. This suggestion aligns with the overarching goal of the proposed architecture to streamline healthcare information exchange and enhance patient care.

In conclusion, the feasibility of the proposed architecture has been evaluated through both a proof of concept and feedback from interviewees. healthcare professionals recognize the potential benefits of the solution in improving the accessibility of healthcare information and facilitating more effective patient-centric care for individuals with chronic brain diseases such as dementia.

5.4 Limitations of this research

Throughout the course of this research, several limitations were encountered that may have influenced the outcomes obtained.

Firstly, the list of vital healthcare information was derived exclusively from interviews with professionals working with patients suffering from chronic brain diseases. Consequently, the applicability of this list to the broader healthcare landscape may be limited. While the insights gained are tailored to the care of patients with chronic conditions, there remains the potential for relevance to researchers, caregivers, and healthcare providers involved in the treatment of other ailments.

Additionally, the interviews conducted encompassed perspectives from professionals and caregivers across various healthcare facilities. While this approach provided valuable insights into the diverse practices and systems employed, it also introduced limitations. Notably, the absence of input from healthcare professionals utilizing every system may impact the comprehensiveness of the findings and potentially alter the research outcomes.

One limitation and potential future direction for the proposed healthcare information exchange system is the complexity of using SparQL query language, particularly for healthcare providers. As such, a necessary step forward involves devising methods to automate the generation of queries based on the specific information needs of users. This would entail transforming their queries into SparQL format, thereby enabling them to access and utilize healthcare information pertaining to patients with chronic brain diseases for the delivery of personalized care. Large Language Models (LLMs) have the potential to assist in formulating straightforward queries.

Another limitation to consider is the implementation of the proposed solution, which would necessitate an organization or company to adjust and integrate it with their existing healthcare information system. This could pose challenges for smaller organizations with limited resources for implementation. However, it's worth noting that smaller organizations may find implementation comparatively easier due to the reduced volume of data and fewer legacy systems, potentially resulting in lower costs.

Furthermore, another limitation pertains to the operational requirements of the proposed solution. Presently, its implementation demands the management of patient information across multiple recording systems, specifically the CEDAR template and the information system utilized by the healthcare organization. This dual administrative burden presents considerable challenges, particularly considering the already perceived high administrative workload.

In situations where connectivity issues arise or the proposed tools outlined in the architecture are unavailable, caregivers and healthcare specialists face limitations in accessing healthcare information from external facilities. Currently, administrative tasks are duplicated across both the sending and receiving ends, mitigating dependency on multiple tools or connectivity. While this redundancy ensures data availability during such contingencies, it also significantly escalates the administrative workload.

As a result of these operational challenges, the proposed solution is not yet ready for implementation within Dutch healthcare facilities. Moreover, the FAIRification of legacy information remains a prerequisite for utilizing the data visiting tools outlined in the architecture.

Furthermore, the issue of access control and patient consent warrants consideration. The determination of who can access specific information is contingent upon patient consent, yet the mechanisms for regulating access are not fully integrated into the current solution. Addressing this aspect necessitates the establishment of standardized protocols governing access permissions, alongside mechanisms for patients to exert control over data accessibility.

In conclusion, standardizing access protocols and incorporating patient preferences into data accessibility are vital considerations for the successful implementation of our proposed solution within the healthcare ecosystem. These challenges underscore the need for further refinement and development before widespread adoption can be realized.

5.5 Future work

Several areas have been identified for future work aimed at implementing and enhancing personalized patient-centric care for individuals with chronic brain diseases.

Firstly, there is a need to explore efficient methods for linking the CEDAR template with various healthcare information systems. This is essential because healthcare specialists face challenges in processing information across different systems and the CEDAR template simultaneously, mainly due to the high administrative burden and existing labor and time shortages in the healthcare sector.

Moreover, efforts should be made to establish standardized procedures or courses for healthcare information administration to ensure uniformity and accuracy. By developing standardization documents and offering courses for healthcare professionals, the interpretation of healthcare information can be improved, providing a more comprehensive understanding of patients' healthcare situations.

An additional critical aspect for future research pertains to the exchange of healthcare information with patients and caretakers. Insights gleaned from interviews with healthcare providers underscored reservations about using the healthcare information system to communicate directly with patients and caretakers. Concerns were raised that such direct communication might lead healthcare providers to exercise greater caution in recording healthcare information for patients, potentially omitting important details. Furthermore, it is imperative to explore whether caretakers and patients should be granted the ability to contribute information to the healthcare information system. While this could potentially enhance the availability of healthcare information for healthcare providers, it also raises concerns due to the lack of medical background among patients and caretakers, which may result in errors or misinterpretations. Thus, further research in this area is crucial to assess the potential benefits and risks associated with involving patients and caretakers in the healthcare information exchange process.

The adoption potential was not subject to this study but should be investigated in further research, involving all stakeholders. In order to implement the proposed solution effectively, a structured roadmap has been developed. This roadmap outlines specific steps to be taken, each contributing to the ultimate goal of achieving an efficient healthcare information exchange system.

