### UTRECHT UNIVERSITY

MASTER THESIS

## Who is Responsible for Your Health Data? Towards a Framework for Ownership and Responsibilities Within The Dutch Healthcare Sector

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A thesis submitted in fulfilment of the requirements for the degree of Master of Science

in

Business Informatics Department of Information and Computing Sciences

June 10, 2020





#### UTRECHT UNIVERSITY

### Abstract

Graduate School of Natural Sciences Department of Information and Computing Sciences

Master of Science

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by P.L.F.M. VAN DER VOORN BSc.

Healthcare in the Netherlands is a collection of individual entities like General Practitioners, authorities, insurers and hospitals rather than an integrated chain. Within it, the declaration process, includes various flows and these flows are complicated. A clear governance structure and architecture are missing within these different flows, such as grouping different health transactions and combining them with a price to these transactions. The consequences of this lack of information make it hard to rely on the quality of the information provision in the healthcare sector. In the declaration chain, the absence of harmonisation and uniformity prevents the proper functioning of the intended cooperation among the different entities. The chain concept here refers explicitly to social chains, large-scale interorganisational processes that yield a social product like healthcare.

To solve this problem, the main research question is structured as follows: *What is a suitable framework that can be used in the context of assigning responsibilities and ownership to data elements in a chain computerisation perspective for the Dutch healthcare sector?* With three sub-questions, an attempt to investigate this question will be conducted. The Design Science Cycle of Wieringa is used as a research methodology.

Based on interviews with all the organisations involved in the declaration chain, a framework is introduced that includes three views. The first view consists of the process and data flows, followed by a CRUD Matrix of the CRUD mutations that each organisation can perform on a data element. Finally, an overview per data element presents who is responsible for the correct registration and the source of the data.

Two validation interviews conclude that the developed framework indeed captures the essential elements of the declaration chain, which can help to create an understanding of the whole process to medical professionals and administrative workers.

## Outline

This research report is structured as follows; first, an introduction (Chapter 1) is given to provide some context, followed by the research plan (Chapter 2) where a detailed overview is provided in which the problem statement, research goal, questions, and research methodology are described. The conceptual framework is created to link the different concepts as building blocks to the research questions and their underlying relations. This framework will highlight the approach for this research and what deliverables and processes are required. The processes are further elaborated with a Process-Deliverable Diagram.

After this, a literature study (Chapter 3 and 4) is performed to identify the gap in the literature, provide definitions and presents the state-of-art literature about the declaration chain.

The next chapter, (5), is data analysis in which the results from the interviews are discussed, and the framework is proposed. To validate the framework, in Chapter 6, a validation is presented. Every research has threats to validity, and that is discussed in Chapter 5. To conclude, in Chapter 6, the conclusions are presented, and future works are highlighted.

## Acknowledgements

In September 2019, I started the final journey of my master's programme, writing my thesis. It was a long trip with some strange turns due to COVID-19, but eventually, I'm satisfied with the results. Of course, I did not do this alone. I would like extend my gratitude to Nico Brand, my first supervisor for his meaningful, sharp feedback and our discussions about skiing and cycling. He was always supportive and helpful, and we had pleasant off-topic conversations.

My second supervisor, Sietse Overbeek, was providing me with interesting suggestions to improve my research. I want to thank him for his advice and the classes he thought me over the years.

Furthermore, I would like to thank Symen Polman for his advice, time and effort he put in me. For the first time, I was in a long-distance relationship since we almost only spoke over the phone due to our different locations. I could not have written my thesis without some breaks and coffee with table football in the KPMG office with my colleagues. This results in a lot of crawling, and the Vrijmibos were fun as well!

Of course, I want to thank my family and friends for supporting me and relaxing during the thesis period.

Now MBI has ended for me, I look proudly back on all the exams, reports and research we have done to achieve our study, and I am curious what the future will bring me.

# Contents

Ał	ostrac	ct	ii
01	utline	e	iii
Ac	knov	wledgements	iv
Li	st of I	Figures	vii
Li	st of '	Tables	viii
Li	st of .	Abbreviations	ix
1	Intr	oduction	2
	1.1	Setting the Data Scene	2
	1.2	Complications in Broader Perspective	3
	1.3	Summary	
2	Res	earch Plan	5
	2.1	Problem Statement	5
	2.2	Contributions	7
	2.3	Research Goal and Scope	8
	2.4	Research Questions	10
	2.5	Outline of and Justification for Chosen Research Method	11
	2.6	Research Methods	13
	2.7	Process-Deliverable Diagram	18
	2.8	Conceptual Framework	21
3	Lite	rature Review	22
	3.1	Chain Computerisation and Interorganisational Definitions	22
	3.2	Concepts and Definitions in the Context of Data Governance	25
	3.3	General Data Protection Regulation	27
	3.4	Frameworks for Ownership and Responsibilities	30
4	Hea	lth Overview	34
	4.1	The Dutch Healthcare Sector	34
	4.2	Data Elements Within the Declaration Chain	37
	4.3	Patient Journey	42
	4.4	Regulation Requirements by the NZa	45
	4.5	Summary	45

5	Data	a Analysis	47
	5.1	Interviewees	47
	5.2	Expert Interview Results	48
	5.3	Improved Declaration Chain Overview	54
	5.4	Improved ERD	56
	5.5	Framework Formalisation	56
	5.6	Summary	61
6	Con	solidated Framework	62
	6.1	Evaluation in Design Science Research	62
	6.2	Validation Interviews	63
	6.3	Summary	68
7	Dise	cussion and Limitations	69
	7.1	Limitations	69
	7.2	Threats to Validity	69
	7.3	Contributions	71
8	Con	clusions	73
	8.1	Conclusions	73
	8.2	Future Work	75
Bi	bliog	raphy	77
A	Con	sent form	86
B	Inte	rview Protocols	87
	B.1	Interview Protocol Vecozo	87
	B.2	Interview Protocol CZ	88
	B.3	Interview Protocol Hospitals	89
	B.4	Interview Protocol Hospitals	90
	B.5	Validation Interview Protocol	91

# **List of Figures**

2.1	Visualised Figure of the Research Scope	10
2.2	The Design Science Cycle Adopted From Wieringa (2014)	12
2.3	Sub-Questions Combined With Design Cycle Phases	13
2.4	NVivo Node Tree	17
2.5	Process-Deliverable Diagram of the research	20
2.6	Conceptual Model of the Research	21
3.1	The GDPR Principles Visualised in Context	29
4.1	Schematic Overview of the Declaration Chain Derived from Kennis-	
	groep Keteninformatiemanagement (2016) and in collaboration with	
	a Partner from KPMG	36
4.2	Entity Relationship Diagram for the Declaration Process based on Ned-	
	erlandse Zorgautoriteit (2020a)	38
4.3	The Patient Journey of a Person With Pain in the Wrist and that Un-	
	dergoes Surgery	42
4.4	The Decision Tree of the Grouper for Plastic Surgery, on the Right is	
	the Derived Healthcare Product Visible in Orange	44
4.5	The Health Product Code in the DIS With the Number of Patients	45
5.1	Schematic Overview of the Declaration Chain Improved Via Interviews	55
5.2	Relation of the Three Models Visualised	57
5.3	BPMN of the Declaration Chain With ERD and Overview Combined .	58
5.4	Responsible for Correct Registration and Source of the Data	60
6.1	Responsible for Correct Registration and Source of the Data Based on	
	Validation Interviews	67

# List of Tables

2.1	The research methods that are used to answer the SQs	13
2.2	Overview of the Search Strategy Metrics	15
4.1	Receipt of Health Insurer for Wrist Surgery	43
4.2	Health Activities Related to the Wrist Surgery	43
5.1	Overview of the Interviewees	48
5.2	CRUD Matrix for the Data Elements	59
6.1	CRUD Matrix for the Data Elements	66

# List of Abbreviations

AP	Dutch Data Protection Authority			
AGB General Data Management (Dutch: Algemeen GegevensBe				
DTC Diagnosis Treatment Combination				
ERD	Entity-Relationship Diagram			
GDPR General Data Protection Regulation				
GP General Practitioner				
HIS	Hospital Information System			
IONS	Interorganisational Networks			
IS Information Systems				
NIVEL	Netherlands Institute for Health Services Research			
NZa Dutch Health Authority				
PDD Process Deliverable Diagram				
RAM	Responsibility Assignment Matrix			
ZiNL	Care Institute Netherlands			

## **List of Definitions**

AGB Is a national code with which the care provider can be recognised. With this unique code, healthcare providers are registered in a national database. This system is managed by Vektis (Vektis, 2020).

Artefact An object, in this context, for example, methods, techniques, notations, and algorithms used in software and information systems (Wieringa, 2014).

**Patient Journey** The patient's experience by separating the management of a specific condition or treatment into a series of consecutive events or steps, for example, interventions, actions or staff interactions (Trebble et al., 2010).

**Data Element** A logical collection of data-items (Beynon-Davies, 2004)

DTC A diagnosis-treatment combination (DTC) is a chargeable performance, which is the result of (a part of) the total care process from the diagnosis that the healthcare provider makes up to and including the (possible) treatment that follows. (Nederlandse Zorgautoriteit, 2020b)

**Grouper** An application in a secure environment that derives DTC health products on the basis of a declaration data set supplied in accordance with the performance and rate tables and decision trees set by the NZa. (Nederlandse Zorgautoriteit, 2020b)

**Health Activity** The building blocks of the DTC care product that together form the profile of a DTC care product. Health activities determine, in combination with the registered sub-trajectory, which performance has been delivered and which DTC care product may be declared. In addition, the subdivision into healthcare activities forms the basis for other healthcare products (Nederlandse Zorgautoriteit, 2020b)

# **List of Translations**

Care Institute Netherlands Health Track Sub-Health Track Health Activity Horizontaal Toezicht Zorgproduct Zorg Instituut Nederland Zorgtraject Subtraject Zorgacitviteit Horizontal Supervision Health Product

## 1 Introduction

#### **1.1** Setting the Data Scene

"Data is the new oil". Humby (2006) was one of the first ones who made this statement which reflects that more data is generated than ever before (Desjardins, 2019). However, this will bring new problems like data privacy, security, incompleteness and the timeliness of data (Kanchi et al., 2015). Ritter and Mayer (2018) are arguing that with all this data production, more guidance is required:

"Data has now become a new kind of property - an asset that is created, manufactured, processed, stored, transferred, licensed, sold, and stolen. Nevertheless, on a global basis, there is no legal regulatory framework or model that provides guidance on how transactions using data as an asset are to be constructed" (Ritter and Mayer, 2018, p. 221).

One of those guidance mechanisms is the introduction of the General Data Protection Regulation (GDPR). Since its introduction in May 2018, the GDPR causes problems for organisations that are handling (personal and medical) data. The Dutch Data Protection Authority (AP) has imposed a fine of 460,000 euros on a hospital in The Hague for careless handling of patient data<sup>1</sup>. This new regulation is, therefore, a pain for businesses that can cause financial damage. Some organisations are not aware or do not understand the changes that the GDPR will bring to their businesses (Tikkinen-Piri, Rohunen, and Markkula, 2018). The Institute of Directors conducted a survey between July and August 2017 among 869 of its members in the United Kingdom and revealed that 30% of Company directors have not heard of the GDPR. 40% of the members were still unsure about whether their company will be affected by the GDPR<sup>2</sup>. The cause of these problems is rooted in the ambiguous, vague and verbose nature of regulations. Individuals who do not possess legal expertise often find it challenging to understand what the consequences are. These problems can jeopardise compliance with the GDPR (Ayala-Rivera and Pasquale, 2018). Even with the novelty of the GDPR data protection mechanisms, lessons can be learned from the analysis of the current certifications. Existing certifications already have mechanisms in place: contractual arrangements, assessment methodologies, and auditors

<sup>&</sup>lt;sup>1</sup>https://nos.nl/artikel/2293700-hoge-boete-voor-haga-ziekenhuis-na-rel-rond-dossierbarbie.html

<sup>&</sup>lt;sup>2</sup>https://www.pinsentmasons.com/out-law/news/survey-reveals-lack-of-awareness-of-gdpramong-company-directors

that should be used in the creation of the GDPR data protection mechanisms (Best et al., 2016).

GDPR already shows problems regarding medical data, but another issue that currently plays in the Netherlands is the long history of poor collaboration between healthcare and patient information. In recent news articles, doctors are arguing that because of missing patient information, emergency care cannot guarantee patient safety<sup>3,4</sup>. Doctors do not have access to all the required medical information of patients, because their medical records are stored in a different hospital. Even within hospitals, medical personnel cannot access information from other hospital wards. In the healthcare sector, many organisations contribute to the ecosystem, and therefore, proper coordination is required (Grijpink, 2014).

#### **1.2 Complications in Broader Perspective**

These problems are primarily occurring in the so-called interorganisational networks or chain computerisation perspective. There are many definitions of interorganisational networks in the scientific literature. Essentially, the foundation of all lies the concept of networks consisting of the structure of relationships between actors (organisations and individuals), the essence of the links between actors, and the meaning of those relationships (Popp et al., 2014).

The chain concept of chain computerisation explicitly refers to a 'social' chain: large scale interorganisational processes that yield a social product such as safety, prosperity or health and not to logistic chain (handling goods) that often can be found in the business community. Logistics, linked information systems, linked transactions, and data chains are by all means components of a social chain, but Grijpink focussed explicitly on the level of chain-wide co-operation of organisations and professionals (Grijpink, 2014).

For this thesis, I have selected this scope because my motivation for investigating chains lies in the interest to solve complex puzzles and chains are complex systems. Due to my experience with hospitals myself, I have gained a high interest in the healthcare sector and especially, hospital care. I hope that this research can contribute to better organised and streamlined information flow by combining these two principles.

Within chains, many organisations are involved, but no-one knows for what they are responsible. When it comes to data elements (a logical collection of data-items (Beynon-Davies, 2004)) within those chains, vagueness overrules. For example, who is responsible for the registration of the age of a patient within the healthcare chain;

<sup>&</sup>lt;sup>3</sup>https://nos.nl/artikel/2301892-oplossing-ict-problemen-in-de-zorg-niet-zo-moeilijk.html <sup>4</sup>https://nos.nl/artikel/2301859-ict-problemen-zijn-risico-voor-patientveiligheid.html

is it the general practitioner, the hospital, the insurance company or the government? Division and change of tasks, responsibilities and authorities within and between organisations often entail a shift in existing roles and positions of organisations. Power and mutual competition play an important role here (Matthijsse, 2016).

Debates regarding privacy and data ownership have been around in academic circles since the emergence of computers and digital records in the 1960s (Miller, 1969; Contreras, 2019). In recent years, increasing wealth inequality and the rise of digital platforms have renewed the discussion about the ownership of personal information (Fairfield, 2017; Posner et al., 2018). Joining this debate, some health law scholars have raised concerns regarding individual autonomy, privacy, and distributive justice by arguing for the propertisation of genetic and other health information (Roberts, 2018).

#### 1.3 Summary

This research aims to dive into the complex world of health registration and their data flows. The main contribution is to gain insights on how the data travels between organisations and who is responsible for the correct registration and processing of data. More contributions of this research are highlighted in Section 2.2.

The following can be expected in this thesis; in the next Chapter (2), the research plan is presented in which the problem statement, research goal, questions, and research methodology are described. After this, a literature study (Chapter 3 and 4) is performed to identify the gap in the literature, provide definitions and presents the state-of-art literature about the declaration chain. Chapter 5, presents the data analysis in which the results from the interviews are discussed, and the framework is proposed. Chapter 6 discusses the validation of the models and their applicability in practice, and Chapter 5 presents the discussion. To conclude, in Chapter 6, the conclusions are presented, and future works are highlighted.

## 2 Research Plan

#### 2.1 Problem Statement

The healthcare that citizens receive is necessarily a product of a system. This system can be more or less organised (Elhauge, 2010). For example, a patient who undergoes a bypass procedure is necessarily treated by a "system". This system includes the primary care of a physician, who refers the patient to the specialists, the specialists who diagnose the problem that requires treatment, the surgeon who performs the procedure, the nurses and other medical providers who provide care to the patient, the hospital that provides the resources for the procedure, the medical device and pharmaceutical manufacturers whose products are used, and so on to eventually come back to the primary care physician who will advise the patient on the lifestyle that might prevent the need for another operation (Enthoven, 2016).

