



# Health Information Exchange in the Netherlands

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# ABSTRACT

Health information exchange (HIE) is the activity of exchanging healthcare information between various systems and parties. It has received increasing attention in the Netherlands. Currently, many companies are investing in HIE as it can bring many advantages to the healthcare sector. Some promises of HIE include its potential to remove repetitive work, increase the quality of care, and save costs and time. However, despite these promises, the real benefits of HIE have not been widely realized. This is partly traceable to the complexity of the stakeholders' requirements and their incomplete understanding of the HIE market. Currently, a combination of laws, upcoming standards, and the wide variety of HIE initiatives create a complex market. As a result, a structured understanding of the market holistically and from each player's perspective is missing. This, in turn, hinders companies interested in HIE adoption in developing their business and technology strategies.

In this thesis, we seek to provide a structured and stakeholder-centric understanding of the HIE market. Our research aims to guide stakeholders in the healthcare market to understand HIE in a way that helps them develop a future-proof business strategy. We achieve this by designing stakeholder perspectives, which indicate stakeholders' most important goals and requirements.

This research project employs a research process that implements Wieringa's Design Science Research Methodology (DSRM) and consists of three phases: *problem investigation*, *treatment design*, and *treatment validation*.

The problem investigation phase started by conducting a semi-structured literature review to find the drivers behind HIE as reported in scientific publications. Our review concludes that the goals of implementing HIE align with providing better healthcare. The main drivers of HIE are to improve patient outcomes, save costs and increase efficiency. Moreover, the literature sources that studied the effect of HIE have indicated a positive relationship between HIE adoption and improvements regarding all these factors. Our literature review is complemented by an exploration of earlier attempts by the Dutch government to regulate HIE. Starting at the end of the twentieth century, the government attempted to implement a national electronic health record (EHR). Ultimately this attempt failed in 2011 primarily due to privacy requirements that could not be satisfied. To further understand the state of the HIE practice in the Netherlands, we also explored key stakeholder groups. The current state of the practice consists of (i) laws, some of which have already been implemented while others are still in development, (ii) a broad range of stakeholders, and (iii) diverse initiatives which implement HIE in different ways. The following stakeholder groups have been identified as central to HIE and are considered in our research process: (1) citizens (Dutch residents, i.e., healthcare service consumers/patients), (2) insurers, (3) healthcare providers, and (4) healthcare technology providers (HTPs).

The treatment design phase started by conducting a qualitative interview study that extracted goals and requirements from representatives of the four identified stakeholders. We interviewed 13 people that collectively represented all groups. The results of this interview study were used to create **the artifact** of our research: *stakeholder perspectives*. In total, we create six perspectives. The HIE needs of citizens and insurers are aligned within the stakeholder groups, resulting in one perspective per group. As alignment was not observed in healthcare providers and HTPs, we present two perspectives per stakeholder group. Specifically, the focus for healthcare providers lies primarily in striving for excellence by collaborating with others or focusing on internal businesses. Unlike this, the focus for HTPs differs in providing applications that actively influence the care process and facilitate collaboration and applications that focus on continuity and internal integration. The differences of focus present the extremes, which aim to cover all variations of strategies that stakeholders may employ.

In the treatment validation phase, we carried out a preliminary evaluation study with four industry experts. The stakeholder perspectives are evaluated according to expert opinion as described in DSRM by Wieringa. Our evaluation indicates that according to the perceptions of the evaluation study participants, the stakeholder perspectives give a good representation of key stakeholders. Combined with the background information presented in this thesis, our included experts indicated that the stakeholder perspectives help understand the healthcare sector. In addition, the structured way of presenting stakeholders may help promote HIE collaboration. Finally, the evaluation indicated that specialists in the HIE field are likely to use the proposed stakeholder perspectives in their daily work.

This thesis makes three contributions. First, our most significant contribution is the artifact. We present a total of six stakeholder perspectives representing the most important stakeholders in the HIE market. They are structured according to the Layer Framework, differentiating between different levels relevant to HIE. Second, this thesis summarizes the drivers behind HIE, analyzes historical events, and describes the current healthcare market in the Netherlands. This forms a contribution to practice. In fact, the implications for practice are the structured way of presenting stakeholder strategies. Third, we contribute an empirical evaluation of the stakeholders' perspectives. While this is the first evaluation, its participants agree that the artifact covers each stakeholder sufficiently well and has the potential to add value. Of course, we cannot claim universal generalizability of the suitability of the artifact to all contexts beyond the Dutch HIE marketplace. However, following Wieringa's approach to generalizing from a limited number of contexts, we could think that the artifact might well fit contexts similar to ours. For example, the artifact might be suitable in countries in northern Europe that have a similar way of organizing the healthcare sector and form a similar market with similar drivers, goals, and stakeholder requirements. Of course, more empirical evaluation is needed to substantiate this claim, which we consider an important line for future research.

This thesis offers some venues for future research. First, we recommend more research within the current research scope. This is to address the limitations of our work and present a more thorough evaluation of the stakeholder perspectives. Examples of achieving this are through more extensive interviews, including personas for the citizen stakeholder perspective, and a comprehensive evaluation study. These evaluation studies could contain several case studies in which the application of the stakeholder perspectives is evaluated in practice. Secondly, we recommend extending the research scope. This can address two points, (1) better understand the current state, and (2) explore solutions for the implementation of HIE. By looking at other countries' healthcare markets, we can evaluate if the stakeholder perspectives apply elsewhere. In addition, it can be studied how these countries address HIE-related issues. Secondly, other sectors can be explored. The challenges of standardizing and exchanging information are not unique to the healthcare sector. Therefore, other sectors might have found solutions that can be used for HIE.

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# ACRONYMS

CIM	Clinical information model (zorginformatiebouwsteen)
EHR	Electronic Health Record
HIE	Health Information Exchange
HTP	Healthcare Technology Provider
PHR	Personal Health Record (Persoonlijke gezondheidsomgeving)
UTAUT	Unified Theory of Acceptance and Use of Technology
VWS	The Ministry of Health, Welfare, and Sport
WEGIZ	Law for electronic healthcare exchange (Wet elektronische gegevensuitwisseling in de zorg)
WLZ	Long-Term Care Act (Wet langdurige zorg)
WMO	The Social Support Act (Wet maatschappelijke ondersteuning)
ZVW	Healthcare Insurance Act (Zorgverzekeringswet)



# 1 INTRODUCTION

The healthcare sector is performing better than ever before. We can treat more diseases, and life expectancy in the Netherlands has increased drastically compared to decades ago (Centraal Bureau Statistiek, 2019). The improvements in health are accompanied by the growth of our healthcare sector. The number of people working in Dutch healthcare is still increasing as well as the number of healthcare providers. In 2016, 1,2 million people were active in the healthcare sector, and this number is increasing every year (Wessels & Driesten, 2018). Healthcare is the second largest industry in the Netherlands, with people working in over 55 thousand healthcare institutions (*Zorgkaart Nederland*, n.d.).

The progress and growth of our healthcare sector increased the need for collaboration. Citizens often receive care from more than one healthcare professional. For example, citizens in need of surgery encounter an average of 26.6 healthcare professionals. These professionals can vary from doctors and nurses to other supportive professionals (Whitt et al., 2007). Therefore, collaboration is required from multiple healthcare institutions. For instance, chronically ill people have on average 6.2 different healthcare providers (Nictiz, 2013). Close cooperation between healthcare providers is required to ensure that these people receive appropriate and correct healthcare. One part of this collaboration is the exchange of healthcare information.

Healthcare information includes all information related to a person's medical history, including X-rays, lab results, and earlier treatments. Health information exchange (HIE) is the exchange of healthcare information for various reasons. For example, multiple parties can be involved in the same treatment process; hence exchange of information is needed. Another use of HIE arises in emergencies or urgent hospital visits. During these visits, it can be vital to know earlier complications of a patient. In all cases, healthcare information stored at one party must be exchanged with another. Research on HIE has been an area of interest for over three decades. Scholars started looking into the benefits of exchanging data between healthcare providers in the early nineties. Initial research found significant benefits for most involved stakeholders (Hasman et al., 1992). In the Netherlands, HIE also got traction. Electronic health records (EHRs) had an essential role in modernizing the administration of healthcare providers. In addition to the benefits of replacing paper files, EHRs were also supposed to facilitate healthcare information exchange.

Fast forward to 2021, and HIE is still not universally implemented. Although some steps have been made, earlier promises of quality improvements, efficiency increase, and time savings have still not been achieved in the Netherlands. This raises the question; why is there not a nationwide solution for HIE? Standardization is something people have come to expect in every aspect of their lives. There is no question whether a phone will connect with a specific WiFi point. Here, the standardization process has long been completed (Jakobs, 2017). This research aims to give insight into the current state of HIE and aims to give guidance for stakeholders in the healthcare market.

## 1.1 Problem statement

Currently, there is a need for clarity in the Dutch HIE market. At the moment, there are hundreds of initiatives that facilitate some form of information exchange. There are endless options, varying from chat messaging services to complete integration platforms. Initiatives are promoted 'top-down' by government subsidies and the pressure of upcoming laws. At the same time, small initiatives arise that try to tackle the problem bottom-up. The development of laws, competing standards, and diverging platforms all provide uncertainty. This hinders companies (i.e., healthcare organizations, healthcare technology providers, insurers, and government bodies) interested in HIE adoption in developing their business and technology strategies. The opportunity cost of investing in an HIE initiative can be substantial, while the payoff is still unclear. Insight into HIE developments is required so companies can formulate a viable and future-proof business strategy.

To the best of our knowledge, research into the Dutch HIE market has not been conducted before. In this research, we address this knowledge gap by exploring various aspects of the market and designing an artifact that provides a structure for stakeholders.

## 1.2 Research goal

To specify the goal of this research, we make use of the design problem template formulated by Wieringa (Wieringa, 2014). Wieringa proposes a template that clearly describes the problem context, artifact, requirements, and stakeholder goals. Our objective is to address the problem identified in section 1.1 by designing stakeholder personas that provide insight. The template for a design problem is as follows:

- *Improve* <a problem context>
- *by* <(re)designing an artifact>
- *that satisfies* <some requirements>
- *in order to* <help stakeholders achieve some goals>.

The *problem context* is the situation in which the current problem exists. In this research, that is the Dutch HIE market. To help resolve the problem context, we will design an *artifact* in this research. An artifact is something that can be designed and be placed in the problem context. The *requirements* indicate conditions that need to be accomplished in the artifact design. Finally, the artifact should contribute towards *stakeholder goals*. Applying this template to the problem statement results in the following design problem:

- *Improve* the clarity around design choices for health information exchange
- *by* proposing stakeholder perspectives of relevant stakeholders
- *that satisfies* the need for improvement of healthcare cost, quality, and efficiency
- *in order to* allow stakeholders in the Dutch healthcare market to provide better and future-proof healthcare services.

## 1.3 Research questions

To achieve the research goal specified in the previous section, we formulate the following research question:

*What stakeholder perspectives can we design for companies looking to adopt health information exchange that allows them to develop a future-proof business strategy?*

To guide our research, we formulate the following sub-questions:

1. What are the drivers behind health information exchange?  
*Rationale: Healthcare information exchange is gaining popularity. We explore drivers and (dis)advantages of HIE to provide a basis for this research.*
2. How did the Dutch government influence health information exchange?  
*Rationale: In the first decade of the twentieth century, there was a government-led initiative to implement a national EHR. In combination with RQ1, this will provide a background for understanding the current HIE market.*
3. What is the current state of health information exchange in the Netherlands?  
*Rationale: To understand why unclarity exists in the sector, we explore its current state. This includes relevant stakeholder groups and HIE initiatives.*
  - a. What stakeholder groups can we identify?
  - b. What initiatives to promote health information exchange can we identify?
4. What stakeholder perspectives exist in the Dutch health information exchange market?  
*Rationale: To improve the clarity in the HIE sector, we design stakeholder perspectives that describe different actors in the market.*
  - a. What goals do different stakeholders have?
  - b. How can we group stakeholder goals for the different stakeholder groups?

5. Do the stakeholder perspectives contribute to a better understanding of the Dutch health information exchange market?  
*Rationale: The stakeholder perspectives are evaluated to see if they help clarify design choices for health information exchange.*

## 1.4 Methodology

### 1.4.1 Design Science Methodology

This research is structured using Design Science Methodology (DSM) proposed by Wieringa, which describes how to do design research (Wieringa, 2014). DSM is an outcome-based methodology in line with our research goal since a design will be made to address a real-world problem. Wieringa's methodology covers three steps: problem investigation, treatment design, and treatment validation. The combination of these steps forms the design cycle, shown in Figure 1-1. Figure 1-2 provides an overview of our research design. This figure shows the research questions, other key activities and maps these to the corresponding phases in the design cycle.

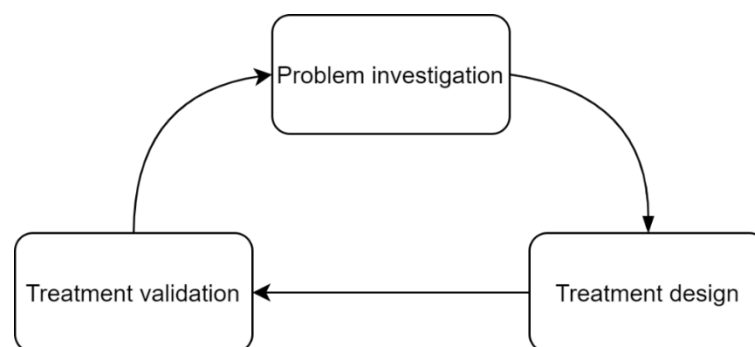


Figure 1-1: Design Cycle of Design Science Methodology, adapted from (Wieringa, 2014)

- **Problem investigation**  
This stage should lead to a better understanding of the problem before the design of an artifact is started. Stakeholders and goals are identified using literature and interviews. During this stage, we explore the HIE market and its stakeholders. We conduct a literature study to identify stakeholders and to gain an understanding of the problem context.
- **Treatment design**  
In the treatment design part of the cycle, we start designing a new artifact: stakeholder perspectives. By combining findings from our literature study and interviews, we collect the requirements and desires of different stakeholders. These results are used to create stakeholder perspectives. This artifact has the aim of contributing to stakeholder goals when placed in the problem context.
- **Treatment validation**  
We validate if the designed artifact contributes to stakeholder goals in the problem context during the final phase. The validation phase exists to validate whether the stakeholder perspectives help to resolve the problem. For our evaluation, we make use of expert opinion. This evaluation method relies on the experience of experts to evaluate how a design could function once placed in the problem context.

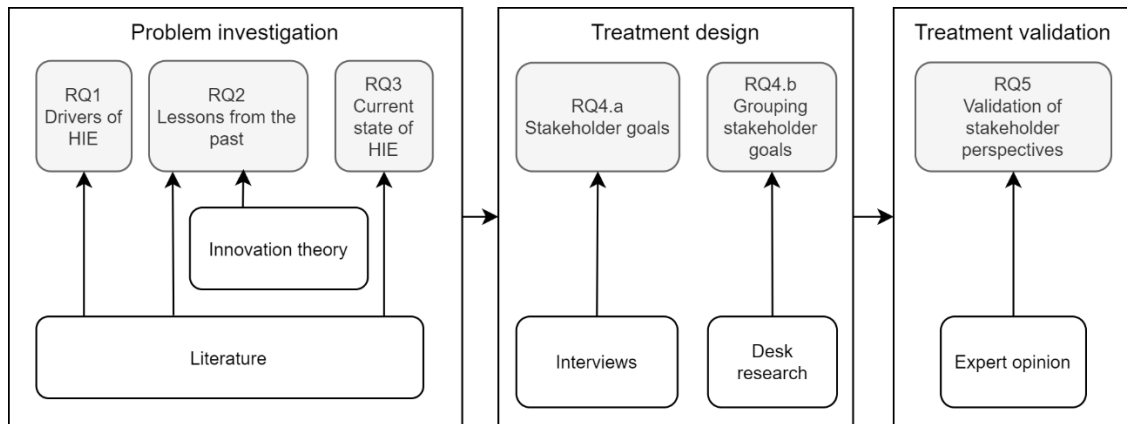


Figure 1-2: Research design

### 1.4.2 Other methodologies

In addition to the design problem mentioned in section 1.2, knowledge questions must be answered. Our research makes use of a mixed-method approach to accomplish this. There are several reasons for this approach. First, the research can be categorized as empirical research. We cover markets and historical aspects. Secondly, the research goal is to lead to a broad understanding of HIE, not to be exhaustive on previous research. These characteristics align well with a mixed-method approach.

Research Questions 1 through 3 are answered by conducting semi-structured literature reviews. This allows for a combination of depth and breadth in the various topics. Research Question 4a is addressed through semi-structured interviews. Semi-structured interviews guide conversations while remaining versatile and flexible. Research Question 4b is part of the treatment design in DSM. Research Question 5 is answered by adopting the unified theory of acceptance and use of technology (UTAUT). Table 1-1 provides an overview of the different research questions and their respective methodology. It provides a mapping to the sections that describe their method in detail.

Throughout the research, we use various terms like goals, requirements, and stakeholders. These terms originate from research presented by Lauesen (1982) and Alexander & Beus-Dukic (2009). In addition to their definitions, we use methods related to requirements and stakeholder analysis.

Table 1-1: Overview of methodologies

<b>Research Question</b>	<b>Methodology</b>	<b>Description</b>
<i>RQ1</i>	<i>Semi-structured literature review</i>	<i>2.1.1</i>
<i>RQ2</i>	<i>Semi-structured literature review</i>	<i>2.2.1</i>
<i>RQ3a</i>	<i>Semi-structured literature review</i>	<i>3.4</i>
<i>RQ3a</i>	<i>Semi-structured literature review</i>	<i>3.5</i>
<i>RQ4a</i>	<i>Semi-structured interviews</i>	<i>4.1</i>
<i>RQ4b</i>	<i>Design Science Methodology</i>	<i>5.1</i>
<i>RQ5</i>	<i>UTAUT</i>	<i>6.1</i>

## 1.5 Thesis outline

This thesis describes our research through several chapters. Below we present an overview of the contents of each chapter. In addition, Table 1-2 gives an overview of the research questions mapped to the chapters in which they are addressed.

Chapter 2 covers the background of this thesis. Section 2.1 explains the drivers behind HIE based on literature. Section 2.2 explores earlier attempts of the Dutch government to regulate and promote HIE. We use innovation theory to analyze government strategy.

Chapter 3 covers the current state of HIE in the Netherlands. We present an overview of the healthcare market and various stakeholders working on HIE.

Chapter 4 presents the results of stakeholder interviews. We first introduce our interview methodology. Next, the interview design is presented, along with a description of the interview sessions. The following section presents interview results using stakeholder groups. Finally, the chapter concludes by discussing threats to validity.

Chapter 5 covers the design of our research. Based on the results from the interviews, we design stakeholder perspectives. These perspectives provide an overview of the goals and desires of each stakeholder group. The chapter is concluded by reflecting on the different stakeholder perspectives.

Chapter 6 presents a first evaluation study with the use of expert interviews. We first present the evaluation methodology and interview design. A description of the evaluation interviews is provided, and the results of the evaluation interviews are presented. Results first cover the evaluation of our artifact, along with changes made based on expert feedback. Then, using UTAUT, we evaluate the acceptance of the proposed stakeholder perspectives. The result covers experts' reflections on the current state of HIE. The chapter is concluded by discussing threats to validity and a conclusion summarizing our findings.

Chapter 7 covers the discussion and conclusion of our research. It answers the research questions, discusses contributions to practice, contributions to theory, and limitations. We also present recommendations for future work.

Table 1-2: Thesis overview

<b>Research Question</b>		<b>Chapter</b>
<i>RQ1</i>	What are the drivers behind health information exchange?	2.1
<i>RQ2</i>	How did the Dutch government influence health information exchange?	2.2
<i>RQ3.a</i>	What stakeholder groups can we identify?	3.4
<i>RQ3.b</i>	What initiatives to promote health information exchange can we identify?	3.5
<i>RQ4a</i>	What goals do different stakeholders have?	4
<i>RQ4b</i>	How can we group stakeholder goals for the different stakeholder groups?	5
<i>RQ5</i>	Do the stakeholder perspectives contribute to understanding health information exchange in the Netherlands?	6

## 2 BACKGROUND

This chapter will answer RQ1 and RQ2 by exploring two background topics related to health information exchange (HIE). Section 2.1 will look at the drivers behind HIE along with expected benefits or drawbacks. Section 2.2 takes a historical perspective. We explore an earlier attempt of implementing HIE in the Netherlands and relate this to the role of the government.

### 2.1 Drivers behind health information exchange

Health information exchange (HIE) is suggested to have many advantages. HIE has the primary goal to have less repetition, preventing mistakes in transfers, and reduce unnecessary work. This should lead to better care, more efficiency in healthcare provision, and cost savings (Chen et al., 2019).

This section aims to answer RQ 1: *what are the drivers behind health information exchange?* We will explore claimed benefits, problems, reasoning, and literature regarding HIE in the context of the Dutch healthcare market.

#### 2.1.1 Methodology

Due to the diverse nature of information regarding HIE, a mixed approach was used in this chapter. For scientific literature, parts of Wolfswinkel's methodology have been used (Wolfswinkel et al., 2013). Selected search engines are Scopus and Google Scholar. Articles have been reviewed in iterations using different search terms. This iterative approach allowed for refinement of the search terms during the search. "*Healthcare data exchange*" was used to provide an initial context. This search term helped discover the more common terminology "*healthcare information exchange*" and "*health information exchange*". After exploring the relevant concepts, we focused on HIE survey papers. This helped to get a good understanding of the current knowledge body. To address specific questions about HIE, more focused queries were made by including "*benefits*", "*results*", "*cost*", "*patient outcomes*", and others. Publications have been selected on relevance based on title, abstract, publication year, and popularity. Due to the quick pace of technical advancements, only recent papers are used. We selected publication dates after 2015. As a measurement of popularity, we looked at the number of citations of a publication or engagement scores when available. Additional literature was found through backward and forward reference searches from relevant papers and reports.

In addition to scientific literature, non-academic sources were used. These were essential to cover all developments in the Netherlands and explore demographic trends. For an up-to-date overview, the most recent developments had to be incorporated, for which publications were not available through common scientific search engines. Sources were found from dedicated knowledge institutions like Nictiz (Nictiz, n.d.-a), official government outlets (Rijksoverheid, n.d.), and publications from private organizations. Other sources have been identified through the use of search engines like Google. Also, for the non-academic sources, additional reports and information were found through backward reference analysis.

#### 2.1.2 Patient outcomes

The focus of healthcare is shifting from the volume of delivered services to delivered value (Porter et al., 2016). Porter defines value as patient outcomes achieved relative to the cost. Patient outcomes are the most important goal: providing good health care. This brings us to the first argument for HIE: the reduction of medical errors. Research from the US states that medical error could be the third leading cause of death (Makary & Daniel, 2016). Medical error is also a big problem in the Netherlands. Research indicates that medication mistakes alone are responsible for 27000 preventable hospitalization cases every year (Sturkenboom et al., 2017). In this same research, possible solutions are discussed. By providing healthcare professionals with all available information, mistakes can be minimized. Improved information exchange can therefore contribute to patient outcomes.

A subject that is often mentioned alongside medical errors is self-reliance in healthcare. Self-reliance focuses on what people can contribute to their health and highlights the impact of their behavior. It should prevent medical errors by actively incorporating patients in the care process. A vision document from a group of patient organizations summarizes the main concepts of self-reliance in healthcare (Bakker et al., 2013). By focusing policies on people's capabilities and self-reliance, healthcare quality should increase, and the costs decrease. Literature also suggests self-reliance helps to increase the quality of healthcare. The health quality of various chronic patients increases when introducing self-reliance. Researchers also indicated that costs would likely decrease, mainly due to less usage of healthcare facilities (Heijmans et al., 2015).

An example of a modern initiative that promotes self-reliance is called MedMij. This initiative got traction recently and aims at providing people insight into their healthcare information using personal health records (PHRs). The idea is that people should be more involved with their care process by allowing them to view their healthcare information (Informatieberaad, 2020). Patient information is generally stored in electronic health records (EHRs). These EHRs are used by each organization providing healthcare and contain information related to patient's interaction with that specific healthcare provider. Essential for MedMij, and self-reliance in general, is that patients can access all relevant information from their electronic health records (EHRs). To enable this, HIE is required of every healthcare provider to view information from their EHRs in a single place.

In addition to reducing medication errors and contributing self-reliance, HIE also directly influences patient outcomes. Research explicitly looking for the influence of HIE on patient outcomes found a positive relationship. The primary reason was a reduction in readmissions of patients (Chen et al., 2019). In other research, a survey is performed regarding the effects of HIE. Healthcare quality and patient outcomes were found to have a positive relationship in 90% of the analyzed studies (Menachemi et al., 2018). This brings us to the first reason for HIE.

*Reason 1: improve patient outcomes.*

### **2.1.3 Healthcare efficiency**

Efficiency in healthcare has a bad stigma. Minimizing time spent with a patient increases efficiency but might decrease patient outcomes. Despite this, the efficiency of healthcare is still essential. Its relevance is best described with some examples. Much of the communication with a hospital is still done through faxing (Nictiz, 2016; V&VN, 2018). Also, the inability of systems to exchange information with each other leads to much administrative work. Treating a case of breast cancer in the Jeroen Bosch hospital in Den Bosch requires over 40 transitions of data from one system to another (HL7 Netherlands, 2019). These are clear examples where healthcare efficiency is desirable and could even increase patient outcomes by preventing mistakes. The need for more efficiency in the healthcare sector is sparked by two trends in the Dutch healthcare sector.

The first trend is population growth. According to CBS, the Dutch central bureau for statistics, the Netherlands will undergo a slight population growth during the following decades. The total population is expected to grow to a maximum of 19 million in 2039. This population growth is accompanied by an aging population. The result is that the size of the labor force will decrease compared to the total population (Centraal Bureau Statistiek, 2020). Grey pressure is a statistic that expresses the ratio of people over 65 to people between 20 and 64. The grey pressure was 33 percent in 2019 and is expected to increase to almost 50% in 2040, as shown in Figure 2-1. Thus, in two decades, there will only be two people working for every person over 65. Combined with the fact that people over 65 require significantly more healthcare (RIVM, 2017), this will result in a growing need for healthcare over the next two decades.

The second trend in the healthcare sector is a growing shortage of healthcare professionals. In 2016, 1,2 million people were employed in healthcare (Wessels & Driesten, 2018). There is an existing shortage of healthcare workers, which could grow to over 100 thousand by 2022 (ActiZ, 2019; Tweede Kamer, 2017). As a result of this growing shortage, work pressure is increasing. CBS conducted a survey in which almost half of the employers in the healthcare sector indicated work pressure increased in recent years. The number one reason for this trend is regulations and administrative burden (Mooren & Gielen, 2019). General practitioners experienced the most considerable increase in working pressure

with 77%. Other sources also confirm this. An inquiry by Berenschot of 7700 healthcare professionals working in long-term care indicated that 35% of their time was spent on administration, while 23% is seen as acceptable. As a result of these trends, professional associations have called for a decrease in administrative pressure (Hanekamp et al., 2019).