- **Address Limitations**: The first step involves addressing any limitations identified during the research phase. This includes conducting further investigation to understand the challenges and constraints associated with the proposed solution. By thoroughly researching these limitations, it becomes possible to refine and improve the proposed solution as needed.
- **Data Provenance**: Make a data management plan to specify how you will manage the (meta)data and the information that is needed for future reuse of the (meta)data.
- **Implementation at One Healthcare Facility**: Once the limitations have been addressed, the proposed solution should be implemented at one healthcare facility. While this initial implementation may not directly enhance the overall healthcare information exchange system, it serves as a crucial first step in improving the findability and availability of healthcare information within that specific organization. This allows for testing and refinement of the solution in a controlled environment.
- **Enhancing Interoperability**: The next step involves expanding the implementation to another healthcare facility. This aims to improve interoperability between different healthcare organizations by implementing the proposed solution in a standardized manner across multiple facilities. By ensuring consistency in the implementation approach, standards can be improved, leading to better communication and exchange of healthcare information.
- **Municipal-wide Implementation**: Following successful implementation at multiple healthcare facilities, the next phase involves scaling up the solution to an entire municipality. This broader implementation significantly enhances the efficiency of healthcare information exchange within the municipality, benefiting both healthcare providers and patients. While the proposed solution facilitates internal information exchange within healthcare facilities, traditional methods may still be used for exchanging information outside the facility.
- **Achieving System-wide Efficiency**: The final step is to achieve system-wide efficiency by implementing the solution across all municipalities. This comprehensive implementation ensures that the benefits of improved healthcare information exchange are realized on a broader scale, leading to a more efficient and streamlined system. With the solution fully integrated at all levels, stakeholders can enjoy improved access to vital healthcare information, ultimately enhancing patient care outcomes.

By following this roadmap, it is possible to systematically implement and refine the proposed solution, ultimately leading to a more efficient and effective healthcare information exchange system.

To address the issue of connectivity, it is advisable to consider implementing a smart card system for vulnerable patients with chronic brain diseases, allowing them to carry essential medical information in case of emergencies or when the proposed solution encounters connectivity issues. This interim measure can provide vital assistance until connectivity problems are resolved and the proposed solution becomes fully stable.

Furthermore, future research could focus on extrapolating findings from this study to propose solutions for healthcare information exchange systems in other regions, both within Europe and globally. This comparative analysis would help identify areas where other countries may benefit from similar solutions.

The results of this thesis will be disseminated to all individuals who have contributed and participated in the interviews conducted. This dissemination aims to raise awareness regarding the possibilities outlined in the thesis, empowering stakeholders to enhance their efforts in integrating new and innovative solutions and technologies. By doing so, we aspire to foster improved interoperability of healthcare information among healthcare organizations while simultaneously enhancing the availability of healthcare information within their respective organizations. Through sharing these findings, we endeavor to catalyze collaborative efforts towards advancing healthcare information exchange practices and facilitating better patient care outcomes.

Importantly, this research serves as a foundation for further investigation. Other master's students are already building on these findings, with one examining data interoperability in dementia care while considering insights from this study. Additionally, the topic will be explored further by master's students participating in the Data Science in Practice course at Leiden University in September 2024. Moreover, various companies have expressed interest in exploring the implementation of these findings. This commitment to further research underscores the importance of addressing the identified limitations and leveraging future opportunities to advance patient care for individuals with chronic diseases and their caregivers nationwide.

6 Conclusion

In this concluding chapter, we will summarize the key findings of our study in relation to the research objectives and questions.

The main issue identified in the current healthcare landscape is the inefficiency and sometimes impossibility of health information exchange. This leads healthcare providers to inquire extensively about patients' medical histories and preferences during appointments. For vulnerable patients with chronic brain diseases, articulating or recalling health information is often challenging. This lack of effective communication prevents healthcare providers from obtaining crucial insights into patients' health and preferences. Additionally, the burden on healthcare providers to manually request or exchange health information exacerbates administrative duties, which are already overwhelming. As a result, the central issue at hand concerns the unavailability of vital healthcare data for patients with chronic brain diseases, arising from inadequate information exchange between healthcare facilities and the complexities of existing healthcare information systems. Therefore, ensuring the accessibility of medical information in a privacy-preserving manner becomes essential.

In this research, it was identified why it is important that healthcare information from patients with chronic brain diseases is available and exchanged efficiently and effectively:

- To provide general care for patients with chronic brain diseases.
- To provide personalized care for patients with chronic brain diseases.
- To prevent the rapid deterioration of patients with chronic brain diseases.
- It enables patients to avoid unnecessary dependence on others.
- To prevent mistakes with medicine and dosages.
- To support the decision making of healthcare specialists.
- To Eliminate the need to repeatedly request the same information.
- To prevent a reliance on patients, families and caretakers for medical information.

Once the identified issues and their significance were clear, it became imperative to devise a solution. Consequently, an innovative healthcare information exchange system was proposed, aiming to integrate FAIR data principles into the current healthcare infrastructure. Our proposed system incorporates essential elements, such as metadata for healthcare data, enhancing data accessibility and machine-actionability. By ensuring data FAIRness and enabling cross-facility access to patient health information, we address the challenge of interoperability among disparate healthcare systems, particularly for patients with chronic brain diseases.