According to the World Health Organisation (WHO), an integrated healthcare system (IHS) is the ultimate goal of providing healthcare. IHS is defined by the WHO as "The organisation and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money" (World Health Organization, 2008). Health services are the central part of health systems and make a significant contribution to population health and the quality-of-life of people. The existence of these systems provides workplaces and a feeling of security for large parts of the population (Gröne and Garcia-Barbero, 2001). Enthoven (2016) calls this an integrated healthcare delivery system and defines it as "one in which all the providers whose services affect a patient work together in a coordinated fashion, sharing relevant medical information, sharing aims or goals (often measurable and measured), sharing responsibility for patient outcomes, and resource use" (Enthoven, 2016). However, this system can also be fragmented (Enthoven, 2009). "Fragmentation" in healthcare delivery is the systemic misalignment of incentives or lack of coordination among providers, that covers inefficient allocation of resources or harm to patients (Enthoven, 2009).

Rosenbaum (2010) is arguing that the question is whether the medical data themselves are owned. There are strong arguments that health information cannot be owned, at least not in its original form (Rosenbaum, 2010). The unsettled nature of the problem can be expected to enhance as paper medical records are replaced with an electronic highway along which information is free to move. Hall (2009) has observed that ownership of information was never in doubt in an age of paper because the paper record containing the information was owned by its creator (subject to certain rights of access at common law and under federal and state statutes in the USA). However, the electronic information age has ushered in an era in which the content of information can be *"digitised and freed from any particular storage medium"* (Hall, 2009) and thereby creating uncertainty as to the right of ownership and control.

While privacy considerations slow the march toward data access, issues of the owner in both a personal and business context become highly pertinent as well. There is surprising and wide-ranging uncertainty in the US law, regarding the ownership of health information contained in medical records, claims forms, and other data repositories spread throughout the reaches of the healthcare system (Rosenbaum, 2010). The law regards records holding data as property owned by their creators (with specific access rights granted to patients, insurers, and government agencies as a matter of federal or state law, as is the case with the HIPAA Privacy Rule) (Rosenbaum, 2010).

An information infrastructure is different from the principle of bound organisation borders. Chain computerisation differs substantially from internal automation. A bridge is created between the cooperating organisations (Matthijsse, 2016). The parties involved then each sacrifice a bit of autonomy, but that is where the problems lie with the development of an information infrastructure. A strong relationship between the parties is required to achieve and maintain the intended win-win effects. Systems designed to cross organisational boundaries will become a growing part of the digital economy and information society (Bemelmans, 2004; Grijpink, 1997; Matthijsse, 1998; de Man, 2006). Structural information problems in business chains often prove difficult to solve with only internal information systems. New possibilities are opened by an application-independent information infrastructure tailored to the standard requirements of a business chain or a government chain (Matthijsse, 2016).

According to Kennisgroep Keteninformatiemanagement (2016), healthcare in the Netherlands is not yet an integrated chain but a collection of individual entities. For example, the healthcare sector, and within it, the declaration process, includes various flows and these flows have become complicated. A clear governance structure and architecture of the information are missing within these different streams (Kennisgroep Keteninformatiemanagement, 2016). Moreover, data governance and master data management are also missing, so that data not can be guided through the entire chain without any problems, and that makes management difficult remains. As a result, the complex chain is not directed in its entirety. Also, it is sometimes unclear exactly where the responsibilities and powers lie and who is addressed to what (Kennisgroep Keteninformatiemanagement, 2016; Plotkin, 2014). Douma (2019) argues as well that it is unclear who is the owner of medical data in the Netherlands.

The consequences of this lack of information cause that it is hard to rely on the quality of the information provision in the healthcare sector, but information quality is of great importance. Several entities supervise the healthcare sector, which means that the same check of information is now carried out multiple times (Kennisgroep Keteninformatiemanagement, 2016). A good information infrastructure makes sharing information between entities more efficient and effective, which leads to a better working process (Kennisgroep Keteninformatiemanagement, 2016; Welters, 2016). In the care chain, the absence of harmonisation and uniformity prevents the proper functioning of the intended cooperation, which results that the complex chain is not directed in its entirety (Kennisgroep Keteninformatiemanagement, 2016). Eventually, if the chain is well managed, this will results in fewer errors and failures in the chain and less manual activities to repair the errors and failures (Kennisgroep Keteninformatiemanagement, 2016). Establishing ownership requires understanding how the data is managed and who uses it, then discovering who can best be responsible for the content and quality of the data elements (Plotkin, 2014).

The problem that this research aims to solve is that there is a need to provide more insights who is the owner and who is responsible for data, and specific different data elements in the declaration chain of the healthcare sector, in the Netherlands. This can be summarised by the problem statement formulated according to the design science template from Wieringa (2014):

**How to** create a framework **to satisfy** the need of having ownership and responsibilities of data elements clear **so that** organisations that are participating in a chain know who is responsible for which data **in** a chain computerisation perspective and more specifically in the declaration chain of the Dutch healthcare sector?

#### 2.2 Contributions

This research project had both scientific and societal contributions. As scientific contributions, this study is relevant because it provides to specify ownership and responsibilities within in the Dutch healthcare sector. No frameworks or literature is found on this topic what shows that there is a gap; this will be further elaborated in the literature review in section 3. With this research, a better alignment will be created with the use of a constructed framework to have the ownership and responsibilities of data clear.

As societal contributions, chain partners work together to achieve a common goal. They coordinate their organisations and processes to ensure that the implementation process that runs through their organisations will go as smoothly as possible (Matthijsse, 2016). It will result in better functioning of the chain collaboration because chain partners are warned about chain problems or are alerted to alternatives or new opportunities (Grijpink and Plomp, 2009; Paans, 2014). The framework will

help to contribute to these improvements in chain collaboration. Other impacts are the optimisation of efficiency and effectiveness in the chain that also potentially lead to positive effects for citizens because the quality of care can be further improved (Welters, 2016). During the interviews, it became clear that there is no available overview of the declaration chain in the health sector - especially regarding responsibility. To exemplify, healthcare insurers and hospitals have received many questions from patients about the declaration process. This framework can help the patient to understand better how the pricing of their medical treatments works since, for a regular patient, it is hard to follow. KPMG will use the framework to help (healthcare) clients to get a better overview of the data ownership and responsibilities. Regarding generalisability, this research is only applicable to the Netherlands because the Netherlands has an registration system that is created from scratch (Busse et al., 2013) and is therefore unique. Furthermore, healthcare can be seen as part of Maslow's Hierarchy of Needs (Huitt, 2007). By improving healthcare only a bit, with a framework to have the ownership and responsibilities clear, it will contribute to the improvement of the healthcare sector and so, the greater good.

#### 2.3 Research Goal and Scope

#### 2.3.1 Research Goal

The research goal of this research is twofold:

- 1. To design a framework that indicates ownership and responsibilities of medical data elements within the Dutch healthcare sector.
- 2. Apply and validate this framework in a case study within a specific healthcare flow.

#### 2.3.2 Scoping

For this research project, scoping is an important step to make boundaries what will be investigated and what not. According to Gregor and Jones (2007) scoping is "what the system is for" or the set of meta-requirements or goals that specifies the type of system to which the theory applies and in conjunction also defines the scope, or boundaries, of the theory (Gregor and Jones, 2007).

In the domain of Information Sciences, we zoom-in on the concept of chain computerisation, and within that, we will investigate how responsibility and ownership are managed of different data elements within the Dutch healthcare sector. In the healthcare sector, we will look at the declaration chain and the "cure" flow. Since the 1970s of the last century, a distinction is made between "cure" and "care" in the Dutch healthcare sector (Keet, 2008). Cure focuses on healing and recovery. The associated activities are short-term medical care and associated nursing and care. The timeframe is short, and the place of action is the hospital, for example, a successful operation or treatment of an infectious disease. Care aims to minimise the disadvantages of diseases, disorders and limitations as much as possible. The associated activities are nursing, guidance and care (Keet, 2008). To narrow the scope even more, a patient journey will be used to follow the path of a patient. A patient journey is useful to understand the patient's experience by separating the management of a specific condition or treatment into a series of consecutive events or steps, for example, interventions, actions or staff interactions (Trebble et al., 2010). The scoping is visualised in Figure 2.1.

Out-of-scope is within the healthcare sector, the availability of user-generated data that is increasing. User privacy and ownership of the user-generated data remain an under-explored territory from policy and regulatory perspectives while becoming a booming business for the social media industry, and medical technology manufactures (Olson and Tilley, 2014). Furthermore, an in-depth investigation of privacy mechanisms that are feasible for data elements is not in the scope of this project. However, GDPR is seen as part of data governance and for that reason taking into account for this research. In medical specialist healthcare, a patient can only receive healthcare if it has a referral letter from the general practitioner (GP). We will not look at this step since our focus is at when the patient enters the hospital, but it is essential to mention that it officially starts at the GP.

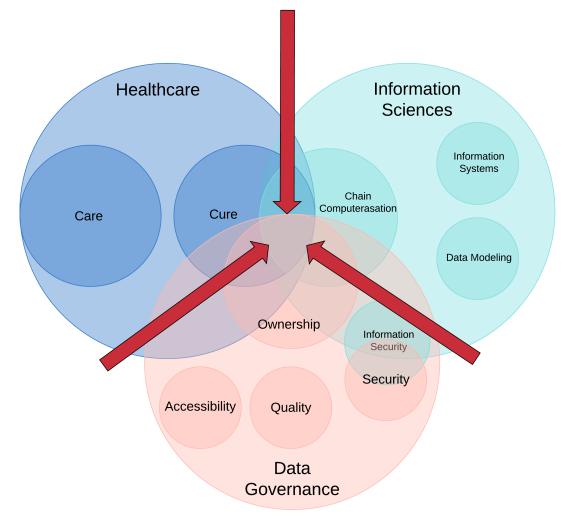


FIGURE 2.1: Visualised Figure of the Research Scope

#### 2.4 Research Questions

To satisfy the created research goals, research questions are created in order to direct the inquiry in this study. It consists of the main research question (MRQ), which is the underlying question of this study, and multiple sub-questions (SQ) that support the MRQ. According to Wieringa (2014), these questions are called design research problems, or technical research questions because the following questions express to improve some artefact, the framework, in some context, healthcare. Derived from the problem statement, our primary goal, the MRQ is formulated as follows:

**MRQ**: What is a suitable framework that can be used in the context of assigning responsibilities and ownership to data elements in a chain computerisation perspective for the declaration chain in the Dutch hospital healthcare sector?

In order to answer the main research question, the analysis is categorised into several topics that more or less built upon each other. These topics have been formulated

into a set of subquestions (SQs) stated and explained below.

SQ1: What is the state-of-the-art of the literature about chain computerisation in relation to healthcare?

- 1.1 What is chain computerisation?
- 1.2 What are the major flows in the healthcare sector and how can a patient journey be created?
- 1.3 Which data elements exist in the patient journey within the declaration chain computerisation flow?

SQ2: What are the requirements for a framework for responsibilities and ownership of data elements?

- 2.1 Which concepts occur in the context of data governance and what is their definition?
- 2.2 What current frameworks exist for assigning ownership and responsibilities concerning data elements?
- 2.3 What is the current situation of assigning ownership and responsibilities to data elements?
- 2.4 Which parties are responsible and accountable for which data elements within the healthcare sector?

SQ3: How can the framework be applied in a case study?

- 3.1 How does the framework perform?
- 3.2 What recommendations can be made?
- 3.3 Is the framework applicable to different chains in different sectors regarding generalisability?

#### 2.5 Outline of and Justification for Chosen Research Method

Within this research, a new object (artefact) is constructed to improve the problems as mentioned earlier (context). The artefact is iteratively investigated and designed using existing and newly gained knowledge. This study will, therefore, be characterised as Design Science (Wohlin and Aurum, 2015). We follow the method of Design Science from Wieringa (2014). This method is created to solve a problem by creating an artefact. In this research, we will use the Design Science Cycle for creating a framework to have responsibilities and ownership clear in a chain computerisation setting.

Designing research consists of two separate sets of activities; the first activity set involves selecting what you wish to achieve with the research project. This can be achieved by modelling the content of the research; we call this the conceptual design of a research project. The second activity set concerns how to realise all this during the implementation stage of the project. This is called the technical research design (Verschuren, P. & Doorewaard, 2010). The conceptual model determines what, why, and how much we are going to study.

*"Design Science creates and evaluates IT artefacts intended to solve identified organisational problems"* (Hevner, A. R., March, S. T., Park, J., & Ram, 2004, p. 77).

The Design Science Cycle contains five phases: Problem Investigation (1), Treatment Design (2), Treatment Validation (3), Treatment Implementation (4) and Implementation Evaluation (5). For the sake of feasibility and due to limited time, we will only execute the first three phases of the Design Science Cycle. To show how the Design cycle is applied to this thesis, the first three phases, along with their goals and outputs, are shown in Figure 2.2.

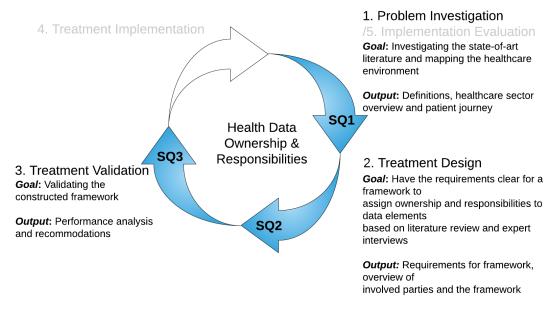


FIGURE 2.2: The Design Science Cycle Adopted From Wieringa (2014)

In Figure 2.3, an overview of the sub-questions in relation to Wieringa's Design Cycle phases is presented.

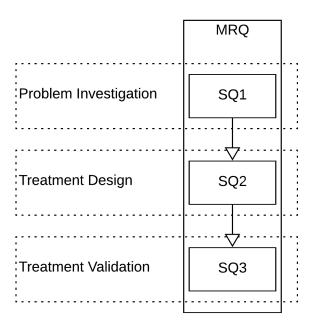


FIGURE 2.3: Sub-Questions Combined With Design Cycle Phases

#### 2.6 Research Methods

To answer the sub-questions, we use several research methods during the study. Table 2.1 shows the research methods that are used per sub-question. For SQ1, a thorough literature study is performed. Some findings will be validated by speaking to experts, but the primary research method for this SQ is a literature review. SQ2 will be answered via multiple expert interviews but to get a basic understanding, literature research will be conducted to figure out what is already in place. To dive deeper into these concepts, the experts will function as the primary source of information and therefore, be the main research method for this SQ. The literature review is separated into two parts, one regarding the data governance and concepts based on scientific literature, and the other part is focusing on healthcare in the Netherlands. This second part is mainly based on literature from government institutions like the NZa and is considered more grey literature. Eventually, the framework will be tested via a case study what will result in the answers for SQ3.

Research Method	SQ1			SQ2				SQ3		
Research Method	1.1	1.2	1.3	2.1	2.2	2.3	2.4	3.1	3.2	3.2
Literature Review	X	X	X	X	X					
Expert Interviews						X	X			
Case Study								X	X	X

TABLE 2.1: The research methods that are used to answer the SQs.

#### 2.6.1 Literature Research Protocol

In order to get a good overview of existing research and provide some groundwork for the research questions, a literature review must be performed. In order to do this structurally, a literature research protocol must be defined. This contents for this protocol can be derived from the research questions, which are stated in a logical order that can be followed when researching literature.

#### Objective

As the literature review is the first step in understanding and analysing the context, it provides a basis for the rest of the research project. Furthermore, giving an overview of known information about chain computerisation, healthcare and existing frameworks, is an integral part of the research. These different kinds of sources include scientific studies and grey literature such as round table meetings and knowledge gained through business cases. Together, all information should result in answers for different sub-sub-questions on what this research could further build on.

#### Search Strategy

When looking at the different topics for which literature must be found, both forward snowballing, backwards snowballing and ad hoc ways of searching are used, where whenever additional topics pop up, literature about them is searched. This snowballing is a method described by Wohlin (2014), which is using the reference list of- or citations to- a specific paper to identify other relevant papers in the domain further. To provide a background in order to appropriately position new research activities, the proposed guideline of Kitchenham (2004) for systematic reviews is used.