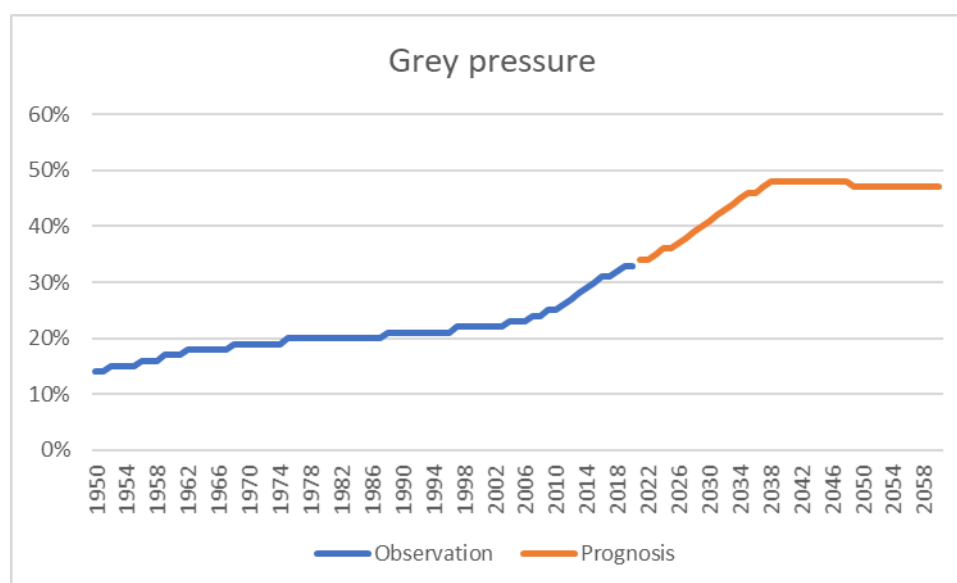


Figure 2-1: Prognosis of grey pressure (Centraal Bureau Statistiek, 2020)

HIE can play an essential role in combating these challenges. Research indicates it can help prevent duplicated procedures, thus saving valuable time for healthcare professionals (Menachemi et al., 2018). HIE also reduces other duplicative medical procedures like laboratory and radiology testing (Hersh et al., 2015). These factors both improve the efficiency of healthcare, which is essential if the sector wants to handle the population trends described before. This presents the second reason for HIE.

*Reason 2: increase efficiency in healthcare.*

## 2.1.4 Healthcare costs

Another result of the growing and aging population is increased healthcare costs. The average yearly cost of healthcare rises significantly with age. On average, each person makes €5.692 of healthcare expenses in their early sixties which rises exponentially to € 56.559 for people over 95 (RIVM, 2017). Due to the increasing grey pressure, there are fewer people available to cover healthcare costs. This makes it essential for the healthcare sector to save costs to ensure our social security remains intact.

This is another area where HIE can help. Reason 2, increased efficiency, has a side benefit of creating more cost-effective care. The removal of duplicate actions leads to less time that has to be spent on each patient. This reduces the cost per treatment. In addition to the efficiency-related cost savings, some processes can be left out entirely. For example, redundant testing of lab results or burning physical DVDs is no longer required. Results from other sources can be transferred digitally using HIE. Removing these activities can save costs by removing steps with much overhead.

Another way HIE facilitates cost saving is by allowing better integration with various parties in the healthcare chain. Transferring healthcare from the hospital to general practitioners or home is one of the measures intended to save costs. However, communication between patients, general practitioners, and hospitals is required to implement this properly. Cost savings are also found in the literature. Two recent surveys visit research on HIE and its implications. Both surveys found many implications of HIE, including significant evidence for cost savings (Hersh et al., 2015; Menachemi et al., 2018). This brings us to the third reason for HIE.

*Reason 3: save costs in healthcare.*



### 2.1.5 Downsides of HIE

We found no claims of negative consequences associated with HIE in literature. However, some literature suggests that the advantages of HIE are not proven (Rahurkar et al., 2015). In a survey looking at the effects of HIE on costs and quality of care, only 57% of the papers they analyzed showed benefits. However, other research suggests a much stronger claim on the positive effects of HIE (Menachemi et al., 2018).

A sidenote is that many of the articles we reference state that HIE should be used as a means, not a goal. Many other factors are also relevant to the efficiency and quality of healthcare. Implementing HIE will positively impact these factors but not guarantee they are achieved.

### 2.1.6 Conclusion

In the sections above, we give an overview of the most important reasons for HIE. In general, reasons for HIE are aligned with providing better healthcare altogether. Population trends in the Netherlands spark a need for more efficient and cost-effective healthcare. We find there are many subjects related to HIE and cover the most important ones. Figure 2-2 gives an overview of these reasons and how they relate to each other. The most significant benefits of HIE are improving patient outcomes, save costs, and increase efficiency. While some benefits might be related, like costs savings through increased efficiency, each benefit is mentioned separately in literature.

Although these reasons were found to be the most important, many related reasons exist. An increase in working pleasure is a positive effect of a lower administrative load. More working pleasure can also address the staff shortage in the healthcare sector. However, the most significant benefit is still the increase in efficiency (that may lead to more working pleasure). For the clarity of this research, these reasons have not been individually addressed.

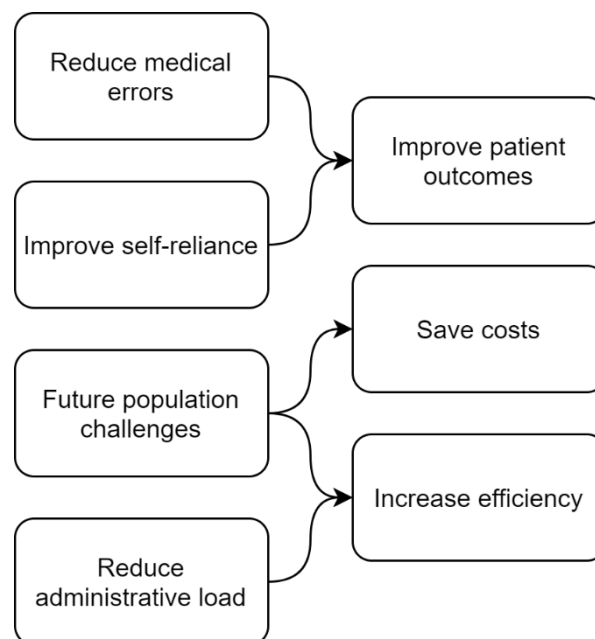


Figure 2-2: Relations of reasons for HIE

## 2.2 Previous attempts at harmonizing health information exchange

This section aims to answer RQ 2: *how did the Dutch government influence health information exchange?* After establishing the reasons for health information exchange (HIE), we now explore an earlier attempt at harmonizing HIE. Our focus is on the implementation of a Dutch national electronic health record (EHR). We analyze the government's influence by applying the seven functions proposed by Hekkert et al. (2007).

### 2.2.1 Methodology

To establish what historical events took place, we consulted several sources. We started by exploring sources in the scientific literature using Scopus and Google Scholar with the search term “*elektronisch patiëntendossier*”. Like section 2.1, other sources were used as well to get a complete image. Search engine Google was used to explore non-scientific sources on the EHR implementation. Additionally, we explored several government documents that were referenced by literature or linked to specific events. Finally, our findings were checked on completeness by an expert involved with the different phases of the ERH implementation.

For our analysis, we make use of innovation theory. Innovation can be defined in many ways; we will consider the following definition. “*The implementation of a new or significantly improved product (good or service), or process, a new marketing method, or a new organizational method in business practices, workplace organization or external relations*” (OECD & Eurostat, 2018). The implementation of the national EHR (*Dutch: elektronisch patiëntendossier, EPD*) was intended to facilitate more, faster, and more complete exchange of patient data. Therefore, it is a combination of technological and organizational innovation. The following section will first describe historical events. Next, the implementation of the EHR will be discussed in terms of the seven functions proposed by Hekkert et al. (2007). Hekkert's research is well established in the innovation theory field and has been cited over 2600 times. Additionally, Hekkert has validated the usage of his seven functions with empirical research (Hekkert & Negro, 2009).

### 2.2.2 A brief history of the Dutch national EHR

The story of exchanging healthcare information in the Netherlands started in the mid-1990s. At that time, the focus was still on the initial digitalization of the sector. Minister of Health of the time, Els Borst, concluded that the healthcare sector was slow with ICT adaptation. In 1996, the ministry passed a bill that noted the situation in the healthcare sector. The bill also projects some options for the future. Information exchange is deemed vital to keep the healthcare sector efficient and effective. An advisory body related to the healthcare sector (Raad voor de Volksgezondheid en Zorg) was asked for suggestions on how to continue. Their recommendations focus on a more advanced administration with the most crucial advice to replace paper health records. The minister followed this advice and placed a focus on digitizing the healthcare administration during her term. A program is started to promote the benefits of ICT in healthcare and promote EHR usage in general (Reinders, 2011; Tweede Kamer, 1997).

The government approach changed at the beginning of 2000. The minister concluded that there is an increased desire for the government to take an active role in implementing ICT in healthcare. Nictiz, the “Dutch competence center for the electronic exchange of health and care information”, was created. They were made responsible for further promoting the usage of ICT. A first step in implementing the EHR was made by creating a digital version of general practitioner reports. These should later be combined with more information into a complete EHR. In early 2006 the implementation of these digital reports is started. The reports were combined with a national system that should facilitate and regulate data exchange between different parties. This system called ‘Landelijk Schakelpunt’ (LSP) will remain a vital design component in the rest of the EHR implementation (Tweede Kamer, 2000). Slightly earlier, in November 2005, a change of organizational structure was made. The government was not happy with the pace of implementing the EHR and decided to take more control. Every quarter the house of representatives was to be informed of the current situation, and the ministry of health was made

responsible for the implementation. With the help of another steering committee, the ministry decided on the initial version of the EHR (Tweede Kamer, 2005).

In 2008 a bill was passed that allowed for the Dutch social security number to be used in the national EHR. Additional regulations were passed on requirements for access to medical data, and the role of the LSP was further specified. Although this increases privacy concerns by experts and citizens, the effectiveness of the EHR should be guaranteed. At the end of 2008, the initial implementation of the EHR was completed, and more functions could now slowly be added. Each household received a letter informing them about the upcoming national EHR. Citizens could object to their data being processed in the EHR. This letter caused much commotion in the Netherlands, and the sentiment of the general audience regarding the EHR changed. This helped create a negative public image of the EHR. Privacy concerns and misconceptions of the design of the EHR were the primary reason. Additionally, it was thought that the EHR was a centralized database in which all patient data would be stored. While this was not the case, this misconception was considered as a risk that could expose sensitive healthcare information. During a public hearing in the Senate, it could not be guaranteed that the EHR was a safe place to store healthcare data. After much discussion, the Senate unanimously voted against the national EHR in 2011, ending the government's influence on HIE (Michel-Verkerke, 2013).

In 2021, the EHR in its intended form has still not seen the light of day. The LSP is implemented in an alternative form. Nictiz is still active as a non-profit promoting ICT in the healthcare sector and providing insight into data exchange standards. Without influences from the government, the private sector did not manage to implement an alternative to the national EHR in the last decade (Nictiz, n.d.-b).

### 2.2.3 Analysis of historical events

After describing the attempted implementation of the national EHR, the next section will analyze the process. Different stages of the national EHR introduction were accompanied by different approaches of the Dutch government. Initially, the healthcare sector was mainly informed of the possibilities. Later the government started taking a more dominant role up to the cancellation of the EHR in 2011.

Hekkert proposes a total of seven functions of innovation systems (Hekkert et al., 2007). These functions can be used to analyze an innovation such as the EHR. Using Hekkert's framework, the actions taken by the Dutch government will be evaluated. The seven functions are as follows. (1) *entrepreneurial activities* are crucial in innovation because of their experimental behavior and willingness to take risks. (2) *knowledge development* focuses on efforts or results with regards to the creation of new knowledge. (3) *knowledge diffusion through networks* indicates the sharing of information within innovation systems. (4) *guidance of the search* indicates if there are limitations to the scope of research. This function is especially relevant in the case where government regulation limits the options for innovation. (5) *market formation* describes to what extent new markets can be formed using new technology. (6) *recourses mobilization* is related to other functions since they are often the result of resources that must be made available. (7) *the creation of legitimacy/counteract resistance to change* is the final function that assumes part of implementing innovations is overthrowing an existing regime. Resistance can be expected. Therefore, a counteract to this resistance could arise. After explaining the seven functions, the implementation of the EHR will now be discussed via the seven functions.

1. Entrepreneurial activities were not that relevant during the EHR implementation. The goal was to advance current healthcare companies technologically, and the role of entrepreneurs was not considered in any government measures. Solutions with entrepreneurial nature were not considered.
2. Knowledge development is considered to be a less critical function. While specialized knowledge was required to handle some more complex administration tasks, knowledge development did not receive much attention. Technologies to digitize health records already existed. R&D projects were therefore not as relevant. However, how these technologies were best implemented was a topic some of the created groups focused on. This indicates that the knowledge development function was relevant in some way.

3. Knowledge diffusion through networks was not explicitly addressed. Different expert groups and non-profits were founded to determine how to proceed. The spread of this knowledge seems to have received less focus. Although the healthcare sector is significantly fractured in the Netherlands, the implementation of the EHR was national and run as a single project where knowledge diffusion was not considered.
4. Guidance of the search is a factor that certainly played a role during the development of the EHR. Communication from the Dutch government started as a nudge to the healthcare sector to improve their ICT systems. The digitization of patient records already indicates a small area that would receive more focus over the years. This focus slowly got more specific when the government-initiated parties took up various roles and came up with a set structure for how the exchange of EHRs was envisioned. This focus narrowed the scope until the end, when the Dutch senate blocked further involvement from the government.
5. Market formation is not relevant. Only existing healthcare companies were included in the project, and new institutions that were created have all been initiated by the government. In later stages, this function could start to play a role. While the data exchange only occurs between existing parties, new initiatives that deal with various challenges this data exchange poses are emerging. Currently, multiple companies and foundations are working on innovative ways of sharing healthcare information in a safe and privacy-friendly way. Using new technologies like blockchain could facilitate creating a new market (Nuts, n.d.). This also relates to the first function. While initially, only existing companies had a place in this project, opportunities created by new technologies enable entrepreneurial activities to flourish.
6. Resource mobilization is also heavily related to the government. Since all initiatives during the EHR development were government initiated, resources in the form of subsidies were also provided. The cancellation of the projects brought an abrupt halt to these resources, after which the remaining foundations were abandoned.
7. The creation of legitimacy/counteract resistance to change might have had the most significant influence on the EHR implementation. In the last few years leading up to the repeal of the EHR plans, criticism was expressed from many directions. Civilians, commercial parties, and political parties had their remarks regarding safety and the amount of choice presented to citizens. Most of society objected to the introduction of this new system. Misunderstandings and negative publicity about the EHR caused damage that could no longer be resolved. A big misconception about the EHR was the assumption that all health data would be stored in a central database – which would cause many security and privacy issues. The government failed in refuting this idea once it was conveyed to the public. The negative image that the EHR got over the years is one of the primary reasons the implementation failed (Reinders, 2011).

#### **2.2.4 Conclusion**

By connecting political events to Hekkert's seven functions, we evaluated the various stages of EHR implementation. Most of the functions apply to the national EHR and highlight important aspects of the government's policies. Most other functions show considerable relevance and can contribute to an explanation of why the EHR implementation failed. Only function five proved not to be relevant in the historical events. Function seven is most important due to the resistance that ultimately ended the EHR implementation. Another interesting function is four. The government went through many different roles, varying from entirely passive to active. This function is also relevant for the analysis of the government's strategy today.

## 3 CURRENT STATE OF HEALTH INFORMATION EXCHANGE IN THE NETHERLANDS

This chapter explores the status quo of health information exchange (HIE) in the Netherlands. This answers RQ 3: *What is the current state of health information exchange in the Netherlands?* Our findings conclude the problem identification phase in the design cycle (Wieringa, 2014).

HIE has many different aspects. From technical standards to upcoming laws mandating electronic HIE. Section 3.1 will start by providing a brief introduction to the Dutch healthcare market. Understanding the different stakeholders in the sector and their responsibilities will help provide a clear overview. Next, we will explore legislation that influences the sector, followed by relevant stakeholders, visions, and initiatives regarding HIE.

### 3.1 The Dutch healthcare market

A basic understanding of the Dutch healthcare system is required to understand the HIE market. The total Dutch labor force consists of nine million people. Of these, 1,2 million people were active in the healthcare sector in 2016 (Wessels & Driesten, 2018), making healthcare the second biggest employer in the Netherlands. These people work in over 55 thousand healthcare institutions (*Zorgkaart Nederland*, n.d.). In addition to healthcare providers, there are many other healthcare-related organizations. They can support or monitor healthcare. Other organizations make policies, perform research, or provide education in the healthcare sector.

#### 3.1.1 Laws governing the Dutch healthcare market

Healthcare is a common good: it should be accessible to everyone. In the Netherlands, we employ managed competition in our healthcare sector. Managed competition describes a way of regulation that promotes competition, bound to some regulations. The goal of managed competition is to achieve qualitative healthcare for an affordable price. VWS, the Ministry of Health, Welfare, and Sport, governs healthcare. The ministry sets the ground rules: what rights and obligations different parties have. They are politically responsible for the proper functioning of Dutch healthcare. The Netherlands has a total of five laws that influence the healthcare sector. Wessels & Driesten (2018) describe each law and its functions:

- (1) The Social Support Act (Dutch: wet maatschappelijke ondersteuning, WMO) helps people unable to independently organize their care and support.
- (2) The Youth Act (Dutch: jeugdwet) is there to support people under the age of 18. Both the Social Support Act and Youth Act are the responsibility of municipalities.
- (3) The Public Health Act (Dutch: Wet publieke gezondheid) governs the organization of public healthcare. This law falls under a combined responsibility of municipalities and the central government.
- (4) The Dutch Long-term Care Act (Dutch: wet langdurige zorg, WLZ) ensures permanent care is available for long-term care recipients. This law indicates what care should be available for citizens who require round-the-clock healthcare. What care is covered under the Long-term Care Act is a political decision made by VWS. Every Dutch citizen is included in this law and pays for it through taxes.
- (5) The Healthcare Insurance Act (Dutch: Zorgverzekeringswet, ZVW) is the fifth law governing healthcare. It mandates every Dutch citizen to get basic health insurance. Similar to the WLZ, VWS decides its contents. One of the main goals of the ZVW was to make healthcare more efficient by introducing competitive incentives. However, to guarantee solidarity and accessibility, a regulated framework was set in place (ACM, 2016).

### 3.1.2 Stakeholders in the Dutch healthcare market

The Dutch healthcare market consists of three actors: citizens, healthcare providers, and healthcare insurers. An overview of the actors is shown in Figure 3-1. Each connection between the actors represents a market (van Ginneken et al., 2010).

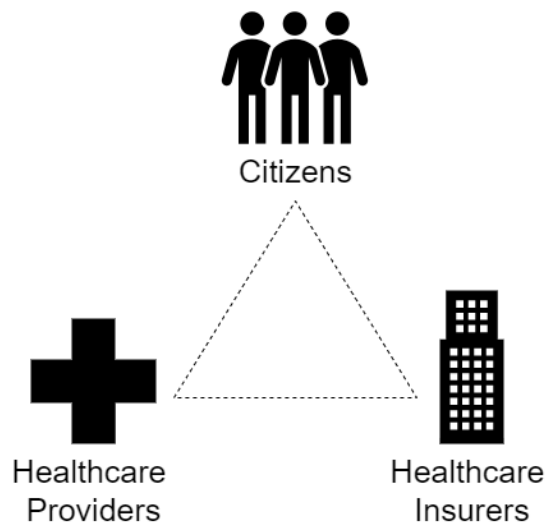


Figure 3-1: Key actors in the Dutch healthcare market

#### Citizens

Citizens can represent every inhabitant of the Netherlands. This covers Dutch citizens, permanent residents, and refugees. Citizens are the consumers of healthcare services in the Netherlands. When needed, they can request care from a healthcare provider. Citizens are obligated to acquire basic healthcare insurance, which covers the majority of their healthcare costs. Access to the healthcare system is possible through two entry points. General practitioners can refer citizens to specific clinical healthcare, and the emergency unit is an entry point in an emergency.

Citizens interact with healthcare providers in the healthcare provision market. A form of competition arises in which healthcare providers must please citizens. Citizens are free to choose from whom they receive care. This stimulates healthcare providers again to provide the best care for the best price. While citizens can choose a healthcare provider, insurance does not necessarily cover a healthcare provider fully. Based on what was agreed in the healthcare purchasing market, only partial compensation may motivate healthcare providers to offer their best services.

#### Healthcare Providers

Healthcare providers represent every organization or professional that provides medical help, support, or care. Examples of healthcare providers are a hospital, general practitioner, or physiotherapist. Home care, where citizens live independently but receive regular assistance, is another example. While individuals providing healthcare also fall under this category, we focus on the organizations representing healthcare providers throughout this research.

Healthcare providers interact with insurers in the healthcare purchasing market. In this market, insurers must fulfill their obligations to citizens by buying care from healthcare providers. Negotiations take place regarding price, quality, and volume of care. Healthcare providers are motivated to offer appropriate, affordable care in this market, with minimal waiting times.

#### Healthcare Insurers

The third role in the market is for insurance companies. They are the healthcare purchasers. On behalf of the citizens, they should aim to acquire qualitative healthcare for an optimal price.

The market between healthcare insurers and citizens is called the health insurance market. In this market, different healthcare insurers compete in attracting citizens. It is obligatory to accept citizens for basic health insurance, and they may not differentiate premiums based on risk. However, they can cover some healthcare providers partially, which allows them to distinguish in price.

Additionally, insurers may offer voluntary health insurance (VHI, Dutch: aanvullende verzekeringen), covering health services that are not part of the basic package. VHI may differentiate in price, and insurers are not obliged to accept everyone for a VHI. Every year citizens can choose to switch health insurance. However, most people stick with the same insurer. Yearly, only 7% of Dutch citizens switch insurers (Fransman & Kraaijeveld, 2018).

### 3.2 Structuring health information exchange

To structure HIE, we make use of the Layer Framework (Sprenger, 2019). We opted for this model due to its relevance to this research. The Layer Framework was explicitly developed to structure discussions on HIE. The model, shown in Figure 3-2, is used to understand better how two organizational units may interact and on what levels they could collaborate. The Layer Framework is instrumental for structuring our thesis in the following chapters. Among others, it is used to classify results during interviews, create stakeholder perspectives, and evaluate our designs.

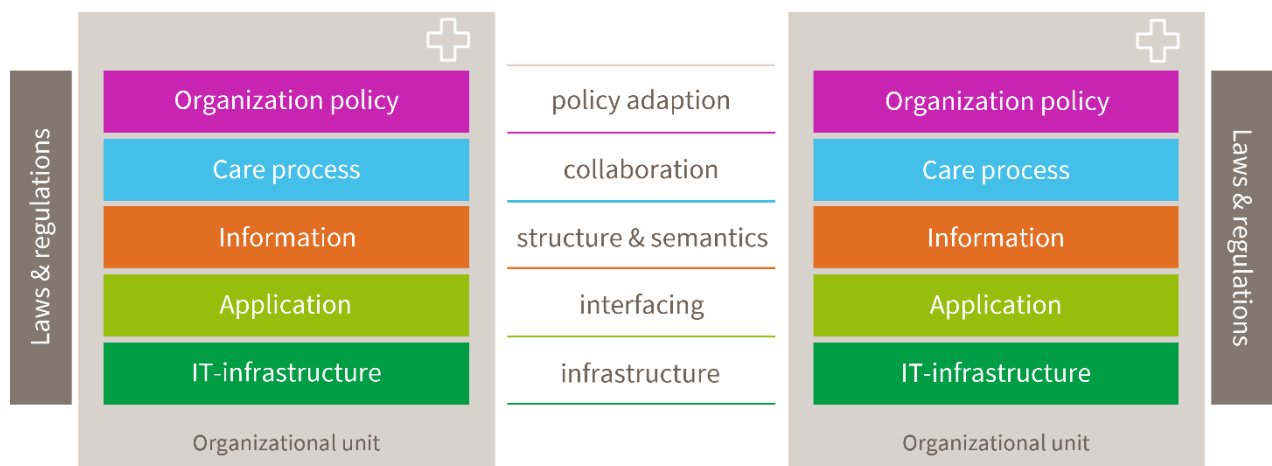


Figure 3-2: Layer Framework, adopted from Sprenger (2019)

Sprenger's framework uses a grey box to represent an organizational unit, which contains relevant aspects for HIE within its scope. Although some colors (e.g., green for IT-infrastructure) are commonly used in other models, colors have no intrinsic meaning (Sprenger, 2019). The lines between the boxes show the aspects at which organizations need to collaborate.

The Layer Framework identifies different layers within an organizational unit. Collaboration is needed on each of these five layers to ensure the proper functioning of information exchange. Vertical integration is required for one organization to have sound processes, and horizontal integration across all layers is a prerequisite for productive collaboration and HIE. The five layers are governed by laws and regulations to which organizations and information exchange must adhere. When the Layer Framework is used for countries, laws & regulations are incorporated as layers since governments can influence laws. In the scope of this research, organizational units will represent stakeholders in the Dutch market. Laws & regulations are therefore shown outside the organizational unit. Below we will summarize what processes are relevant for each layer.

#### Organization policy

This layer represents the management policies of an organization. It covers business strategies and organizational procedures related to healthcare. For example, if an organization collaborates with others during healthcare provisioning.

### **Care process**

This layer covers all processes that are specific or essential to the healthcare field. Because of their importance, they are represented as a separate layer. The care processes distinguish a regular organization from a healthcare organization.

### **Information**

The information layer represents all information processed in an organizational unit. The Layer Framework most commonly deals with healthcare data, as that is one of the challenges in HIE. Information models in healthcare are complex. Therefore, information is represented as a separate layer in the Layer Framework.

### **Application**

The application layer indicates all applications used within an organizational unit. Many applications are specifically developed for the healthcare sector. Typical applications are electronic health records (EHRs) used for storing healthcare information of citizens. The application layer is represented separately from IT-infrastructure, highlighting the importance of healthcare-specific applications. Horizontal integration between the IT-infrastructure and information layer is essential to use applications optimally.

### **IT-infrastructure**

The IT-infrastructure layer represents the physical backbone on which applications run. It can cover hardware, networks, storage, databases, and more. Integration at the technical layer is often a prerequisite for exchanging healthcare information.

## **3.3 Current and upcoming legislation**

In chapter 2, an earlier attempt of the government at harmonizing HIE in the Netherlands is described. From roughly 2000 until 2011, the Dutch government has attempted to implement a national solution to exchange EHRs. As a result, the role of the government changed from passive to active. The implementation of the EHR stopped in 2011 when the senate prevented further influence from the government. This was followed by years of inactivity of the government. However, in recent years the government has been taking a more active role. The government took notice that the market was not able to deliver its own HIE solutions. Therefore, they are increasing their influence again.

### **Current legislation**

On the 1st of July 2020, legislation was effectuated that mandates healthcare providers to give citizens free, digital access to their data. Digital access should make it easier for citizens to access their healthcare data. This law is an addition to existing regulations. Access to medical data was already mandatory. New is that this access should be digital and free. The law was initially effectuated in 2017. To give healthcare providers additional time, this specific section was delayed until 2020 (Ministerie van Volksgezondheid Welzijn en Sport, 2017, 2020c).

### **Upcoming legislation**

This trend of a more active government role also shows in planned regulation. For example, there is a concept law for electronic healthcare exchange in the Netherlands (*Dutch: Wet elektronische gegevensuitwisseling in de zorg, WEGIZ*). This law is on track to be implemented at the end of 2021. In total, the government identified four main problems in the current HIE market:

- No single language
- No single technique
- No integral initiatives for HIE, various interests throughout the sector
- Many different parties, everyone needs to collaborate to make progress

With a *single language*, the government focuses on ways of registering healthcare data. *Single technique* refers to the technical way of exchanging healthcare information. What one person sends should be receivable by another, which requires agreements on a technical level. Both language and technique should be standardized to facilitate HIE.