A critical aspect of our solution is the preservation of patient privacy. Consequently, we emphasize the importance of implementing robust access control policies and techniques. To achieve this, we explore the utilization of distributed ledger technology, which enhances security in authenticating and authorizing healthcare providers and caretakers seeking access to sensitive healthcare information. Our approach leverages smart contracts and verifiable credentials to streamline the authentication process, thereby ensuring secure and efficient data access.

In this thesis, we propose an architecture that streamlines various manual processes inherent in current healthcare information exchange systems. For instance, in the existing system, healthcare providers must manually respond to requests for exchanging healthcare information, which can be time-consuming and inefficient. In our proposed system, authentication and authorization of individuals requesting healthcare information are automated, along with automated checks to ensure that the requester has the necessary permissions to access the data. Once these criteria are met, the data is automatically retrieved and presented to the requester, enhancing both efficiency and effectiveness while establishing a single source of truth.

Furthermore, our system prioritizes patient privacy by maintaining their healthcare information within the original healthcare facility where it was collected. Additionally, transparency is ensured by providing visibility into who accessed the data and when, with the added flexibility for patients to withdraw consent and restrict access to their information. Consequently, our system is poised to enhance the efficiency and effectiveness of healthcare information exchange, enabling personalized, patient-centric care for individuals with brain diseases who may face challenges in communicating their medical history or preferences.

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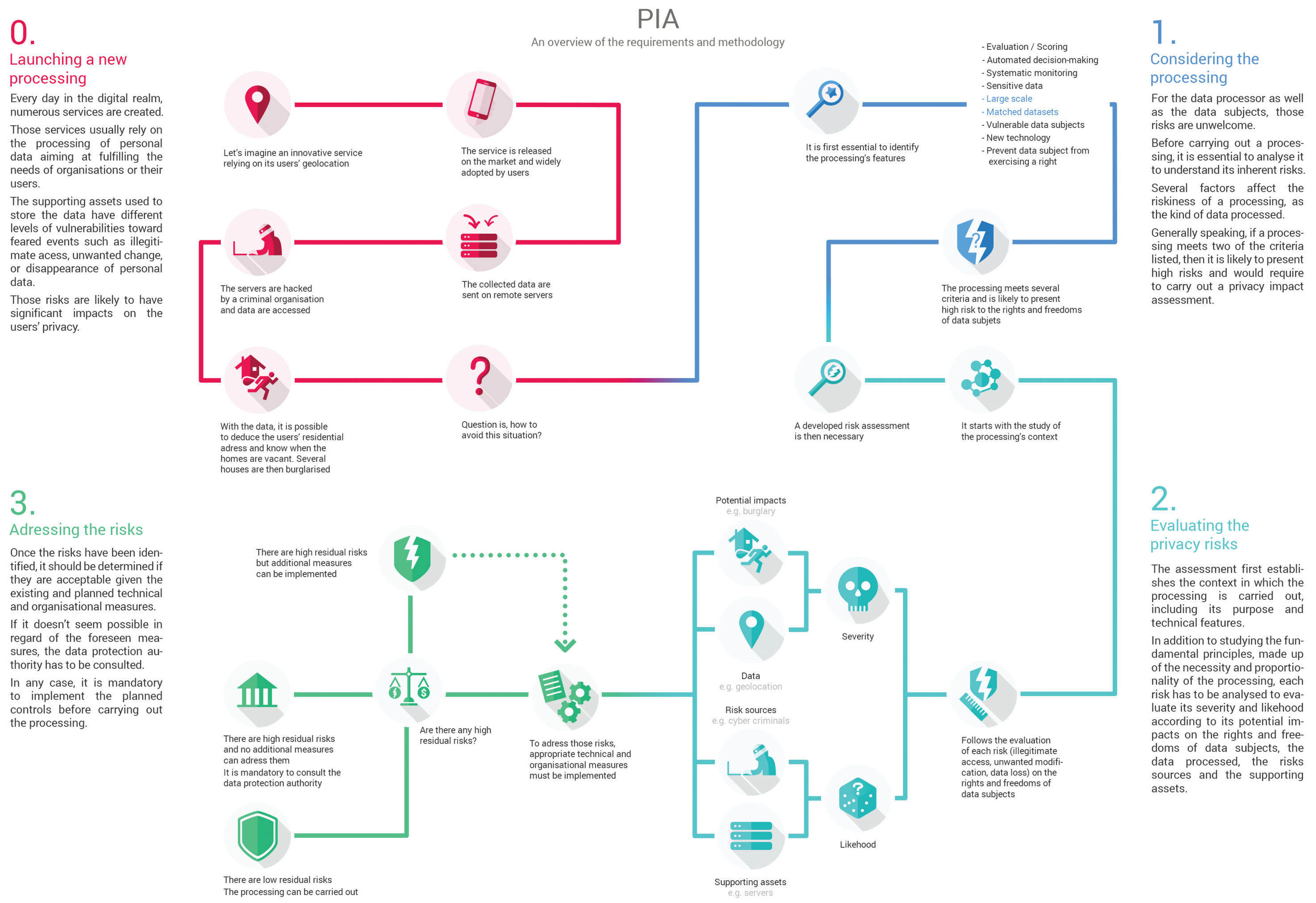
Appendices

A The Privacy Impact Assessment



PIA

An overview of the requirements and methodology

0.
Launching a new processing

Every day in the digital realm, numerous services are created.