	Definition for chain computerisation;
Objectives	Providing definitions for data governance concepts;
Objectives	Identifying current ownership and responsibility frameworks;
	Create a patient journey;
	ACM Digital Library;
	Google Scholar;
	ResearchGate;
Sources	IEEE;
5001005	AIS;
	Information Systems Professional Organisations;
	Google;
	Preferably Scientific Platforms;
	"Chain Computeras[z]ation"
	"Organis[z]ational Networks"
	"Inter[-]Organis[z]ational Networks"
	"Organis[z]ational Collaboration"
Varmanda	"Organis[z]ational Ecosystem"
Keywords	"Organis[z]ational Partnership"
	"Framework for Data Ownership"
	"Framework for Data Responsibilities"
	"Framework for Ownership and Responsibilities"
	"Patient Journey"
Inclusion/exclusion	Definitions should be given in introduction;
Criteria	Framework(s) should be presented in paper;
	Books;
Dogument Trucco	Journals (including company journal);
Document Types	Grey Literature (technical reports, magazine articles);
	Conference Proceedings;

TABLE 2.2: Overview of the Search Strategy Metrics

First, for the main research question, some general and contextual information about chain computerisation must be given. This information leads to an understanding of the research context and the implications thereof.

#### 2.6.2 Patient Journey Literature Review

Journey maps are used to represent the healthcare service from the perspective of the patient (Trebble et al., 2010; Trebble and Hydes, 2011; Zomerdijk and Voss, 2010). This research will look at a patient journey and follow the steps taken in this journey. A method for personifying the requirements gathering process and aiming improved attention towards patient experience is user personas. User personas involve

creating fictive user groups to help design teams in better understanding the mental model of these groups (LeRouge et al., 2013; Maguire, 2001).

#### 2.6.3 Expert interview prospects

Together with KPMG, a preliminary set of interview prospects have been identified for this research that could be relevant. An overview of the healthcare sector and in specific, the declaration chain is presented in Section 4.1.1 which further elaborates on the involved parties. So far, they mainly focus on the healthcare sector.

- Health insurance company;
- Hospital(s);
- Nictiz; stands for National ICT Institute in Healthcare, is the Dutch knowledge centre for national applications of ICT in healthcare;
- NZa; Dutch Health Authority, responsible for supervising the healthcare market in the Netherlands, both on healthcare providers and insurers;
- Vecozo; they draw up rules and standards for communication between chain parties in healthcare concerning the administrative handling of transactions. Within the administrative care domain, Vecozo facilitates a digital environment in which chain parties can exchange data with each other quickly, easily and securely (Kennisgroep Keteninformatiemanagement, 2016);
- Vektis; from each declaration paid by a health insurer, some data is sent to Vektis and recorded in their database. Vektis delivers this information about declared care back to the care sector. Vektis analyses the use, costs and quality of care based on all care declarations and insured person data (Kennisgroep Keteninformatiemanagement, 2016);
- Ronald Batenburg; he is program coordinator health care and workforce planning at Nivel, the Netherlands Institute for Health Services Research. His research areas are labour market studies and transitions, as well as the socio-organisational aspects of ICT;
- Marijn Plomp; did his PhD at Utrecht University and wrote his dissertation about chain computerisation. He was also a member of the Journal of Chain-Computerisation and can be seen as an expert in this field;
- Rene Matthijsse; obtained a PhD in Technical Business Administration, in particular in the field of chain information management and information infrastructure at TU Eindhoven. For one day a week, he is affiliated with the VU University Amsterdam, where he teaches IT Auditing and as a senior lecturer;

Additionally, the interview data is transcribed and processed in NVivo 12; this is a qualitative data analysis software package (Edhlund and McDougall, 2019). Every interview result is derived from almost the same interview structure, but modifications were made per different organisation, so the consistency is approximately the same. For consistency and easy referencing, NVivo allows coding the interviews on

important topics. These topics are called nodes and together form the node tree, which is visualised in Figure 2.4.



FIGURE 2.4: NVivo Node Tree

#### 2.6.4 Case Study

A case study is defined by Runeson and Höst (2009) as "investigating contemporary phenomena in their context, especially when the boundary between the phenomenon and its context is unclear, gathering information from few entities with lack of experimental control". This is confirmed by Stol and Fitzgerald (2018), stating that a case study provides evidence of a phenomenon in its natural setting.

Following the work of Yin (2011), a case study can either be labelled as a single or multiple-case study. In this research, we perform a holistic single-case study be-cause there is a call for a single case study, namely in the declaration chain, without embedded subcases: conditions are tested under which the same findings might be replicated (Yin, 2011).

During the case study, we work with first-degree data collection techniques: data is collected in real-time, and there will be direct contact with the subjects (Lethbridge, Sim, and Singer, 2005). With a case study, we aim to test the developed framework in practice to examine how it performs and which recommendations can be made. Based on the validation interviews, the consolidated framework is further improved to provide an accurate view of the declaration chain. This is necessary to achieve our societal contributions to improve collaboration in the chain by making the ownership and responsibilities clear. Without this case study, it is unknown what the consequences are of the chain with the developed framework and therefore, it results in a validated framework.

#### 2.6.5 Threats to Validity

The limitations of this research are discussed according to the four features of validity for threat to validity for case studies: construct validity, internal validity, external validity and reliability (Runeson and Höst, 2009; Yin, 2017; Wohlin et al., 2012). Cook and Campbell (1979) created a list of threats to validity that can be seen as a checklist.

#### **Construct Validity**

Construct validity reflects to what extent the operational measures that are analysed represent what the researcher has in mind and what is investigated according to the RQs (Wohlin et al., 2012). If, for example, the constructs discussed in the interview questions are not interpreted in the same way by the researcher and the interviewed persons, there is a threat to construct validity (Wohlin et al., 2012). To prevent this research from construct validity, the aim is to interview all the organisations within the chain. By using multiple sources, validity will increase.

#### **Internal Validity**

This aspect of validity is of concern when causal relations are examined. When the researcher is investigating whether one factor affects an investigated factor, there is a risk that the studied factor is also affected by a third factor. If the researcher is not aware of the third factor and does not know to what extent it affects the investigated factor, there is a threat to internal validity (Wohlin et al., 2012).

#### **External Validity**

Wohlin et al. (2012) states that External Validity is concerned with the extent to which the results obtained in the current study can be generalised and can be used in different context, place or people (Wohlin et al., 2012).

#### Reliability

Wohlin et al. (2012) states that reliability is concerned with the extent to which the data and the analysis performed are dependent on the researcher and the same results would be obtained, if the study would be conducted by another researcher (Wohlin et al., 2012).

#### 2.7 Process-Deliverable Diagram

According to Peffers et al. (2007), mental models can help in understanding what is required in the Design Science Research Methodology. A mental model is a "small-scale model can be constructed from perception, imagination, or the comprehension of discourse" (Johnson-Laird, 1983). This will help us to create a global overview of the

processes of this research. Therefore, the research method is visualised in a Process-Deliverable Diagram (PDD) what is introduced by van de Weerd and Brinkkemper (2009). A PDD consists of two parts: processes on the left-hand side, which is based on a UML activity diagram, and deliverables on the right-hand side, which is based on a UML class diagram. With this diagram, visible in Figure 2.5, a clear overview of the processes to produce the required deliverables is presented.

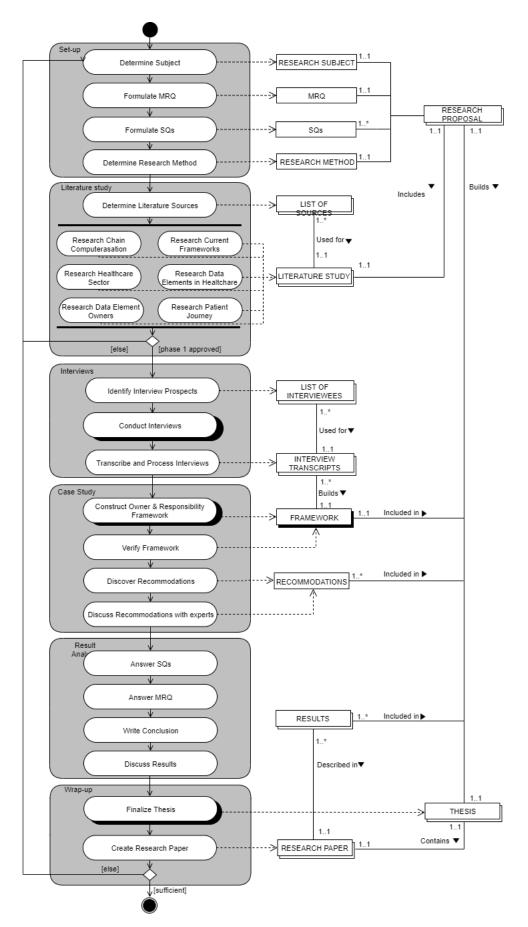
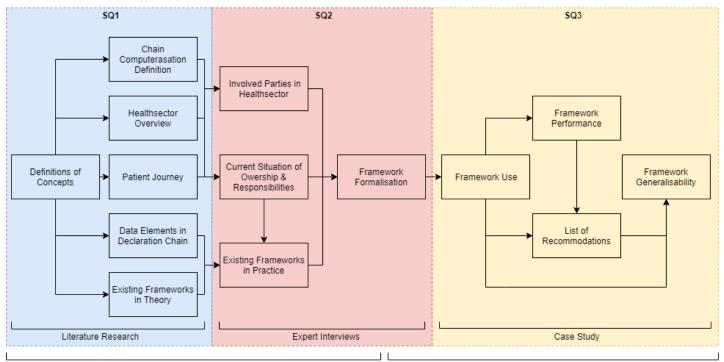


FIGURE 2.5: Process-Deliverable Diagram of the research

#### 2.8 Conceptual Framework

For the outline of this research, besides the PDD, a conceptual framework is developed and visible in Figure 2.6. Basically, it shows how to find answers to the research questions and the research methods which are mapped on the design cycle discussed earlier. Additionally, it visualises the research in general with the according to deliverables, phases, research questions and methods. Meaning, this framework comprehends all the research elements needed to perform proper research. It creates a useful overview of the outline of this research.



Scientific Contributions

Practical Contributions

FIGURE 2.6: Conceptual Model of the Research

## **3** Literature Review

This chapter consists of different sections of literature reviews based on scientific literature; Chain computerisation is a relatively new keyword in the information science community (Grijpink, 2014), what needs further investigation. We will look at the current state about chain computerisation and what it is in Section 3.1 to answer SQ 1.1; What is chain computerisation? To get an understanding in data governance what is related to SQ 2.1; Which concepts occur in the context of data governance and what is their definition? Is presented in Section 3.2. The introduction of the General Data Protection Regulation (GDPR) causes a major shift in how companies should handle personal data. However, to know how the GDPR works, a brief literature study is conducted in Section 3.3. This is followed by Section 3.4 that presents an examination of different frameworks for ownership and responsibilities, for answering SQ 2.2; What current frameworks exist for assigning ownership and responsibilities concerning data elements?.

The next chapter (4) is a literature review as well but is only focusing on healthcare mainly based on grey literature. Therefore, a distinction is made between these two chapters to separate them.

### 3.1 Chain Computerisation and Interorganisational Definitions

To solve the main research question, we need to get an understanding of the field where the problem is happening. In the literature, there are multiple main terms used for describing a collaboration between multiple organisations, namely interorganisational networks/collaboration/ecosystems/partnerships and chain computerasation. In this section, we will look at these definitions and choose one definition to use in this research.

#### 3.1.1 Interorganisational Networks

There are many definitions of interorganisational networks (IONS) in the literature, but there is not one that seems to be the 'dominant' definition (Plomp, 2012; Popp et al., 2014). First of all, a network is defined as an abstract notion that refers to a set of nodes and relationships that are connected (Fombrun, 1982; Brass et al., 2004). The foundation of these definitions lies the concept of networks consisting of the structure of relationships between actors, that can be individuals and organisations, the nature of the links between actors and the meaning of those relationships (Popp

et al., 2014). Information systems that cross the boundaries of a single organisation are also known as interorganisational information systems (Plomp, 2012).

Barringer and Harrison (2000) provides an overview of the different types of interorganisational relationships, similar to what is investigated ten years earlier by Oliver (1990) and go into detail as to how each is different. For example, they somewhat narrowly defined networks as constellations of organisations that come together through the establishment of social contracts or agreements (the provision of health services through referral systems for example) rather than legally binding contracts (Provan, Fish, and Sydow, 2007).

#### 3.1.2 Organisational Collaboration

Interorganisational collaboration is defined by Phillips, Lawrence, and Hardy (2000) as "a cooperative relationship among organisations that relies on neither market nor hierarchical mechanisms of control". Walter and Petr (2000) recognise that collaboration is understood as "working together" (p. 5). Winer and Ray (1994) argues that the terms cooperation, coordination, and collaboration are often used interchangeably. However, the declaration chain we investigate relies on market mechanisms since health insurers have a lot of control because they have the money. They can negotiate with hospitals about prices of treatments what can result as well in a hierarchical mechanism.

#### 3.1.3 Interorganisational Partnership

Another closely related term is interorganisational partnership. Partnerships bring together a coalition of interests drawn from more than one sector to generate agreement (Hutchinson and Campbell, 1998). Interorganisational partnerships can increase efficiency in the form of outsourcing or other means of lowering unit costs (Casey, 2008). Our focus is on the healthcare sector, and within our scope, there is not a cross-sector partnership and not applicable to us. Furthermore, there are many organisations involved in the declaration chain what increase unit costs instead of lowering them. In our context, interorganisation partnership will not resuls in the right term to use.

#### 3.1.4 Chain Computerasation

Porter (1985) describes a value chain through a figure that depicts an organisation as consisting of different activities. These processes can be classified into primary and support activities. The primary activities form a sequence, from inbound logistics through operations to outbound logistics, marketing and sales, after which service is delivered. This explains the name of the value chain: "*a series of activities, a chain, each of which adds value in their own way*" (Porter, 1985).

However, when we look further than the boundaries of an individual organisation, we see that organisations are almost always part of a larger whole of organisations that supply and demand from each other. This has been termed the value system (Porter, 1985) or the industrial value chain, in order to indicate the difference with an individual organisation (Ward, 2002). Every organisation in the value system has a particular input, executes a process on that input in order to provide a specific output.

Grijpink (2010) is arguing that a 'chain' does not mean logistics (the process of handling goods) that often come across in the business community, neither an information chain (closely linked information systems), neither a chain of transactions (subsequent transactions within a process). The chain concept here refers explicitly to social chains, large-scale interorganisational processes that yield a social product such as income support, safety or survival (Grijpink, 2010). In those chains, multiple independent organisations and professionals are collaborating in different combinations to achieve a common goal (Grijpink, 2016). Chain information is vital because it leads to better chain performance utilising alignment of information transfer throughout the organisations. Insights, methods and use of chain computerisation, will lead to better chain performance since a chain communication system can constrain faults and fraud and privacy is better maintained.

The core of this methodology consists of filling in four profiles, each of which describes one aspect of the chain or the chain cooperation (Grijpink and Plomp, 2009; Grijpink, 1998):

- The mission profile: what is the dominant chain problem and which critical data do all parties need in order to be able to tackle this dominant chain problem?
- The coordination profile: are we dealing with a simple or a complex chain, and based on this, what are the required coordination mechanisms?
- The information profile: what are the fault lines in the communication between the various chain parties and how can they be bridged?
- The cooperation profile: what is the current degree of cooperation among the parties in the chain and, thus, the feasibility of various chain initiatives?

De Bruijn and Ten Heuvelhof (2017) are arguing that a network is also a metaphor for a collection of actors and their relationships, but this metaphor emphasises more than chains the multiplicity and mutual dependencies of actors or the idea that everything is connected to everything. A chain can be part of a network, but then forms a specific, predefined set of connections within that network.

It is sometimes a debate about whether one should speak of chains or networks since both concepts have their advantages and disadvantages. A chain is perceived as the more traditional concept: invariable and linear, whereas a network is supposed to be cyclical and dynamic (Plomp, 2012). Governments can be seen as large networks of organisations with contiguous tasks for which an enormous amount of information has to be exchanged. This exchange of information between public organisations is much more problematic than the exchange of information within a public organisation (Grijpink, 1998).