WEGIZ is a framework law. That means the law itself does not enforce specific forms of information exchange. In the years after its implementation, the minister of VWS can dictate what exchange must be digital and optionally what technical standard must be used. If a technical standard is included, certificates will have to be obtained by healthcare organizations. These certificates allow organizations to prove they can adhere to the regulations. The government emphasizes that norms cannot indicate what products or exact data must be exchanged. The regulation will only focus on what exchange should be digital and optionally how.

The implementation of the law contains several steps. After collaboration with various relevant parties, a norm can be decided, which will later be enforced. Before an information exchange can be enforced, both the House of Representatives and Senate must agree (Ministerie van Volksgezondheid Welzijn en Sport, 2020b, 2020a). After the law is implemented, specific types of exchanges will have to go through the standardization process. After this is completed, the first exchanges can become compulsory.

### **3.4 Classification of stakeholders in the Dutch healthcare market**

As was introduced in 3.1, the Dutch healthcare market consists of over 55.000 healthcare providers. We previously indicated that the healthcare market consists of three stakeholder groups by design: citizens, healthcare insurers, and healthcare providers. However, the HIE market consists of more stakeholders. In our exploration, we use the stakeholder identification methodology as presented by Alexander & Beus-Dukic (2009).

When we consider HIE, some relevant parties do not fall in one of these three categories. Software providers can facilitate services for healthcare professionals, citizens, communication, and analysis. They supply electronic healthcare records (EHRs) that are essential for modern healthcare. Hardware providers may facilitate PCs, mobile platforms, smartphones, tablets, and wearables that can be used during the care process. Medical equipment providers need to integrate their tools with other stakeholders, like hospitals, to offer their services. Other parties can provide additional services for professionals and citizens like advice, analysis, and trend watching (Sprenger, 2019). We introduce a fourth type of stakeholder essential for HIE: healthcare technology providers (HTPs). Innovative HTPs can offer initiatives that facilitate information exchange.

In Appendix A, we present some examples of stakeholders and group them to their respective stakeholder groups. The goal is not to be exhaustive on the parties in the Dutch healthcare market but to present some examples of the varying parties that are relevant. Figure 3-3 shows an overview of the stakeholder groups we identified.

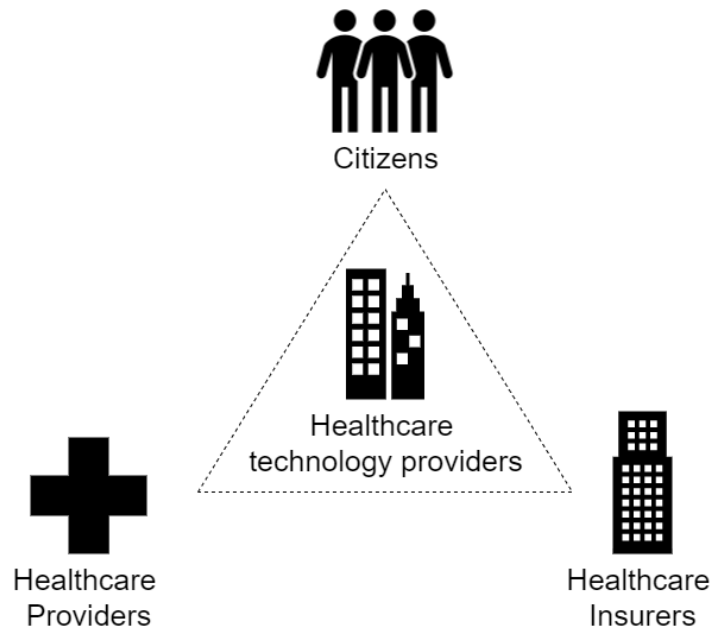


Figure 3-3: Stakeholder groups in the Dutch healthcare market

These stakeholders, combined with the government that influences the sector through subsidies and laws, provide a holistic view. Government is defined as organizations related to or primarily financed by the government.

The size of the Dutch healthcare sector results in many stakeholders. Every stakeholder group represents multiple thousands or even millions of stakeholders. Many of these stakeholders are represented through industry associations or professional associations. These associations represent specific employees of healthcare (technology) providers and advocate requirements particular to these jobs. Many healthcare providers themselves are also represented in industry associations. They collaborate in multiple ways to promote HIE. The size of the sector and various forms of collaboration create a big and complex market that is challenging to navigate.

### 3.4.1 Visions of future health information exchange

Several stakeholders have presented a vision of how HIE should function in the future. In this section, we explore some of these visions. Different stakeholders have expressed their visions on HIE in the Dutch healthcare market. Some relate directly to stakeholders presented in section 3.4. Others are offered by industry organizations representing multiple stakeholders.

This section does not claim to be exhaustive. We incorporate only those perspectives that are essential to our research project. The goal is to give examples of varying visions and show they differentiate in scope and reasoning.

#### **Actiz**

Actiz is an industry association for care organizations, which focus on home care. In their vision is mentioned that that 'traditional' EHRs should be changed to professional environments. These environments are envisioned as a boundaryless system that is loosely coupled, meaning it should integrate well with other software used by care professionals. Actiz defines four characteristics that the EHRs of the future should have.

1. A precise distribution of care-related functionality and administrative tasks should be achieved. The administration has received much attention from software producers lately but is not directly influencing the care process. By disconnecting the two parts, the care-related functions of the software can receive more attention. There is a need for a comprehensive solution that deals with all financial constructions applicable for healthcare provision from the business perspective.

2. The use of national standards for information exchange is essential to modern EHRs. Standardization of messages and transfer of information is required when multiple parties provide care to the same person.
3. Systems should focus on “communication, collaboration, meaningful data and ‘user-centered design’”. This should provide intelligent support of professionals, increasing work pleasure. Additionally, it can help retain and recruit new healthcare professionals in the sector.
4. The application should be “100% web”. According to Actiz, this means that all aspects of the application should be web-native. This should support location-independent work, innovation, and information exchange.

Next-generation EHRs should develop from an application to an environment/platform of functionalities. These functions are loosely coupled. This matches the organizational transformation to a network organization and self-care that Actiz envisions (Actiz & VGN, 2019).

### **Nuts**

Another vision of HIE originates from Nuts. Nuts is a young foundation that was started in 2018 by healthcare IT suppliers. They strive to facilitate a decentralized infrastructure for the healthcare sector. This infrastructure should provide a fertile basis on which HIE can take place. Nuts has strong opinions on the ground rules for their infrastructure, written down in a manifest (Nuts, 2019).

1. Software suppliers want to support healthcare professionals digitally in their work. Software influences quality, sustainability, administrative load, and many other aspects. Software suppliers are responsible for recognizing this and handling this responsibility carefully.
2. The patient deserves an active role in the network. With all modern developments in E-health, fitness trackers, and technological advancements, patients are becoming more involved in their healthcare. The focus will shift from cure to prevention. To facilitate this, Nuts is designing with a focus on the patient. Patients should be able to see and manage the information that is exchanged.
3. Software suppliers should only act as guardians of healthcare data. Patients and healthcare professionals are the fundamental data owners. Data should be available free of charge to authorized users. Software suppliers can earn money by building systems that add value for the end-users.
4. Nuts envisions a robust, decentralized solution for exchanging healthcare data. A monopoly or single point of failure is prevented by working with open source and a decentralized solution.
5. Open standards should be used to design the network. Usage should be standardized and not invoke any costs. By working with open-source technologies, quality and openness can be ensured.
6. Privacy is essential for any system handling patient data. Privacy by design is therefore applied. Permission and access management are built-in to the system from the start to facilitate these requirements.
7. By providing easy access to the network, but protecting its data thoroughly Nuts aims to make a secure, scalable network with a low barrier to entry.
8. Nuts aims to build their network using cryptographic principles. This helps to validate identities during information exchange without the need to rely on a single trusted party.

### **Dutch National Health Information Council**

Another vision regarding HIE is from the Dutch National Health Information Council. This council aims to prevent medical mistakes, put the patient first, promote standardized information exchange, and decrease the administrative load by collecting information once (Informatieberaad, n.d.).

The Information Council’s vision attempts to address a couple of crucial questions: how can flexible, (cost)efficient, user-friendly, reliable, and safe communication be achieved with means of infrastructures in healthcare. To achieve this, the council envisions a combination of shared services and nodes through which information is accessible by various actors. These shared services can access one or more registers with patient data. Services interact with nodes in which care suppliers can exchange information. Different nodes can exchange information in different ways. This decentral vision should ensure the values the council strives for are met (Informatieberaad, 2019).

## **Twiiin**

Twiiin is a collaboration of insurers and healthcare providers to promote HIE. Twiiin has the primary goal of providing “*The right information, in the right place, at the right time. For healthcare provider and patient.*” The initiative consists of two parts. At its core are several agreements between relevant parties. These agreements cover procedures, standards, requirements for joining, and more. The second part is an architecture covering applications, techniques, models, designs, and an implementation guide. In total, the Twiiin architecture covers all five layers from the Layer Framework. The goal of the architecture is to improve efficiency and reduce administrative pressure. Overall, Twiiin tries to work with open standards and incorporate existing platforms. Their proposed solution is in line with the vision of the Dutch National Health Information Council. It consists of many nodes in which information can be exchanged, and different parties can connect.

## **3.5 Examples of exchange initiatives in the Dutch healthcare market**

In this section, we explore the current state of HIE concerning exchange initiatives. Appendix B presents an overview of the initiatives we identified. Initiatives may be initiated by individual healthcare technology providers or collaborations of different actors shown in Figure 3-1.

Nictiz, the “Dutch competence center for the electronic exchange of health and care information”, keeps an inventory of standards related to HIE. These standards are mapped to different layers of the Layer Framework (Nictiz, n.d.-a). This overview does not include attempts to implement these standards. Exchange initiatives consist of one or more stakeholders who try to accomplish HIE with the implementation of standards. In total, we found two sources with listings of exchange initiatives at a national scale (Mallie et al., 2019; Meijboom & Klein Wolterink, 2020). The HIE initiatives are mapped to the layer framework and presented in Appendix B: initiatives.

In total, we explored 11 different HIE initiatives, which all have similar goals. This list does not provide a holistic overview but instead presents a few examples to showcase some initiatives. Some of the initiatives in appendix B are not independent. For instance, Twiiin is complementary to the LSP, and insurers are the primary sponsor of both. Other initiatives, for example, Zorgplatform, provide similar services but by a different provider. The combination of these overlapping initiatives creates a complex structure.

## **3.6 Conclusion**

In this chapter, we introduced the Dutch healthcare sector. The laws governing healthcare are highlighted, along with responsible parties that govern the industry. The Dutch healthcare sector is designed to facilitate managed competition, which should lead to good quality of care services. Citizens are free to select their insurers who purchase healthcare in their best interest. This way, healthcare providers should be motivated to deliver the best possible services. However, in practice, only a tiny proportion of the population switch between insurers, and the intended competition is practically absent.

The HIE market consists of four stakeholder groups: citizens, insurers, healthcare providers, and healthcare technology. Each stakeholder group has specific responsibilities in the Dutch healthcare market.

Our analysis in sections 3.3, 3.4, and 3.5 shows several challenges in the current HIE market. Many of the existing initiatives are overlapping, as shown in Appendix B. They cover the same layers from the Layer Framework and sometimes address the same information exchange challenges. For example, MedMij (Appendix B), an initiative promoting stakeholder perspective health records, can cover similar data used in ‘Medicatieoverdracht’ (Appendix B). While both try to tackle issues that HIE can solve, they do so in entirely different ways. In addition to the scope of HIE initiatives, their way of working can also differ. While Twiiin (Appendix B) uses existing infrastructure, Nuts (Appendix B) is developing entirely from the ground up. We only looked at initiatives at a national level, but many local and regional

initiatives also exist. These regional initiatives can design their implementations differently, creating more complexity for the overall system.

These factors lead to a complex market. They create several challenges for healthcare and healthcare technology providers. Some questions healthcare providers may have are: Is there an initiative that can support our HIE needs? In what initiatives should we invest resources to end up with a functional, legal solution? How can we integrate with another healthcare provider when they implement a different HIE platform than us?

## 4 INTERVIEWS

In this chapter, we explore stakeholder requirements. By conducting semi-structured interviews, stakeholders identified in section 3.4 will be asked for their views on health information exchange (HIE). First, we cover the methodology of semi-structured interviews, followed by interview design. We conclude by presenting the interview results in the last section of this chapter.

### 4.1 Methodology

There are several ways to design an interview. Semi-structured is a common approach in social sciences. This type of interview provides some guidance during a conversation while still being versatile and flexible. It allows for improvised follow-up questions that enable the interviewer to explore interesting subjects that might stay unnoticed in a fully structured interview (Kallio et al., 2016). To guide the creation of semi-structured interviews, Kallio et al. propose five phases. These phases follow from a detailed literature survey.

#### 1. Identifying prerequisites for using interviews

The first phase Kallio suggests aims to evaluate the appropriateness of semi-structured interviews. Previous knowledge of the research topic is required from the researcher. Semi-structured interviews are suitable when looking at complex or emotionally sensitive subjects.

#### 2. Retrieving and using previous knowledge

The second phase is to retrieve and use previous knowledge to provide a comprehensive understanding of the subject. A literature review is a suggested way to accomplish this.

#### 3. Formulating the preliminary semi-structured interview guide

This phase aims to make an interview guide that can be used during interviews. The guide consists of a list of questions that direct the conversation towards the research topic. Due to the nature of semi-structured interviews, a dialog is possible during the interview, and the order of questions can be changed. The goal is to gather spontaneous and in-depth answers.

The semi-structured interview guide consists of two levels: main themes and follow-up questions. Themes cover the focus area of the research in which participants are encouraged to speak freely about their perceptions and experiences. Follow-up questions can be used to make the themes easier to understand. They may also be used to direct the conversation towards the study subject. Follow-up questions can be pre-designed or spontaneous based on earlier answers.

#### 4. Pilot testing of the interview guide

By conducting pilot tests, the coverage and relevance of the guide are tested. Tests can be performed through internal testing, expert review, or a field test with potential interviewees. Field tests also facilitate the reordering of questions and help to determine how much time each session requires.

#### 5. Presenting the complete semi-structured interview guide

After conducting all previous phases, the complete interview guide can be presented in the research. It should have a clear goal and contribution and allow other researchers to replicate similar interviews.

## 4.2 Interview design

This section will use the five phases proposed by Kallio et al. (2016) to design our interview guide. This guide will serve as a guideline during our conversations with stakeholders.

### 4.2.1 Identifying prerequisites for using interviews

The nature of this research matches with the requirements indicated by Kallio et al. (2016). Sufficient prior information could be found in the literature to familiarize researchers with the topic. The challenges of HIE are diverse and contain many different aspects. The wide variety in the background of interviewees also suits a semi-structured interview. Applications of HIE that are important to individuals can freely be expressed outside the determined questions' context.

### 4.2.2 Retrieving and using previous knowledge

We performed literature research to gain a comprehensive and adequate understanding of the subject. Chapter 2 explored various background topics related to HIE, such as reasons, historical implementation, and current state. This gave us a thorough understanding of the goals HIE achieves and some means to achieve them. This knowledge acted as a basis to develop the interview guide and helped with a more thorough understanding of the interviewee's perspectives.

### 4.2.3 Formulating the preliminary semi-structured interview guide

The goal of these interview sessions is to contribute to the research goal. They should help answer RQ 4: *what goals do different stakeholders in the health information exchange market have?*

Questions have been formulated that should extract requirements from the different stakeholders. Although the background of the interviewees varies greatly, similar questions are relevant. The questions aim at understanding the interviewees' needs by exploring what information exchange takes place. This also allows giving interviewees with different levels of expertise the option to express their experiences. After discussing the current state, the interview focuses on the future of HIE.

#### Current situation

- Could you describe your daily work?
  - During which actions does information exchange take place?
  - With whom is information exchanged?
  - How is information exchanged?
- What is your opinion about current information exchanges?
  - What are the good and bad points?

#### Future of health information exchange

- What is your ideal image of health information exchange?
- How would seamless information exchange change your work?

### 4.2.4 Pilot testing of the interview guide

As prescribed by Kallio et al. (2016), we conducted a pilot test. This phase aims to confirm the coverage and relevance of the interview guide. For our pilot test, several experts were asked for their feedback on the preliminary guide. In addition, a complete interview was scheduled with the near-finished guide. This approach allowed us to iteratively improve the interview guide and practice the semi-structured interview setting. Changes were made to the scope of questions to make sure they covered our research questions. Some questions have been rephrased to make them more appropriate for the prospective interview population. Since the pilot interview covered all topics of the interviews, its results are also used in our research.

### 4.2.5 Presenting the complete semi-structured interview guide

After completing the previous steps, we now have a full interview guide for our evaluation interviews. The complete guide is presented in Appendix C.

## 4.3 Interview sessions

The goal of the interviews was to get a representative sample from the Dutch healthcare market. Therefore, all groups identified in section 3.4 are covered by multiple interviewees. Citizens and insurers are expected to have aligned goals based on our analysis in section 3.4.1. Therefore, fewer interviews were planned. In stakeholder groups where more diverse answers are expected, more interviews were scheduled. In total, we contacted 15 people, of which 13 were willing to participate in this research. The interviews were conducted digitally through Microsoft Teams. This allowed for easy scheduling with a wide variety of interviewees. The interviews were held in Dutch. After our analysis described in section 4.4, quotations or relevant remarks are translated into English. All interviewees were involved with their organizations' information exchange, some on a more practical implementation level and others from a managerial perspective. In general, an interview took about an hour. Two sessions had a duration of 30 minutes due to scheduling restrictions of the interviewees. During the sessions, notes were made to keep track of relevant findings. The interview sessions were also recorded for later analysis. Table 4-1 contains an overview of the interviewees and their function, organization, and respective stakeholder group.

Table 4-1 interviewees

Interviewee	Role	Organization	Stakeholder group
1	Director, citizen	Foundation representing healthcare patients	Citizens
2	Healthcare department lead, patient	Educational training company	Citizens
3	Information architect	Hospital	Healthcare providers
4	Information analyst	Hospital	Healthcare providers
5	Chairman management board	General practitioner	Healthcare providers
6	Pharmacist	Pharmacy	Healthcare providers
7	Trendwatcher	Insurer	Healthcare insurers
8	Advisor for information policy	Insurer	Healthcare insurers
9	Product owner	EHR provider	Healthcare technology providers
10	Entrepreneur	EHR provider	Healthcare technology providers
11	Product consultant	HIE provider	Healthcare technology providers
12	Head of interoperability	HIE provider	Healthcare technology providers
13	Entrepreneur advising on healthcare, promotor	HIE initiative	Healthcare technology providers



## 4.4 Analysis methodology

Short notes were made on important remarks during the interviews, and the interviews were recorded. The notes allowed us to keep track of relevant information and ask more in-depth questions on topics relevant to the different interviewees. In addition to direct answers to our interview questions, remarks that resulted from spontaneous questions were also noted. This ensured we could use the semi-structured interview approach as prescribed by Kallio et al. (2016).

Each interview was summarized using our notes and recordings. This approach was favored to transcribing since the latter was not expected to yield additional results. The prerequisites of a semi-structured interview include retrieving and using previous knowledge. Based on this prior knowledge, we analyzed the interview notes and recordings to create relevant summaries.

These summaries were then coded to get our results. We took an approach based on suggestions from Weston et al. (2001). They indicate an evolutionary relationship between a coding system and understanding a phenomenon. Weston et al. also highlight that fully transcribing is not relevant for all research.

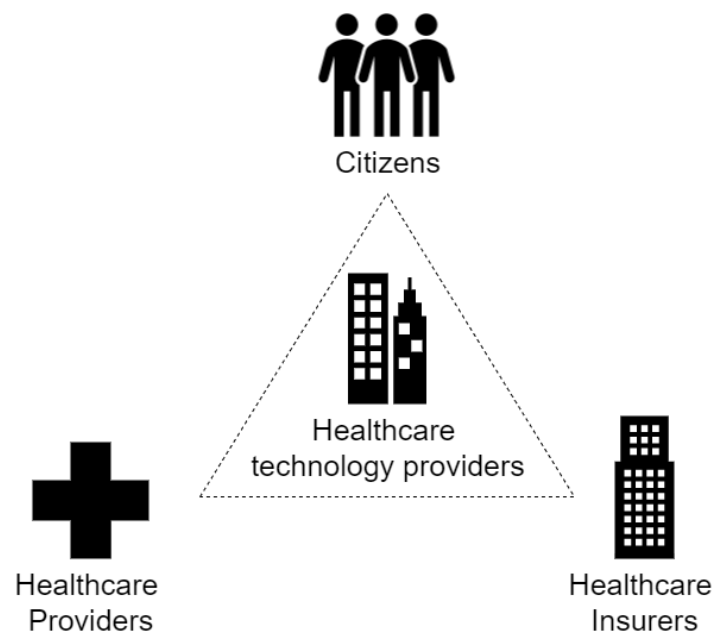


Figure 4-1: Stakeholder classification Dutch healthcare market

In the following sections, we refer to the different interviewees based on their organization or stakeholder group. These stakeholder groups are presented in section 3.4 and repeated in Figure 4-1. The Dutch healthcare sector consists of three major parties: citizens, healthcare insurers, and healthcare providers. In addition, healthcare technology providers have a role in this market as they relate to all other stakeholders.

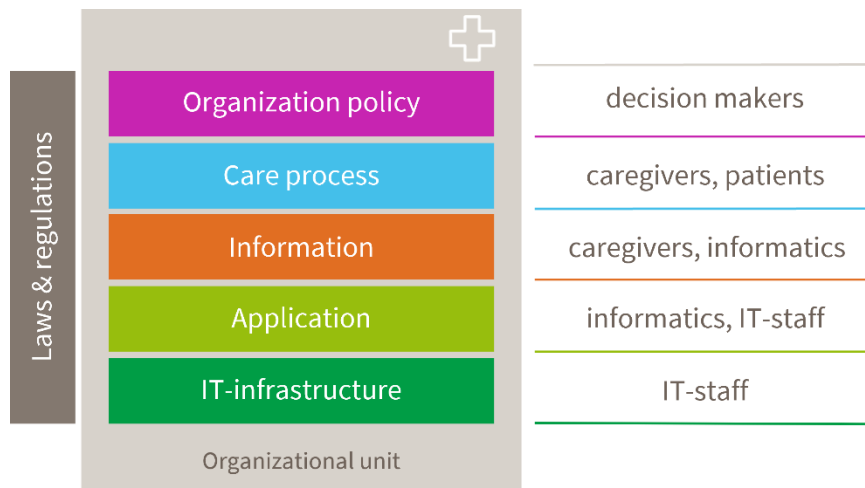


Figure 4-2: Layer Framework, adopted from Sprenger (2019)

In addition to stakeholder groups, we structure our analysis using the Layer Framework presented in section 3.2. The framework is used to categorize various topics discussed during the interviews. Figure 4-2 shows the Layer Framework and relates it to different functions that are relevant at each layer. It provides a bird's eye view of the interviews. Not all interviewees commented on all the topics; therefore, some sections will be more extensive than others. This is expected with the different backgrounds of interviewees. Some layers may relate more closely to their work than others. The layers are presented in the following order: 1. Laws & regulations, 2. Organization policy, 3. Care process, 4. Information, 5. Application, 6, IT-infrastructure.

## 4.5 Interview results

This section presents the results of our interviews. Depending on the background of the interviewee, different aspects of HIE were explored more in-depth. While some interviewees relate to HIE as a concept, other remarks are more technically detailed.

### 4.5.1 Citizens

Citizens have a central role in our healthcare system. They are the receivers of healthcare. As introduced in section 3.1, citizens may receive care from healthcare providers purchased by insurers. Healthcare technology providers help to provide services which the citizen may benefit from, both direct and indirect. In total, we spoke to two citizens. Both are significant users of our healthcare system and receive care from many healthcare providers.

#### 4.5.1.1 Laws & Regulations

A citizen indicated a more active role from the government would benefit the sector. There are no governance bodies regulating information exchange, while this would be required to offer a complete solution. The government indicates they want to promote collaboration across the sector, and regulations should also support this.

#### 4.5.1.2 Organization policy

##### Reason for HIE

One citizen was clear about the problem of HIE. *"Currently, there is no information exchange. When healthcare providers do contact each other, it is through letters. The whole sector is not communicating"*. This results in a situation where the citizen must often repeat their story. Another citizen also elaborated on the many reasons for HIE. It provides insight, control, freedom, efficiency, safety, and ease of use. Finally, structured citizen files can also contribute to better healthcare providers by enabling data aggregation. Safety is promoted through up-to-date records, which all healthcare providers can access.

Mistakes with medications that do not mix well can easily be prevented. This also takes some pressure off a citizen. In complex cases, remembering all appropriate medication is an impossible task. When healthcare providers can access the latest information themselves, this gives some freedom. Finally, ease of use is promoted through less administration.

### **Causes for lacking health information exchange**

A citizen provided a clear perspective on why HIE is not implemented yet. During the COVID-19 pandemic, a lot of information exchanges could be established in weeks. This was vital for providing required healthcare. When someone is being transferred to another hospital without the ability to communicate, understanding a medical background is a question of life and death. Under these circumstances, HIE suddenly came to life. This showcases that politics and people are the limiting factors of HIE.

The citizen further elaborated on more reasons. Many people in the healthcare sector do not work with the citizen in mind. This can result in tunnel vision, in which a healthcare professional only looks at their work and not their effect on the complete citizen journey. Some doctors can be stubborn, not resulting in optimal care for citizens. This also reflects in people who fail to incorporate a human standard. Every citizen is different: a similar diagnosis can require different care. Another issue that was highlighted is an island mentality that is incorporated into our healthcare system. We have various ministries in which departments do not communicate. If this is already a challenge at the regulatory level, the whole healthcare sector could prove even more difficult.

Another reason for lacking information exchange is resistance. Some healthcare providers think citizens cannot handle all the information. They believe that sharing everything from an EHR with citizens will not benefit the overall process.

#### **4.5.1.3 Care process**

The care process is the most relevant layer to citizens. By enabling HIE, the care process can be supported in the best possible way. Care of the citizen should be central, and the whole citizen journey should be incorporated. This requires collaboration from different healthcare providers on all layers.

#### **4.5.1.4 Information**

A citizen's information should be available to all relevant stakeholders: the citizen itself and all involved healthcare providers. This could be done through a personal health record (PHR). Most important is that information is available in a structured way in a single location. Currently, there are many different solutions to exchanging healthcare information. Every healthcare provider has its portal, while one integrated solution could be preferred.

A citizen remarked that healthcare does not stop at the border. Therefore, ensuring our standards are compatible with neighboring countries is vital to allow HIE across borders.

#### **4.5.1.5 Application**

One citizen mentioned that safety and privacy are essential. Information security must be guaranteed before benefits by increased HIE can be utilized.

#### **4.5.1.6 IT infrastructure**

In this layer, no specific remarks were made by both citizens. Privacy and security could be impacted and are therefore the only preference on this layer expressed by citizens.

### **4.5.2 Insurers**

In total, we spoke to two insurers. Insurers have a facilitative role in our healthcare system. They purchase healthcare from healthcare providers, which can be offered to citizens.

#### 4.5.2.1 Laws & Regulations

##### **Law complexity**

An insurer indicated the current regulatory framework creates a lot of complexity. There are a total of four laws governing healthcare provision. One citizen can receive care under regulations from any of these laws. This results in complex administrative situations when organizing the payment of healthcare. The government is focusing on care networking to increase efficiency in the sector. Care networking is related to the central position the citizen should have during healthcare provision. The government's strategy is to provide healthcare in a way that is optimal for citizens. Laws and regulations should support the concept of care networking. Currently, that is not the case. While the government indicates they want to focus on network care, they do not see that represented through current regulations.