Those services usually rely on the processing of personal data aiming at fulfilling the needs of organisations or their users.

The supporting assets used to store the data have different levels of vulnerabilities toward feared events such as illegitimate acess, unwanted change, or disappearance of personal data.

Those risks are likely to have significant impacts on the users' privacy.

1.
Considering the processing

For the data processor as well as the data subjects, those risks are unwelcome.

Before carrying out a processing, it is essential to analyse it to understand its inherent risks.

Several factors affect the riskiness of a processing, as the kind of data processed.

Generally speaking, if a processing meets two of the criteria listed, then it is likely to present high risks and would require to carry out a privacy impact assessment.

2.
Evaluating the privacy risks

The assessment first establishes the context in which the processing is carried out, including its purpose and technical features.

In addition to studying the fundamental principles, made up of the necessity and proportionality of the processing, each risk has to be analysed to evaluate its severity and likehood according to its potential impacts on the rights and freedoms of data subjects, the data processed, the risks sources and the supporting assets.

3.
Adressing the risks

Once the risks have been identified, it should be determined if they are acceptable given the existing and planned technical and organisational measures.

If it doesn't seem possible in regard of the foreseen measures, the data protection authority has to be consulted.

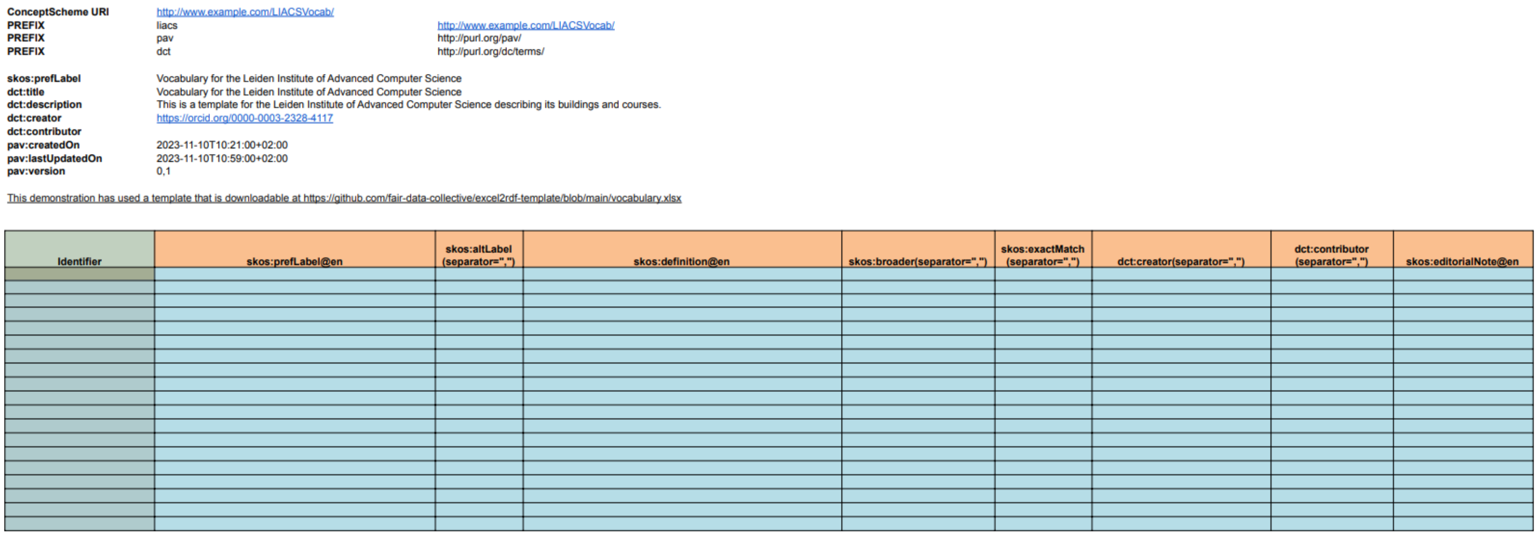
In any case, it is mandatory to implement the planned controls before carrying out the processing.

(*https://www.cnil.fr/en/PIA-privacy-impact-assessment-en*, n.d.)

B The most crucial healthcare information needed in the care of patients with dementia, acquired brain injury and/or multimorbidity.