Chain coordination or chain management is concerned about monitoring the connection between the activities. Wit, Rademakers, and Brouwer (2000) indicates that chain coordination is performed at the policy level. It is about information flows and activities but is not part of it. It differs per chain to which extent chain coordination is required. Sometimes, natural cooperation takes place, but in other cases, cooperation is more enforced. Grijpink (2010) indicates that good cooperation sometimes breaks down in the complexity of chains. Chain partner's objectives are often diffuse and contradictory, due to differences of opinion about the joint chain objectives. The main question is then how management function should be set up within a complex chain because if the natural chain leader is missing, chain management must be organised in a different way (Wijk et al., 2014; Matthijsse, 2016).

The lack of formal hierarchy is the most critical factor in chain computerisation. Large databases with data that are used jointly by the involved organisations require more willingness to cooperate than in chains where formal authority is present (Matthijsse, 2016). According to Grijpink (2010), chain information management focuses primarily on overview and lesser on content.

#### 3.1.5 Summary

To summarise the literature findings for this research, based on the findings by Grijpink, chain coordination is used rather than chain management. Our objective of this research is to improve the ownership and responsibilities of data. Chain cooperation will improve the alignment of information transfer throughout the participating organisations. Since healthcare is as well part of a social product, and there are many problems within that sector, we will use the term "chain" instead of "interorganisational network/parternship/collaboration" through this thesis. To answer SQ 1.1; What is chain computerisation? The chain concept here refers explicitly to social chains, which are large-scale interorganisational processes that yield a social product such as health.

### 3.2 Concepts and Definitions in the Context of Data Governance

This section is dedicated to present the different terms in the field of data governance that is related to the relevant SQ 2.1. We will first explore the term data governance in general and related terms, followed by the role of data stewardship.

#### 3.2.1 Data Governance

Data governance is considered to be an emerging subject in the field information systems (IS) (Hagmann, 2013) and has rapidly gained in popularity (Cheong and Chang, 2007; Khatri and Brown, 2010; Weber, Otto, and Österle, 2009). It has become critical how to govern data because data is to be treated as a valuable asset (Khatri and Brown, 2010). According to Otto (2011a), experts consider data governance as a promising approach for enterprises to improve and maintain the quality and use of their data. Otto (2011b) defines data governance as "A company-wide framework for assigning decision-related rights and duties in order to be able to adequately handle data as a company asset" (Otto, 2011b, p. 47). This is similar to the definition of the DMBOK (Data Management Body Of Knowledge) Project Management Institute (2017) definition: "The exercise of authority, control, and shared decision making (planning, monitoring and enforcement) over the management of data assets" (Project Management Institute, 2017). Gwen (2014) introduced a short definition: "Data Governance is the exercise of decision-making and authority for data-related matters" (Gwen, 2014, p. 3). These definitions are almost similar to the definition of IT governance (Weill and Woodham, 2002) "IT governance defines the decision rights and accountabilities to encourage desirable behaviour in the use of IT within an organisation" (Weill and Woodham, 2002, p. 3).

However, in the academic IS field, data management is used as a term as well (Alhassan, Sammon, and Daly, 2016). The major difference between the terms 'management' and 'governance' is that governance refers to the decisions that must be made and who makes these decisions to ensure effective management and use of resources and in contrast, management involves implementing decisions (Alhassan, Sammon, and Daly, 2016; Fu et al., 2011; Khatri and Brown, 2010). The meaning of data governance indicates who possesses the decision rights and accountability regarding an enterprise's data assets. Hence, the decision domains should be distinguished to assign the right responsibilities and duties (Alhassan, Sammon, and Daly, 2016). Data governance is not a function performed by those who manage information what results that there must always be a separation of duties between those who manage and those who govern (Ladley, 2012).

Data quality is defined by the DMBOK as "the degree to which data is accurate, complete, timely, consistent with all requirements and business rules, and relevant for a given use" (Project Management Institute, 2017).

#### 3.2.2 Data Stewardship

Data Stewardship is an operational aspect of Data Governance in which Data Goverance is performed (Plotkin, 2014). McGilvray (2008) defined data stewardship as: "Data Stewardship is an approach to Data Governance that formalises accountability for managing information resources on behalf of others and for the best interests of the organisation" (McGilvray, 2008). The steward is the business function that owns the data, represented by the business function's representative, the Data Governor who manages something on behalf of someone else (Plotkin, 2014). Governed data is data that is understood and trusted where someone is accountable for both the data and for addressing issues about the data. The Business Data Steward and the Data Governor/Owner for the data elements are individuals who serve as the authority and decision-makers about the data. In other words, these are the people who are accountable for the data. It is essential to recognise that a proposed change to any of the duties at the data element level for fully governed data must be allowed by the Business Data Steward and approved by the Data Governor/Owner. Failing to do so can lead to unexpected implications (Plotkin, 2014). Plotkin (2014) defined some of these duties, which are the standardised business name of the data element, rules for creating the data element and usage rules for the data element.

There are more terms that are occurring in the literature; a Data Consumer is a person who uses data for a specific purpose and can be affected by its quality (Muñoz, Moraga, and Piattini, 2008). Data Quality is defined as data that has quality when it has "fitness for use" when it meets the user requirements (Muñoz, Moraga, and Piattini, 2008).

#### 3.2.3 Summary

This section answered SQ 2.1; which concepts occur in the context of data governance and what is their definition? Data Governance is a term that is frequently used in the field of IS. Different terms exist for this, but this research focuses on Data Governance to maintain the quality and use of data. The Data Steward and Data Governor are essential roles to have implemented to provide a clear structure who owns what data. In the next section, the GDPR will be highlighted as it can be seen as part of data governance.

## 3.3 General Data Protection Regulation

In Section 2.3.2 we argued that we will not look at privacy mechanisms but only at GDPR as a part of data governance. This section will briefly introduce the GDPR to further elaborate on SQ 2.1 as part of the concepts of data governance.

On the 27th of October 1995, The European Data Protection Directive (Directive 95/46/EC) was adopted (European Parliament, 1995). This Directive is created to regulate the processing of personal data- and is the first step to protect the personal data of European citizens.

However, the Data Protection Directive did not live up to its objectives and failed to align the level of data protection within the EU (Voigt, 2017). Therefore, the Directive needed to be improved. In January 2012, the Commission adopted its proposal for a

General Data Protection Regulation abbreviated as GDPR (Council of the European Union, 2015) The Regulation as a two aim to increase data protection rights of individuals and to improve business opportunities by easing the free flow of personal data in the digital market. Directive 95/46/EC is repealed with effect from the 25th of May 2018 what is the starting date of the GDPR (European Parliament, 2016). On the 27th of April 2016, the regulation was adopted, so organisations all over Europe have had fair warning of two years (Renaud and Shepherd, 2018).

Organisations receive a fine up to 2% of their worldwide revenue or 10 million euros, whichever is higher, for a minor breach. However, a warning can be given for first offences. For more major violations, fines of up to 4% of worldwide revenues can be imposed or 20 million euros, whichever is higher (Tankard, 2016). 4% Of the global yearly turnover in case of an enterprise or up to 100 million euros in all cases (Albrecht, 2017).

There are two important roles in the GRPR, the controller and the processor. The controller is defined in the GDPR as "*a natural or legal person, public authority, agency or other body that, alone or jointly with others, determines the purposes and means of the processing of personal data*" and the processor as "*as a natural or legal person, public authority, agency or other body that processes personal data on behalf of the controller*" (European Parliament, 2016).

#### 3.3.1 Principles of GDPR

The GDPR has six general data protection principles fairness and lawfulness; purpose limitation; data minimisation; accuracy; storage limitation; and integrity and confidentiality but data protection by design and default is at the core of the GDPR (Goddard, 2017), Figure 3.1 provides a visual overview of these principles.

- Fairness, lawfulness and transparency; the data subject must be told what processing will occur (transparent), the processing must match this description (fair), and the processing must be for one of the purposes specified in the Regulation (lawful) (European Parliament, 2016; It Governance Privacy Team, 2017; ISACA, 2018b).
- Purpose limitation; The Regulation states that personal data can only be collected for *"specified, explicit and legitimate purposes"* (European Parliament, 2016). That is, to comply with the purpose limitation principle, you must define upfront what the data will be used for and limit the processing to only what is necessary to meet that purpose (It Governance Privacy Team, 2017; ISACA, 2018b).
- 3. Data minimisation; The Regulation states that personal data you collect and/or process should be "adequate, relevant and limited to what is necessary for relation to the purposes for which they are processed" (European Parliament, 2016). This means that you should hold no more data beyond what is strictly required.

After all, it is challenging to lose information that you do not have (It Governance Privacy Team, 2017; ISACA, 2018b).

- 4. Accuracy; The Regulation requires personal data to be "accurate and, where necessary, kept up to date" (European Parliament, 2016). Besides being good practice for any business, this protects the data subject from several threats, such as identity theft. It also ensures that any automated profiling decisions made regarding the data subject use accurate data (I(It Governance Privacy Team, 2017; ISACA, 2018b).
- 5. Storage limitation; The Regulation requires that personal data is "kept in a form which permits the identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed" (European Parliament, 2016). In simpler terms: if you no longer need the data, get rid of it. As you should be defining a purpose for all data collection, it should be quite simple to determine when the data is no longer required (It Governance Privacy Team, 2017; ISACA, 2018b).
- 6. Integrity and confidentiality; This principle is perhaps the most important from a financial perspective. While breaches of the other data protection principles can be damaging to data subjects, the impact is usually limited. Breaches of this principle, however, tend to result in data breaches, which make it very easy for supervisory authorities to prove that data has not been held securely the fact that a data breach has occurred is compelling evidence in itself (It Governance Privacy Team, 2017; ISACA, 2018b).



FIGURE 3.1: The GDPR Principles Visualised in Context

#### 3.3.2 Summary

This section explained the six main principles and provided a brief history of the regulation. The GDPR caused a shift in privacy regulations and companies have to take measures to be compliant with it. Since companies in the healthcare sector have to be obedient as well, the information provided in this section will create a better understanding of how GDPR works and provides a base for questions for the organisation that will be interviewed. It helped us to know more about sub-questions 2.1; Which concepts occur in the context of data governance and what is their definition? Companies need to make agreements on controlling and processing information between different organisations, and these are relevant for the declaration chain that is explained in Chapter 5.

## 3.4 Frameworks for Ownership and Responsibilities

This section will explore what current frameworks for ownership and responsibilities exists. That can be a foundation for our SQ 2.2; What existing frameworks exist for assigning ownership and responsibilities concerning data elements? First, the Responsibility Assignment Matrix is discussed, followed by Responsibility Assignment Modelling, and finally, we explore the CRUD Matrix.

#### 3.4.1 Responsibility Assignment Matrix

Smith, Erwin, and Diaferio (2005) are defining Responsibility Charting as "a technique for identifying functional areas where there are process ambiguities, bringing the differences out in the open and resolving them through a cross-functional collaborative effort" (Smith, Erwin, and Diaferio, 2005). Responsibility Charts are enabling managers and other stakeholders from the same or different organisational levels or programs to participate in a focused and systematic discussion about process-related descriptions of the actions that must be achieved to deliver a successful end product or service (Smith, Erwin, and Diaferio, 2005).

A Responsibility Assignment Matrix (RAM), presents the project resources that are assigned to each work package. RAM is used to clarify the connections between activities, and project team members (Project Management Institute, 2017). On larger projects, RAMs can be developed at two levels; namely, a high-level RAM defines the responsibilities of a project team, group, or unit. In lower-level RAMs, they are used within the group to designate roles, levels of authority for specific activities and responsibilities. The matrix format shows all activities that are associated with one person or organisation and all people related to one activity. This will ensure that there is only one person accountable for one task to avoid disarray about who is eventually in charge or has authority for the work. The IT governance reference framework COBIT uses the RACI chart to define responsibilities as an example of a RAM (Project Management Institute, 2017; Smith, Erwin, and Diaferio, 2005; Cabanillas, Resinas, and Ruiz-Cortés, 2011; ISACA, 2018a). RACI stands for Responsible, Accountable, Consult, and Inform and is defined as follows:

- Responsible: for performing the task (Cabanillas, Resinas, and Ruiz-Cortés, 2011);
- Accountable: a person who must approve the work performed by the person responsible for an activity and who becomes responsible for it after approval. There must be one and only one accountable for each activity (Cabanillas, Resinas, and Ruiz-Cortés, 2011);
- Consult: the consulting role is an individual(s) (typically subject matter experts) to be consulted before a final decision or action (Cabanillas, Resinas, and Ruiz-Cortés, 2011);
- Inform: the individual (s) who needs to be informed after a decision or action is taken (Cabanillas, Resinas, and Ruiz-Cortés, 2011);

Using these four roles in a RACI chart, the work to be done is presented on the left column as activities and columns are (human) resources, and each cell contains zero or more RACI initials indicating the degree of responsibility of such resource on such activity (Cabanillas, Resinas, and Ruiz-Cortés, 2011). A RACI chart is a useful and powerful tool to use to ensure a clear assignment of responsibilities and roles when the team consists of internal and external resources (Project Management Institute, 2017).

#### 3.4.2 Responsibility Assignment Modelling

Responsibility assignment modelling is about developing a picture of how the responsibilities in a Socio-Technical System are administered across the actors and different automated elements in that system (Sommerville, 2007). Socio-Technical Systems (STSs) are according to Paja, Dalpiaz, and Giorgini (2013) defined as "complex systems composed of autonomous subsystems (participants), which are either technical (software) of social (humans and organisations). These subsystems interact to achieve objectives they cannot achieve on their own and to exchange information" (Paja, Dalpiaz, and Giorgini, 2013).

The use of responsibility assignment models is to be a basis for promoting discussions on how responsibilities are scattered in an existing system and for planning the responsibility structure of new systems. There is always some flexibility in any system about 'who does what' and individual responsibilities are always subject to discussion. By making responsibilities explicit, a RAM allows managers, designers and users and to develop a common perception of the responsibility structure in a system. Eventually, designers understand who needs what information and when they need it. Besides, the responsibility assignment model may be a useful supporting mechanism for identifying possible responsibility vulnerabilities in a system (Sommerville, 2007).

Sommerville (2007) is arguing that there are six types of responsibility vulnerabilities:

- 1. Unassigned responsibility; within STS, the responsibility for some critical task is not assigned to any agent. When such limitations arise, it is not clear who should take responsibility for dealing with them.
- 2. Duplicated responsibility; this takes place in a system when several agents believe that they are the holder of some responsibility and each reacts to exonerate that responsibility. If each agent interprets the responsibility in precisely the same way, which results in inefficiency. Negatively, inconsistent information may be created and problems may arise when one agent interprets information created by another.
- 3. Uncommunicated responsibility; there is a formal assignment of responsibility (typically to a role), but this is not transferred to the agent assigned to that role. The consequence is that they are not aware that they should discharge that responsibility.
- 4. Misassigned responsibility; the agent who is assigned the responsibility does not have the competence or resources to discharge the responsibility. The proper discharge of responsibility can, therefore, not be guaranteed.
- Responsibility overload; when the agent who is assigned a set of responsibilities does not have the resources to discharge all of these responsibilities, a responsibility overload occurs.
- 6. Responsibility fragility; this occurs when a crucial responsibility is assigned, but there is no backup designated who can replace the responsibility when responsibility owner is unavailable. This is a particular problem for time-critical responsibilities where there is not an option of merely delaying the responsibility discharge until the owner becomes available again.

Sommerville (2007) eventually presented a graphical modelling notation in his paper to show the assignment of responsibilities. The notation indicates that responsibilities can be seen 'at a glance' so that informed individuals can quickly evaluate a responsibility model. Moreover, graphical notations are generally more accessible to and understandable by system stakeholders who are not experts in reading responsibility models. A RAM includes entities of different types (nodes) and relations (links) between these entities.

#### 3.4.3 CRUD Matrix

CRUD stands for Create, Read, Update and Delete, and the matrix indicates who can modify these on one data entity (Torim, 2012). This makes it a simple tool to make

clear what on the one hand, the authorisations of particular objects are such as roles, actors but also business functions and processes (Dingemans, 2018). Alternatively, the matrix can be used which operation is performed by a particular entity carried out, whereby it does not shed light on the authorisation aspects but more on the dynamic characteristics of behavioural objects on the data entities. The CRUD matrix can indicate on a detailed level (if desired up to attribute level within objects) which stakeholder has access to the data and who has mutation rights on the data entities (Dingemans, 2018).