##### **Permissions**

An insurer added that permissions are one of the significant challenges around facilitating HIE. During the COVID-19 pandemic, permissions changed from opt-in to opt-out. Opt-in means permission from the citizen has to be registered at every healthcare provider participating in information exchange. During the COVID-19 pandemic, healthcare information could be exchanged if none of the involved parties had a registered complaint against information transfer. This temporarily enabled a lot of information transfers. However, insurers are worried things will go back to the old ways after the pandemic has passed.

##### **Subsidies**

The government has invested a lot in programs that should advance different types of information exchange. According to an insurer, the current subsidy regulations facilitate fragmentation. They result in small solutions that only aim to extract subsidies and do not profit HIE in the future. According to this insurer, subsidies are not working as intended and are sometimes even abused.

Another problem an insurer sees is that many different initiatives are promoting HIE. Synergy in these initiatives and all the other advisory bodies would be beneficial. Due to the diverse nature of solution directions, unnecessary costs are made for the Netherlands.

#### 4.5.2.2 Organization policy

##### **Awareness**

An insurer comments that digitalization has been happening for a while now and finally has reached the healthcare sector. The question is how it will take shape. Another insurer also indicates they are actively contributing towards raising awareness. Citizens are informed on the possibilities of HIE to stimulate this from the bottom up. Top-down promotion is also starting. They are training employees responsible for purchasing healthcare to understand more about HIE.

##### **Role of insurers**

The insurers we interviewed were clear on their position in the market. *"Insurers have an important public role. We are responsible for reducing healthcare costs in a socially responsible way"*. This is essential since healthcare costs could have been a lot higher. One way they are attempting to reduce costs is by actively promoting HIE. An insurer indicated the healthcare sector is not as efficient as desired. According to one interview, most healthcare costs are in logistics. This means HIE and process changes can help a lot. This will result in insurers requiring information exchange from healthcare providers. Both insurers indicate they will take HIE into account while purchasing healthcare from healthcare providers. By doing this, healthcare providers are motivated to work efficiently and make investments in HIE.

The growing interest of insurers in how healthcare is provided caused some concern with healthcare providers. They are afraid these new requirements will be linked to the compensation they receive. An insurer indicated they recognized this fear. A few years back, they tried to influence healthcare processes by withholding money. This was answered with much resistance from healthcare providers. They want to decide how to do their job. While the insurer intends to focus on HIE, this will not result in financial stimulations in this case.

One of the insurers took their responsibility further. They envisioned providing basic infrastructure as their responsibility. The bottom layers of the Layer Framework should be in place for both healthcare and healthcare technology providers. This would enable them to focus on added value.

### **Future of HIE**

An insurer indicated that there does not exist a single solution for all HIE questions in the Netherlands. They do not have the ambition or expectation we will end up with a single infrastructure to enable all information exchange. Despite this, the increased demand for HIE requires more tightly integrated healthcare IT systems in the Netherlands. A critical remark is that we can never be done with developing HIE. Technology will always need further development.

### **Resistance**

An insurer also indicates reasons why HIE is not yet in place. Some doctors genuinely think citizens are better off without having all the information available to them. A citizen viewing test results before a healthcare professional can explain them is a clear example of this scenario. Another insurer is often asked who will benefit from HIE. Not many citizens are asking for it at the moment. The insurers' response is that HIE could be a latent need: a problem people do not realize they have. While some citizens are aware of the current situation's consequences, others might be less aware and do not express their need for HIE.

An insurer describes another reason for the lacking HIE implementations by comparing healthcare to other sectors. For example, in the transport sector, information exchange is much further developed. However, in healthcare, we are dealing with people, not packages.

#### **4.5.2.3 Care process**

##### **Most important layer**

The care process is the primary focus of all interviewees. This is where they can add value by providing healthcare or technology services in support of healthcare provision. The other layers should help support this layer.

#### **4.5.2.4 Information**

Information should be available to whoever requires it. Facilitating this will result in a healthcare sector that can perform optimally.

#### **4.5.2.5 Application**

Visions from insurers did not specifically cover the application layer.

#### **4.5.2.6 IT infrastructure**

The vision of insurers is to collaborate regionally but facilitate connections across the Netherlands. This ensures that smaller groups of stakeholders are enabled in their innovation without limiting the possibilities at a national scale. One insurer indicated they are looking into facilitating the basic infrastructure.

### **4.5.3 Healthcare providers**

In total, we spoke to representatives of four healthcare providers: two hospitals, a pharmacy, and a general practitioner. The interviewees had varying backgrounds, resulting in good coverage of the Layer Framework.

#### **4.5.3.1 Laws & Regulations**

##### **Permissions**

Permissions were stated as a significant challenge in HIE by three healthcare providers. Receiving permission to share data is a complex procedure. A pharmacy indicated regulations are outdated. Every organization needs to have permission registered before the digital exchange of information can take place. In a medical emergency, permissions may not be registered, but information exchange is still

vital. While information is available in digital systems, the lack of proper permissions prevents health information exchange. In this case, an emergency request to the source healthcare providers is made through fax. After the request is accepted, the resulting information is faxed back.

A hospital gave an example of research under healthcare recipients to highlight one of the challenges with permissions. Citizens were surveyed with one question: “do you allow sharing healthcare information with other regional healthcare providers.” The caveat was that half of the population received one additional sentence to the question: “while you are unconscious in an ambulance.” The difference in responses was enormous: while the initial question resulted in over 90% negative responses, the additional line resulted in 98% positive responses. The hospital presents this as clear proof that people are unaware of their needs and emphasizes that framing is essential when considering HIE-related questions.

### **Role of the government**

A hospital indicated they would like to have more pressure from the government. This could help with picking standards and infrastructure, which provide significant challenges at the moment.

### **Subsidies**

Subsidies are currently not used as intended. One hospital gave an example of a healthcare technology provider that does not work constructively. *“Some companies implement minimal solutions only to receive a subsidy. While these solutions adhere to the basic requirements of the subsidy, they are not built to be extended later.”* The requirements for a subsidy are met, but often subsidies try to facilitate a minimum viable product. They showcase a form of information exchange but do not yet lead to functioning HIE. This is something that must be added later, but this requires constructive work. A general practitioner confirms this by stating some subsidies are abused. Some parties are keen to use subsidies to their advantage. Others may also receive a lot of money, but it is often not enough to implement a complete solution.

#### **4.5.3.2 Organization policy**

##### **No uniform visions**

One hospital gave a remarkable response to the question of what their company vision was on HIE. They indicated: *“There is no us. Different departments can have diverging opinions about specific HIE solutions”*. While one department may prefer a specific option, that does not mean this desire is uniform within the same company. The hospital provides an example of user authentication. An initiative allows privacy-friendly authentication, but a phone is required during sign-in for two-factor authorizations. While the legal team loves the privacy features of this product, doctors complain they do not want phones in an operation room. If opinions can be so diverse within the same institution, imagine how they are spread across the whole sector.

##### **Awareness**

All healthcare providers indicated there is an increase in awareness within the sector. One commented that a sense of urgency is arising, both with healthcare providers and within the government. A general practitioner expanded on the causes for this upward trend in HIE awareness. According to them, many factors contribute to this change. Maturity of the sector, enthusiastic government officials, younger managers, more focus from the government, increasing subsidies, and more technical possibilities all contribute towards HIE awareness.

In contradiction to this positive trend, one hospital indicated that other hospitals generally do not have a high awareness of the possibilities and need of HIE. *“Most hospitals are used to having the most important role for the citizen. They are focused on their processes and do not consider their role in the whole sector”*. The need for HIE is not apparent to them.

##### **Resistance**

A critical aspect of HIE is resistance. While many people agree that HIE is a good thing that will contribute to many parts of the healthcare sector, there are also skeptics. A hospital indicates this results in a lot of frustration. They work with healthcare technology providers who are unwilling to invest in HIE, while the hospital sees that as a requirement to improve their services.

A pharmacy highlights another way HIE can create resistance. When everyone can extract all information, a pharmacy's position in the market might lose its relevancy. An online pharmacy could easily take over its tasks. The pharmacy indicates this way of thinking does not benefit the Netherlands, yet it represents how most people think of their business.

### **Causes for the current situation**

A general practitioner gave a positive view on why HIE is not established yet in the Netherlands. They indicated our healthcare system is one of the most advanced in the world. General practitioners were some of the earliest to adopt some form of digital administration. This resulted in an initial boost in productivity but also resulted in the peculiar situation we have now. Initially, systems were built to store and retrieve information. Extracting information was not a use case at the time. Other countries have a much more advanced HIE infrastructure. This could have been due to the relatively late modernization of their healthcare sector. By the time they started implementing, more diverse use cases were already known. This phenomenon can be described as the first-mover disadvantage.

### **Dependency on technology providers**

One hospital we spoke with has a solid vision to prevent vendor lock-in. A vendor lock-in describes a situation where one is dependent on a (software) vendor, where changing vendors would introduce high costs or service disruptions. The hospital thinks a lock-in would result in increased costs and less flexibility. To circumvent this, they are working with multiple parties for their HIE needs. This enables them to facilitate intra-operability between various systems, which allows for more flexibility and faster innovation. This approach is the result of a strong vision the hospital has on HIE. By collaborating intensively in the region, the focus can shift from cure to prevention.

Another hospital has an opposing view for similar reasons. They indicated that choices on infrastructure and software are hard to make. Many options are available, and selecting the right one is a challenge. They opted for a single vendor to provide all their IT systems. This ensures they can slowly phase out the 30+ different applications currently in use. This allows for tight integration and reduces waste within their organization. *"You have to act now. We found a vendor that can satisfy our needs with a tightly integrated solution"*. The hospital specifically opted for this vendor lock-in. Waiting for regional standards or government regulation is not working out for them. This approach allows them to collaborate with other healthcare providers by using services from their healthcare technology provider.

#### **4.5.3.3 Care process**

##### **Most important layer**

Care is the primary focus of the healthcare providers we spoke with. HIE should be a means, not a goal. The other layers should help support this layer.

One hospital indicated that a single type of information transfer requires currently requires 1 FTE to handle the administration. These purely wasted resources could be used for better healthcare if intra-operability with the relevant organizations was established. A pharmacy stated most of their job consists of administration. However, they would prefer to ask in-depth questions to ensure medication is selected carefully for their citizens. Since HIE is not in place, they must spend too much time on administration.

A hospital commented that the care process is an essential layer to incorporate in HIE. The other parts of the Layer Framework might be established, but that does not guarantee a smooth flow of information. Doctors can have a hard time finding where digital files are stored, costing valuable time. They provided an example of a state-of-the-art connection they have with another hospital. While the technical link was in place, they were not aware of any transfers that took place. *"Yearly, the required number of transfers is under ten. In these scenarios, there would not be time for the fancy information exchange, and physical records are used"*.

#### **4.5.3.4 Information**

Information is the layer that is related to the actual information flowing through systems. It is what a pharmacy describes as "essential for our job". If they do not have access to previous medication a citizen received, they can do little. They must fall back to asking questions to a citizen, which is time-consuming and more error-prone.

At the same time, a general practitioner indicated that information flows are hard to structure. There are many solutions to the same problem, but they are often not integrated with existing tools or processes. Ideally, information should follow the citizen, and information should be exchanged decentral using open standards.

### **Standardization**

One hospital is also starting to work with clinical information models, or CIMs (*Dutch: zorginformatiebouwstenen*). They indicated that transferring people to a nursing home is a bureaucratic process: *“At this moment, there are 152 sets of information we send over during a transfer. 98% of this information is never used. It was once added because a single institution required a specific information set”*. Standardizing this type of exchange will benefit both parties: the administrative burden of the hospital and nursing homes decreases when sending relevant information in a standardized way.

One of the hospitals indicated a downside of this movement. CIMs are an upcoming form of national standardization, but they are far from complete. This prevents HIE from being utilized to its full capability. Standards are in development but not usable in their current state. The development process for these standards is agile: changes and additions are made in newer versions. The version that is currently implemented does not contain enough details for all types of transfers. This is a point where this hospital makes the conscious decision not to adhere to the standard. They prefer sending complete information in an unstructured way.

#### **4.5.3.5 Application**

##### **Integrations**

A hospital indicated that even within the same organization, many different applications could be used. This can cause difficulties in transferring information when these applications are not integrated thoroughly. A combination of physical files, faxes, and emails are some of the many ways information arrives. Different information flows end up in a variety of applications. This creates lots of administrative burdens, where healthcare providers would prefer spending time on other things.

##### **Standardization**

Standardization in the use of applications can also be challenging. A hospital gave an example. They have an application that creates medical pictures with a field reserved for a social security number. However, in some cases, this information is not desired as it prevents the healthcare provider from sharing the images in a privacy-friendly way. Other healthcare professionals prefer a specific type of information while they examine this image. They request the field to be filled with blood group or age. This creates an image with additional information that could vary greatly. This showcases that even when standardization is intended by design, the users of an application must still agree.

A hospital indicated that while initiatives for the personal health record (PHR) are becoming more widespread, they don't see the benefit for this standardization in application use. Currently, they can offer applications with far more capabilities than PHRs will have. More detailed information sets, updating citizen information, and communication with healthcare professionals are some features that PHRs lack. The hospital acknowledges that providing citizens access to their data is essential, but how they want to achieve it differs. Their applications are much more feature-rich. In this area, standardization would negatively impact the citizen. To ensure the information they provide is complete, other healthcare providers could provide their data to the hospital instead of to a PHR.

#### **4.5.3.6 IT infrastructure**

##### **Decentral versus centralized**

One significant discussion on IT infrastructure relates to a fundamental principle. One option is to build an infrastructure with a single source of truth and one responsible party. Alternatively, you can create a distributed system. This ensures there is no single party responsible for everything.

One hospital emphasized the importance of a decentralized solution. This prevents a single point of failure and monopoly in the HIE market. A distributed solution can be more competitive and result in a more robust infrastructure.



A hospital, pharmacy, and insurer voiced the other side of this debate. They indicate the variation in current solutions could be solved by establishing a single central system. This would solve all standardization questions and provide a quick route to enable HIE. A hospital indicated that a dominant technology provider or the government would be the relevant party to implement this.

A general practitioner had an interesting remark on this topic. They indicated there is usually the best and most feasible solution. The best option from a market and privacy perspective might be decentralized. However, they think a central solution is more likely. This is preferred by the bigger parties and, therefore, the most likely option.

#### **4.5.4 Healthcare technology providers**

In total, we spoke to five healthcare technology providers. Two are so-called EHR providers; they provide software that healthcare professionals use to register provided healthcare. The other three interviewees contribute to some form of HIE. Two have a product that allows healthcare providers or healthcare technology providers to implement HIE. The third is an upcoming initiative seeking to facilitate various aspects of HIE.

##### **4.5.4.1 Laws & Regulations**

###### **Role of the government**

Two healthcare technology providers commented on the role of the government. Their actions have been relatively fruitless until now. Both healthcare technology providers indicated a more active role from the government could be beneficial to the situation. There is a lot of unclarity, and a possible solution is more steering from the government. This could help with picking standards and infrastructure.

An EHR provider and HIE initiative indicated an alternative response. Waiting on the government to present a solution takes too long, in their opinion. They determined their vision and values and started developing now. This prevents further delay and enables quicker advancements in HIE. The EHR provider provided an altruistic argument for facilitating HIE. They have resources available and are willing to work on a solution that can benefit the whole sector.

##### **4.5.4.2 Organization policy**

###### **Value proposition**

All the health technology providers we spoke with are aware of their value proposition. Their main goal is to add customer value by providing solutions for care processes. All interviewees agreed that layer 3, the care process, should be their core business. Other layers should be supportive of this function. One of the health technology providers indicated that connecting care systems is currently part of their business strategy. However, these connections are work-intensive and, therefore, costly. When intra-operability has been established, their focus can shift to developing new features that support the care process as much as possible. Advancing HIE is, therefore, a logical step. It helps to make more time and resources available for healthcare itself.

###### **Awareness**

Three health technology providers note an increased awareness of HIE. All parties, citizens, healthcare providers, and insurers are more aware of HIE possibilities. One EHR described this by indicating that the number of requests for integrations with other healthcare providers increases. They emphasize that awareness is essential for collaboration. This can also be related to the Layer Framework. From an organizational perspective, the layers should be followed from organizational policy down. If there is no need at the business level, it makes no difference what technical infrastructure is in place. Only when the need for HIE is universal can companies start collaborating. The healthcare sector should move from small islands to a whole that is collaborating.

One HIE provider indicated that awareness is a relevant benchmark to keep in mind when discussing intra-operability. For example, some regions are just starting to collaborate, while others have already set up working information exchanges.

## **Reasons HIE**

An HIE provider pointed out the logic behind HIE. It will help offer choice, allow the market to compete as intended, and help citizens switch between healthcare providers. It is up to the different healthcare (technology) providers to remain relevant in this new digital era of the healthcare industry.

## **Role of insurers**

One HIE provider highlighted he would like insurers to make more steps to facilitate HIE. Financial stimulation for healthcare providers to stimulate HIE would be beneficial to all parties.

## **Causes for the current situation**

An HIE initiative highlighted that the cause of the problem could also be explained by the lack of IT knowledge at the managerial level. Managers are generally not aware of the possibilities and challenges related to IT. Still, managers make business decisions, while employees know what is best.

### **4.5.4.3 Care process**

#### **Most important layer**

The care process is the primary focus of all five health technology providers. This is where they can add value by providing technology services that support citizens and healthcare professionals. The other layers should help support this layer.

#### **Health information exchange creating new use cases**

An HIE provider highlighted HIE could create new workflows that did not exist before. They are working on a personal health record (PHR) pilot in which citizens can view their information online. After the initial version launched, a reasonable assumption arose that people could update their data. There is always a possibility incorrect data will make it into a system. It would be helpful if a citizen could correct this. However, this created a whole workflow that did not exist before. There is no standard way for citizens to update their health records stored at a healthcare provider. Personal details that are changed must first be checked to make sure no relevant data is accidentally erased. This results in some more administration, for which someone must be made responsible.

### **4.5.4.4 Information**

#### **Standards**

All healthcare technology providers indicated they are working with standards and that doing so is essential for guaranteeing intra-operability. FHIR by HL7 is a standard that was brought up in four of the conversations. Clinical information models or CIMS are other upcoming standards. The government is running several projects to promote and kickstart the implementation of CIMS, and the HTPs acknowledged this. The more widespread usage of similar standards was experienced positively by everyone as it provides clarity regarding the future. As one ERH supplier highlighted, working with open standards is an excellent way to move forward.

### **4.5.4.5 Application**

#### **Integrations**

An EHR provider mentions a related point. Essentially every healthcare technology provider is building the same functions. Every application needs a way to extract and share data with other healthcare providers. This provides an opportunity. When technology providers collaborate on parts of an application that practice HIE, everyone can profit. By sharing technical components aimed at HIE, integrating applications will then take significantly less time. This way, you ensure that every technology provider can focus on adding value to their application.

### **4.5.4.6 IT infrastructure**

#### **Decentral versus centralized**

An EHR provider stressed why a decentral solution is essential. This prevents a single point of failure. It also allows competitors to collaborate on information sharing and makes sure a monopoly does not arise. An HIE provider added that a decentralized solution is possible, but it will require more work than a centralized alternative. An HIE initiative indicated that decentral is strongly preferred, but it might be hindered by current regulation requiring central components.

Another EHR provider highlights that infrastructure provides the same challenges as other standardization questions. There are many alternatives, and choosing an option does not guarantee success.

## 4.6 Threats to validity

In this section, we examine different threats to validity and how they were circumvented.

### Generalizability

One goal of this research is to strive for coverage. We examine the whole Dutch healthcare sector to get a representative sample. Stakeholder groups were identified, and multiple stakeholders from each group were invited to interviews. This resulted in a diverse group of interviewees with different backgrounds and different stakeholder types. Due to the large size of the healthcare sector, as presented in section 3.1, a representative sample is challenging. Therefore, we invited more stakeholders from the healthcare providers and healthcare technology providers, as they were expected to have more diverse goals than citizens and insurers.

Another threat to validity might occur through network limitations. If the interviewees were sampled from a single network, this could inevitably lead to a bias in this group. Therefore, networks of multiple people with different backgrounds were used to contact potential interviewees. In total, four different people provided contact details to reach potential interviewees. In addition, one interviewee was contacted directly.

Seddon & Scheepers provides a framework for generalization of qualitative research, including from a single case study. They state, *“If the forces within an organization that drove observed behavior are likely to exist in other organizations, it is likely that those other organizations, too, will exhibit similar behavior”* (Seddon & Scheepers, 2012). The sample of organizations we contacted should represent a broad section of the organizations in our healthcare market. Therefore, we argue that results from these interviews are expected across the sector. Still, we acknowledge further research is required to get a more comprehensive view of stakeholder goals in the healthcare market.

### Bias from interviewer

During interviews, specific questions can channel responses from interviewees. This could be created by a bias in our initial literature research that influenced previous knowledge. To circumvent this as much as possible, a detailed methodology to interview creation was taken as proposed by Kallio et al. (2016). A preliminary interview guide was created, and several iterations with feedback from field experts and other researchers took place to refine the interview guide. These steps help prevent a bias in the interview questions.

Analysis of the results could also present a bias. To limit this as much as possible, we followed a systematic procedure to analyze all interviews. During the interview, answers provided by interviewees were summarized shortly to validate a correct understanding. Interview summaries were written based on interview notes and by re-listening to recordings of the interviews. This results in a complete overview, highlighting all relevant topics. These summaries were then coded, which allowed us to combine all pieces of relevant information.

## 5 DESIGN

This chapter presents the design of our research: stakeholder perspectives. The goal of this research is to provide insight into the workings of the HIE market. In chapter 4, we conducted interviews with people representing all major stakeholders in the Dutch healthcare sector. This provided us with a clear picture of their perspectives on health information exchange (HIE). In this chapter, we use our findings from chapter 4 to create stakeholder perspectives.

### 5.1 Methodology

This chapter describes the treatment design phase from the design cycle by Wieringa (2014). The design cycle is part of DSM, which was introduced in chapter 1.4. The treatment design has the goal of creating an artifact. This artifact should contribute to stakeholder goals once put into context. In our research, we create stakeholder perspectives, which give an overview of different stakeholder strategies and goals in the HIE market.

To create stakeholder perspectives, we will use our interviews' findings to generate insight into the market. Responses in chapter 4 are grouped per stakeholder group. These responses will be grouped into similar requirements. The derived requirements will then be mapped on the Layer Framework to create a stakeholder perspective. Depending on the divergence of the responses, one or more stakeholder perspectives will be made per stakeholder group. The finalized perspectives represent different stakeholder strategies in the Dutch healthcare market. In our analysis, we only use layers that the respective stakeholders can influence. Laws & regulations are therefore not included.

### 5.2 Stakeholder perspectives

We cover all stakeholder groups from the Dutch HIE market: citizens, insurers, healthcare providers, and healthcare technology providers. For every stakeholder group, we present one or more stakeholder perspectives and key requirements relevant to the specific stakeholder perspective.

#### 5.2.1 Citizens

In total, we interviewed two stakeholders representing citizens. Both are active users of our healthcare system, and they show a solid united interest. Currently, they experience a lot of problems due to lacking HIE. Solving these problems in a way that supports citizens is in their best interest. This results in a single stakeholder perspective. Two remarks are that the desires of a citizen can change depending on their health. Healthy citizens have different needs for HIE than someone who requires regular care. Additionally, citizens may not always be the source of the requirements mentioned below. For example, if a patient can no longer care for themselves, a caregiver or representative could express similar HIE requirements.

##### 5.2.1.1 Citizen stakeholder perspective

At a policy level, citizens want to live a carefree life. This is visualized as *optimize quality of life*. Other ways to represent the desires at the policy level are to *live a carefree life*, *live life as desired*, or *have the least possible burden of illness and our healthcare system*. Focusing on the quality of life combines these aspects into one statement.

The care process is represented by a statement common in the Dutch healthcare sector: “*right treatment, in the right pace, at the right time*”. This should optimally contribute to the quality of life: a treatment should cause the least disruption to a citizens' life. Care provided following this statement best supports a citizens' need.

Information should support the care process in the best possible way. Therefore, the need for information is represented as “*the right information, in the right place, at the right time*”. The right information in this context indicates both correct information and relevant information. Too much or

irrelevant information is not of use to a citizen. Information should flow effortlessly to where the citizens need it. Required information should be available in the digital systems the citizens desire. The *right* information also holds the requirement for updating information when needed. The *right place* includes the need to withhold information from parties that should not have access.

On the application layer, a citizen would like to pick an application of their choice. This application should be integrated with other applications so that the requirements from higher in the Layer Framework are met: *the right information in the right place at the right time*. Currently, many healthcare providers have developed custom applications, resulting in administrative troubles for citizens. Integrated applications should resolve this. Another goal is that healthcare provider applications should be integrated. They should incorporate information from other systems so citizens do not have to repeat themselves.

Finally, at the IT-infrastructure level, patients do not have many explicit requirements. However, privacy and security are essential and therefore highlighted at this level.

Figure 5-1 presents a visual overview of the citizen stakeholder perspective.

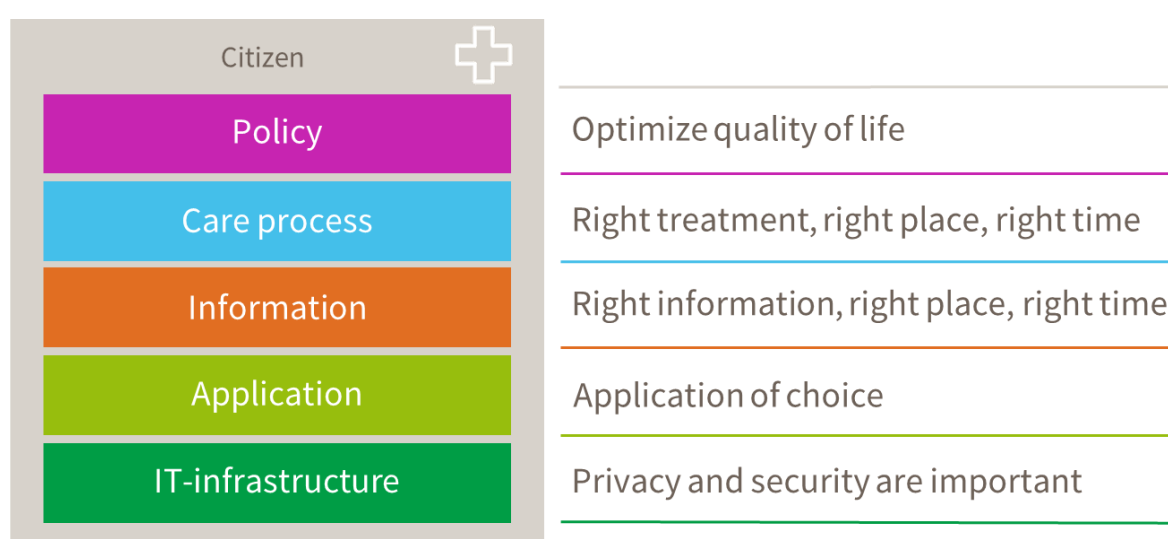


Figure 5-1: Citizen stakeholder perspective

### 5.2.1.2 Citizen key requirements

The most crucial HIE requirements are in the care process and information layer. The key requirements of a citizen are, therefore:

- The right treatment, in the right place, at the right time.
- The right information, in the right place, at the right time.