Historical personal data	Preferences	Medical data
Personal data	**Hobbies**	**Medical history**
Citizen service number of the patient	Preferred music	Diagnosis of the patient
Name	Preferred activities	Level of dementia
Age	Personal experiences	Description of diagnosis
Gender	Preferred sport/physical activity	Participation lab research (no alcohol consumption)
Date of birth	Other activities	Past surgeries
Address	Preferred movies/television channels	Prognosis for (future) treatment
Postal code	Engagement in activities	Hereditary diseases
City of residence	Do they operate a mobile/smart phone	Is the patient born with the disease?
Known family	Variability in activities is preferred?	
List of contacts (friends/families)	Other	
Emergency contact(s)		**Medication**
Main caretaker	**Preferences in environment**	Time when medication is needed
	Preferred resting surfaces	Current medication
Personal history	Preferred materials (clothes/bedding/etc.)	How important is the time of medication
Previous jobs	Preferred way of making contact	Does patient take meds themselves?
Drinking	Good days/bad days (their husband died, specific holidays)	Known side effects of medications
Smoking	Is the home care provider allowed to go in themselves	Medical allergies
Traumas	Willingness to speak about profound matters	Procedure in hospital (what are next steps)?
Religion	Degree of housing adaptation now	
Other	Degree of housing adaptation wanted	**Physical condition**
	Other	Physical limitations
Daily schedule		Past complications
Who does what (caregiver or home care provider)		DNR
List of activities and their dates		Current treatment
Wake up time		Personal condition for transport
Preferred sleeping time		Expected outcome of treatment
Behavorial changes		Mobility independence
		Mobility dependence
		Ability to communicate needs/wants
		Presence of pressure ulcer / intertrigo / incontinence-related skin damage
		Presence of wounds
		Degree of difficulty with eating/drinking/chewing/swallowing/digesting
		BMI
		Blood sugar levels
		Degree of oral health
		Degree of constipation
		Presence of COPD or respiratory infection
		Sleep pattern
		Risk of infection
		Degree of vision
		Degree of hearing
		Degree of difficulty with language
		Degree of loneliness
		Emotional state
		Other
		Medical care preferences
		Washing preferences
		Food preferences
		Food allergies
		Medical warning
		Used support technologies
		Preference for use of external parties
		Need/want for ADL/PDL
		Other

C The Excel template from the Leiden Institute of Advanced Computer Science for creating a new ontology.