As the abbreviation already shows, CRUD consists of four basic concepts

- 1. Create; create objects or records;
- 2. Read; read the contents of an object, record or a dataset;
- 3. Update; mutation of the content of a data entity;
- 4. Delete; delete or destroy a data entity.

## 3.4.4 Summary

Based on the available literature, three methods are found that are usable for assigning responsibilities and ownership to data elements what solves SQ 2.2; What current frameworks exist for assigning ownership and responsibilities concerning data elements? Responsibility Assignment Matrix, Responsibility Assignment Modelling and CRUD Matrix are useful methods to indicate the different roles of activities. This research orientates towards a framework which makes a CRUD matrix is adaptable for showing the mutations that can be performed by the different roles on the data elements.

# 4 Health Overview

This chapter will focus on the health aspect of this research and can be seen as an extended part of the literature review but now only focusing on health. First, in Section 4.1 an overview of the Dutch healthcare sector is provided and within, we zoom in on de declaration chain in Section 4.1.1. Furthermore, for SQ 2.3; Which data elements exist in the patient journey within the healthcare chain computerisation flow? We investigate which data elements exist in the chain in Section 4.2. A patient journey is introduced in Section 4.3 to follow a path of health data that is occurring in medical specialist care. This will help us to answer SQ 1.2; What are the major flows in the healthcare sector, and how can a patient journey be created?

## 4.1 The Dutch Healthcare Sector

To start with, we will investigate the Dutch healthcare sector. The Health Systems and Policy Monitor (HSPM) is an international platform that works on country monitoring. It consists of national counterparts that are regarded at the national and international level and have particular strengths in the area of health services, health systems, public health and health management research. The Netherlands Institute for Health Services Research (NIVEL) have for the Netherlands created an HSPM (Kroneman et al., 2016). This section will provide an introduction to the Dutch healthcare sector and the proper flow will be discussed for this research.

The Netherlands contains a wide range of public bodies in the field of health. They oversee different elements of the health system, such as fair competition between insurers and providers (the Dutch Healthcare Authority, NZa) and the content of the basic health insurance package and care quality (Care Institute Netherlands, ZiNL). Other bodies provide advice and evidence on different aspects of health, which includes scientific research institutes like the National Institute for Public Health (RIVM). They produce four-yearly reports on the state of public health in the Netherlands. The integration of health across all policies is fragmented, although there is increasing interest in the topic at the municipal level (Kroneman et al., 2016).

The healthcare is principally (72%) financed through the compulsory health insurance contributions from citizens, and with an additional 13% from general taxation (Kroneman et al., 2016). The basic benefits package includes GP care, hospital care, maternity care, home nursing care, mental healthcare and pharmaceutical care. In 2018, 100.0 billion euros was spent on care and welfare, that was 12.9% of the Dutch GDP (CBS, 2019). The health cost expenditure as a share of GDP is above the EU average in 2017 (OECD/EU, 2018).

Health providers and insurers negotiate on price and the quality of care, although competition on quality is still in its beginning phase. For around 30% of the hospital care, price negotiation is not possible for such as emergency care (not plannable) or organ transplantation (too few providers), the NZa establishes maximum prices for this. Hospitals receive money through an adapted type of diagnosis-related group (DRG) system called Diagnosis Treatment Combinations (DTC). While general practitioners are paid by a combination of fee-for-service, capitation, pay-for-performance (focused on issues such as accessibility and referral patterns) and bundled payments for integrated care (Kroneman et al., 2016). Most healthcare providers use a form of electronic patient records. All the general practitioners are using an electronic patient record system, which includes an electronic prescription system. However, the national roll-out of an electronic patient record system to connect these systems failed. This is mainly due for reasons of privacy, and therefore a more limited system is being implemented in its place (Kroneman et al., 2016).

The Dutch government is actively providing information to patients to choose among healthcare providers regarding patient empowerment. For decisions focusing on the admission of treatments and procedures in the benefits package, health technology assessments are essential. The information basis in primary care is at a high-level (Kroneman et al., 2016).

Development of health policy in the Netherlands is complex because due to the involvement of many actors and, although the final responsibility for the health sector lies with the government, it has only limited opportunities to act autonomously based on this responsibility. The private provision of services, financing via a system of social health insurance and self-regulation, have created a healthcare sector that is lead by many mutually dependent actors with different backgrounds (Kroneman et al., 2016).

Healthcare in the Netherlands consists of different sectors. The Dutch Health Authority defined those sectors as (Nederlandse Zorgautoriteit, 2019):

- Pharmaceutical care
- Birthcare
- Mental healthcare (GGZ) and Forensic healthcare (FZ)
- General Practitioner care
- Short-term care
- Long-term care
- Medical specialist care
- Oral care
- Paramedical care
- District nursing

Health insurers

#### 4.1.1 The Declaration Chain

As mentioned in the problem statement, Kennisgroep Keteninformatiemanagement (2016) and Douma (2019), identified that there are problems in the declaration chain of the 'cure' part in the healthcare sector. This can be best described by the 'short-term care and medical specialist care' sectors as defined by the NZa. Kennisgroep Keteninformatiemanagement (2016) created a schematic overview of the declaration chain in the healthcare sector. The overview shows the main flows that exist within the sector with healthcare providers and health insurers and the most essential entities around it.

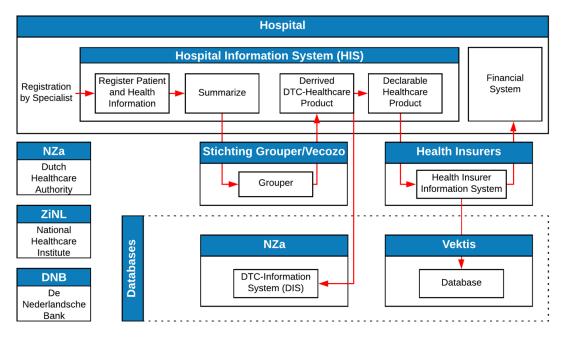


FIGURE 4.1: Schematic Overview of the Declaration Chain Derived from Kennisgroep Keteninformatiemanagement (2016) and in collaboration with a Partner from KPMG

The hospital starts where the specialist registers the patient were DTC stands for "Diagnosis Treatment Combination" (Zorgwijzer, 2019). A DTC is a nine-digit code that says something about all activities and operations that a patient goes through within the care during a set period (Zorgwijzer, 2019). All services that can be claimed are expressed in so-called DTC healthcare products, and there are approximately 4,400 DTC healthcare products. Recording takes place in the Hospital Information System (HIS), the care systems and financial systems of a hospital and this includes the diagnosis of a specialist, hospital treatments and Follow-up checks (Kennisgroep Keteninformatiemanagement, 2016; Zorgwijzer, 2019). Vecozo and Stichting Grouper draw up rules and standards for communication between chain parties in healthcare concerning the administrative handling of transactions. Within the administrative care domain, Vecozo facilitates a digital environment in which chain parties can exchange data with each other quickly, easily and securely. The Grouper lead a set of transactions. Via the decision tree of the Grouper, the transactions are grouped into individual DTCs with the price associated with this set of transactions. These DTCs are sent back to the HIS to be entered as a declaration there (Kennisgroep Keteninformatiemanagement, 2016).

Health insurers receive invoices that are sent by the hospitals, after which they are paid to the insured person after many checks (formal check, appropriate use, fraud, etc.) (Kennisgroep Keteninformatiemanagement, 2016).

ZiNL oversees the quality, accessibility and affordability what the pillars of the Dutch healthcare system are. The Netherlands Care Institute has an important position in this system: they ensure that these pillars form a strong foundation (Kennisgroep Keteninformatiemanagement, 2016).

From each declaration paid by a health insurer, some data is sent to Vektis and recorded in their database. Vektis delivers this information about declarations of healthcare back to the sector. Vektis analyses the use, costs and quality of care based on all care declarations and insured person data. This provides support for decision-makers in healthcare when making choices to maintain the quality and affordability of healthcare (Kennisgroep Keteninformatiemanagement, 2016).

De Nederlandsche Bank (DNB) as an independent central bank and regulator, is responsible for, among other things, a stable financial system, a safe and efficient payment system and, regarding health insurers, for sound and sound financial institutions that can meet their obligations (Kennisgroep Keteninformatiemanagement, 2016).

## 4.2 Data Elements Within the Declaration Chain

In the previous section, we have established an overview of the declaration chain based on the literature. The red arrows in Figure 4.1 represent data elements, but the question is, what are these data elements exactly? This section is dedicated to answering SQ 1.3; what data elements exist within the declaration chain? This section consists of multiple sub-sections in which the different data elements will be explained with their attributes. For each of these data elements, someone is responsible. Therefore, this will be used as a foundation for the interviews to assign the responsibilities to the data elements what is important for SQ 2.4; which parties are responsible and accountable for which data elements?

To create a better understanding of the whole declaration chain, we will continue by identifying the underlying data elements. The entity-relationship diagram (ERD) (Chen, 1976) is one of the most widely used conceptual data models. An ERD models the data structure of reality in terms of entities, relationships, and attributes (Shoval, Danoch, and Balabam, 2004). Based on the information by Nederlandse Zorgautoriteit (2020b), Nederlandse Zorgautoriteit (2020a), and Federatie Medisch Specialisten (2019), an ERD for the declaration chain has been constructed. The ERD is visible in Figure 4.2.

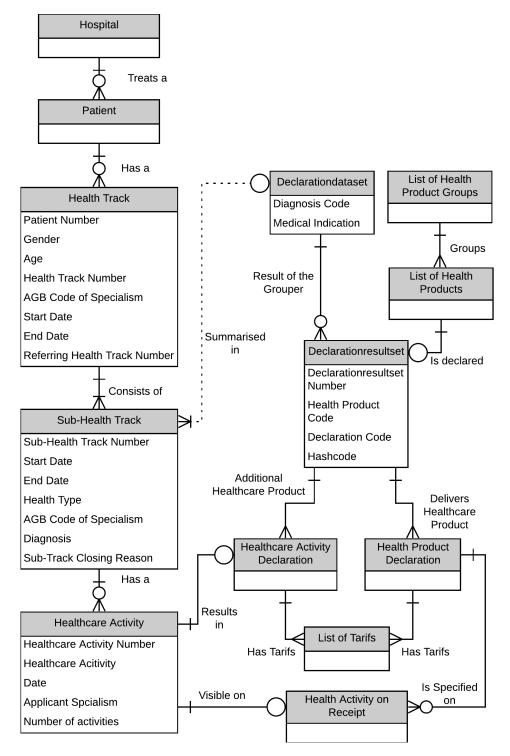


FIGURE 4.2: Entity Relationship Diagram for the Declaration Process based on Nederlandse Zorgautoriteit (2020a)

In the next sub-sections, we will elaborate what all the data entities are with their attributes. A short explanation is presented on each attribute to cover all the data elements within the declaration chain.

## 4.2.1 Health Track

The first data element is the Health Track. A health track is opened when a patient comes to a specialist with a health-related question. During the health track, the required information that will be registered are (Nederlandse Zorgautoriteit, 2020a; Federatie Medisch Specialisten, 2019):

- Patient number;
- Gender;
- Age;
- Health track number: a health track number is a unique number that helps to identify the healthcare path within the institution. This number can be automatically generated by the HIS;
- AGB Code of specialism: code of the specialism that covers the healthcare process;
- Start date: the start date on which the first activity takes place as a result of the demand of the patient. This can be the date of the first medical check, but also, for example, the date of the first outpatient visit. When using the linking mechanism to link healthcare activities to a health product afterwards, is it important to ensure that the start date of the care process is the same as the date on which the first healthcare activity was performed;
- End date: the date on which the healthcare process is closed. In most cases the HIS can fill in the end date automatically based on the automated one closing rules;
- Referring health track number (is automatically filled in by the HIS and refers to the healthcare process from which reference is made for healthcare processes);

## 4.2.2 Sub-Health Track

A sub-health track is opened automatically when a health track is created. These sub-tracks close after a specific amount of days. When a sub-health track is closed, they are sent to the insurer so that the hospital receives money for their medical procedures. If the sub-track is closed when the patient is healed, it can take months or years after the hospital receives money. Therefore, the sub-track will be closed during a specific amount of days to get the money during the medical treatment to have a positive cash flow. This process provides the following information (Nederlandse Zorgautoriteit, 2020a):

- Sub-health track number: A unique number that identifies the sub-track within the hospital is identified. This number can be automatically generated by the registration system;
- Start date: The start date of a sub-route is: The date on which the first activity takes place after the opening of the healthcare process;
- End date: This is the date on which the sub-trajectory is closed. In some cases, the IT system can automatically set the end date based on the closing rules to fill in;
- Health type: the health type is a component within the DTC registration that indicates the type of sub-route. A distinction is made between initial sub-processes (health type 11), follow-up sub-tracks (health type 21) and peer-to-peer consultations (health type 13);
- Specialism code: AGB code of the medical specialist or specialisation that performs this treatment;
- Diagnosis: The typical diagnosis is the diagnosis that best describes the healthcare provided over the sub-track period to be declared;
- Sub-Track closing reason: The closing reason is coded according to the closing reason table.

## 4.2.3 Healthcare Activities

This sub-section describes what information needs to be recorded for healthcare activities. Healthcare activities are the actual delivered healthcare procedures like "placing a cast" or "removing a cast". Healthcare activities are always performed within a sub-health track, so they must be linked to a health track (Nederlandse Zorgautoriteit, 2020a).

The healthcare activity data elements consist of the following attributes:

- Healthcare activity number: a unique number that identifies the healthcare activity within the hospital. This number is automatically generated by the HIS;
- Healthcare activity: the code of the healthcare activity from the healthcare activities table of the NZa;
- Date: date of execution of healthcare activity;
- Applicant specialism: AGB code of the specialism that has the healthcare activity requested;
- Number: the number of care activities performed. In general, "1" is used.

## 4.2.4 Declaration Dataset

The registered information (diagnosis and health activities) are summarised per sub-health track in one structured dataset, the declarationdataset. This declarationdataset is sent to the grouper to derive health products (Nederlandse Zorgautoriteit, 2020a). The summarising of sub-health tracks is as much as possible an automated process within the HIS (Nederlandse Zorgautoriteit, 2020b).

Based on the information of Nederlandse Zorgautoriteit (2020a), a Declarationdataset consists among of:

- Diagnosis Code: a collection of health activities that have been performed;
- Medical Indication: determines whether or not a reimbursement claim is made from the basic health insurance package.

More information can not be found since it is a large dataset that contains a lot of summarised sub-tracks.

## 4.2.5 Declaration Resultset

When the declarationdataset is sent to the Grouper, the Grouper returns the dataset as a declarationresultset. The derived declarationresultset is of high importance since it links a price to a health product, that the hospital sent to the insurer to get compensated for their medical treatment. The declarationresultset contains the following information (Nederlandse Zorgautoriteit, 2020a; Federatie Medisch Specialisten, 2019):

- Declarationresultset Number: with every delivery to the Grouper a new unique declarationresultset number is linked to the declarationresultset;
- Health Product Code: the DTC health product code is composed of a DTC Health Product group code (six positions) supplemented with the DTC Health Product code within the group (three positions);
- Declaration Code: a 6-digit code that displays the health product and the regulated rate or the agreed price of the DTC health product;
- Hashcode: the healthcare product that is derived by a grouper is given a seal, a so-called hashcode. This hashcode guarantees the health insurer and the DIS that the Grouper did the derivation It assures that no changes took place between receiving the declarationresultset back at the hospital and sending the claim to the health insurer or DIS.

#### 4.2.6 Summary

In the previous sub-sections, we have explored the ERD of the declaration chain that includes the data elements with their attributes. With this information, a foundation is created for SQ 1.3; which data elements exist in the patient journey within the declaration chain computerisation flow? Furthermore, the ERD and their attributes

are of importance for the interviews to assign responsibility towards these attributes. In the next section, we will explore the patient journey in which the data elements are used in a real situation with real examples.