## 5.2.2 Insurers

In total, we spoke to two insurers. Section 4.5.2 indicates that both insurers have a similar vision and goal. They see their role as intended in the Dutch healthcare market, as examined in section 3.1. This results in a uniform image of the insurer. However, there are some nuances as to how specific goals are reached. This is included in the textual description of the stakeholder perspective.

### 5.2.2.1 Insurer stakeholder perspective

On the policy level, insurers are clear that they are responsible for affordable care. Insurers have a specific role in the Dutch healthcare system: to ensure people get the best healthcare services for the best price. They want to “*manage the cost of healthcare, in a socially responsible way*”. Since healthcare costs can grow enormously, it is their responsibility to keep costs under control.

At the care layer, insurers strive towards universal, affordable care. This facilitates a sustainable care process that is accessible to everyone. In addition, insurers indicate they envision a more active role in enforcing HIE. This could be done by purchasing healthcare from suppliers that meet specific HIE requirements. However, this desire is not yet experienced by other players in the healthcare market.

At the bottom, three layers receive less focus from insurers. They mainly play a facilitative role. This is done in two ways. On the one hand, by working with other insurers to provide HIE solutions at a national level. Secondly, individual insurers also promote HIE with tailored solutions for their customers or by funding innovations.

Figure 5-2 presents a visual overview of the insurer stakeholder perspective.

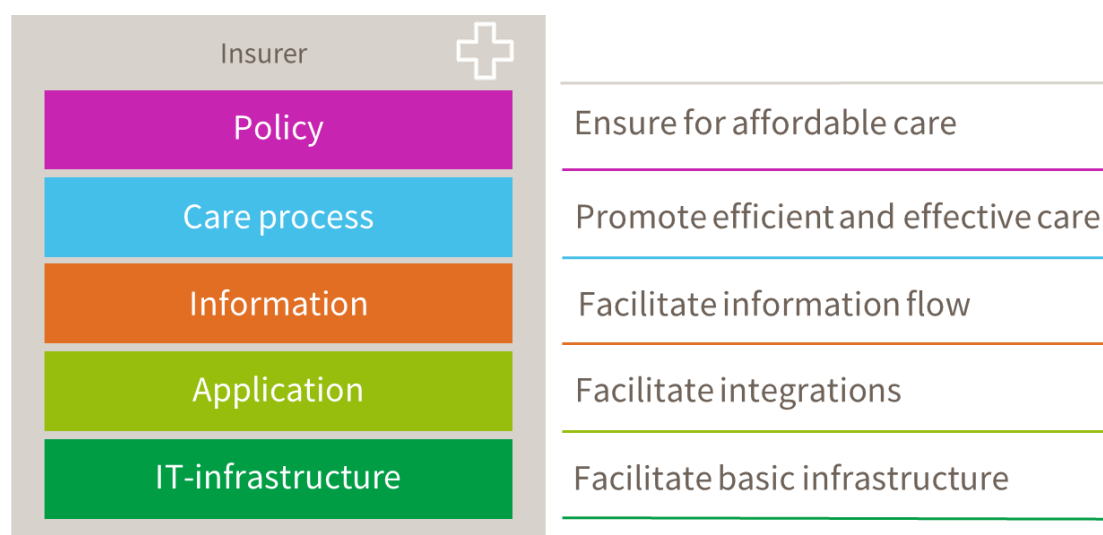


Figure 5-2: Insurer stakeholder perspective

### 5.2.2.2 Insurer key requirements

The statement at the policy level is what insurers indicated is their most important role. This is their function as intended in the Dutch healthcare system.

- Manage costs of healthcare in a socially responsible way

## 5.2.3 Healthcare providers

In total, we interviewed four healthcare providers. Views on their role in the healthcare market and how to achieve specific goals varied within these interviews. While all interviewees we spoke with want to provide adequate healthcare, how they go about this process changes. To accommodate this, we designed two stakeholder perspectives covering both ends of a spectrum on which you could find healthcare providers.

Two general remarks are in place regarding the perspectives. (1) Combinations of different layers are also possible. The stakeholder perspectives represent the extremes in the HIE market. A different focus is possible per layer, and strategies that lay in the middle of the two perspectives are also possible. (2) Both stakeholder perspectives have a primary monetary motivation. Their strategy for obtaining a profit differs, that does not make one party inherently better than the other.

### 5.2.3.1 Healthcare provider A stakeholder perspective

Healthcare provider A represents a typical smaller or younger healthcare provider.

They focus on innovation and their market position on the policy level by cooperating with other healthcare providers.

In the care process, they work towards contributing added value and focusing on effective care. In addition, healthcare provider A focuses on flexibility, which allows them to collaborate with other healthcare providers.

On the information layer, they use open standards and collaborate intensively with other healthcare providers. These open standards can be easier adopted due to the smaller sizes and younger age. Since smaller organizations have less power in the market, using open standards is required for collaboration.

For the application layer, the focus lies on remaining vendor-independent. Therefore, they acquire diverse applications that are interdependent. This allows them to provide specialized features of specific products and expand IT features faster by cherry-picking suppliers.

On the IT-infrastructure layer, the focus is on privacy and security. Collaborations are also crucial at this level, for example, by participating in regional HIE initiatives.

Figure 5-3 presents a visual overview of the healthcare provider A stakeholder perspective.

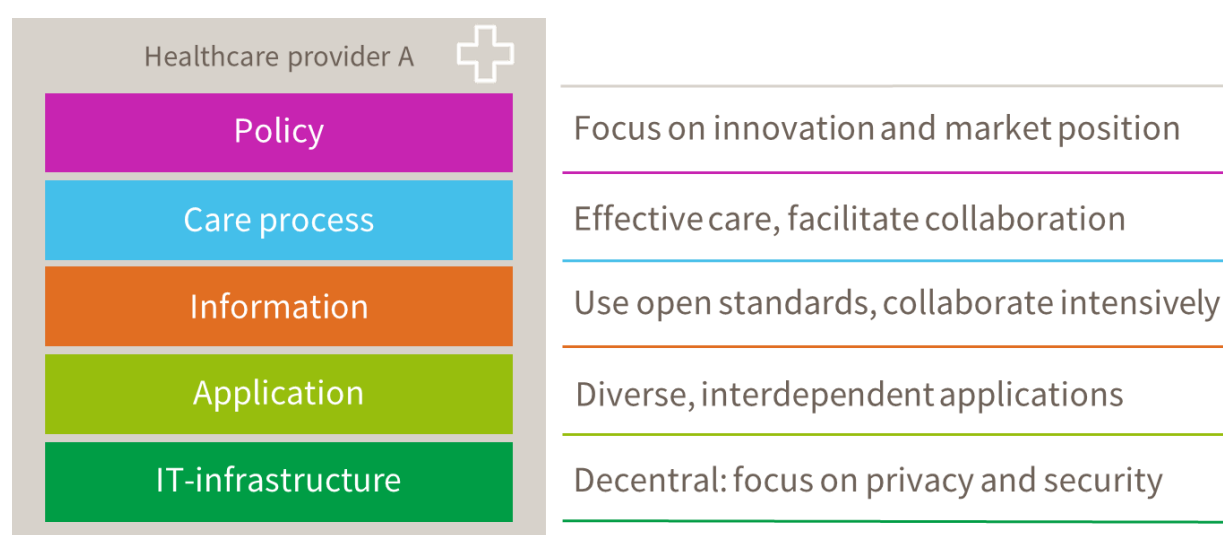


Figure 5-3: Healthcare provider A

### 5.2.3.2 Healthcare provider A key requirements

This healthcare provider is trying to provide added value by facilitating healthcare best suited to their patients. Their key requirement is the following:

- Provide the right healthcare, in the right place, at the right time

### 5.2.3.3 Healthcare provider B stakeholder perspective

Healthcare provider B represents a typical bigger healthcare provider. Examples are hospitals, which have been around for a long time and employ thousands of people.

On the policy level, they focus on aligning internal business processes. As a result, collaboration is less critical, and integrating internal processes receives the most focus.

On the care process also this healthcare provider wants to supply effective care. This is done by providing an integrated healthcare process throughout the organization.

In the information layer latest standards are not implemented. Instead, they value complete information over the latest developments. Once standards have proven themselves and are adopted by other organizations, they can be implemented.

On the application layer, healthcare provider B collaborates with a single healthcare technology provider. This HTP provides all applications within the healthcare provider. This has two benefits. Applications and processes throughout the healthcare provider can be streamlined, and HIE options from this HTP can be utilized.

At the infrastructure layer, a centralized solution is preferred. An IT-infrastructure can be supplied by their HTP or by a national initiative. Centralized solutions solve a lot of challenges and have a higher likelihood of adaptation.

Figure 5-4 presents a visual overview of the healthcare provider B stakeholder perspective.

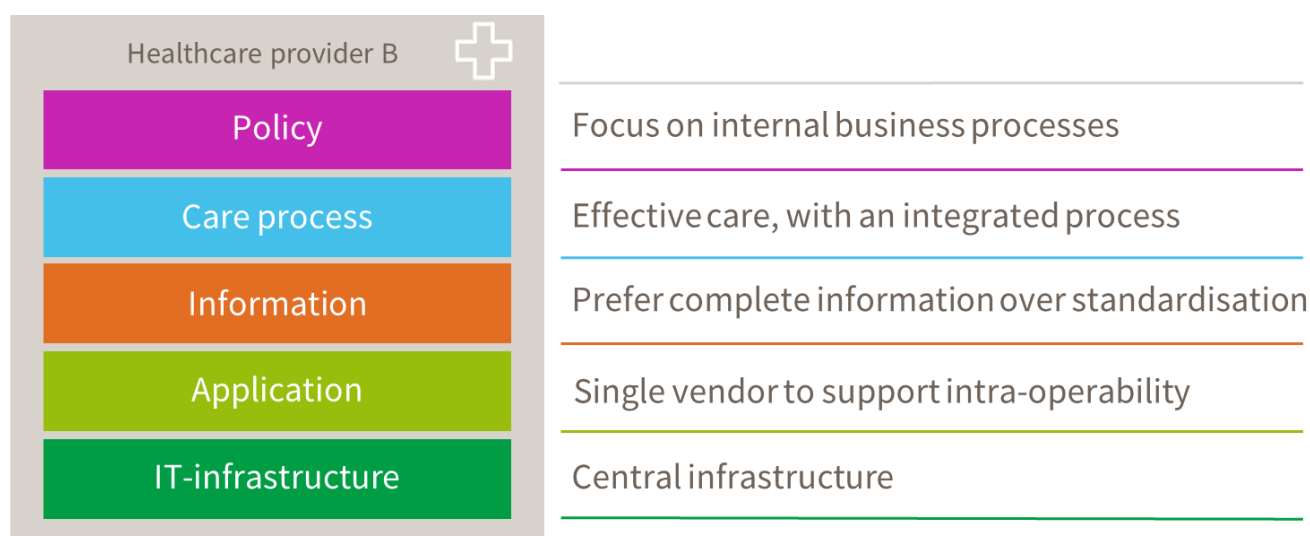


Figure 5-4: Healthcare provider B

#### 5.2.3.4 Healthcare provider B key requirements

This healthcare provider has a stronger focus on its healthcare performance. While this could be at the cost of flexibility, the quality of care could improve. Therefore, their key requirement is:

- Provide the right healthcare, focus on perfecting internal processes

### 5.2.4 Healthcare technology providers

All healthcare technology providers we spoke to have a similar vision. They want to provide added value to the care process. However, they vary in their strategy of accomplishing this. This leads to two HTP stakeholder perspectives. Similar to healthcare providers, these two perspectives indicate the extremes. There are many different HTPs, and combinations of specific layers can be made. Stakeholders that fall in the middle between both perspectives are also possible. In addition, not all HTPs focus on all layers. For example, some suppliers may not be involved in the IT-infrastructure layer. Similar to healthcare providers it should be noted that both stakeholder perspectives have a primary goal of making a profit. However, the strategy for earning money may differ greatly.

#### 5.2.4.1 Healthcare technology provider A stakeholder perspectives

Healthcare provider A represents typically younger, relatively smaller HTPs. They are clear on their position in the market: their role is to support healthcare providers and citizens in the best possible way.



HIE should be a given in that process and not be part of their core business. The business strategy of this HTP aligns best with smaller healthcare branches like home care.

Healthcare provider A is looking to provide added value to the care process and is actively investing in HIE on the policy level. This can be done by developing infrastructure or building initiatives that allow for the sending or receiving of healthcare data.

The care process should be supported in the best possible way. To accomplish this, HTP A is actively influencing how healthcare should be organized through its applications. They have a vision of how healthcare can be best organized and incorporate this in their application.

On the information layer, open standards are adopted. Collaborations are intensive, resulting in interoperable applications. Due to the smaller size of this HTP, standards have to be adopted to fulfill customers' requests for HIE.

The application layer also focuses on open standards. This is a vital part of the business strategy, as collaboration is often required.

On the IT-infrastructure layer, an active approach is taken. When infrastructure to exchange healthcare information does not exist yet, own solutions are developed. This gives them an edge over the competition by providing HIE.

Figure 5-5 presents a visual overview of the healthcare technology provider A stakeholder perspective.

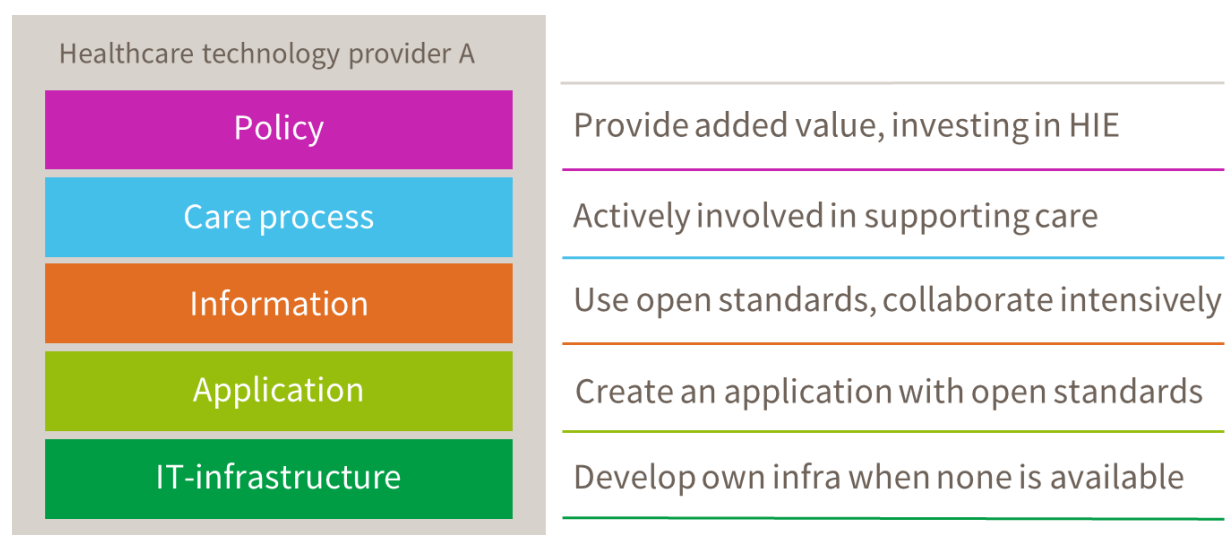


Figure 5-5: Healthcare technology provider A

#### 5.2.4.2 Healthcare technology provider A key requirements

The focus of this HTP is to provide added value. This results in the following requirement:

- Facilitate efficient and effective care, focus on adding value to the care process.

#### 5.2.4.3 Healthcare technology provider B stakeholder perspectives

The second healthcare technology provider represents a larger, more traditional HTP. They support more prominent clients, typically hospitals. The focus lies more in the continuity of service, which these clients often require. This HTP has been around longer, which resulted in lots of legacy applications.

At the policy layer, they want to support the care process. To ensure continuity, and since changes to legacy applications are expensive, not many innovations are created.

The care process is facilitated but not influenced in any way. Their vision is to provide digital solutions to healthcare providers and let healthcare providers organize the care process.

For information, proven standards are used. When opportunities are present, collaborations are started. However, the benefit of implementing this solution should be clear to both the HTP and its clients.

On the application, layer focus is on providing a stable, consistent application. Proven standards are implemented, and collaborations are started when possible. Continuity of service is most important.

On IT-infrastructure this healthcare provider is not taking the initiative. Instead of potentially spending money on a solution that will not be widely adopted, they wait on proven infrastructure.

Figure 5-6 presents a visual overview of the healthcare technology provider B stakeholder perspective.

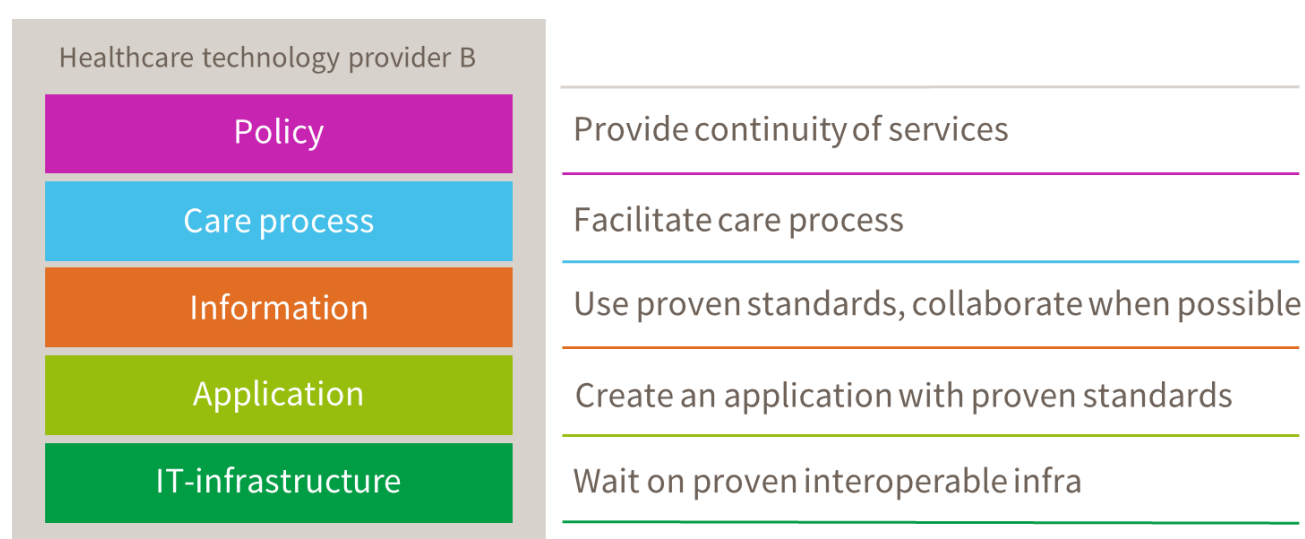


Figure 5-6: Healthcare technology provider B

#### 5.2.4.4 Healthcare technology provider B key requirements

This HTP takes a more facilitative role, focusing on the continuity of their services. This results in the following key requirement:

- Facilitate efficient and effective care. Focus on continuity of service.

## 5.3 Conclusion

In this chapter, we presented the stakeholder perspectives of all major stakeholder groups. Based on interview sessions, requirements were grouped and presented using the Layer Framework. For citizens and insurers, this resulted in a uniform stakeholder perspective. On the other hand, healthcare providers and healthcare technology providers are split into two perspectives, highlighting different strategies.

### Diverging goals

From our analysis, we find diverging strategies for different stakeholders. A significant difference can be found in different healthcare branches. We saw one HTP perspective focus on collaboration while the other focused on continuity of services. This strategy could also be linked to the branch in which organizations are active. Smaller organizations must adopt the latest standards, while older organizations with a steady client base and market share can have more power to enforce their own way of working. These different market positions lead to diverging strategies and requirements at an HIE level.

At healthcare providers, there is a similar trend. Some healthcare providers collaborate intensively with other stakeholders, mainly in smaller branches like home care. This strategy aligns with the smaller HTPs. Others focus on internal processes and an integrated care process. Again, this aligns better with the bigger HTPs that can guarantee a continuity of service.

**Converging goals**

In contrast, we also find converging goals of different stakeholders. The needs of insurers and some healthcare technology providers are aligned. Insurers indicate they want to provide or facilitate HIE solutions so that HTPs and healthcare providers can provide added value. Some HTPs want exactly this: have infrastructure taken care of so that they can focus on delivering added value.

## 6 EVALUATION

This chapter presents our first evaluation study concerning the created stakeholder perspectives. The study makes use of expert opinions as described by Wieringa (2014). Based on expert feedback, we improve our stakeholder perspectives and explore if they are experienced as useful. The perspectives presented in chapter 5 will be evaluated on several points; correctness, completeness, and several factors indicating their usefulness. This chapter also uses input from experts to reflect on the healthcare information exchange (HIE) market.

### 6.1 Methodology

This part of our research fits in the treatment validation part of the design cycle by Wieringa (2014). In their design, they propose implementation evaluation questions. This phase aims to develop a design theory of an artifact in a context that allows us to predict what would happen if the artifact were transferred to its intended problem context. The challenge here is the fact that this research is done before its actual implementation. Both the treatment and the context are not real-world and therefore have assumptions. We study the interaction between an artifact and its context by studying a model of it. The visual designs from section 5.2 represent the model of the artifact. The experts imagine the model of the problem context. Their professional experience is used to imagine how the problem context and artifact will interact.

To measure experts' intention to use the perspectives, we will use the unified theory of acceptance and use of technology (UTAUT) proposed by Venkatesh et al. (2003). We chose this theoretical model because of its suitability to our context and because other researchers in Information Systems Research have used it. This section presents the original model and then describes how it is adapted for application in our context. See Figure 6-1.

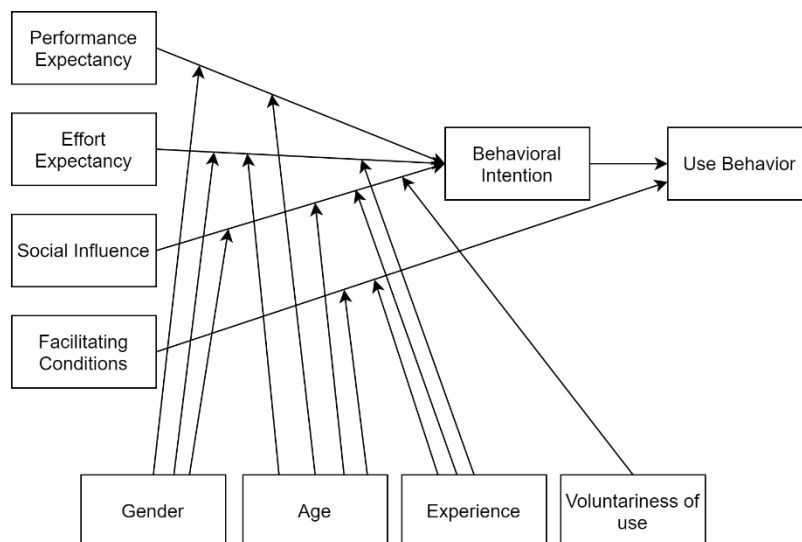


Figure 6-1: Original UTAUT Model proposed by Venkatesh et al. (2003)

In the field of information systems, many models measure usage intention. Venkatesh proposed the unified theory of acceptance and use of technology. They base their design on many iterations of earlier research. Constructs found in earlier research are combined, and their method is thoroughly validated. With over 34 thousand citations, it is the most widely applied technology acceptance model.

UTAUT consists of four key constructs. Performance expectancy (PE), effort expectancy (EE), social influence (SI), and facilitating conditions (FC). The first three constructs influence behavioral intention. Behavioral intention, combined with facilitating conditions, influences use behavior. Gender, age, experience, and voluntariness of use have a moderating effect on the different relations. Ultimately,

partly through behavioral intention (BI), these constructs estimate use behavior (UB). Several statements can operationalize every construct. These statements are scored on a 5-point Likert scale, varying between “*poor*” and “*excellent*”. The statements we use are presented in Appendix C. They have been altered slightly to make them more relevant to the designed artifact, for example, by replacing “*system*” with “*stakeholder perspective*”.

### 6.1.1 Changes to UTAUT model

Gender, age, experience, and voluntariness of use are indirect determinants of intention. Therefore, they are not incorporated in this study. The study population is too small to take their effect into account. Additionally, social influence is left out. We speak with experts on the topic in the evaluation interviews, as is introduced in section 6.2. Measuring social influence includes questions related to pressure from colleagues or bosses. The intended research population for expert interviews consists of experienced people with mostly entrepreneurial backgrounds. Social influence is therefore not expected to be relevant during this evaluation. This results in the following adaptation of the UTAUT model, see Figure 6-2.

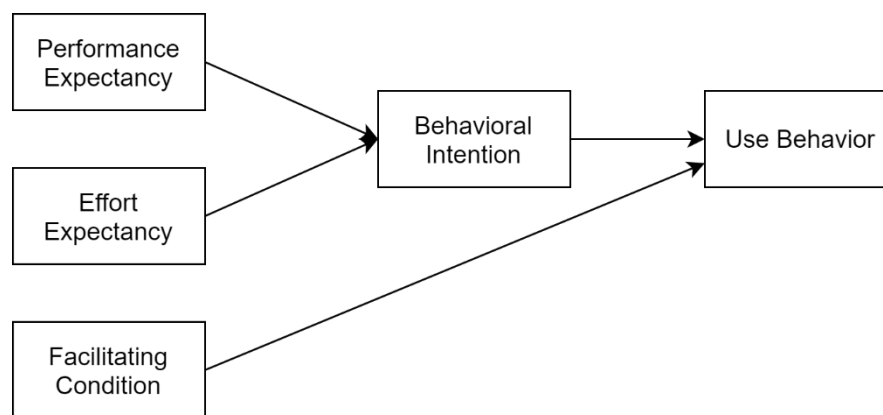


Figure 6-2: Adapted UTAUT model

## 6.2 Interview sessions

The evaluation interview has two main goals: collecting feedback on the stakeholder perspectives and validating if they are beneficial. For this, we used a combination of open-ended questions and questions extracted from UTAUT. Appendix C presents the complete interview guide.

In total, we had four evaluation interviews, three of which with new participants. We selected experts with many years of experience in the HIE sector and healthcare in general for our interviews. In addition, we opted not to choose interviewees from the different stakeholder groups but rather experts with broad experiences and perspectives. This allows them to work as a proxy for evaluating the different stakeholder perspectives.

Two interviews were conducted through Google Meet, one using Microsoft Teams, and one interview took place physically. All sessions were scheduled for an hour. The shortest interview took 48 minutes, and the longest session was 64 minutes in total. Answers to the questions were noted down during the interview. This allowed us to summarize and validate the correct understanding of the provided answers. Additionally, all interviews were recorded for later analysis. This approach is similar to the interviews described in chapter 4.

Table 6-1 contains an overview of the interviewees, their role, and experience with HIE.

Table 6-1: Background of evaluation experts

Expert	Role	Description
1	Program manager HIE	>35 years of experience. Started working with HIE after obtaining a doctorate in political sciences. Implemented email as one of the first digital information exchanges in the healthcare sector. Has experience leading integration projects and addressing HIE challenges together with healthcare providers and competence centers.
2	Product owner	13 years of experience with HIE and a background in IT. For the last three years working as a product owner of HIE features for an EHR provider.
3	Innovation officer/entrepreneur	>25 years of experience and a background in administrative digitalization. Worked with healthcare and ICT since 1995. After functions like IT-manager and project manager, now active as an entrepreneur and innovation officer.
4	Consultant	28 years of experience and a background in public administration with a specialization in digitalization. Always been active in healthcare and ICT. Helped with various EHR implementations and HIE initiatives. Currently working as a consultant for healthcare providers and government. Is also part of the architecture board, which advises the government on HIE.