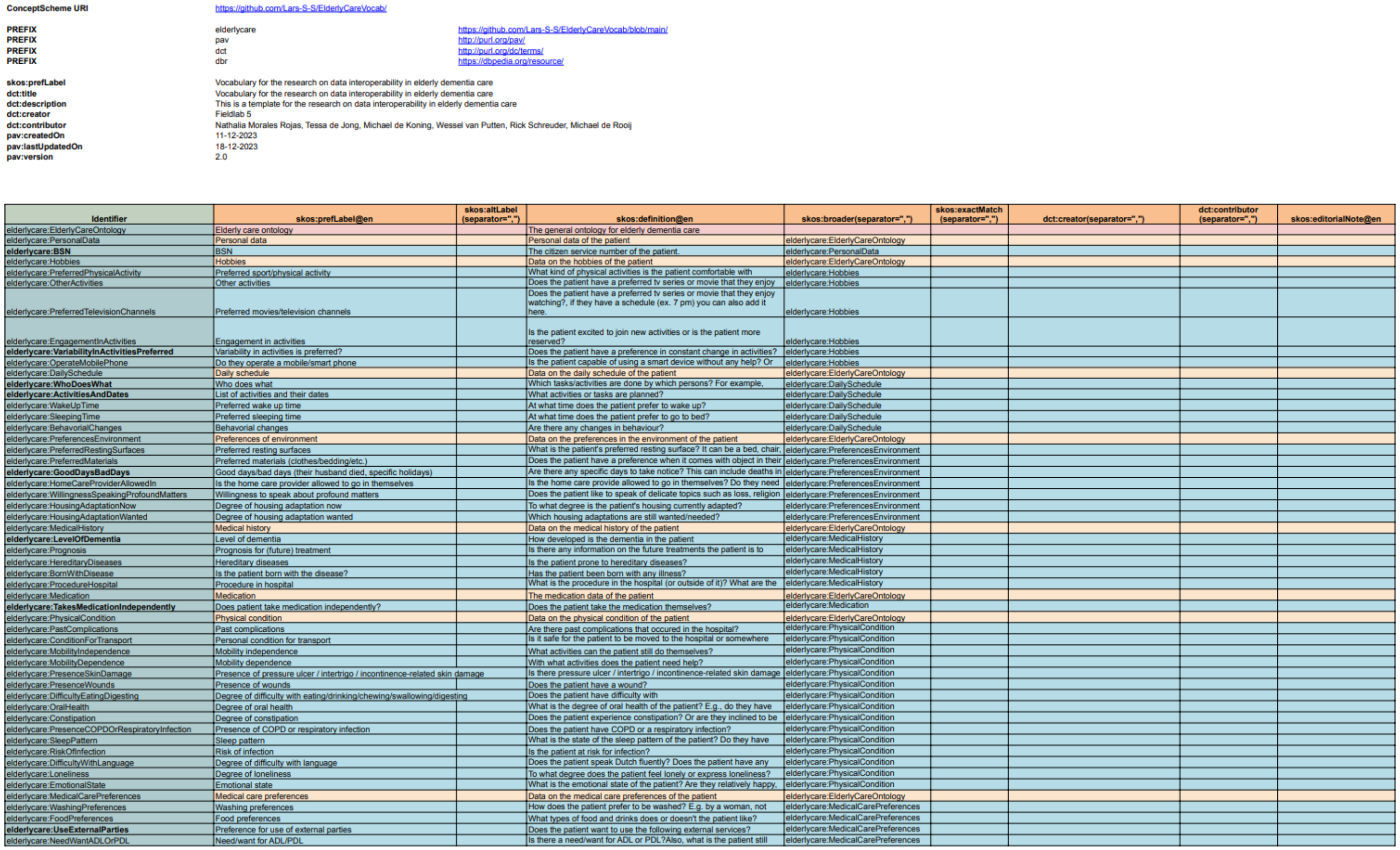


ConceptScheme URI	http://www.example.com/LIACSVocab/	
PREFIX	liacs	http://www.example.com/LIACSVocab/
PREFIX	pav	http://purl.org/pav/
PREFIX	dct	http://purl.org/dc/terms/
skos:prefLabel	Vocabulary for the Leiden Institute of Advanced Computer Science	
dct:title	Vocabulary for the Leiden Institute of Advanced Computer Science	
dct:description	This is a template for the Leiden Institute of Advanced Computer Science describing its buildings and courses.	
dct:creator	https://orcid.org/0000-0003-2328-4117	
dct:contributor		
pav:createdOn	2023-11-10T10:21:00+02:00	
pav:lastUpdatedOn	2023-11-10T10:59:00+02:00	
pav:version	0,1	

This demonstration has used a template that is downloadable at https://github.com/fair-data-collective/excel2rdf-template/blob/main/vocabulary.xlsx

Identifier	skos:prefLabel@en	skos:altLabel (separator=",")	skos:definition@en	skos:broader(separator=",")	skos:exactMatch (separator=",")	dct:creator(separator=",")	dct:contributor (separator=",")	skos:editorialNote@en

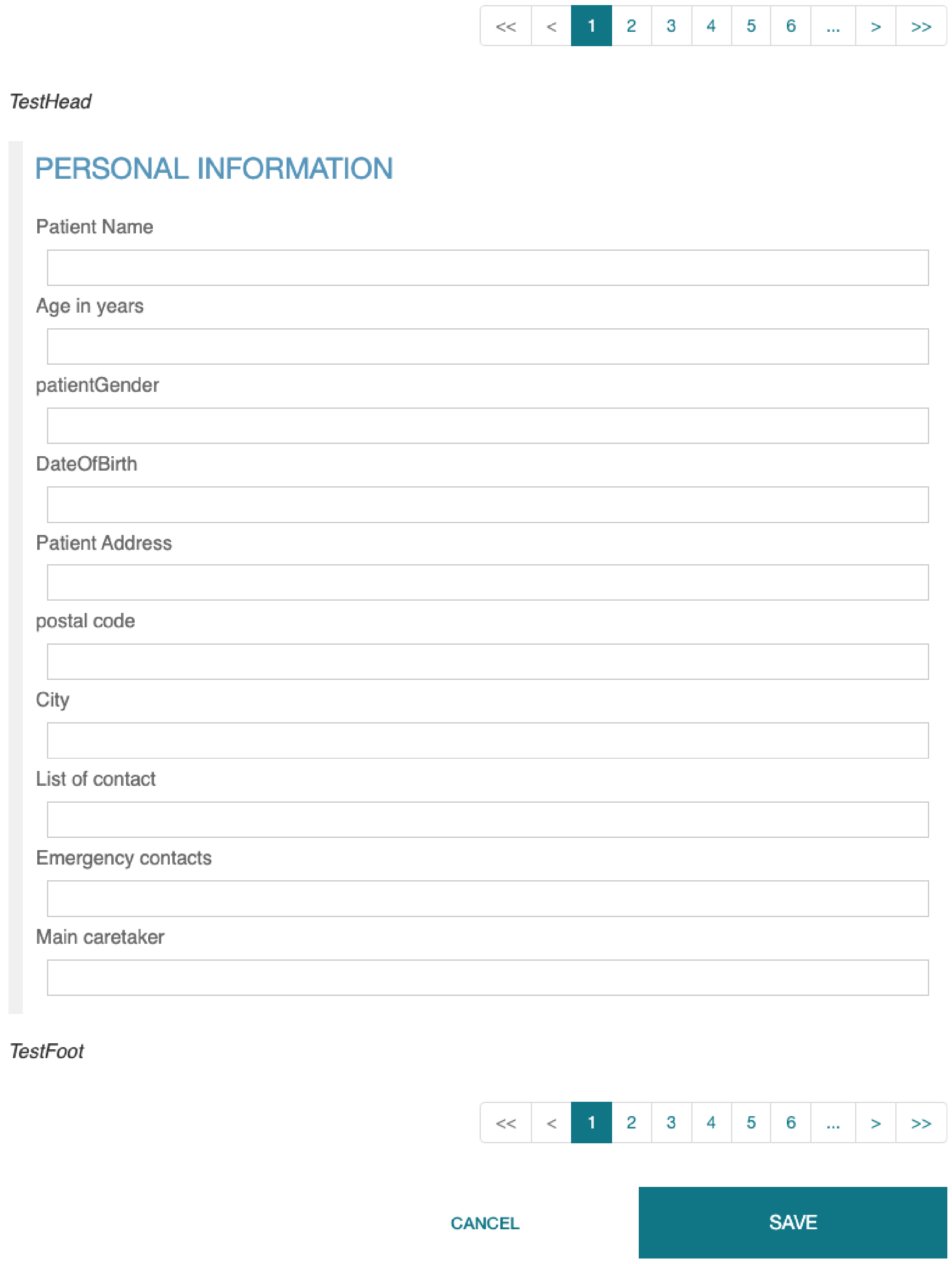
D The excel file that was used to create an ontology for the care of patients diagnosed with a chronic brain disease like for example dementia.