# 4.3 Patient Journey

Now we have an understanding of how the health sector and more specifically, the declaration chains works, we can create a patient journey. This will make it easier to understand how the declaration chain works for this research as it provides a reallife example. Doyle, Lennox, and Bell (2013) and Coulter, Fitzpatrick, and Cornwell (2009) are arguing that patient experience is becoming more recognised as one of the three 'pillars of quality in healthcare' alongside patient safety and clinical effectiveness. Actions focused on improving patient experience have also been shown to lead to a better level of overall quality (McCarthy et al., 2016).

Journey maps are used to represent the healthcare service from the perspective of the patient (Trebble et al., 2010; Trebble and Hydes, 2011; Zomerdijk and Voss, 2010). This research will look at a patient journey and follow the steps taken in this journey. A method for personifying the requirements gathering process and aiming improved attention towards patient experience is user personas. User personas involve creating fictive user groups to help design teams in better understanding the mental model of these groups (LeRouge et al., 2013; Maguire, 2001).

To create a realistic environment, a patient journey that is experienced by myself is used for the sake of access to that information. Because of this, correct and realistic healthcare services and activities are included. The patient journey for someone who has pain in the wrist and visualised in Figure 4.3.

Patient comes to GP	Patient is diagnosed	Patient is treated	Patient is discharged
<ol> <li>Patient has pain in wrist</li> <li>GP checks wrist</li> <li>GP recommend to make a picture and sends patient to hospital</li> </ol>	<ol> <li>X-rays are taken in hospital</li> <li>Doctor checks the photos</li> <li>Patient speaks with doctor and receives diagose</li> <li>Doctor prosposes surgery</li> <li>Patient respects doctors advice</li> </ol>	<ul> <li>9. Patient goes to hostipal for hospitalisation</li> <li>10. Patient receives anesthesia</li> <li>11. Patient undergoes surgery</li> <li>12. Doctor is making X-rays in the operation room for checking the surgery</li> <li>13. Patient receives bandage and a cast</li> </ul>	<ul><li>12. Patient stays a night in the hospital</li><li>13. Patient receives a discharge check to move and walk</li><li>14. Patient is discharged</li></ul>

FIGURE 4.3: The Patient Journey of a Person With Pain in the Wrist and that Undergoes Surgery

## 4.3.1 Health Product and Activities

During the surgery, multiple health activities are conducted. Each activity has its own code and the code relates to a specific procedure and cost. During surgery on the wrist, a receipt is created by the insurance company of the health product, visible in Table 4.1. Also, it lists the health activities that are performed in this health product, and these are visible in Table 4.2.

Submitted by:	Healthcare Provider	
Feature:	578055	
Transaction date:	01/11/2018 through 1/24/2019	
Date of receipt:	06-02-2019	
Specialism:	Plastic surgery	
Diagnosis:	H def m.vasc free h / sp / bone patch (code: 025)	
Type of healthcare	Hospital	
provider:	Tospital	
Name of healthcare	Diakonessenhuis	
provider:	Diakonessennuis	
	A hospitalisation for a complex and extensive	
Operation:	operation of muscles/tendons/ blood vessels/nerves	
	by a plastic surgeon (code: 990004012)	
Referred by:	Specialist XXX	

TABLE 4.1: Receipt of Health Insurer for Wrist Surgery

## TABLE 4.2: Health Activities Related to the Wrist Surgery

Date	Health Activity	Code
	X-ray check during placement of bone fractures or	
12-12-2018	location determine foreign body object (also: X-ray	
12-12-2010	check when inserting pen in ankle, elbow and so,	
	in the OR or of unconscious accident patients).	
	Transferring or replacing tissue with blood supply	
12-12-2018	and/or improving blood supply. Complicated surgery,	039046
12-12-2010	for example with a hand or foot, obtaining multiple	039040
	tissue flaps from outside the wound area is included.	
12-12-2018	Nursing day in an institution for specialist medical care.	190218
13-12-2018	Nursing day in an institution for specialist medical care.	190218
13-12-2018	Making a large cast that does not allow movements.	038905
27-12-2018	Removal of small cast	038894
27-12-2018	Making a large cast that does not allow movements.	038905
15-01-2019	Removal of large cast.	038895
15-01-2019	Applying cast for hand and forearm.	039102
24-01-2019	Removal of large cast.	038895

#### 4.3.2 Tracking the Patient Journey

Since we have seen the receipt of the medical treatment in the previous section, we would like to know how it is derived. The structure of the Grouper is available online <sup>1</sup>. It is possible to fill in the Health Activities and the Health Product will be derived based on the activities and Health Product Group. The decision tree of the Group is visible in Figure 4.4. Additional information is visible on the website about Health Products, for example, the price that the healthcare provider charges that has been agreed with the health insurer. For this product is not a maximum price set by the NZa. The Declaration Code is 15D167; the first two numbers indicate that the Health Product is covered by the basic insurance but that there is negotiated about the price.

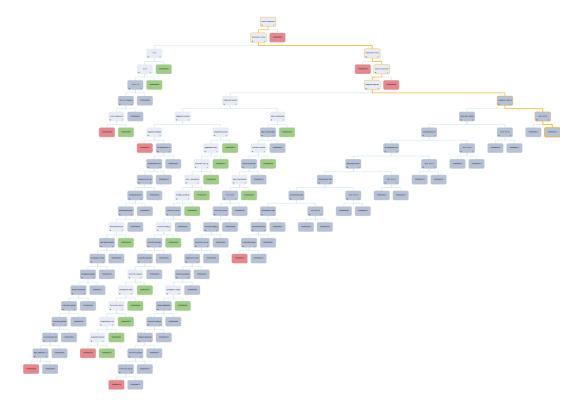


FIGURE 4.4: The Decision Tree of the Grouper for Plastic Surgery, on the Right is the Derived Healthcare Product Visible in Orange

The DIS <sup>2</sup> is a platform what contains partly open data. It is possible to find the Health Products and Health Activities with the number of times it is consumed per year, and, if applicable, the price of a Health Product is indicated. For the Health Product Code used in the patient journey, the number of patients of the last three years can be found in Figure 4.5

<sup>&</sup>lt;sup>1</sup>https://zorgproducten.nza.nl/ZorgproductViewer

<sup>&</sup>lt;sup>2</sup>https://www.opendisdata.nl/msz/zorgproduct

2016		
Specialisme	Diagnose	Aantal patiënten
0304 - Medisch specialisten, plastische chirurgie	025 - Herstel defect met microvasculaire vrije huid / spier / bot-lap	77
2017		
Specialisme	Diagnose	Aantal patiënten
0304 - Medisch specialisten, plastische chirurgie	025 - Herstel defect met microvasculaire vrije huid / spier / bot-lap	70
2018		
Specialisme	Diagnose	Aantal patiënten
0304 - Medisch specialisten, plastische chirurgie	025 - Herstel defect met microvasculaire vrije huid / spier / bot-lap	69

FIGURE 4.5: The Health Product Code in the DIS With the Number of Patients

# 4.4 Regulation Requirements by the NZa

The health care professional who performs the gate function is responsible for determining whether the medical indication requirements are met in the treatment of a patient on the basis of the Health Insurance Act. In addition, he/she is also responsible for properly recording this when registering the healthcare activity (Federatie Medisch Specialisten, 2019).

The Dutch Healthcare Authority came up with a list of declaration provisions for DTC healthcare products:

- 1. The DTC Health Product is declared to the patient or to the health insurer where the patient is on the start date of the DTC Health Product is insured.
- 2. A care provider may only declare a DTC Health Product if the performance has been recorded in accordance with the registration provisions laid down in this regulation and the descriptions and definitions of care activities from the policy rule for services and rates for specialist medical care.
- 3. When declaring a DTC Health Product, the healthcare provider must state the sub-track number.
- 4. The declaration of a DTC Health Product has a seal (hash code), which shows that it is passed through a grouper is distracted.

## 4.5 Summary

In this chapter, we have discussed how the Dutch healthcare sector from a broad perspective. We zoomed in on medical specialist care and more specific, on the declaration chain of it. These are the flows in the healthcare sector what answers SQ 1.2; What are the major flows in the healthcare sector, and how can a patient journey be created? Based on the available literature, we created a schematic overview of the involved parties. An example of a personal patient journey is created, based on the activities that are experienced by myself and the receipts of the health insurer. The patient journey will create a better understanding of what is happening within the different steps of a health question. To solve SQ 1.3; which data elements exist in

the patient journey within the healthcare chain computerisation flow? We focused more on the different data elements within the declaration chain, and the different data elements are visualised in an ERD. The data elements are explained with their function and information in it. The literature we analysed in this chapter does not indicate which party is responsible for what data. Based on this chapter, we can conduct experts interviews to validate and improve these models and identify who is responsible for the data and create a framework around it.

# 5 Data Analysis

In Chapter 3, we have analysed how the declaration chain looks like and which data it involves derived from the literature. Based on this information, Section 5.1 introduces the interviewees, while Section 5.2 presents the highlights of the results of the interviews. The Sections that follow shows improved models of the ERD and declaration chain. Finally, Section 5.5 presents the proposed framework. This chapter is further dedicated to answering SQ 2: What are the requirements for a framework for responsibilities and ownership of data elements?

## 5.1 Interviewees

As stated in the methodology chapter, there are multiple interview prospects identified. After three months of trying to arrange and conducting the interviews, a total of nine interviews took place at eight different organisations and 11 people are interviewed. An interesting observation was that the organisations were eager to help with the interviews, while the academic prospects did not reply to the requests. Therefore, the list of interviewees is slightly different from the intended interview candidate list in Chapter 2. An overview of the different organisations and interviewees with their function is visible in Table 5.1. All of the leading organisations in the declaration chain are interviewed and analysed, which results in almost a full cover of the chain. The interviews were conducted at the beginning of 2020. Based on the interviews, the Ministry of Health, Welfare and Sport is added to the chain but due to time constraints and feasibility, not followed for an interview.

Organization	Function	Size	Interview	Interview	
Organisation	Function	Size	Duration	Date	
Nictiz	Senior Advisor	200	46	09-01-2020	
Health Insurer	Manager Internal Audit, IT Auditor	2.500	1h02	16-01-2020	
i leatur insurer	and Operational Auditor	2.500	11102	10-01-2020	
Health Insurer	Manager Internal Audit	2.500	1h02	16-01-2020	
Vecozo	Business Manager	200	52	17-01-2020	
Hospital X	Head of Health Control	1.100	1h28	22-01-2020	
NZa	Advisor Information Management	400	55	23-01-2020	
ZiNL	Team Manager Data Management	400	45	28-01-2020	
Hospital Y	Staff Advisor Health Registration	12.000	1h04	29-01-2020	
Vektis	Head of Compliance, Audit & Risk	120	48	03-02-2020	
Hospital Y	Coordinator Healthcare Purchasing	12.000	1h42	05-02-2020	
	Planning & Control	12.000	11142	05-02-2020	
Hospital Y	Head of Invoicing and Debtor	12.000	1h42	05-02-2020	
	Management	12.000	11142	00-02-2020	

TABLE 5.1: Overview of the Interviewees

# 5.2 Expert Interview Results

This section is dedicated to present in short the findings per interview. The most important findings are explained here. The interviews are conducted to evaluate the declaration chain overview that was derived from the literature (Figure 4.1) and the ERD of data elements (Figure 4.2), explore who is responsible for what data element based on the findings in section 4.2 and discuss how the collaboration is in the chain. Based on the interviews, we can answer SQ 2.3; What is the current situation of assigning ownership and responsibilities to data elements? And explain SQ 2.4; which parties are responsible and accountable for which data elements within the healthcare sector?

## 5.2.1 Nictiz

Nictiz is not visible at the front of the declaration chain, but more located at the back. They are more focused on quality information with regard to information standards.

"We are at the dawn of digital transformation, and the Dutch way of financing is yet not linked to this"

There is cohesion within the declaration chain, but there is a lack of insights. A lot of data is available and it would become useful if it is possible to make realtime connections with different data streams to see what the consequences are of the actions as a specialist in the hospital. It is possible to increase health productivity with this information. Based on this interviews, we can conclude Nictiz is not very relevant for the sake of this research, and therefore, we did not go into detail who is responsible for what during this research.

## 5.2.2 Health Insurer

One of the main challenges in healthcare is how to get costs down while the quality will go up. There should be a constant discussion with chain partners to better align processes is one example of how to improve the chain. During the interview, more examples were mentioned how the chain could be improved. The interviewees identified that there was no line back from the insurer to the hospital in the declaration figure since they do not approve all the declarations. This is essential for us to know so that we can improve the declaration chain overview.

For the framework we want to create, the interviewees stated that the hospital is the owner of the declarations, and the insurer is responsible for the data that they are processing in their systems. The data in the insurer systems is their argument for the declaration payment. To validate the ERD, the interviewees said that it looks complete and covers the scope of this research and no modifications have to be made.

"In this chain, everyone is responsible for their own data. You can not point to another party because there are so many checks"

The GDPR caused internally in their insurance company that handling data should be very specific and limited to only the people who are allowed to see the information. There are medical specialist on their payroll and only they have the authority to review medical files. One of the biggest improvements in the chain is the implementation of Horizontal Supervision. Horizontal Supervision is a form of cooperation between health insurers and healthcare providers that relies on trust, mutual understanding and transparency. Horizontal Supervision focuses on the regularity of healthcare expenditure. This is on the one hand about correct registration and invoicing and on the other hand about the appropriate use of healthcare.

## 5.2.3 Vecozo

Vecozo manages the Grouper, which is decreed by the Grouper Foundation. The foundation is the owner of the Grouper. The foundation consists of branch organisations of hospitals and insurers. Health insurers have a twofold role; they are the client and user of Vecozo. They communicate with the different parties via interfaces and with certificates.

Vecozo is a processor of a health insurance company and healthcare providers are responsible for the processing of the data and remain responsible for the data in the declaration portal. If the data has arrived at a health insurer again, it is their processing responsibility for the data. A healthcare provider submits a message to them and until Vecozo is responsible and once they have delivered it to the insurer, that processing manager is responsible. The healthcare provider will remain responsible for the content of the messages. This information is important to assign different responsibilities to the data elements.

From the perspective of Vecozo, ownership of those declaration messages belongs to the health insurer, while Vecozo is the processor for the health insurer. Vecozo is not the owner of that data but is a controller responsible for the declaration dataset and the declaration results the decision rules and product structure are both managed by the NZa.

*"From the Vecozo point of view, we have always been working on laws and regulations, and we just had to make some things suitable for the GDPR"* 

From the perspective of privacy legislation, Vecozo can be regarded as the processor of the health insurers which can be seen as the controller. Compared to Vecozo, the healthcare provider can be marked as a third party based on privacy legislation. The healthcare provider always remains responsible for the content and accuracy of the message that they sends through the services of Vecozo.

#### 5.2.4 Hospital X

The interviewee argued that it is a challenge how healthcare can stay manageable. In the hospital, the board of directors is always responsible for everything that happens in the hospital. For the registration of health activities and health, tracks are the medical specialist owner and are accountable. For the declarationdataset, Planning & Control is responsible that the data will be grouped and sent to the payment department. This is information that is useful for our framework. The presented declaration overview is complete and presents the right scope according to the interviewee. Additional background information is that the hospital does a data dump to the DIS every two months.

"ValueCare It is a shell around the HIS, and there are all kinds of controls built-in that you can make yourself. We have built many controls in this and based on that we can see what can be corrected and points for attention"

Because of the GDPR, the department of Planning & Control is busy to rearrange authorisation matrices. Typically the department can modify files, so it lowers the administration for the medical specialist. Nevertheless, now there is uncertainty if they can continue doing this, good reasons are required to do so, or otherwise, the medical specialist has to do more administration and has less time for patient care. This information is relevant for our framework, in which we can assign different rights to the Planning & Control department.

This hospital is one of the first ones with Horizontal Supervision. Horizontal Supervision is a form of cooperation between health insurers and healthcare providers that relies on trust, mutual understanding and transparency. Horizontal Supervision focuses on the regularity of healthcare expenditure. On the one hand, this is about correct registration and invoicing and on the other side about the appropriate use of healthcare (horizontaaltoezichtzorg, 2016).

There is uncertainty in the chain because the government delegated all the responsibilities to third parties. The current system is not controlled; there are too many variations and possibilities for interpretation in the regulations. This results in many discussions on whether someone should receive money (hospital) or give (health insurer) and then the NZa must make a statement about this which will also be subject to a conflict situation. Nowadays, the insurers have a lot of influence since they have the money.