## 6.3 Interview results

This section presents the results of our evaluation interviews. In 6.3.1, expert feedback on the stakeholder perspectives is given. Section 6.3.2 highlights the second part of our interview results, indicating how likely experts are to adopt the proposed perspectives. Finally, section 6.3.3 offers the answers to reflective questions on the current state of the HIE sector.

### 6.3.1 Evaluation of stakeholder perspectives

#### 6.3.1.1 Citizens

Several remarks were made on the citizen stakeholder perspective. Below we present a description of the various points. Table 6-2 summarizes these suggestions and highlights how the feedback is incorporated into our design. In general, the citizen perspective was complete and correct, although some remarks were made on specific layers.

One expert remarked that quality of life is the most crucial goal in their sector for the policy layer. This description is more common than “freedom to live life as desired”. Another expert added a different phrasing: “experience the least possible burden of their illness and our healthcare system”.

Two experts mentioned the phrasing in the application layer. They clarified that the most crucial part is the availability of information where the citizen desires. They want information in the right place, not a portal for every institution that can show information. One expert highlighted: “I think citizens want the ability to pick their application, but not have to change to a new application all the time”. The phrasing in the application layer suggested that there should be one integrated solution. This is not the case; citizens want their information available in the system they desire. That could be multiple but is probably a single application of their choice.

Another point of feedback was on a semantic issue: the naming of this stakeholder. Initially, citizens were named patients. When receiving healthcare, the relation between a healthcare provider and healthcare recipient, or patient, seems clear. However, different people use different naming. In hospitals or with general practitioners, the term patient is used. In home care, it is customary to use the term client. From a government perspective, the term citizen is more common. As one expert indicated: “A patient is always a citizen. However, a citizen is not always a patient.” Another expert expanded that the needs of a citizen can change depending on their health status.

One expert indicated that the phrasing of the *right* information could be confusing. For example, right can imply ‘not incorrect’ information, but in this case, it is intended as only information relevant to the citizen. This could be clarified.

A final remark from an expert was on whom this stakeholder perspective represents. For example, there exist cases when a citizen is no longer mentally competent. In that case, the citizen itself is not explicitly the source for these requirements. Instead, a caregiver may represent the citizen and is the source for these requirements in that case.

Table 6-2: Expert feedback on citizens stakeholder perspective

Expert’s suggestion	Use of feedback
Rephrase policy layer goal.	Striving for quality of life fits better with the description of a citizen. This is updated accordingly in the final design in section 5.2.1.
Information in the application layer.	Made a minor adjustment to highlight information that should be available in the desired application in section 5.2.1.
Rename patient to citizen.	In the context of receiving healthcare, patient seems more fitting. However, when considering the healthcare system as a whole, citizen is the correct term. Furthermore, preventive care is upcoming, in which case citizen is a far more applicable term. Therefore, usage throughout the research has been changed.
Right information should indicate relevant information to the citizen, not correct information.	That was intended in the design. Therefore, the description of section 5.2.1 is updated to reflect this.
Sometimes the citizen is not the source of these requirements.	Valid remark, the suggestion is incorporated in the description of section 5.2.1.

### 6.3.1.2 Insurers

On the insurer stakeholder perspective, we received a few points of feedback. Table 6-3 presents an overview of the feedback we received and how it is incorporated into our final designs. All experts agreed on the key requirement.

Three experts indicated that individual insurers do not put much emphasis on the lower layers. Facilitating HIE in general, as was described, is a task aimed for by the industry organizations for insurers. Individual insurers can have smaller initiatives to promote HIE. These are generally focused on bringing value to their customers, for example, by collaborating regionally.

An expert highlighted that individual insurers do not play a truly facilitative role. They do not provide solutions for HIE. However, they work together with healthcare and healthcare technology providers to provide financing options for new initiatives. One example this expert provided is that healthcare providers can declare hours on the technology used for a citizen. Insurers provide financing to facilitate the use of technology in this way. A health technology provider provides the application layer itself. Another expert indicated that insurers “dream of a more active role, but do not often take it” This puts their intention to influence HIE with money into a different perspective. However, this expert does not experience the results from this intention.

An expert also indicated that the facilitative role of insurers could indicate a desire for control in HIE initiatives. Insurers might want to ensure their position in the market remains relevant.

One expert provided a final remark. The stakeholder groups we present are missing two actors also purchasing healthcare in our market. These are Care Administration Offices and municipalities. While significantly smaller than insurers, these actors also fulfill a role as purchasers of healthcare. In the same category also falls the regulatory framework provided by the government. That is not incorporated in the perspectives.

Table 6-3: Expert feedback on insurer stakeholder perspective

Expert's suggestion	Use of feedback
Information, application, and IT infrastructure layer are not insurers' prime focus.	Also follows from interviews, the description of section 5.2.2 has been updated.
Split into insurer and insurer industry organizations.	Overall, changes between insurer and insurer industry organization strategy are not big. The description in section 5.2.2 is updated to incorporate this feedback.
Insurers generally finance initiatives, not facilitate them.	Description in section 5.2.2 has been updated accordingly.
The facilitative role could imply a desire for control.	While this might be the case, other foundations for this claim have not been found. The designs are therefore not updated.
Include Care Administration Offices and municipalities as healthcare purchasers.	We agree that this would improve the completeness of our research. These actors are not incorporated in the current designs. However, the suggestion is added to future work in section 7.5.1.

### 6.3.1.3 Healthcare providers

Below we present expert feedback on the healthcare provider stakeholder perspectives. Table 6-4 provides an overview of the provided feedback.

All four experts indicated that the stakeholder perspectives are recognizable. Although it might be a slight oversimplification, they agree that more conservative and more proactive healthcare providers exist. Some hospitals tend to fall in the conservative group, while smaller or younger organizations are more open to adopting new standards. One expert indicated multiple reasons for this: less tradition and less impact due to a smaller size. Hospitals have traditionally always had a dominant position in our healthcare system. They have the most money, longer-running IT systems, and work in an established market with a limited number of suppliers. According to this expert, hospitals tend to focus on their work. Healthcare in other areas is not of interest. Another expert added some clarification on why this is the case. "Hospitals are huge companies, sometimes employing over ten thousand employees. Continuity is therefore much more important than new innovative solutions." In addition, the governance of a hospital is complex. It consists of a combination of directors and doctors. This organization makes revolutionary change unlikely. Some hospitals try to become more innovative but have much trouble doing so. The expert indicates it should not be unexpected innovation is stagnating since a change in large organizations is always challenging.

One expert highlighted that an application strategy could also indicate the difference in approach. For example, stakeholder perspective A is working with a best of breed, while stakeholder perspective B is working towards a best of suite. Best of breed allows for specialistic solutions to be implemented for specific purposes. On the other hand, best of suite is looking to optimize business processes by tighter internal integration. Tighter integration is accomplished by selecting services from a single provider. Another option that is gaining popularity is best of both. This allows for a combination of best of breed and best of suite.



An expert indicated that the care process itself could also differ between the two stakeholder perspectives. For example, stakeholder perspective A allows for more flexibility, whereas stakeholder perspective B might provide a more integrated process. In addition, stakeholder perspective A also allows for more collaboration and flexibility, whereas stakeholder perspective B focuses on healthcare within its walls.

One expert remarked that decentralized is not necessarily the focus of stakeholder perspective A although it is possible.

One expert indicated that the distinct difference in stakeholder perspectives was recognizable. However, another expert expressed a slightly different opinion that combinations of the two stakeholder perspectives are also possible.

A final remark was from an expert that indicated complexity in HIE partly arises due to the diverging strategies of all the healthcare providers. However, they also indicate that the best stakeholder perspective might not be by design but could have emerged spontaneously.

Table 6-4: Expert feedback on healthcare providers stakeholder perspectives

Expert's suggestion	Use of feedback
Differentiate care process within stakeholder perspectives	Different focus on the care layer makes sense and also follows from the results in section 4.5.3. Therefore, the design in section 5.2.3 has been updated.
Combinations of stakeholder perspectives are possible.	Expert opinions differ on this point. However, all agree that these perspectives represent the extremes. The description of section 5.2.3 has been updated to illustrate this better.

#### 6.3.1.4 Healthcare technology providers

In this section, we present expert feedback on the healthcare technology provider (HTP) stakeholder perspectives. Table 6-5 provides an overview of the provided feedback.

An expert remarked that some HTPs tend to only focus on their circle of influence. Therefore, exchanging data beyond its intended use is not possible in most cases. This allowed for the creation of new initiatives that focus on specific types of information exchange between HTPs. While this improved exchange possibility, these systems also created new borders. On a more positive note, the expert recognizes that network organizations are upcoming. These organizations take note of their position in the health chain and try to collaborate with relevant parties.

Two experts indicate that the strict distinction between stakeholder perspective A and stakeholder perspective B cannot be made. HTPs can focus on providing a best-of-breed solution or facilitate collaboration by creating a product that works well as a best-of-suite. The expert continues by stating that the stakeholder perspectives seem to cover the extremes. All possible strategies of HTPs are present. However, every possible combination of individual layers is also possible.

One expert indicated that there could be a distinction in the care process layer. Here both stakeholder perspectives are presented as equal, but this does not represent the vision of the expert. Stakeholder perspective A could be considered more modern, which can also be combined with an active opinion in the care process. Stakeholder perspective B is more conservative, only facilitating the care process. Another expert made a similar comment. They stated that HTPs might focus on different layers. For example, some do not provide infrastructure or are not involved in the care process.

Two experts highlighted the relationship between company size and age and their strategy. Many new players are innovative. Small players have to adopt the latest standards: they do not have the size to enforce other standards. They tend to relate closer to stakeholder perspective A. Some more prominent suppliers relate better to stakeholder perspective B. They have a lot of legacy code, and making changes is costly. Their dominant market position ensures that action is not needed. They tend to wait

until standards are proven. The differences between perspectives A and B can also be explained in terms of business strategy and branch. Smaller healthcare branches like home care tend to have different requirements that align with perspective A. Bigger institutions like hospitals have a more substantial need for continuity and alignment with perspective B.

A final remark from an expert indicates a motivation is missing from the perspectives. The current designs could indicate that perspective A is the good guy and perspective B is the bad one. However, that is explicitly not the case. In the Dutch healthcare market, both extremes are private parties that try to make a profit. The only difference is the strategy for obtaining this profit.

Table 6-5: Expert feedback on healthcare technology provider stakeholder perspectives

Expert's suggestion	Use of feedback
Stakeholder perspectives represent the extremes.	This is a valid point. While the extremes are recognizable by experts, the description in section 5.2.3 has been updated to state that different combinations of layers are also possible.
Differentiate in the care process layer, indicate not all HTPs focus on all layers.	This suggestion is in line with differentiating business strategies of the companies presented in section 4.3. Accordingly, the stakeholder perspectives in section 5.2.3 have been updated.
Incorporate both perspectives want to make a profit.	This may not always follow logically in the healthcare market and makes sense to mention explicitly. Therefore, the description in section 5.2.3 has been updated accordingly.

### 6.3.2 Acceptance of the proposed designs

After collecting feedback on the contents of the stakeholder perspectives, the next step was to collect feedback on user acceptance towards the models. For this, we used an adapted version of the UTAUT model as presented in section 6.1.1. The adapted UTAUT model was used to create interview questions, as shown in Appendix C.

Table 6-6 presents descriptive statistics of the UTAUT questions from our interviews. Min and max indicate the respective minimum and maximum scores given to an indicator. Mean shows the arithmetic mean. N indicates the number of responses. The four experts have answered all questions.

Table 6-6: Descriptive statistics of UTAUT results (scores ranging from 1 = poor to 5 = excellent)

Indicator	Min	Max	Mean	N
PE1: Using the proposed stakeholder perspectives would improve my job performance	3	4	3,8	4
PE2: Using the proposed stakeholder perspectives enables me to accomplish tasks more quickly	2	4	3,3	4
PE3: Using the proposed stakeholder perspectives increases my productivity	3	4	3,5	4
EE1: It would be easy for me to become skillful at using the proposed stakeholder perspectives	4	5	4,3	4
EE2: Overall, I believe the proposed stakeholder perspectives are easy to use	3	5	4,0	4
EE3: Learning to use the proposed stakeholder perspectives are easy for me	2	5	3,8	4
FC1: I have the knowledge necessary to use the proposed stakeholder perspectives	5	5	5,0	4
FC2: I have the resources necessary to use the proposed stakeholder perspectives	4	5	4,8	4
FC3: I think that using the proposed stakeholder perspectives fits well with the way I like to work	4	5	4,8	4
BI1: I intend to use the proposed stakeholder perspectives in the future to help me complete my job	4	5	4,3	4
BI2: I predict that I will use the proposed stakeholder perspectives in the future to help me complete my job	4	4	4,0	4
BI3: I plan to use the proposed stakeholder perspectives in the future for helping me in dealing with HIE	4	5	4,3	4
Average performance expectancy	2	4	3,5	-
Average effort expectancy	2	5	4,0	-
Average facilitating conditions	4	5	4,8	-
Average behavioral intention	4	5	4,2	-

### 6.3.2.1 Performance Expectancy

Performance expectancy is the degree to which an individual believes that using the system will help them to attain gains in job performance (Venkatesh et al., 2003). This construct indicates how useful the artifact is to the experts. Figure 6-3 shows the results of the questions that are relevant to this construct. Performance expectancy is moderately positive. Table 6-6 shows the average result is 3,5. This indicates that experts think that the proposed stakeholder perspectives can provide a moderate contribution to their job performance. PE2 is rated slightly lower, indicating that experts have a neutral expectation of the efficiency benefits of the perspectives. PE1 and PE3, indicating performance and productivity, received more positive results.

One expert clarified why PE2 was scored fair. They indicated that using the artifact will not necessarily result in a faster process. Therefore, the question '*Using the proposed stakeholder perspectives enables me to accomplish tasks more quickly*' is scored with a two. The expert highlighted that using the perspectives could lengthen their regular work since more steps have to be added. A critical remark is that the perspectives help to do work better. While using the stakeholder perspectives might take more time, it will help to achieve better results.

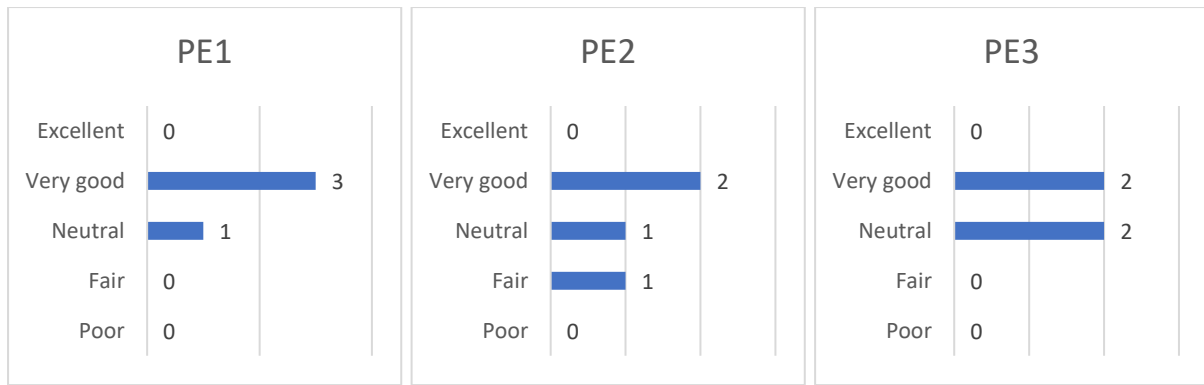


Figure 6-3: Performance expectancy interview results

### 6.3.2.2 Effort Expectancy

Venkatesh defines effort expectancy as the degree of ease associated with using the system (Venkatesh et al., 2003). The construct indicates the user-friendliness of the artifact and how easy it is to adopt. Figure 6-4 presents the answers we received to the questions supporting this construct. Table 6-6 shows that experts give an average of 4,0 to this question. This indicates that experts think it is easy to use the suggested perspectives. EE1 and EE2, indicating how easy it is to become skillful in the proposed approach and ease of usage, are rated positively. EE3, reflecting on how easy getting acquainted with the perspectives was, received one lower response of 'fair'.

One expert highlighted that global acquaintance with the stakeholder perspectives would be accessible. However, an in-depth understanding of the Layer Framework and stakeholder perspectives will take more time. Another expert also confirmed this. *"I am well aware of how the Layer Framework works. For others, this might be a bigger challenge. Context is essential to understanding the overall inner workings"*. This explains the scattered answers to this question. One expert took getting familiar with the market and Layer Framework into account. Some background knowledge is required, increasing the required effort to work with the stakeholder perspectives.

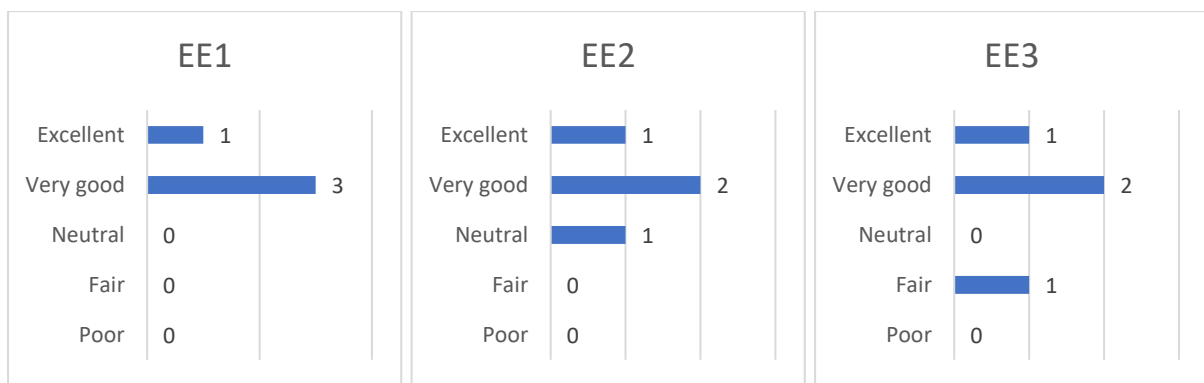


Figure 6-4: Effort expectancy interview results

### 6.3.2.3 Facilitating Conditions

Facilitating conditions are defined as the degree to which an individual believes that an organization and technical infrastructure exists to support the use of the system (Venkatesh et al., 2003). Figure 6-5 presents the results to the questions supporting this construct. The majority of the facilitating conditions questions have been rated as excellent. As follows from Table 6-6, this results in an average rating of 4.8. FC1 indicates experts are confident they have the required knowledge to use the stakeholder

perspectives. FC2 states that experts have the needed resources available to use the perspectives. Finally, FC3 also indicates a good fit for their way of working.

The background of the experts can primarily explain these positive responses. All four experts are acquainted with the healthcare market, and they are familiar with the Layer Framework. One highlighted it is commonly used during work. Another expert added that once the Layer Framework is familiar, using the stakeholder perspectives should be easy.

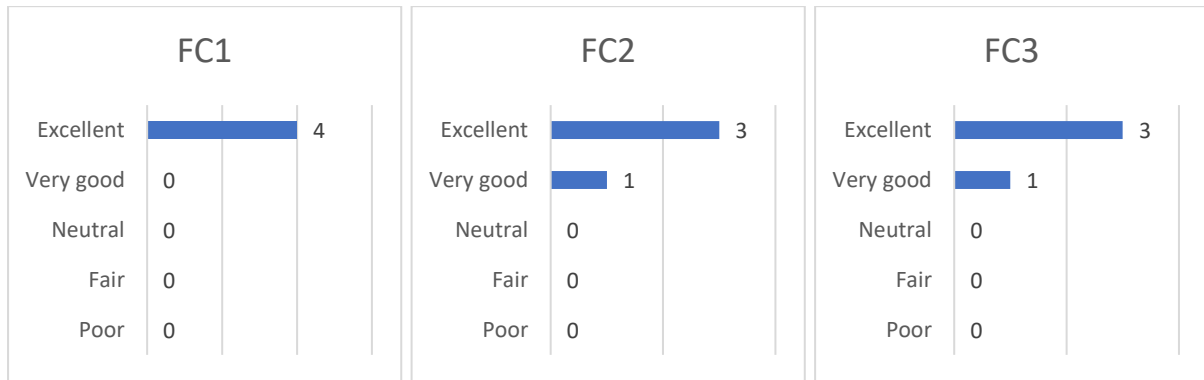


Figure 6-5: Facilitating conditions interview results

#### 6.3.2.4 Behavioral Intention

Behavioral intention indicates the intention of usage of an artifact. It has a significant contribution to the use of an artifact (Venkatesh et al., 2003). This variable depends on the constructs that have been explored above. Figure 6-6 presents the results of these questions. The behavioral intention indicator has received only positive responses. Table 6-6 shows that the average score is 4,2. The different questions indicate experts are positive about their intention, prediction, and planning of using the stakeholder perspectives.

Results indicate a solid behavioral intention. All questions are rated very good or higher. These results indicate that experts intend to use the proposed stakeholder perspectives in their work. One expert highlighted that the Layer Framework is already being used. The extension with stakeholder perspectives will be a valuable addition. Another expert states that the designs indicate where solutions and problems may be found in their daily work. *“On one hand, some designs are stating the obvious. Even tough, different needs are usually not made explicit. This is where the stakeholder perspectives have added value”*. The combination of the different stakeholder perspectives gives a good overview of the various interests. These interests determine if things will change.



Figure 6-6: Behavioral intention interview results

### **6.3.3 Reflection on health information exchange market**

To conclude our evaluation interviews, each expert was asked two questions: “what do you think are the reason(s) for the current state of HIE?” and “what are the most important upcoming developments?”. The sections below summarize their responses.

#### **6.3.3.1 Reasons for the current state of health information exchange**

##### **Legacy systems**

One expert indicated a significant reason for the current state: installed base of technology, also known as legacy code. All existing software generally runs on older standards. Only newer parties can rely on more recent standards that are better optimized for exchanging healthcare information. The expert provides an example where a new standard for medication received subsidies but is still running on an older standard. Many investments have been made in older technology, and there is much incentive to keep that running. Younger companies that are not bothered by legacy systems can move a lot quicker.

##### **Power of stakeholders**

The expert highlights another example where some suppliers will not fully support an upcoming standard. After the standard had been developed for several years, an HTP decided they did not want to implement it. The HTP indicated they have some problems with the standard. This even though many healthcare professionals working in the sector had been involved with its design. The expert highlights this as a display of power by one of the more prominent players.

The expert continues to indicate that this problem also exists with healthcare providers. Established organizations, generally hospitals, have a lot of decision power. If they can exchange healthcare data, they are satisfied even though the whole health chain does not support information exchange. Like with HTPs, the expert here describes an example where healthcare providers do not want to adopt a new standard. They are convinced it will not work out, and current solutions are superior. The expert concludes by stating, “working together is easiest when working alone.”

##### **Subsidy abuse**

One expert indicates subsidies have not been used as intended. Some stakeholders try to use subsidies while investing minimal effort. This results in applications that are qualified to receive a subsidy but are not suitable for expanding HIE features. In addition, some subsidies seem to contradict each other. The expert gave an example where some subsidies were aimed at creating vendor-specific portals for citizens. On its own, this seems like a reasonable effort. However, other subsidies aimed at creating generic personal health records, making the portals redundant.

##### **Looking for the holy grail**

One expert indicates we are looking for the holy grail. The world keeps changing, which requires a certain amount of agility. Perfect HIE can never be achieved. Currently, the time to market of some solutions is exceptionally long. An alternative is that we do not aim for the perfect solution but try to make small steps.

Another expert emphasizes a similar point. We want to exchange all information that is stored in our digital systems. The question is if we can even use that information. A small example is brought up “I asked the first surgeon I ever spoke to what information they need in their work. The response was some basic background information. Based on that, the surgeon can determine if more information is required.”

##### **Market design**

The Dutch healthcare market is unique through its introduction of managed competition. An expert indicates this design could be of influence on the current situation. Market mechanisms do not always work correctly. On the one hand, we expect the market to resolve things itself, while on the other hand, we are creating legislation that should enforce standards top-down (introduced in section 3.3). An economical value chain is easy to automate: the advantages show quickly. However, a healthcare chain is not always a value chain. There are many nuances and hidden agendas that prevent action.

The market also creates perverse incentives. The expert states that one cannot expect hospitals to send patients home when this reduces their income. Even when it would be good for the overall society. There are some attempts to remove these incentives, but the market design itself creates numerous challenges. The same holds for citizens. The citizen is not the customer of healthcare. We make some attempts to stimulate this, but ultimately citizens want to get the best possible help. Best help conflicts with affordability. This results in cases where citizens display customer behavior: they are shopping for healthcare they do not medically require. As long as someone can find a doctor who agrees, healthcare costs will be paid. Again, that is not optimal for society, although one cannot expect citizens to act differently.

Another expert nuanced that remark by stating the market is not necessarily limiting. In their opinion, the stakeholders in the market are the limiting factor. The sector has proven to be quite agile, for example, by adopting new ways of working. The COVID-19 pandemic showed that care layers could change quickly. Whoever, some big players cannot keep up with these changes.

### **Not a clear requirement**

Citizens do not see HIE as a clear need. An expert indicates if someone breaks their leg, they want it fixed. A citizen is less likely to worry about the information exchange possibilities of a specific hospital. This only arises when a citizen meets multiple healthcare providers in more complex situations. In that case, the healthcare providers have already been selected. The same sometimes holds for healthcare technology providers. They do not always receive questions to exchange healthcare information and are therefore not inclined to implement it.

### **Wrong approach**

One expert highlights a critical analysis. *“95% of the energy is spent developing standards, running pilots, etcetera. This is never perfect and will therefore never be finished. It is a relatively easy approach. We are not spending enough energy at the policy levels. Different needs are often hard to discuss”*. The expert continues that the Layer Framework is used upside down, starting with a technical implementation instead of the other way around. It would be helpful to emphasize the financing of initiatives, regulations, and what measures will contribute to good healthcare.

## **6.3.3.2 Upcoming developments in health information exchange**

### **Upcoming legislation**

Two experts indicated the upcoming legislation presented in section 3.3 could contribute to HIE. Although there are some remarks on the actual implementation and possibly bureaucratic look of the certification process, the law is expected to influence the situation positively. However, one expert expresses their confusion as to why a law was required in the first place.

### **eHealth**

One expert thinks eHealth will advance the digitalization of the healthcare sector. By providing more technical solutions to citizens, the need for more integration will emerge. For example, if citizens can take measurements at home, they will want to share these details. This pressure from citizens will make doctors want to use it. Additionally, the expert indicates that this should help facilitate a shift from curing to prevention. Our system is now designed to heal people, not to keep them from becoming sick. eHealth will present innovative ways that help stimulate prevention.

### **Awareness**

Another expert mentions the improved awareness of HIE. Digital solutions implemented during the COVID-19 pandemic, subsidies, and a more active role from the government have all helped contribute to this awareness increase. The government initiatives may seem bureaucratic, and subsidies are not always used optimally, but progress is being made. Both the government and suppliers are making steps in the right direction, and technical methods are also advancing.

## 6.4 Threats to validity

Our evaluation study includes some limitations. One of which is the small study population, which could threaten the generalizability of the evaluation. A more extensive study population would have led to more representative results. However, the experts in our evaluation are carefully selected. They have many years of experience with HIE and have diverse backgrounds. Practical experiences range from EHR implementations to technical integrations and government advice. This allows them to function as a proxy and represent multiple stakeholder types instead of a single one.

As indicated by Wieringa (2014), the goal of the expert opinion validation method is not to survey all opinions that are out there. Instead, experts use their experience to imagine how the proposed design would function in context. Experts understood the artifact, and their expertise allows them to imagine a realistic problem context. This allows a realistic imagining of the effects the artifact would have in context.