ConceptScheme URI	https://github.com/Lars-S-S/ElderlyCareVocab/	
PREFIX	elderlycare	https://github.com/Lars-S-S/ElderlyCareVocab/blob/main/
PREFIX	pav	http://purl.org/pav/
PREFIX	dct	http://purl.org/dc/terms/
PREFIX	dbr	https://dbpedia.org/resource/
skos:prefLabel	Vocabulary for the research on data interoperability in elderly dementia care	
dct:title	Vocabulary for the research on data interoperability in elderly dementia care	
dct:description	This is a template for the research on data interoperability in elderly dementia care	
dct:creator	Fieldlab 5	
dct:contributor	Nathalia Morales Rojas, Tessa de Jong, Michael de Koning, Wessel van Putten, Rick Schreuder, Michael de Rooij	
pav:createdOn	11-12-2023	
pav:lastUpdatedOn	18-12-2023	
pav:version	2.0	

Identifier	skos:prefLabel@en	skos:altLabel (separator=",")	skos:definition@en	skos:broader(separator=",")	skos:exactMatch (separator=",")	dct:creator(separator=",")	dct:contributor (separator=",")	skos:editorialNote@en
elderlycare:ElderlyCareOntology	Elderly care ontology		The general ontology for elderly dementia care					
elderlycare:PersonalData	Personal data		Personal data of the patient	elderlycare:ElderlyCareOntology				
elderlycare:BSN	BSN		The citizen service number of the patient.	elderlycare:PersonalData				
elderlycare:Hobbies	Hobbies		Data on the hobbies of the patient	elderlycare:ElderlyCareOntology				
elderlycare:PreferredPhysicalActivity	Preferred sport/physical activity		What kind of physical activities is the patient comfortable with	elderlycare:Hobbies				
elderlycare:OtherActivities	Other activities		Does the patient have a preferred tv series or movie that they enjoy	elderlycare:Hobbies				
elderlycare:PreferredTelevisionChannels	Preferred movies/television channels		Does the patient have a preferred tv series or movie that they enjoy watching?, if they have a schedule (ex. 7 pm) you can also add it here.	elderlycare:Hobbies				
elderlycare:EngagementInActivities	Engagement in activities		Is the patient excited to join new activities or is the patient more reserved?	elderlycare:Hobbies				
elderlycare:VariabilityInActivitiesPreferred	Variability in activities is preferred?		Does the patient have a preference in constant change in activities?	elderlycare:Hobbies				
elderlycare:OperateMobilePhone	Do they operate a mobile/smart phone		Is the patient capable of using a smart device without any help? Or	elderlycare:Hobbies				
elderlycare:DailySchedule	Daily schedule		Data on the daily schedule of the patient	elderlycare:ElderlyCareOntology				
elderlycare:WhoDoesWhat	Who does what		Which tasks/activities are done by which persons? For example,	elderlycare:DailySchedule				
elderlycare:ActivitiesAndDates	List of activities and their dates		What activities or tasks are planned?	elderlycare:DailySchedule				
elderlycare:WakeUpTime	Preferred wake up time		At what time does the patient prefer to wake up?	elderlycare:DailySchedule				
elderlycare:SleepingTime	Preferred sleeping time		At what time does the patient prefer to go to bed?	elderlycare:DailySchedule				
elderlycare:BehavorialChanges	Behavorial changes		Are there any changes in behaviour?	elderlycare:DailySchedule				
elderlycare:PreferencesEnvironment	Preferences of environment		Data on the preferences in the environment of the patient	elderlycare:ElderlyCareOntology				
elderlycare:PreferredRestingSurfaces	Preferred resting surfaces		What is the patient's preferred resting surface? It can be a bed, chair,	elderlycare:PreferencesEnvironment				
elderlycare:PreferredMaterials	Preferred materials (clothes/bedding/etc.)		Does the patient have a preference when it comes with object in their	elderlycare:PreferencesEnvironment				
elderlycare:GoodDaysBadDays	Good days/bad days (their husband died, specific holidays)		Are there any specific days to take notice? This can include deaths in	elderlycare:PreferencesEnvironment				
elderlycare:HomeCareProviderAllowedIn	Is the home care provider allowed to go in themselves		Is the home care provide allowed to go in themselves? Do they need	elderlycare:PreferencesEnvironment				
elderlycare:WillingnessSpeakingProfoundMatters	Willingness to speak about profound matters		Does the patient like to speak of delicate topics such as loss, religion	elderlycare:PreferencesEnvironment				
elderlycare:HousingAdaptationNow	Degree of housing adaptation now		To what degree is the patient's housing currently adapted?	elderlycare:PreferencesEnvironment				
elderlycare:HousingAdaptationWanted	Degree of housing adaptation wanted		Which housing adaptations are still wanted/needed?	elderlycare:PreferencesEnvironment				