## 5.2.5 Dutch Healthcare Authority

According to the interviewee, a sustainable information system within the healthcare that everyone agrees on is one of the challenges. Now the primary process in the health sector is providing healthcare and the secondary processes do not have this attention yet.

"We are certainly more than a participant. We have the authority to impose registration obligations. That is why the NZa is a director in that sense"

For the validation of the declaration chain figure, the interviewee argued that it is not entirely correct; there is not only a Grouper but a declaration portal as well. Via the Declaration Portal, the insurer receives the declarations. Vecozo is responsible for both applications. There are so-called "other healthcare products" and they are not indicated in the declaration chain. NZa has to decide which health output can be reimbursed and under which conditions and the Grouper decide which output will be derived. This information is used to improve the overview in the next section.

The NZa prescribes how the Grouper should function and how the summarise should look like. Ownership of the DIS lies with the NZa. The goal of the DIS is to look at the derived health products of all patient of the Netherlands and which prices were charged. Besides hospitals and insurers negotiate over health prices, the NZa creates a list of maximum rates that can be charged by hospitals. These pieces of information is taken into account when we will design the framework. The introduction of the GDPR did not change a thing in the declaration chain. All the information that is registered is essential for the declarations of healthcare. Internally, the NZa created a lot of measures around the DIS.

## 5.2.6 Health Institute Netherlands

The role of ZiNL in the chain is mainly focused on "risk equalisation". The idea behind this is that insurers are not allowed to make a distinction between high and low-risk groups. At the back in the declaration chain, there is compensation for an equal level playing field of health insures in the Netherlands.

"We are quite advanced with the coordination and integration of declaration traffic and the use of declaration data"

ZiNL receives a lot of data via different sources like DIS, Vektis and insurers, but the health insurer always remains responsible for the declaration. Via accountant statements, they need to prove that the data is checked and paid. This is relevant information for our framework. Regarding the declaration overview, the interviewee agreed that it provides a good overview.

Concerning the GDPR, the involvement of third parties has become more difficult. There were already agreements in place between hospitals and healthcare providers, and nothing has to change for that. However, with third parties, there has to be a processing agreement. The GDPR makes everything more complicated in a judicial way.

To conclude, the interviewee argued that quality data is a challenge in this chain. Many organisations have a lot of data but can not use it for research because it is hard to get permission for it. Most of the time, the data is only used for statuary duties.

## 5.2.7 Hospital Y Staff Advisor Health Registration

To validate the declaration overview, the interviewee argued that the registration process in the HIS is complicated, but the medical specialist is always responsible for their DTCs. Declaration chain is complete, but there is a line missing from the hospital directly to the patient. If there are no medical needs, the treatment is not covered by the insurer, and the receipt will go to the patient.

"The current DTC system is very complicated and complex"

According to the interviewee, the ERD looks complete, but the process of negotiating prices is complex, and there is not a standard price for every hospital and insurer. The IT department is responsible that the internal Grouper works and that the HIS is

working. Planning & Control is responsible for making prices between the insurers and inserting them into the HIS. The Billing department is responsible for approving invoices. This information will be used in the framework as well.

In the hospitals, the goal is to lower the administrative burden, but outside the hospitals, they want to justify everything that happens within the hospital what results in an increase in administrative tasks.

## 5.2.8 Vektis

The main takeaways from this interview are that from the point of view of Vektis, the health insurer always is responsible for the declaration data. The Ministry of Health (VWS) must probably take control of the chain. It would help Vektis if there someone with a legal role in the whole.

A healthcare provider is responsible for correctly completing the declaration standard. A health insurance company is then responsible for reliably translating it into an invoice. It is not formally recorded who is responsible for what within this chain, and with that, this research could help. Furthermore, the ERD and declaration chain are complete and validated by the interviewee.

"What makes Vektis unique is that it provides a total picture of the entire healthcare sector. We have information from all health insurers, so we have information from all insured persons in the Netherlands. No other party in the Netherlands has that information"

VWS is a policymaker in healthcare. The healthcare authority is more enforced and supervised, while the Ministry of Health, Welfare and Sport creates policy for how healthcare should be organised in the Netherlands. VWS is responsible for ensuring that the chain looks the way it looks.

## 5.2.9 Hospital Y Planning & Control

The interviewees argued that the declaration chain figure is complete, but it depends on which level of detail the focus is. If the focus is on a high-level view, the figure looks good. Since this hospital is using Horizontal Supervision, there are work instructions and procedures created that are accounted for by two health insurers. For all the processes within health administration until receiving the money, there are process owners. Therefore, they know who is responsible for all the processes and how the processes are constructed.

In terms of responsibilities, medical specialists can have a so-called "extended arm construction", which means that they can delegate responsibilities to other people within the department like administrative people. However, everything falls under the responsibility of the specialist. The head of Invoicing and Debtor Management is the owner of the declarationdataset. Together with IT and Chipsoft, they make sure that a declarable product will be derived. The summarise activity is as well the responsibility of the Invoicing and Debtor Management. Planning & Control is responsible for the prices. This is essential and valuable information for our framework.

The GDPR caused many consequences for their workflows. It takes a lot more steps to communicate with patients electronically and as well as communicating with other hospitals.

"We have controls in place to predict where incorrect registrations are likely to happen"

There are logical controls in the HIS system, but they are not very detailed and based on law and regulations. They are using a system called Notiz to manually create new controls that can not be built in the HIS.

## 5.3 Improved Declaration Chain Overview

We presented earlier an overview of the declaration chain in Figure 4.1. In the interviews, we presented this overview and asked if it is correct and how it can be improved. Based on the information gathered from the interviews, the declaration chain that is derived from the literature is improved and therefore validated. The new model is presented in Figure 5.1 and the different connections are elaborated below the Figure. This will help us in answering SQ 2.4; Which parties are responsible and accountable for which data elements within the healthcare sector?

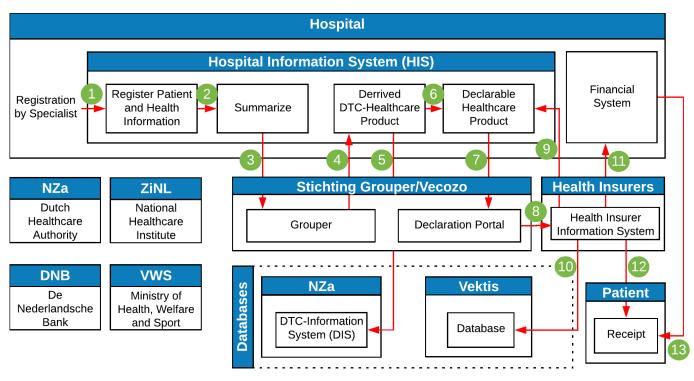


FIGURE 5.1: Schematic Overview of the Declaration Chain Improved Via Interviews

- 1. Medical specialist (or someone who has permission) registers information about the patient and performed healthcare activities;
- 2. All health activities are combined and grouped into a declarationdataset;
- 3. The declaration dataset is sent to the Grouper, for hospital X this happens every Wednesday afternoon;
- 4. The Grouper returns a healthcare product to the hospital;
- 5. Dutch Healthcare Authority receives around every two months a data dump from hospitals based on the output of the Grouper;
- 6. Each hospital has a price for each healthcare product that will be linked to the healthcare products;
- 7. Declaration from the hospital is sent to the Declaration Portal of Vecozo;
- 8. Via the Declaration Portal, the declaration will go to the health insurer;
- 9. The declaration can get rejected by the insurer and it goes back to the hospital for control. Adjustments can be made in the declaration so that the insurer will accept it;
- 10. Every health insurer needs to send monthly information about all their declarations to the Vektis Database for analysis;
- 11. If the declaration is approved by the insurer, the hospital gets paid;
- 12. A patient will receive a receipt of the insurer that contains information about the own risk and costs;
- 13. Some medical activities will not go via the insurer, but the receipt goes directly to the patient. In most of the cases, this is for uninsured healthcare like plastic surgery for non-medical reasons.

## 5.4 Improved ERD

The ERD that we have created based on the literature in Figure 4.2 was presented to the interviewees as well for validation; however, no significant comments were made. For the scope of this research, it presented the different elements on an appropriate level what is usable for this perspective. Minor comments were made about the names of different data elements since they are translated from Dutch to English. The choice to exclude the additional healthcare products was made to do not go too deep in the details for a clear overview. There were comments that there are no additional healthcare products in the figure, but after elaborating, the interviewees agreed that this was not necessary for our overview. Therefore, there is no need to change the figure, and the model derived from the literature presents the right information.

## 5.5 Framework Formalisation

#### 5.5.1 Method

So far, we have answers for SQ 1.2; what are the major flows in the healthcare sector? SQ 1.3; which data elements exist in the declaration chain? SQ 2.2; what frameworks exist for assigning ownership and responsibilities? Lastly, based on the interviews, SQ 2.4; which parties are responsible and accountable for the data elements? We will combine the outcomes of these SQs to create the framework and to answers SQ 2; what are the requirements for a framework for responsibilities and ownership of data elements?

Based on SQ 1.2 and 1.3, we can combine these two models into a single figure, what represents a global overview of the parties, activities and data elements. Section 5.5.2 will go into detail and present the overview.

During the interviews, it became clear that it is hard to assign ownership and responsibilities towards data elements because there are many different viewpoints. Therefore, an attempt is made to create a better understanding of different views. In SQ 2.2, we have identified the different frameworks for ownership and responsibilities. The CRUD Matrix is selected because it will give us an overview of the data elements and which basic operations can be done on the data by the different organisations. In Section 5.5.3, we will elaborate on the CRUD Matrix.

With the CRUD Matrix, we can assign the mutations per data element, but not at the attribute level. As identified in Section 5.2 in the interview results, the interviewees have indicated who is responsible for the registration of the attributes and what is the source information of the attributes. With this information, an attempt is made to show who is responsible for the correct registration of the attribute and indicate the source. Section 5.5.4 presents the results.

However, not everything that is argued by the interviewees could be modelled into the figures. There are a few exceptions, and those are captured in a set of business rules. Section 5.5.5 will elaborate on those business rules.

With every viewpoint, we will zoom-in into detail on the data elements. So, in short, the three different viewpoints we will explore are:

- 1. An overview of how the different processes correlate with the data elements;
- 2. Indicate which party can create, read, update and delete the data elements;
- 3. Indicate who is responsible for the correct registration of the data and what is the source of the data.

To visualise these viewpoints, Figure 5.2 presents the correlation between the viewpoints.

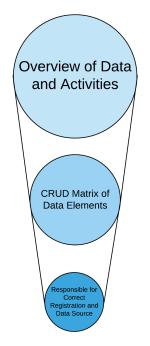


FIGURE 5.2: Relation of the Three Models Visualised

## 5.5.2 BPMN

To capture the first viewpoint for activities and data elements, a Business Process Model and Notation (BPMN) is created. A BPMN is a standard for business process modelling that provides a graphical notation for specifying business processes in a Business Process Diagram (BPD) (Simpson, 2004) based on traditional flowcharting techniques. The objective of BPMN is to support business process modelling for both technical users and business users, by providing a notation that is intuitive to business users, yet able to represent complex process semantics (Rosing et al., 2015). For our purposes, it is a combination of the early identified declaration chain overview (Figure 5.1) and the Entity Relationship Diagram (Figure 4.2). The BPMN is visualised in Figure 5.3.

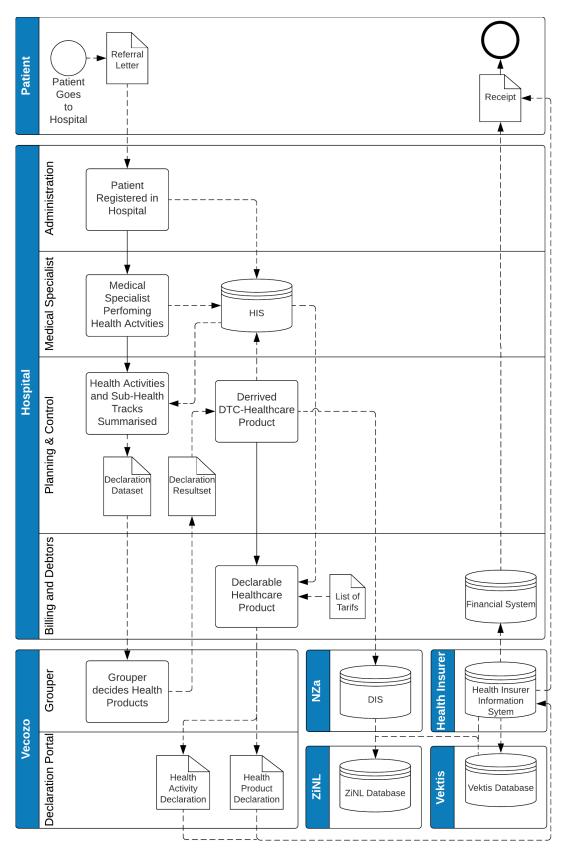


FIGURE 5.3: BPMN of the Declaration Chain With ERD and Overview Combined

## 5.5.3 CRUD Matrix

In Chapter 3, we explored the different models for ownership and responsibilities. Via the conducted interviews and available literature, the first attempt is made to create an understandable overview of those ownership and responsibilities. The CRUD Matrix is selected for this because it is a simple table that contains valuable information that can quickly be interpreted. Table 5.2 presents the CRUD Matrix for the different data elements. It indicates who creates, reads, updates and deletes the data.

	Vektis	<b>N</b> 7	NZa	Health		Hosp	ital	
	Vektis	Vecozo	INZa	Insurer	Planning	Invoicing	Health	Medical
					& Control	involenig	Admin	Specialist
Health Track							CRUD	CRUD
Sub-Health							CRUD	CRUD
Track							CROD	CROD
Healthcare							CRUD	CRUD
Activity								
Declaration		R			CRUD			
Dataset								
Declaration		С	R		R	R		
Resultset					K	K		
List of Health		R	C	R	R	R	R	R
Products				K				
List of Health		R	С	R	R	R	R	R
Groups								
Health Activity				R	CRUD	CRUD		
Declaration				K	CROD			
Health Product				R	CRUD	CRUD		
Declaration				IX.	CROD	CROD		
List of Tariffs		R	CRUD	CRUD	R	CRUD		
Health Activity	R	R	R	CRUD	R	R		
Receipt	К	К	К	CROD	К	К		

TABLE 5.2: CRUD Matrix for the Data Elements

## 5.5.4 Responsibilities and Source of Data Elements

For each of the data elements and even on attribute level, someone is responsible for the correct registration of information. Most of the data come from a master table, like the AGB code. Vektis is the owner of the AGB register that contains all the AGB codes of all healthcare professionals and institutions. The medical specialist is responsible for inserting the right AGB code. Still, if the specialist once received the wrong one, Vektis is accountable for assigning the correct AGB codes to the professionals.

In the interviews, the participants have attempted to indicate the different responsibilities and sources. The overview is presented in Figure 5.4.