Similar to section 4.5.4, we base our claims on Seddon & Scheepers's framework for generalizations of qualitative research, including a single case study. They state, *"If the forces within an organization that drove observed behavior are likely to exist in other organizations, it is likely that those other organizations, too, will exhibit similar behavior"* (Seddon & Scheepers, 2012). Similar results could be expected since the level of expertise and familiarity with HIE is also anticipated in other organizations. Based on Seddon & Scheepers' framework, we argue that the results from our evaluation are likely to be similar to perceptions other experts with an equivalent level of expertise would have. Still, we acknowledge that further research is required to produce more evidence for our findings.

Similar to the threats presented in section 4.5.4, researcher bias may also provide a threat to validity. As with our earlier interviews, we worked with a structured approach, selected a proven methodology, and let an expert in Information Sciences review our script before the interviews. Of course, we acknowledge that a bias can never wholly be prevented in qualitative research.

## 6.5 Conclusion

We interviewed four experts to get feedback on the stakeholder perspectives created in chapter 5. All experts have a long history with HIE.

Feedback on the design of the stakeholder perspectives is presented in section 6.3.1. Each subsection includes specific points of feedback, including how it is used to improve our research. For example, some of the points have been used to create an extra design iteration which improves the designs presented in chapter 5. This allowed us to make a complete iteration of the design cycle proposed by Wieringa (2014).

In the second part of our evaluation, we looked at the usage intention of the experts. Results show a strong interest in the usage of the stakeholder perspectives. Experts indicate it helps to provide an overview of different intentions and highlight where problems arise in the HIE sector. One aspect that was rated relatively low in our evaluation was the ease of use. This is caused by general knowledge of the sector and the Layer Framework required to utilize the stakeholder perspectives optimally. While the information presented in the stakeholder perspectives was not necessarily new to the experts, the way of presenting was. By structuring HIE challenges using the proposed perspectives and Layer Model, sensitive conversations can be broken down into structured parts. Experts indicate this is of added value to their work.

To conclude our interviews, we asked reflective questions on the current state and future of HIE. Experts indicated several reasons for the current state of HIE, including misaligned interests, market design, and legacy systems. However, experts were optimistic on the future of HIE, upcoming legislation, eHealth, and a rise in awareness should help advance the healthcare sector.



## 7 DISCUSSION AND CONCLUSION

This research aimed to design an artifact that could provide insight into the working of the Dutch HIE market. We took a mixed-method approach, combining literature studies and interview sessions. Using these findings, we designed stakeholder perspectives. This artifact was evaluated to see if it will contribute to stakeholder goals once put into context. In this chapter, we discuss the results of our research.

Answers to our research questions are presented in section 7.2. Implications for practice are covered in section 7.3. Section 7.3 covers the implications for theory. Limitations to this research are discussed in section 7.4. Finally, suggestions for future work are addressed in section 7.5.

### 7.1 Answers to research questions

In this thesis, we explored five research questions with the goal of designing stakeholder perspectives. These perspectives should address unclarity in the HIE sector by showing what stakeholders exist in the market and their intentions. In this section, we summarize our answers to these research questions.

#### **RQ1:** *What are the drivers behind health information exchange?*

In section 2.1, we did a semi-structured literature study to find the drivers behind HIE. We found that drivers of HIE are aligned with providing better healthcare. Many reasons were found, which we grouped into several primary drivers. Figure 2-2 presents a visual overview of these points. The most important drivers were found to be:

- **Improve patient outcomes**  
Patient outcomes, more commonly known as quality of healthcare, are the primary reason for implementing HIE. HIE helps facilitate information exchange and thereby prevent medical mistakes. In addition, by providing citizens access to their healthcare information, self-reliance is promoted, further improving patient outcomes.
- **Increase efficiency**  
Due to a growing and aging population, the number of healthcare workers relative to healthcare recipients decreases. HIE can help in this aspect by increasing healthcare efficiency. This is done by removing redundant actions and prevent duplicate work.
- **Save costs**  
A side effect of increasing efficiency can be cost-saving. In addition to efficiency increase, HIE can also save costs by making actions redundant.

Section 2.1 also explores the potential downsides of HIE. The most negative claims regarding HIE are that its benefits are not proven. However, papers we found with this narrative were refuted by other reports showcasing positive effects. A sidenote presented in most of the literature on HIE is that it should be used to reach the goals mentioned above. Thus, HIE should not become a goal in itself.

#### **RQ2:** *How did the Dutch government influence health information exchange?*

Section 2.2 explores an earlier attempt of the Dutch government to incorporate HIE in our healthcare system. We explore various sources from government, literature, and unstructured websites. From these sources, we create a summary of historical events. From the end of the nineties to 2011, the Dutch government attempted to implement a national electronic health record (EHR). The government started with an advisory role and eventually led the development of its own EHR. In 2011 it became apparent that privacy concerns could not be met. This resulted in the Senate preventing further government involvement.

Next, we analyzed the government influence using innovation theory, specifically the seven functions proposed by Hekkert et al. (2007). They allow us to evaluate the government approach on several factors. The most important factor was *guidance of the search*, which gives an idea to what extent the

government is influencing the market. In the early nineties, the government started with the promotion of HIE to modernize the healthcare sector. Slowly they started taking more initiative by organizing knowledge institutions to promote HIE. When progress was found to be too slow, a more active approach was taken. The government started to develop a national EHR. This implementation went through several phases but began to receive lots of critiques. Some of the resistance arose since citizens' privacy could not be guaranteed, which ultimately led to the Senate blocking government involvement in the national EHR. The most crucial factor in its decline was resistance by stakeholders, most notably due to privacy concerns.

**RQ3:** *What is the current state of health information exchange in the Netherlands?*

- **RQ3a:** *What stakeholder groups can we identify?*

By exploring the Dutch healthcare sector, we identified the four most important stakeholder groups:

- Citizens
- Insurers
- Healthcare providers
- Healthcare technology providers

The Dutch healthcare system is designed to consist of *citizens*, *insurers*, and *healthcare providers*. These three players combine to form the basis of our healthcare system. Between every pair of players exists a market in which services can be sold or purchased. They operate in a free market but are bound to regulations, creating managed competition. In our analysis of the HIE market, we identified a fourth stakeholder: *healthcare technology providers* (HTPs). This stakeholder represents both software suppliers of healthcare systems and companies that offer specific HIE services.

- **RQ3b:** *What initiatives to promote health information exchange can we identify?*

We continued our literature study by looking at current HIE initiatives. We formed a list of various initiatives on a national scale. This list was not extensive but indicative of the initiatives on the market. To categorize the different initiatives, the Layer Framework was used. This allowed us to indicate at what levels initiatives promote collaboration. We find initiatives with various origins. Some started by major players in the market, and others by small non-profit organizations. While some initiatives address different HIE challenges, we also find many initiatives that address similar types of exchange in different ways. This creates a confusing market with many alternatives, resulting in challenges for stakeholders trying to adopt HIE.

**RQ4:** *What stakeholder perspectives exist in the Dutch health information exchange market?*

- **RQ4a:** *What goals do different stakeholders have?*

After identifying stakeholder groups in RQ3a, we conducted interviews to find out what goals different stakeholders have. In total, we interviewed 13 stakeholders: two citizens, two insurers, four healthcare providers, and five healthcare technology providers. We identified the challenges, requirements, and expectations on HIE for each stakeholder by conducting semi-structured interviews. This provides a comprehensive overview of the HIE market. We find that goals are generally aligned with delivering better healthcare services. However, many nuances were found in approaches to reach this goal.

Section 4.5 presents an overview of the interview results and all stakeholder goals. We present our results per stakeholder group and use the Layer Framework to structure interview responses. In addition to highlighting strategies for the layers of the Layer Framework, stakeholders express specific issues they experience with HIE. The results from section 4.5 are further used to develop stakeholder perspectives.

- **RQ4b:** *How can we group stakeholder goals for the different stakeholder groups?*

Using the findings from RQ4a, we develop stakeholder perspectives. Responses to the interviews were grouped per stakeholder group and divided into sections that follow the Layer Framework. By grouping similar stakeholder needs, we designed a total of six stakeholder perspectives. For every stakeholder perspective, key requirements were included to describe the stakeholder needs better. The full stakeholder perspectives are presented in section 5.2. Below we briefly summarize the most important goals of every stakeholder group.

The goals of the citizens are aligned. Their key requirements are to have *the right treatment, in the right place, at the right time*, and have *the right information, in the right place, at the right time*. This helps to improve the quality of life.

The goals of insurers were also found to be aligned. Their key requirement is to *manage the costs of healthcare in a socially responsible way*. Insurers indicate their position in the Dutch healthcare market is essential to keep costs under control. They envision themselves in a facilitative role regarding HIE.

Healthcare provider goals were not aligned. Therefore, two stakeholder perspectives were created. The first perspective describes a healthcare provider that collaborates intensively with other institutions. Their key requirement is to *provide the right healthcare at the right time in the right place*. The second healthcare provider is focusing on aligning internal processes. This results in less collaboration with other parties. Their key requirement is *providing the right healthcare, focus on perfecting internal processes*.

Diverging HTP goals also resulted in two stakeholder perspectives. The first perspective focuses on providing added value and is investing in HIE. Their key requirement is to *facilitate efficient and effective care, focus on adding value to the care process*. The second HTP emphasizes the continuity of service and is less involved with the care process. Their key requirement is to *facilitate efficient and effective care. Focus on continuity of service*.

**RQ5:** *Do the stakeholder perspectives contribute to understanding health information exchange in the Netherlands?*

To evaluate if the created stakeholder perspectives were perceived as valuable, we performed a first evaluation study. We used the unified theory of acceptance and use of technology (UTAUT) proposed by Venkatesh et al. (2003). UTAUT is used due to its suitability to our context and popularity in Information Systems Research.

In total, we interviewed four experts with an average experience of over 25 years in the HIE sector. They envisioned the stakeholder perspectives in the problem context to evaluate if it contributes to stakeholder goals. Based on this evaluation, the experts are likely to work with the stakeholder perspectives. Experts note that the information presented in the stakeholder perspectives is not new. In their experience with the healthcare sector, they encountered many stakeholders making the information presented in the perspectives redundant. However, experts indicate the structured approach to visualizing stakeholder goals offers additional value. Stakeholder groups and the Layer Framework help structure conversations on HIE, leading to better results (see section 6.3.2.1).

One downside found by our evaluation was that the stakeholder perspectives alone do not guarantee an understanding of the Dutch HIE market. Experts indicated that background knowledge on the Layer Framework and the Dutch healthcare market is required to use the stakeholder perspectives optimally. Practitioners in the HIE will have to introduce this information or combine the background information presented in this thesis with the stakeholder perspectives for a comprehensive understanding.

## 7.2 Implications for practice

This section presents our implications for practice. It covers recommendations for companies looking to adopt HIE and answers some questions stakeholders expressed throughout this research. First, in Section 7.2.1, we summarize the most important findings for practice. Then, section 7.2.2 discusses the reasons for the current state of HIE. Finally, section 7.2.3 reflects on the use of government instruments like subsidies and laws.

In section 1.2, we introduce the design problem of our research: *“Improve the clarity around design choices for health information exchange, by proposing stakeholder perspectives of relevant stakeholders, that satisfies the need for improvement of healthcare cost, quality, and efficiency, in order to allow stakeholders in the Dutch healthcare market to provide better and future-proof healthcare services”*. Then, in chapter 5, we present the artifact that should address this design problem: stakeholder perspectives. The stakeholder perspectives are experienced as valuable by our expert evaluation in chapter 6. While the contents of the perspectives are not new to experts, the structured way of presenting stakeholders is expected to improve collaboration. Companies and people unfamiliar with the HIE market can use the stakeholder perspectives to get acquainted with the market. Companies

looking to adopt HIE can use the perspectives to structure their conversations with other parties when implementing HIE.

The problem statement presented in section 1.1 focuses on the design choices that must be made when adopting HIE. This problem could also be addressed by designing or comparing specific solutions. We chose to take a bird's eye view of the HIE market instead of focusing on particular solutions. There are many options available any attempt to create an overview would inevitably be limited. Such a solution would not be beneficial to all stakeholders. Instead, we strived to provide insight into the market itself, which should help understand its workings. By providing insight, actors can better understand its functioning, allowing them to determine their strategy better.

## **7.2.1 Lessons learned**

This section summarizes the most significant implications for practice and lessons learned in this thesis.

### **Stakeholder perspectives**

The main contribution of this research is the stakeholder perspectives. The perspectives presented in chapter 5 give a birds-eye view of HIE in the Dutch healthcare sector. They indicate the goals and motivations of the most important stakeholders. Given sufficient background knowledge, they address unclarity in the market and can contribute to productive collaborations.

While the contents of the perspectives are familiar to most experts, their structured way of presenting stakeholder goals and needs shows our most significant contribution to practice. Experts indicate using these perspectives helps to discuss different strategies by stakeholders. This enables working on collaboration while discussing sensitive topics constructively.

### **Showcase importance of policy layer**

As follows from sections 4.5 and 6.3.3.1, one of the more significant reasons HIE initiatives fail is the differences in policy level. We found that numerous initiatives promote HIE, focusing on the technical difficulties of exchanging healthcare data. While the technical aspects can present many challenges that need to be resolved, this does not necessarily result in productive collaborations. As illustrated in section 3.2, the Layer Framework is intended to be followed from the top down. Experts gave examples of standards that have been worked on for several years, only to be disregarded when one of the involved parties disagreed. While technical alignment is required for functioning HIE, alignment on the policy layer should come first.

Instead of focusing on technical solutions, we recommend that agreements at the policy level should be made first. When the common ground can be found on the policy layer, all relevant parties have an intrinsic motivation to collaborate. This advice is applicable for individual HTPs as well as the government strategy. For HTPs, it is essential to discuss motivation at the policy level. Recognizing that incentives for companies are different and having an open talk about this is the first step to better collaboration.

### **Present opportunities and challenges for collaboration**

Chapter 5 shows that stakeholder goals have aspects that are converging and diverging. Knowing this, we can advise different stakeholders to take this into account. An example of a converging goal is that the visions of the insurers, citizens, and some HTPs match. Insurers see it as their combined responsibility to facilitate a basic HIE infrastructure. Both citizens and HTPs welcome the presence of this infrastructure. While visions are matching, this basic infrastructure is not yet experienced by stakeholders. This might indicate an opportunity for collaboration.

An example of diverging goals is that not all HTPs have the same strategy. This is indicated as an issue during some of the interviews in section 4.5. For example, the government has set up specific subsidy programs assuming that every HTP will use this to motivate implementing HIE. However, as we saw in section 7.2.1, ill-distributed effort requirements or payoff can influence the motivation of some HTPs. This is a significant result of our research: not every stakeholder wants to achieve HIE goals in the same way.

### **Reasons for the current state of healthcare information exchange**

In this research, we also provide context on why HIE is so challenging. The basics of HIE seem simple. Our literature study shows that more intense collaboration is good for the healthcare sector and the Netherlands. Individual stakeholders should also experience benefits: HIE increases healthcare quality, efficiency and lowers costs. While these statements are factual, reality shows a lot more nuance. Many reasons contribute to the current state. Understanding these reasons might help guide future attempts to implement HIE. Section 7.2.2 presents a discussion of the reasons for the current state.

#### **7.2.2 Reasons for the current state of health information exchange**

In this research, reasons for the current state of HIE have been covered multiple times. The literature study in section 2.2 describes a historical perspective. During the interviews in section 4.5 and evaluation in section 6.3, many reasons were given for the current state. Below we will briefly summarize various factors and reflect on their influence on the state of HIE.

##### **No unified demand**

As follows from our interviews of several stakeholders, demand is not unified. This is experienced by citizens that want to be actively involved in their care process, insurers that want to save costs, healthcare providers that want to promote initiatives, and healthcare technology providers that try to connect their applications. Demand is scattered due to various reasons: some people or businesses simply do not express their demand. Other times they might not experience the need for HIE.

An example was provided during one of the evaluation interviews. Citizens' needs may vary greatly depending on their condition. For example, when a citizen is healthy, they can request integrated applications in a privacy-friendly way. However, in a case of emergency, you want to be treated as fast as possible, and demand for HIE may change (section 6.3.1.1).

Other examples arise when the benefits of HIE are disproportionate. For example, home care is transferring information more often than hospitals. Some doctors in a hospital may not experience the downsides of current HIE implementations. This may result in a demand formulated by a home care organization but not expressed by a hospital.

##### **Disproportionate effort requirements**

A related factor is that investments from all parties are required for some information exchanges, which can create unfairness. While benefits should be visible for all parties, this is not always the case. An example may be where an established HTP has a lot of legacy software. Implementing newer standards requires a disproportionate amount of work compared to a new player in the market. This may lead to some forms of HIE not being implemented.

##### **Diversity of approaches and opinions**

A factor that is related to demand is the vision of actors. Many people think there are different ways HIE should be implemented. For example, there is a discussion between central and decentral initiatives. Opinions also differ on regulations. HIE can be enforced top-down, or individual players can be supported to develop innovative solutions from the bottom up. Some people like to focus fundamentally on privacy, healthcare provision, and healthy competition. Others would prefer a monopoly by an HTP that would streamline and standardize many forms of HIE.

This also shows in the design of our stakeholder perspectives. We created two perspectives for healthcare providers and healthcare technology providers to highlight the companies' diverging strategies. Our expert interviews also confirm this. In section 6.3.3.1, we find that reasons for the complex market are diverging policies of healthcare providers. Lack of cohesion is an essential factor in the current HIE state.

##### **Agility and time to market of the healthcare sector**

Another factor in the current state of HIE is the agility of the sector. Other markets also show a diverse number of visions. For example, opinions on phone design may differ significantly. However, in this branch, time to market and time to failure is faster. The phone market also has a lower barrier of entry compared to the healthcare market. As one interviewee commented in section 4.5.3, everything must

directly work in healthcare. If a company spends years perfecting an approach before finding out it does not support the right process, that is a big waste of resources. This nature of the healthcare sector prevents agile practices from being implemented, preventing faster progress.

Agile processes also relate to costs in the sector. Some interviewees in section 4.5 highlight the diversity in HIE approaches costs the Netherlands money; we are working on different solutions to the same problem and therefore wasting money. While initiatives are sometimes contradicting, this might be required to achieve the end goal. We cannot tell what solutions will be implemented in the future. As we showed in section 2.2, working on a single HIE implementation does not guarantee a complete solution will be reached. Focusing on a single implementation does not necessarily save costs when developing HIE.

### **First-mover disadvantage – legacy software**

During one of our interview sessions, the first-mover disadvantage was introduced (section 4.5.3.2). The narrative goes that our healthcare system is one of the most advanced in the world. The advancements of the healthcare sector create the situation we have now. Digital solutions were adopted relatively quickly. However, extracting healthcare information was not an everyday use case in the beginning. Therefore, it requires more effort to achieve the same goals as for other countries. The amount of legacy software created when HIE was not yet on the agenda could contribute to the current situation in which progress is hard to make.

### **Market size**

Another aspect of why HIE is hard to organize became apparent through the literature study and evaluation sessions. In section 3, we concluded that healthcare is the biggest employer in the Netherlands. Due to the size of the market, changes are hard to make. During the evaluation interviews, an example was provided in the form of a hospital. Some hospitals have over ten thousand employees. In section 5.3.1.3, we found hospitals have complex board structures, making changes incredibly hard to accomplish. This helps us to put HIE advancements into perspective. Changes in big companies are always challenging. Corporations with thousands of employees are generally not agile. A significant factor in the current state of HIE is therefore inherent to the market itself.

## **7.2.3 Reflection on government instruments**

Government instruments were first introduced in section 2.2 when the Dutch government started promoting HIE. Currently, there are several initiatives led by the government. These initiatives mainly take the form of subsidies to finance investments in HIE and upcoming legislation. Through a framework law, specific types of information transfer will be made obligatory. In addition, the government is facilitating a conversation with relevant parties in the Informatieberaad (Appendix B). In our research, we found some critique on two of these approaches.

### **Reflection on laws and subsidies**

Subsidy abuse was mentioned during the initial interviews and evaluation sessions in sections 4.5 and 6.3. Part of the critique is that there is no overall architecture in mind. Subsidies are not used efficiently because there is no design of a to-be state. This could cost the Netherlands a significant amount of money. This aspect is related to agile working. The government has to choose between making steps now, possibly working towards a wrong solution. Alternatively, they could first design every HIE component before initiating subsidy programs. From our evaluation, the first option seems to be the better approach. In section 6.3.3.1, experts indicate that while subsidy is not always used optimally, it did advance the sector significantly.

Another point of concern is an upcoming law mandating specific types of HIE. In section 2.2, we saw that an earlier attempt to regulate HIE was not successful. Therefore, the government is now taking another approach. This time the government envisions a framework law that will enforce specific types of HIE. Optionally, a certification process can be at the start of this. In section 6.3.3.2, experts indicate there is a concern the certification will become too bureaucratic. However, experts conclude that overall, the upcoming law should have a positive effect on the sector.

### **Recommendations for government strategy**

In addition to reflecting on current government strategies, we will cover some recommendations from our research.

There are many ways the Dutch government tries to influence HIE. Similar recommendations for practice in section 7.2.1, it is essential that the government keeps the policy level in mind when implementing measures. That should guarantee an effective promotion of HIE. The strategy they are employing now, combining subsidies with legislation that enforces specific types of information exchange, could work. However, they must take the goals and incentives of all stakeholders in mind.

A question expressed by many stakeholders in chapter 4 is guidance in HIE implementations. A party that can offer such guidance is the government. They can provide this by working more actively on a future state architecture, which subsidies and laws can then support. This architecture would also help to spark the discussion of how specific HIE initiatives are financed. Responsibilities can be appointed to the market, insurers, or individual HTPs. Every alternative has its benefits and limitations, and making choices regarding this design is an important political decision. By actively conducting this debate, the government can provide more clarity for all stakeholders in the HIE market.

## **7.3 Implications for theory**

Our research also presents several implications for theory. As Wieringa (2014) described, the goal of design research is to add to the scientific knowledge body. In this research, we created several forms of posterior knowledge, which will be summarized below.

### **State-of-the-art health information exchange research**

In chapter 2, we summarize the effects of HIE following various studies. Through a literature review, we explored the drivers behind HIE. In addition to scientific literature, additional sources were studied to look at other trends in the Netherlands that spark the need for HIE. We find multiple factors and summarize the most important ones. Finally, we present an overview of the different reasons and how they relate to each other. We find that HIE can address several critical challenges in the Dutch healthcare sector, presenting a clear motivation for this research.

### **State-of-the-art health information exchange in the Netherlands**

Our evaluation study in section 6.3.2 shows that specific background knowledge is required to understand our stakeholder perspectives. This research presents an overview of the current state of HIE. Chapter 2.2 describes a historical view of HIE developments. Literature and other sources are used to explore a national EHR implementation. Novel in this analysis is the application of innovation theory in the form of Hekkert's seven functions (Hekkert et al., 2007).

Secondly, we add to the scientific body by presenting a summary of the design of the Dutch healthcare market. We explore laws and regulations that govern the healthcare market and identify key stakeholders. Finally, we present examples of stakeholders and exchange initiatives in the Dutch HIE market. While these overviews are not exhaustive, they help understand the HIE market design.

### **Application of Layer Framework**

To the best of our knowledge, applying the Layer Framework on a national scale to create stakeholder perspectives has not been done before. We use the Layer Framework to present how the Dutch healthcare market functions by showing examples of typical stakeholders. An initial evaluation indicates that experts recognize the stakeholder perspectives. The stakeholder perspectives give a novel way to represent a complex market with many interests. The structured way of presenting these stakeholders can guide conversations around sensitive and politically sensitive topics, as per our evaluation in section 6.3.2. Other sectors with complex structures and diverse stakeholder needs may benefit from a similar analysis.

We use effect generalization proposed by Wieringa (2014) to argue its use further. Wieringa states that *an artifact designed like this interacting with a context satisfying these assumptions produces effects*

*like these*. We argue that stakeholder perspectives may produce similar results in other markets with complex structures. Conversations regarding sensitive subjects may benefit from the structured presentation of interests.

## 7.4 Limitations

In this section, we reflect on several limitations that can be found in this research. This should help to ensure a good understanding of our results and increase transparency.

### Scope

A limitation raised during the evaluation interviews is the scope of this thesis. As was indicated during expert evaluation in section 6.3.1.2, we did not incorporate all relevant parties in the Dutch healthcare market. For example, care administration offices and municipalities are also actors that purchase healthcare for citizens. While their role is smaller than insurers, they are relevant to understanding the entire healthcare market. The same holds for the role of the government. While we included them in a historical perspective, government representatives could also be included in the interviews to describe the HIE market better. Also, the scope of this research focuses on the Netherlands. In section 7.5, we propose several areas in which future research can resolve these limitations.

Another issue related to the scope is our focus on HIE. Chapter 2.1 shows there are many reasons and arguments for HIE. Improving patient outcomes, saving costs, and increasing efficiency are found to be the most significant reasons. However, it is essential to note that health information exchange is not the only way to achieve these goals. Many other changes can be made in the healthcare sector that will also help achieve these factors. In addition, we note that HIE is not a silver bullet that solves all ICT-related challenges in the healthcare sector. Many other challenges are not related to the exchange of healthcare data. Some examples are applications that do not support the right use cases, bureaucratic processes, and people who disagree on the correct approach. Nevertheless, many promises are made when considering the possibilities of exchanging healthcare information, and many advantages can be found. However, we should not forget that *exchanging* healthcare information is only part of the many challenges we face during the digitization of our healthcare sector.

### Literature study

In the background section of the research, several literature studies are conducted. These studies were limited in several ways. First, there was a lot of material to study, which was not easily organized. Second, due to the scope of the study, only some sections of scientific literature were applicable. In some sections, sources from non-scientific nature were most relevant, for example, when answering RQ3b. This creates a limitation in our study since completeness cannot be guaranteed.

It should be noted that, as indicated in chapter 3, we did not strive to be exhaustive in our study. Our analysis is meant to describe specific properties of the HIE sector. The goal was to work towards a broad understanding, not to be exhaustive of research and market design. In line with this goal, we were conscious of striking a balance between breadth and depth whenever possible.

### Interviews

A limitation of our interviews is the possible existence of an availability bias. Although people are selected through various channels, we only spoke to people familiar with HIE. This could lead to an unexpected bias in questions on awareness or overall opinions of HIE. While the background of the interviewees covers a broad spectrum, most interviewees had technical experience. In future research, we also recommend interviewing stakeholders who are not familiar with the topic. This should help to get a more representative response.

Another limitation is the number of interviewees. We try to cover the whole healthcare sector by only interviewing some stakeholders. A more diverse audience in every stakeholder group would have created a better representation of the healthcare market. Specifically, just as many citizens and insurers as the other stakeholders to ensure a broad view of those stakeholders. Additionally, more diverse HTPs could lead to a better image of the market. We spoke to a relatively small number of companies.



By incorporating more varied sizes of companies, a better understanding of the market could be achieved. This could also improve the design of the healthcare provider B stakeholder perspective. We did not speak with HTPs that expressed their desires. Other interviewees and experts mostly fill them in.

### **Evaluation**

The number of experts in our evaluation interview is also a limitation. Further evaluation is required to prove the application of our artifact achieves stakeholder goals. While this is an area we could improve upon, the experts used in this study were selected carefully. The experts have a lot of experience with HIE and have diverse backgrounds. This allows us to generalize their answers. Due to these factors, other experts are expected to provide similar responses.