elderlycare:MedicalHistory	Medical history		Data on the medical history of the patient	elderlycare:ElderlyCareOntology				
elderlycare:LevelOfDementia	Level of dementia		How developed is the dementia in the patient	elderlycare:MedicalHistory				
elderlycare:Prognosis	Prognosis for (future) treatment		Is there any information on the future treatments the patient is to	elderlycare:MedicalHistory				
elderlycare:HereditaryDiseases	Hereditary diseases		Is the patient prone to hereditary diseases?	elderlycare:MedicalHistory				
elderlycare:BornWithDisease	Is the patient born with the disease?		Has the patient been born with any illness?	elderlycare:MedicalHistory				
elderlycare:ProcedureHospital	Procedure in hospital		What is the procedure in the hospital (or outside of it)? What are the	elderlycare:MedicalHistory				
elderlycare:Medication	Medication		The medication data of the patient	elderlycare:ElderlyCareOntology				
elderlycare:TakesMedicationIndependently	Does patient take medication independently?		Does the patient take the medication themselves?	elderlycare:Medication				
elderlycare:PhysicalCondition	Physical condition		Data on the physical condition of the patient	elderlycare:ElderlyCareOntology				
elderlycare:PastComplications	Past complications		Are there past complications that occured in the hospital?	elderlycare:PhysicalCondition				
elderlycare:ConditionForTransport	Personal condition for transport		Is it safe for the patient to be moved to the hospital or somewhere	elderlycare:PhysicalCondition				
elderlycare:MobilityIndependence	Mobility independence		What activities can the patient still do themselves?	elderlycare:PhysicalCondition				
elderlycare:MobilityDependence	Mobility dependence		With what activities does the patient need help?	elderlycare:PhysicalCondition				
elderlycare:PresenceSkinDamage	Presence of pressure ulcer / intertrigo / incontinence-related skin damage		Is there pressure ulcer / intertrigo / incontinence-related skin damage	elderlycare:PhysicalCondition				
elderlycare:PresenceWounds	Presence of wounds		Does the patient have a wound?	elderlycare:PhysicalCondition				
elderlycare:DifficultyEatingDigesting	Degree of difficulty with eating/drinking/chewing/swallowing/digesting		Does the patient have difficulty with	elderlycare:PhysicalCondition				
elderlycare:OralHealth	Degree of oral health		What is the degree of oral health of the patient? E.g., do they have	elderlycare:PhysicalCondition				
elderlycare:Constipation	Degree of constipation		Does the patient experience constipation? Or are they inclined to be	elderlycare:PhysicalCondition				
elderlycare:PresenceCOPDOrRespiratoryInfection	Presence of COPD or respiratory infection		Does the patient have COPD or a respiratory infection?	elderlycare:PhysicalCondition				
elderlycare:SleepPattern	Sleep pattern		What is the state of the sleep pattern of the patient? Do they have	elderlycare:PhysicalCondition				
elderlycare:RiskOfInfection	Risk of infection		Is the patient at risk for infection?	elderlycare:PhysicalCondition				
elderlycare:DifficultyWithLanguage	Degree of difficulty with language		Does the patient speak Dutch fluently? Does the patient have any	elderlycare:PhysicalCondition				
elderlycare:Loneliness	Degree of loneliness		To what degree does the patient feel lonely or express loneliness?	elderlycare:PhysicalCondition				
elderlycare:EmotionalState	Emotional state		What is the emotional state of the patient? Are they relatively happy,	elderlycare:PhysicalCondition				
elderlycare:MedicalCarePreferences	Medical care preferences		Data on the medical care preferences of the patient	elderlycare:ElderlyCareOntology				
elderlycare:WashingPreferences	Washing preferences		How does the patient prefer to be washed? E.g. by a woman, not	elderlycare:MedicalCarePreferences				
elderlycare:FoodPreferences	Food preferences		What types of food and drinks does or doesn't the patient like?	elderlycare:MedicalCarePreferences				
elderlycare:UseExternalParties	Preference for use of external parties		Does the patient want to use the following external services?	elderlycare:MedicalCarePreferences				
elderlycare:NeedWantADLOrPDL	Need/want for ADL/PDL		Is there a need/want for ADL or PDL?Also, what is the patient still	elderlycare:MedicalCarePreferences				

E The first page of the form that is generated by the CEDAR template.



TestHead

PERSONAL INFORMATION

Patient Name

Age in years

patientGender

DateOfBirth

Patient Address

postal code

City

List of contact

Emergency contacts

Main caretaker

TestFoot