### **Researcher limitations**

Another limitation we highlighted earlier in this research is researcher bias. Due to the nature of semi-structured qualitative interviews, a bias can be present in formulating questions and processing results. Our interview methodology and structured analysis aim at preventing this. However, we acknowledge the research type can inherently introduce a bias.

Another possible limitation is the experience in the healthcare field. Before the execution of this research, our knowledge of the healthcare sector was minimal. At the same time, this has several upsides, such as preventing strong opinions on specific market trends. However, it can also limit the findings of our research. Certain pieces of information may be missing. Due to the unstructured way in which information had to be retrieved, completeness cannot be guaranteed. For example, exciting or promising HIE initiatives can be excluded from this research.

### **Changes to UTAUT**

We changed the UTAUT model to make it relevant for our research. The moderating variables were excluded, as well as the social influence construct. This resulted in an application of the model with questions that were relevant to the experts. While these changes make sense due to our experts' small research population and background, and other researchers make similar adjustments (Attuquayefio & Addo, 2014), they are not validated. The actual adoption of our artifact could not be measured, and due to the small sample size, we cannot verify the adapted model. Results are therefore only indicative and do not provide the same guarantee a fully validated model would have.

### **Study circumstances**

The COVID-19 pandemic caused the majority of this research to be conducted from home. While this created some new challenges and limited social interactions during our study, it also had benefits. During the pandemic, online meetings became the norm. Since everyone was acquainted with tools for digital meetings, we were able to schedule interviews with a wide variety of stakeholders with diverse backgrounds. In addition, we could interview people from across the country in a relatively short period. This helped us to increase the scope and applicability of this research.

## **7.5 Future work**

In this section, we present recommendations for researchers looking to extend our research. Additional research can expand on subjects covered in this thesis or broaden the scope by exploring new areas. Both directions present opportunities to add to the exciting field of health information exchange. For each topic shown below, we include an example research question that could guide future researchers.

### **7.5.1 Extend current research**

Extending current research can help answer interesting questions. It addresses the limitations of this research and may increase the effectiveness of our work. In addition, it will help to evaluate if the created stakeholder perspectives work as intended.

#### **Extended evaluation and implementation study**

In our research, we present an initial evaluation study, which yielded positive results. To further evaluate the stakeholder personas presented in this research, additional evaluation is needed. Several case

studies could be performed in which HIE negotiations are relevant. This allows implementation of the created artifact and testing if it addresses stakeholder goals in challenging environments. Based on the results of these cases, a more thorough evaluation of the stakeholder perspectives can be presented.

Research question: *“What contribution do the designed stakeholder perspectives bring when implemented in the problem context?”*

#### **Increase scope**

While we tried to incorporate the whole Dutch healthcare market, not every aspect was covered. As indicated in 6.3.1.1, municipalities and care administration offices are also institutions that can purchase healthcare. While insurers are the biggest purchasers of healthcare, these other institutions are also relevant to the market. To expand the scope of our research and cover more of the healthcare sector, we suggest including them to reach an even better understanding of the HIE sector.

Research question: *“How can the entire Dutch healthcare market be represented using stakeholder perspectives?”*

#### **Bigger interview sample**

As indicated in section 7.4, one of the limitations of this research is the number of interviewees. This presents several possibilities to expand on our study. First, the number of interviewees for each stakeholder can be increased to increase the generalizability of the findings. This is specifically interesting for the citizens and insurers, of which we only had two in our sample. In addition to increasing the sample size, interviewees with more diverse backgrounds could be included. For example, by interviewing people in management positions of organizations, a better understanding of awareness and intentions towards HIE can be derived. Additionally, we recommend interviewing more diverse healthcare providers and HTPs of various sizes. To further improve the interview sample, government representatives can also be included in the interview. That should help to create an even more complete understanding of the HIE market.

Research question: *“What stakeholder perspectives can be created following more extensive stakeholder interviews?”*

#### **Create personas**

In addition to interviewing more citizens, their representation in the stakeholder perspectives could be expanded. For example, there is a single perspective of a high-volume healthcare user citizen in the current design. This was also a point addressed in the evaluation presented in section 6.3.1.1. Therefore, more citizens should be interviewed to create a complete image. In addition, more data could be used to create personas. In addition to just the Layer Framework with different needs, personas describe the diverse backgrounds of the citizens. For example, different personas could represent a sick citizen without privacy concerns, a healthy citizen with a high privacy standard, and a healthy citizen who wants to share data for scientific research on specific conditions.

Research question: *“Can the creation of personas extend the effectiveness of stakeholder perspectives?”*

### **7.5.2 Expand research scope**

Expanding the research scope can help address two fundamental questions. First, it might help to address the explanation of our current state. Secondly, it can help find possible solutions to problems in the healthcare sector by looking past existing scope limitations.

#### **Explore health information exchange in other countries**

An interesting question is to what extent our stakeholder perspectives are relevant in other countries. Wieringa described that, in similar contexts, our artifact should yield similar results. Other (Western) countries may have healthcare sectors with a similar market design to the Netherlands. If traits presented in chapter 3 are also applicable in these countries, the artifact should be relevant. While managed competition might be unique to the Netherlands, other market traits appear in different countries.

Switzerland is an example that might show similar results. They have many small local authorities that are responsible for adequate healthcare. In 2017 a law was implemented that aims to implement a universal EHR. By 2022 every healthcare organization should work with this EHR. Otherwise, payments through national health insurance will no longer be made. A national committee has been appointed that oversees the standards to be used (Neuchâtel: Federal Council, 2020). The government presents several incentives to achieve this shared EHR. Also, financial support from the national and regional levels is available to help with the transition. This approach seems similar to what we do in the Netherlands. Instead of explicitly mandating a specific platform, legislation forces relevant stakeholders to modernize their processes. Additional support is available to support this conversion by financing indirect channels that aim at promoting HIE.

Research question: *“Do generalizations of the stakeholder perspectives hold in countries with a similar healthcare market design as the Netherlands?”*

Countries with different structures also could be studied to see if they hold interesting suggestions for solving HIE challenges. An excellent example of that is Sweden. Scandinavian countries have long been known for having an organized healthcare system that is generally accessible (Health Management, 2010). Although all countries require co-payments for hospital and medicine bills, most healthcare-related costs are paid through taxation. Sweden is a country that implemented a national EHR (Hägglund, 2017). Each healthcare information system is supposed to connect to this national implementation, providing citizens with a single place to view their health records. While this sounds promising, some challenges still need to be solved. Some care providers do not grant citizens access to all their data. Also, healthcare providers doubt whether people will understand the EHRs and are afraid they will be bombarded with questions. Other studies also found that resistance from healthcare providers is a significant challenge. Despite these remarks, almost 90% of respondents in a Swedish survey indicated that access to EHRs is good for them. This approach is more similar to the earlier attempt at HIE by the Netherlands explored in chapter 2.2. Exploring differences between the two implementations and lessons from countries like Sweden could yield valuable results.

Research question: *“How did other countries address health information exchange challenges?”*

### **Explore health information related challenges in other sectors**

Standardizing and exchanging information in competitive environments is not unique to the healthcare sector. While our evaluation in section 6.3.3.1 indicated the healthcare sector is fundamentally different, other sectors might still hold valuable solutions to challenges in HIE.

An example is the construction sector. Building Information Modelling (BIM) is common in this sector. The Encyclopedia of Sustainable Technologies defines BIM as “a collaborative way for multidisciplinary information storing, sharing, exchanging, and managing throughout the entire building project lifecycle including planning, design, construction, operation, maintenance, and demolition phase” (Abraham, 2017). Using BIM, engineers and contractors have new innovative ways to communicate. It provides a shared information repository for many stakeholders involved throughout the lifetime of a facility (Kubba, 2014). BIM addresses similar problems as those found in the health sector.

Another example comes from the logistics sector. iSHARE is an initiative that demonstrates extensive collaboration and data sharing. According to their definition, iSHARE is “a uniform set of agreements or schemes for identification, authentication, and authorization. Thanks to iSHARE, everyone can share logistics data with everyone else in a simple and controlled way.” (ishareworks, n.d.). iSHARE went live in 2018 and facilitated a standard in the Dutch logistics sector. The focus was explicitly not on data standards but instead on identification, authentication, and authorization. The benefits of this scope are that a decentral solution could be taken. Data remains under the control of the respective owners, which addressed trust issues that existed in the sector (Support Centre for Data Sharing, 2020). Challenges mentioned by iSHARE are also discussed by some of the initiatives we explored in section 3.5. Solutions implemented by iSHARE could therefore be relevant in the HIE sector.

Research question: *“How do other sectors address challenges found in the health information exchange sector.”*

# BIBLIOGRAPHY

- Abraham, M. (2017). *Encyclopedia of sustainable technologies*. Elsevier.
- ACM. (2016). *Competition in the Dutch health insurance market*. February.
- ActiZ. (2019). *Digitaal denken en doen 2019-2022 - Digitalisering als aanjager van toekomstbestendige zorg voor ouderen en chronisch zieken*. 1–28.
- Actiz, & VGN. (2019). *Professionele Omgeving voor Zorgprofessionals Nieuw ontwerp voor het ECD, op weg naar een modulair opgebouwd ECD dat de zorgprofessional ondersteunt*.
- Alexander, I. F., & Beus-Dukic, L. (2009). *Discovering Requirements: How to Specify Products and Services*.
- Attuquayefio, S. N., & Addo, H. (2014). Using the UTAUT model to analyze students' ICT adoption. *International Journal of Education and Development Using Information and Communication Technology*, 10(3), 75–86. <http://www.springerlink.com/content/q673t8h540267411/>
- Bakker, J., Deddens, R., Dulfer, H., Hoogland, J., Hoeve, M. van, Kolder, M., Kraaijeveld, M., Pagrach, D., Rijke, S. de, Saers, A., & Vlist, P. van der. (2013). *Eigen regie als basis*. Initiatiefgroep Eigen Regie.
- Centraal Bureau Statistiek. (2019). *Levensverwachting in 2019 toegenomen*. <https://www.cbs.nl/nl-nl/nieuws/2020/39/levensverwachting-in-2019-toegenomen>
- Centraal Bureau Statistiek. (2020). *Bevolkingsprognose*. <https://www.cbs.nl/nl-nl/visualisaties/dashboard-bevolking/leeftijd/ouderen>
- Chen, M., Guo, S., & Tan, X. (2019). Does health information exchange improve patient outcomes? Empirical evidence from florida hospitals. *Health Affairs*, 38(2), 197–204. <https://doi.org/10.1377/hlthaff.2018.05447>
- Fransman, R., & Kraaijeveld, K. (2018). *Zó werkt de zorgverzekering*. De Argumentenfabriek.
- Hägglund, M. (2017). *How Sweden is giving all citizens access to their electronic health records*. <https://www.philips.com/a-w/about/news/archive/future-health-index/articles/20171030-access-electronic-health-records.html>
- Hanekamp, M., Heesbeen, S., Helm, I. van der, & Valks, R. (2019). *Administratieve belasting langdurige zorg 2019*. Berenschot.
- Hasman, A., Ament, A., Arnou, P. C., & van Kesteren, A. C. A. (1992). Inter-institutional information exchange in healthcare. *International Journal of Bio-Medical Computing*, 31(1), 5–16. [https://doi.org/10.1016/0020-7101\(92\)90049-X](https://doi.org/10.1016/0020-7101(92)90049-X)
- Health Management. (2010). Country Focus: The Nordic Countries Overview of the Healthcare Systems in the Nordic Countries. *Health Management*, 4(1).
- Heijmans, M., Lemmens, L., Otten, W., Havers, J., Baan, C., & Rijken, M. (2015). Zelfmanagement door mensen met chronische ziekten. In *Nivel* (Issue December). <https://www.nivel.nl/sites/default/files/bestanden/Kennissynthese-Zelfmanagement.pdf>
- Hekkert, M. P., & Negro, S. O. (2009). Functions of innovation systems as a framework to understand sustainable technological change: Empirical evidence for earlier claims. *Technological Forecasting and Social Change*, 76(4), 584–594. <https://doi.org/10.1016/j.techfore.2008.04.013>
- Hekkert, M. P., Suurs, R. A. A., Negro, S. O., Kuhlmann, S., & Smits, R. E. H. M. (2007). Functions of innovation systems: A new approach for analysing technological change. *Technological Forecasting and Social Change*, 74(4), 413–432. <https://doi.org/10.1016/j.techfore.2006.03.002>
- Hersh, W. R., Totten, A. M., Eden, K. B., Devine, B., Gorman, P., Kassakian, S. Z., Woods, S. S., Daeges, M., Pappas, M., & McDonagh, M. S. (2015). Outcomes From Health Information Exchange: Systematic Review and Future Research Needs. *JMIR Medical Informatics*, 3(4), e39. <https://doi.org/10.2196/medinform.5215>
- HL7 Netherlands. (2019). *Nog betere zorg en meer werkplezier!* <https://www.hl7.nl/component/zoo/item/nog-betere-zorg-besems.html>
- Informatieberaad. (n.d.). *Over het Informatieberaad*. Retrieved February 3, 2021, from <https://www.informatieberaadzorg.nl/over-het-informatieberaad>
- Informatieberaad. (2020). *Minister Bruno Bruins: €75 miljoen voor ziekenhuizen om medische gegevens digitaal aan patiënt beschikbaar te stellen*. <https://www.informatieberaadzorg.nl/actueel/nieuws/2020/02/11/minister-bruno-bruins-€75-miljoen-voor-ziekenhuizen-om-medische-gegevens-digitaal-aan-patient-beschikbaar-te-stellen>

- Jakobs, K. (2017). Two dimensions of success in ICT standardization—A review. *ICT Express*, 3(2), 85–89. <https://doi.org/10.1016/j.ict.2017.05.008>
- Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, 72(12), 2954–2965. <https://doi.org/10.1111/jan.13031>
- Lauesen, S. (1982). Software Requirements. *Pure and Applied Mathematics*, 105(C), 62–64. [https://doi.org/10.1016/S0079-8169\(08\)61475-0](https://doi.org/10.1016/S0079-8169(08)61475-0)
- Makary, M. A., & Daniel, M. (2016). Medical error-the third leading cause of death in the US. *BMJ (Online)*, 353(May), 1–5. <https://doi.org/10.1136/bmj.i2139>
- Mallie, M., Bus, B., Gelder, E. van, Gondelach, S., Holland, R. van, Meijboom, G., Pelt, V. van, Settels, M., Stigchel, B. van der, Tesink, W., & Vos, J. (2019). *Visie op samenhang in de zorginfrastructuur in Nederland*. 0, 0–24. <https://www.informatieberaadzorg.nl/publicaties/publicaties/2019/11/07/visie-op-samenhang>
- Meijboom, G., & Klein Wolterink, G. (2020). *Informatiestandaarden - Basis voor gegevensuitwisseling in de zorg*.
- Menachemi, N., Rahurkar, S., Harle, C. A., & Vest, J. R. (2018). The benefits of health information exchange: An updated systematic review. *Journal of the American Medical Informatics Association*, 25(9), 1259–1265. <https://doi.org/10.1093/jamia/ocy035>
- Michel-Verkerke, M. (2013). *Electronic patient record: what makes care providers USE IT? (PhD Thesis)*. <http://purl.org/utwente/doi/10.3990/1.9789036534994>
- Ministerie van Volksgezondheid Welzijn en Sport. (2017). *Elektronische gegevensuitwisseling in de zorg*. <https://www.rijksoverheid.nl/documenten/brochures/2017/06/01/elektronische-gegevensuitwisseling-in-de-zorg>
- Ministerie van Volksgezondheid Welzijn en Sport. (2020a). *Concept Wetsvoorstel Elektronische Gegevensuitwisseling in de Zorg*. <https://www.internetconsultatie.nl/gegevensuitwisseling>
- Ministerie van Volksgezondheid Welzijn en Sport. (2020b). *Wegiz toelichting*. <https://www.gegevensuitwisselingindezorg.nl/gegevensuitwisseling/wetgevingstraject/video-toelichting-wetsvoorstel>
- Ministerie van Volksgezondheid Welzijn en Sport. (2020c). *Wet aanvullende bepalingen verwerking persoonsgegevens in de zorg*. <https://wetten.overheid.nl/BWBR0023864/2019-07-01#Hoofdstuk3a>
- Mooren, F. van der, & Gielen, W. (2019). *Werkgeversenquête zorg en welzijn* (Issue September, p. 14). Centraal Bureau Statistiek.
- Neuchâtel: Federal Council, F. S. O. (2020). *Swiss Confederation Health Statistics*. <https://www.e-health-suisse.ch/fr/page-daccueil.html>
- Nictiz. (n.d.-a). *About Nictiz*. Retrieved April 13, 2021, from <https://www.nictiz.nl/english/>
- Nictiz. (n.d.-b). *Over Nictiz*. Retrieved December 21, 2020, from <https://www.nictiz.nl/over-nictiz/>
- Nictiz. (2013). *Hoeveel zorgverleners ziet iemand met een chronische aandoening?*
- Nictiz. (2016). *eHealth, de apotheker is er klaar voor*. <https://www.nictiz.nl/rapporten/rapport-ehealth-de-apotheker-is-er-klaar-voor/>
- Nuts. (n.d.). *Nuts — Een decentrale infrastructuur voor de zorg*. Retrieved December 21, 2020, from <https://nuts.nl/>
- Nuts. (2019). *Manifest*. <https://nuts.nl/manifest/>
- OECD, & Eurostat. (2018). *Oslo Manual 2018*. <https://doi.org/https://doi.org/https://doi.org/10.1787/9789264304604-en>
- Porter, M. E., Larsson, S., & Lee, T. H. (2016). Standardizing Patient Outcomes Measurement. *The New England Journal of Medicine*. <https://doi.org/10.1056/NEJMp1511701>
- Rahurkar, S., Vest, J. R., & Menachemi, N. (2015). Despite The Spread Of Health Information Exchange, There Is Little Evidence Of Its Impact On Cost, Use, And Quality Of Care. *Health Affairs*, 34(3), 477–483. <https://doi.org/10.1377/hlthaff.2014.0729>
- Reinders, F. (2011). *Het Elektronisch Patiëntendossier - Geschied of ongeschikt? (Master Thesis)*. Rijksoverheid. (n.d.). *Over Rijksoverheid*. <https://www.rijksoverheid.nl/over-rijksoverheid-nl>
- RIVM. (2017). *Kosen van ziekten 2017*. <https://data.overheid.nl/dataset/e6b5460c-62b3-4401-863a-e5187a3b0a13>
- Seddon, P. B., & Scheepers, R. (2012). Towards the improved treatment of generalization of knowledge claims in IS research: Drawing general conclusions from samples. *European Journal of Information Systems*, 21(1), 6–21. <https://doi.org/10.1057/ejis.2011.9>
- Sprenger, M. (2019). *Electronic Information for Health and Care Services*.

- Sturkenboom, M. C., Vanrolleghem, A., van den Bemt, P. M., de Smet, P. A., & Hek, K. (2017). *Vervolgonderzoek Medicatieveiligheid*. 1–129.
- Support Centre for Data Sharing. (2020). *iSHARE Sharing Dutch transport and logistics data*. <https://eudatasharing.eu/examples/ishare-sharing-dutch-transport-and-logistics-data>
- Tweede Kamer. (1997). Kamerstuk 25669 nr 2. In *Stand*. Sdu Uitgevers.
- Tweede Kamer. (2000). Kamerstuk 27529 nr 1. In *Stand*. Sdu Uitgevers.
- Tweede Kamer. (2005). Kamerstuk 30300 XVI. In *Stand*. Sdu Uitgevers.
- Tweede Kamer. (2017). *Aan het werk voor ouderen*.
- van Ginneken, E., Schäfer, W., & Kroneman, M. (2010). Managed competition in the Netherlands: an example for others ? *Eurohealth*, 16(4).
- Venkatesh, V., Morris, M. G., Davis, G. B., & Davis, F. D. (2003). *UTAUT*. 27(3), 425–478.
- V&VN. (2018). *ICT moet werk in de zorg makkelijker maken, niet moeilijker*. <https://www.venvn.nl/nieuws/ict-moet-werk-in-de-zorg-makkelijker-maken-niet-moeilijker/>
- Wessels, K., & Driesten, G. van. (2018). Zó werkt de zorg in Nederland. In *De ArgumentenFabriek*.
- Weston, C., Gandell, T., Beauchamp, J., McAlpine, L., Wiseman, C., & Beauchamp, C. (2001). Analyzing interview data: The development and evolution of a coding system. *Qualitative Sociology*, 24(3), 381–400. <https://doi.org/10.1023/A:1010690908200>
- Whitt, N., Harvey, R., McLeod, G., & Child, S. (2007). How many health professionals does a patient see during an average hospital stay? *The New Zealand Medical Journal*, 120(1253), U2517.
- Wieringa, R. (2014). *Design science methodology*. Springer. <https://doi.org/10.1145/1810295.1810446>
- Wolfswinkel, J. F., Furtmueller, E., & Wilderom, C. P. M. (2013). Using grounded theory as a method for rigorously reviewing literature. *European Journal of Information Systems*, 22(1), 45–55. <https://doi.org/10.1057/ejis.2011.51>
- Zorgkaart Nederland*. (n.d.). Retrieved April 12, 2021, from [www.zorgkaartnederland.nl/](http://www.zorgkaartnederland.nl/)

## Appendix A      STAKEHOLDERS

The different initiatives are classified using the stakeholder groups identified in chapter 3.

Table A-1: Some stakeholders in the Dutch healthcare market classified by stakeholder group

Name	Description	Classification
VWS	Dutch Ministry of health. Striving to get the right care in the right place, therefore also right information in the right place. They do so by getting people together, subsidize, and ultimately enforcing through legislation.	Government
Informatieberaad	Group of representatives from all stakeholders involved with HIE. Advises the government on regulation and tries to find solutions.	Government
Nuts foundation	A foundation building Nuts, a standard to exchange data with blockchain as a basis to guarantee privacy. Backed by multiple healthcare technology providers.	Healthcare technology provider
Nictiz	National competence center for the electronic exchange of health and care information in the Dutch health sector.	Government
Actiz	An industry association for care organizations.	Healthcare provider
V&VN	A professional association for nurses.	Healthcare provider
VZVZ	Union of Providers for Health Care Communication ( <i>De Vereniging van Zorgaanbieders voor Zorgcommunicatie</i> ).	Healthcare provider
VECOZO	Organization promoting HIE, partial focus on the exchange of insurance-related information.	Healthcare insurer
RSO Nederland	Union of multiple regional initiatives promoting HIE.	Healthcare provider
Patiëntenfederatie Nederland	Organization looking after the interests of citizens. Initiator of personal health records initiative.	Citizen

## Appendix B INITIATIVES

The different initiatives are classified using the Layer Framework, with the following numbering.

- Laws & regulations (1)
- Organization policy (2)
- Care process (3)
- Information (4)
- Application (5)
- IT-infrastructure (6)

Table B-1: Some HIE initiatives in the Netherlands classified using the Layer Framework

Name	Description	Classification
LSP	Former government-owned initiative to be a central hub for exchanging data. Managed by a group of healthcare providers. After providing consent, information about patients can be exchanged between hospitals, general practitioners, and pharmacies.	4-6
MedMij	A standard for sharing healthcare information (in PHRs). Initiated by government and patient-related organizations.	4-6
Nuts	An open-source, decentralized platform for facilitating HIE. Supported by healthcare technology providers.	5,6
Medicatieoverdracht	Government program working to allow electronic transfer of medication-related data.	2-4
Twiiin	Collaboration platform with multiple healthcare providers, currently funded by insurance companies. Twiiin aims to facilitate a universal HIE solution.	2-6
Zorgplatform	A platform created by healthcare technology provider ChipSoft that facilitates HIE.	2-6
Zorg informatie bouwstenen	Government initiative to define information standards for different care areas.	4
Handreiking Interoperabiliteit tussen zorginstellingen	An initiative to standardize aspects of XDS (cross-enterprise document sharing), initiated by groups of healthcare providers.	1-2,4-6
Landelijke beeldbeschikbaarheid	An initiative that allows radiologists to view history and other sources of patient images.	3-4
HealthRI	An initiative that promotes HIE to advance medical research.	2-6
Onafhankelijke commissie governance kwaliteitsregistraties	A commission looking at recommendations for governance and quality registrations.	1



# Appendix C INTERVIEW GUIDE

## Introduction

*The researcher thanks the participant for participating in this interview. A brief background is given on the goal of this research. The researcher indicates results will be processed confidentially.*

- Do you allow the recording of this interview?
- Can you introduce yourself?
  - Name
  - Company, role

## Current situation

- Can you describe your daily work?
  - During which tasks is information exchange applicable?
  - With what parties do you exchange information?
  - What information is exchanged?
  - What steps are required to exchange this information? Are you aware of the used products/standards?
- What is your opinion on current health information exchange?
  - Can you give examples where problems occur during information exchange?
  - Have you experienced improvements in information exchange?

## Future of health information exchange

- How would your ideal future of information exchange look like
  - Do you have specific requirements?
  - Do you have a vision or plan to achieve this future?
- How would seamless information exchange change your work?
  - Would it save money or time?

## Closure

- Are there other topics that could be interesting to this research that we did not discuss yet?
- Can we contact you after this interview in case follow-up questions arise?
- Do you wish to receive the results of this research?

# Appendix D EVALUATION INTERVIEW

## Introduction

*The researcher introduces the goal and structure of this meeting after providing a background on the study and findings. Finally, the researcher indicates results will be processed confidentially.*

## Personal background

*The interview is started with some smaller questions. These are intended to understand the interviewees' background in HIE and make them comfortable with the interview setting.*

- Can you introduce yourself?
  - Name
  - Background
  - Earlier jobs in health information exchange

## Presentation and evaluation of stakeholder perspectives

*Here we present the created stakeholder perspectives along with key requirements identified for every stakeholder group. Stakeholder perspectives are shown per stakeholder group. After a short explanation of the design, we ask for feedback on their completeness and correctness.*

- In your opinion, is the citizen stakeholder perspective
  - Complete?
  - Correct?
- In your opinion, is the insurer stakeholder perspective
  - Complete?
  - Correct?
- In your opinion, are the healthcare provider stakeholder perspectives
  - Complete?
  - Correct?
- In your opinion, are the healthcare technology provider stakeholder perspectives
  - Complete?
  - Correct?
- Do you think the stakeholder perspectives combined give a complete overview of relevant stakeholders in HIE?

## UTAUT questions

*In this section, we evaluate the expected benefit interviewees can experience by using the proposed stakeholder perspectives. Interviewees are asked to answer on a scale from 1 to 5, where one indicates 'poor' and five means 'excellent'.*

### Performance expectancy

- Using the proposed stakeholder perspectives would improve my job performance
- Using the proposed stakeholder perspectives enables me to accomplish tasks more quickly
- Using the proposed stakeholder perspectives increases my productivity

### Effort expectancy

- It would be easy for me to become skillful at using the proposed stakeholder perspectives
- Overall, I believe the proposed stakeholder perspectives are easy to use
- Learning to use the proposed stakeholder perspectives are easy for me

### Facilitating condition

- I have the knowledge necessary to use the proposed stakeholder perspectives
- I have the resources necessary to use the proposed stakeholder perspectives
- I think that using the proposed stakeholder perspectives fits well with the way I like to work

### Behavioral Intention to Use

- I intend to use the proposed stakeholder perspectives in the future to help me complete my job
- I predict that I will use the proposed stakeholder perspectives in the future to help me complete my job in dealing with clients
- I plan to use the proposed stakeholder perspectives in the future to help me in dealing with HIE.

**Final questions**

*To conclude the interview, additional questions are explored.*

- What factors contribute to the current state of HIE?
- What will be the most important developments related to HIE in the coming years?