Health Track	Registration	Source
Patient Number	HIS	HIS
Gender	Administration	HIS
Age	Administration	Age
Health Track Number	HIS	HIS
AGB Code of Specialism	Medical Specialist	Vektis
Start Date	HIS	HIS
End Date	HIS	HIS
Referring Health Track Number	Administration	GP
Sub-Health Track	Registration	Source
Sub-Health Track Number	HIS	HIS
Start Date	HIS	HIS
End Date	HIS	HIS
Health Type	Medical Specialist	NZa
AGB Code of Specialism	Medical Specialist	Vektis
Diagnosis	Medical Specialist	NZa
Sub-Track Closing Reason	Medical Specialist	NZa
Healthcare Activity	Registration	Source
Healthcare Activity Number	HIS	Nza
Healthcare Acitivity	HIS	NZa
Date	HIS	HIS
Applicant Specialism	Administration	HIS
Number of activities	Administration	HIS
Declaration Dataset	Registration	Source
Declaration Dataset Diagnosis Code	Registration Medical Specialist	Source NZa
	-	
Diagnosis Code	Medical Specialist	NZa
Diagnosis Code Medical Indication	Medical Specialist Administration	NZa Health Insurer
Diagnosis Code Medical Indication Declaration Resultset	Medical Specialist Administration Registration	NZa Health Insurer Source
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number	Medical Specialist Administration Registration Grouper	NZa Health Insurer Source Grouper
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code	Medical Specialist Administration Registration Grouper Grouper	NZa Health Insurer Source Grouper NZa
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code	Medical Specialist Administration Registration Grouper Grouper Grouper	NZa Health Insurer Source Grouper NZa NZa
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper	NZa Health Insurer Source Grouper NZa NZa Grouper
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Registration	NZa Health Insurer Source Grouper NZa NZa Grouper Source
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Registration Hospital	NZa Health Insurer Source Grouper NZa NZa Grouper Source HIS
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Hospital Registration	NZa Health Insurer Grouper NZa NZa Grouper Source HIS Source
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Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration List of Tarifs	Medical Specialist         Administration         Registration         Grouper         Grouper         Grouper         Grouper         Hospital         Registration         Hospital         Registration         Hospital         Registration         Hospital	NZa Health Insurer Source Grouper NZa NZa Grouper Source HIS Source HIS Source NZa/Hospital/Health Insurer
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration List of Tarifs	Medical Specialist         Administration         Registration         Grouper         Grouper         Grouper         Grouper         Hospital         Registration         Hospital         Registration         Hospital         Registration         Hospital         Registration         Hospital	NZa         Health Insurer         Source         Grouper         NZa         Orouper         Source         HIS         Source         HIS         Source         NZa         Source         HIS         Source         HIS         Source         Source         Source         NZa/Hospital/Health Insurer
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration List of Tarifs	Medical Specialist         Administration         Registration         Grouper         Grouper         Grouper         Grouper         Hospital         Registration         Hospital         Registration         Hospital         Registration         Hospital         Registration         NZa	NZa Health Insurer Grouper NZa NZa Grouper Source HIS Source HIS Source NZa/Hospital/Health Insurer NZa/Hospital/Health Insurer
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration List of Tarifs	Medical Specialist         Administration         Registration         Grouper         Grouper         Grouper         Grouper         Grouper         Hospital         Registration         Hospital         Registration         Hospital         Registration         Hospital         Registration         Hospital         Registration         Hospital         Registration         Hospital	NZa Health Insurer Grouper NZa NZa Grouper Source HIS Source HIS Source NZa/Hospital/Health Insurer NZa/Hospital/Health Insurer

FIGURE 5.4: Responsible for Correct Registration and Source of the Data

## 5.5.5 Business Rules

Not everything can be modelled. For these derivations, business rules exist. Many definitions of business rules are presented in published work (Ross, 2003). According to Hay, Healy, and Hall (2000), a business rule is a statement that defines or constrains some aspect of the business. It is intended to assert business structure or to control the behaviour of the business (Hay, Healy, and Hall, 2000). In the literature and during interviews, some statements were made or found that are important to know but can not be modelled. Therefore, these statements are stated below as business rules:

- 1. NZa prescribes which information should be supplied to the grouper and to the health insurers;
- 2. NZa prescribes how healthcare products should be derived and under which conditions;
- 3. The EI standard (EI = External Integration), whereby the technical specifications (such as file structure, record types, etc.) for the electronic exchange of declaration data between healthcare providers and healthcare insurers. This is a technical template for how information should be sent between parties and is managed by Vektis;
- 4. Vecozo is the controller (Dutch: verwerkingsverantwoordelijke) of the Declaration Dataset and the Declaration Resultset.

## 5.6 Summary

This chapter discussed what the results are of the interviews. It highlighted the main takeaways and interesting insights. Based on these interviews, the Declaration Chain overview is improved for our scope of research. It indicated that organisations internally assigned responsibilities to different data elements but not between organisation within the whole chain, what answered SQ 2.3; what is the current situation of assigning ownership and responsibilities to data elements? Furthermore, it confirmed that the created ERD based on the literature is complete. We have answered SQ 2.4; which parties are responsible and accountable for which data elements within the healthcare sector? By creating different models that together are the framework for this research.

In the next chapter, we will validate with validation interviews if the created models are indeed correct and how it will contribute to the declaration chain.

# 6 Consolidated Framework

During the evaluation of the consolidated framework, we let domain experts evaluate the proposed framework. This information is elicited from a series of semistructured interviews to answer SQ 3; how does it perform, what recommendations can be made and is the framework applicable to different chains in different sectors regarding generalisability? In Section 6.1, an introduction into evaluation in Design Science research is provided followed by Section 6.2 were the interviews are analysed and improvements for the framework are proposed.

#### 6.1 Evaluation in Design Science Research

Now we have created the different figures and tables based on the interviews; we need to validate if they are representing correct views, information, and help to fill the gap in the literature and practice. March and Smith (1995) define evaluation as "the process of determining how well the artefact performs." (p. 254). The central purpose of DSR evaluation is to rigorously demonstrate the utility of the artefact being evaluated (Stufflebeam, 2000). DSR design artefacts "are assessed against criteria of value or utility" (March and Smith, 1995).

"Evaluate an instantiation of a designed artifact to establish its utility and efficacy (or lack thereof) for achieving its stated purpose" (Venable, Pries-Heje, and Baskerville, 2012, p. 4251).

The fundamental purpose of evaluation in DSR is to determine how well a designed artefact or ensemble of artefacts achieves its expected environmental utility (an artefact's main purpose) (Venable, Pries-Heje, and Baskerville, 2016). The second purpose of an evaluation is the substantiation of design theory in terms of the quality of the knowledge outcomes (Kuechler and Vaishnavi, 2012), that is, to provide evidence that the approach leads to some developed artefact that will be useful for solving some problem or making some improvement (Venable, Pries-Heje, and Baskerville, 2016).

Based on the evaluation criteria by (Prat, Comyn-Wattiau, and Akoka, 2014), an evaluation protocol is created. Prat, Comyn-Wattiau, and Akoka (2014) created a holistic view of evaluation criteria, a model providing a high-level abstraction of evaluation methods, and generic evaluation methods, which are instantiations of this model. The interview protocol can be found in Appendix **B.5**.

#### 6.2 Validation Interviews

#### 6.2.1 Interview Participants

For the validation of the different models, two validation interviews are performed. For the sake of ease and expertise, one prospect from the earlier interview is used, namely the Hospital Y Staff Advisor Health Registration. To gain more insights from a different perspective and to increase validity, a Senior Manager IT Assurance Healthcare of KPMG is interviewed. More interviews will increase validity and therefore, a third participant was selected, but the validation is declared invalid what will be highlighted in the next sub-section.

#### 6.2.2 Threats to Validity

At the time of writing the validation process, the COVID-19 crisis is currently happening. This results that the interviews can not take place in person. Therefore, the interview with the KPMG Manager has taken place over Skype, and Hospital Y is asked to fill in the interview questions on paper. It is a threat to validity to have one person who was interviewed during the information elicitation phase and is now used to validate the framework. However, since the models are based on nine interviews, the perception of the other interviewees is captured as well what results in a broad view of the problem and is not limited to only a few interviews. For the framework validation, a third interview was planned but not considered valid because when it came back via the mail, the validation protocol was not followed by the participant. Due to time constraints, it was not feasible to get the third validation.

#### 6.2.3 Results

#### BPMN

The interviewees made a few comments regarding the BPMN. What is important to keep in mind is the purpose of the models. Not all the variant deviations are modelled, but that is a specific choice since there are a lot of exceptions within this whole process. The KPMG Manager argued that the name for Planning & Control is not precisely the right name. Usually, Finance & Control is the commonly used name for departments like this. Therefore, the name Finance & Control would present a better view.

The interviewee from Hospital Y argued the same. The step of "Planning & Control" mainly includes parts that are carried out by the Healthcare Administration. Planning & Control is, therefore, not the correct term in practice; Nationally, it is often referred to as the healthcare administration/health control department. Planning & Control is the department where prices are agreed, where the budget is made and where the finances are monitored.

#### **CRUD** Matrix

This CRUD Matrix presents a correct view for the purposes of this research, especially regarding generality. The CRUD of the price lists is in Finance & control. This is often referred to as healthcare purchasing, which can be a department under Finance & Control. The billing cannot update the price lists but Planning & Control that controls healthcare purchasing contracts. So billing cannot update the price lists; otherwise, this is a threat, and alarm bells will go off.

The interviewee from Hospital Y identified that the CRUD is a valuable overview which gives a nice overview. Also, more organisations can Read the different data elements. Therefore, adjustments need to be done in the CRUD matrix to present the current situation.

#### **Registration and Source**

Overall, the interviewees agreed that this is a complete table. There are some small remarks; End date does not have to go automatically because, for example, the patient can die. The administration is therefore responsible for the end date. This is a good level for an overview and a high-level overview. But if a system needs to be designed based on this, the level of detail should go deeper.

#### 6.2.4 Recommendations

The interviewees said that the perspective is at the detail level, and it seems to be right there. The view that is missing is all deviations in the DTCs and alternative routes, but our model has consciously opted for this.

The framework can help in two areas:

- The specialists never really understand why this registration is complicated; they have to make people better and not do administration work. This model does not provide insight into the complexity that happens behind the scenes. The KPMG manager had experienced this in practice when he was a manager in a health institution; he invited care providers to look at the administration and let administrative employees walk with care providers. So this works well to provide healthcare providers with insight into the primary process.
- 2. This would help make the process leaner, how can it be more efficient. The KPMG manager always says that there are only two important things at a healthcare institution: the billing and salary department. If they are not suitable then you have a problem, this is said as a joke, but there is some truth in it.

The interviewee from Hospital Y said: "This will probably not improve cooperation, but only if there are also solutions, joint interests are present, and if communication is constructive".

#### 6.2.5 Generalisability

Mental healthcare (Dutch: GGZ) is very similar to medical specialist care, and the models can easily be transformed into models for that sector. Instead of a medical specialist, there are psychologists or psychiatrists. There are no health activities and sub-tracks because everything is registered on time, and there can be group treatments or individual treatments. Those components in time then add up to a healthcare product. In the elderly and disabled care, it is significantly different from other parameters.

Hospital Y argued the same that it is relatively comparable for GGZ because it also uses DTCs. Care at home and care for the disabled work differently; although the steps of refer-treat-register-declare-price-agreements are also present there.

"I find the overviews very clear and visual, so it is definitely an added value." - Interviewee Hospital Y

This implies that the models are indeed filling a gap in practice.

#### 6.2.6 Improved Models

Based on the two validation interviews, improvements to the CRUD Matrix and Registration Table are made for completeness. In Figure 6.1, the improved CRUD Matrix is visible with mainly more Reads added.

	Vektis	<b>N</b> 7	NZa	Health		Hospi	ital	
	vektis	Vecozo	INZa	Insurer	Finance	Invoicing	Health	Medical
					& Control	mvoicing	Admin	Specialist
Health Track			R	R	R	R	CRUD	CRUD
Sub-Health			R	R	R	R	CRUD	CRUD
Track			R	K	K	K	CROD	CROD
Healthcare			R	R	R	R	CRUD	CRUD
Activity			K	<u>к</u>	K	K	CROD	
Declaration		R			CRUD	R	CRUD	
Dataset					eneb			
Declaration		С	R	R	R	R	R	
Resultset								
List of Health		R	С	R	R	R	R	R
Products							R	
List of Health		R	С	R	R	R	R	R
Groups								
Health Activity				R	CRUD	CRUD		
Declaration					eneb			
Health Product				R	CRUD	CRUD		
Declaration					CROD			
List of Tariffs		R	CRUD	CRUD	R	RD		
Health Activity	R	R	R	CRUD	R	R		
Receipt	IX.	, K	IX.	CROD	IX.	IX.		

TABLE 6.1: CRUD Matrix for the Data Elements

Figure 6.1 presents the improved overview of which party is responsible for the registration and source of the data.

Health Track	Registration	Source
Patient Number	HIS	HIS
Gender	Administration	HIS
Age	Administration	Age
Health Track Number	HIS	HIS
AGB Code of Specialism	Medical Specialist	Vektis
Start Date	HIS/Administration	HIS
End Date	HIS/Administration	HIS/NZa
Referring Health Track Number	Administration	GP
Sub-Health Track	Registration	Source
Sub-Health Track Number	HIS	HIS
Start Date	HIS/Administration	HIS
End Date	HIS/Administration	HIS/NZa
Health Type	Medical Specialist	NZa
	·	Vektis
AGB Code of Specialism	Medical Specialist	
Diagnosis	Medical Specialist	NZa
Sub-Track Closing Reason	Medical Specialist	NZa
Healthcare Activity	Registration	Source
Healthcare Activity Number	HIS	Nza
Healthcare Acitivity	HIS	NZa
Date	HIS/Administration	HIS
Applicant Specialism	Administration	HIS
Number of activities	Administration	HIS
Declaration Dataset	Registration	Source
Declaration Dataset Diagnosis Code	Registration Medical Specialist	Source NZa
	-	
Diagnosis Code	Medical Specialist	NZa
Diagnosis Code Medical Indication	Medical Specialist Administration	NZa Health Insurer
Diagnosis Code Medical Indication Declaration Resultset	Medical Specialist Administration Registration	NZa Health Insurer Source
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number	Medical Specialist Administration Registration Grouper	NZa Health Insurer Source Grouper
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code	Medical Specialist Administration Registration Grouper Grouper	NZa Health Insurer Source Grouper NZa
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code	Medical Specialist Administration Registration Grouper Grouper Grouper	NZa Health Insurer Source Grouper NZa NZa
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper	NZa Health Insurer Source Grouper NZa NZa Grouper
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Registration	NZa Health Insurer Source Grouper NZa NZa Grouper Source
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Registration Hospital	NZa Health Insurer Source Grouper NZa NZa Grouper Source HIS
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Registration Hospital Registration	NZa Health Insurer Grouper NZa NZa Grouper Source HIS Source
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Hospital Registration Hospital	NZa Health Insurer Grouper NZa NZa Grouper Source HIS Source HIS
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Hospital Registration Hospital Registration	NZa Health Insurer Grouper NZa NZa Grouper Source HIS Source HIS Source
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration List of Tarifs	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Megistration Hospital Registration Hospital Registration	NZa Health Insurer Grouper NZa NZa Grouper Source HIS Source HIS Source NZa/Hospital/Health Insurer
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration List of Tarifs	Medical Specialist         Administration         Registration         Grouper         Grouper         Grouper         Grouper         Hospital         Registration         Hospital         Registration         Hospital         Registration         Registration         Registration         Registration         Registration	NZa   NZa   Health Insurer   Source   Grouper   NZa   NZa   Grouper   Source   HIS   Source   HIS   Source   NZa/Hospital/Health Insurer   Source   Source
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration List of Tarifs	Medical Specialist         Administration         Registration         Grouper         Grouper         Grouper         Grouper         Hospital         Registration         Hospital         Registration         Hospital         Registration         Hospital         Registration         NZa	NZa         NZa         Health Insurer         Source         Grouper         NZa         NZa         Grouper         Source         HIS         Source         HIS         Source         NZa/Hospital/Health Insurer         NZa/Hospital/Health Insurer
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration List of Tarifs	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Megistration Hospital Registration Hospital Registration NZa Registration	NZa         NZa         Health Insurer         Source         Grouper         NZa         NZa         Grouper         Source         HIS         Source         HIS         Source         NZa/Hospital/Health Insurer         NZa         NZa         Source         NZa/Hospital/Health Insurer         Source         NZa         Source         NZa
Diagnosis Code Medical Indication Declaration Resultset Declarationresultset Number Health Product Code Declaration Code Hashcode Health Activity Declaration Health Product Declaration List of Tarifs List of Tarifs List of Health Product Groups	Medical Specialist Administration Registration Grouper Grouper Grouper Grouper Megistration Hospital Registration Hospital Registration NZa Registration NZa	NZa         NZa         Health Insurer         Source         Grouper         NZa         NZa         Grouper         Source         HIS         Source         HIS         Source         NZa/Hospital/Health Insurer         NZa         NZa         NZa         NZa/Hospital/Health Insurer         NZa         NZa         NZa         NZa

FIGURE 6.1: Responsible for Correct Registration and Source of the Data Based on Validation Interviews

#### 6.3 Summary

The main takeaways from this chapter are that the different models are creating added value in the declaration chain. We have answered SQ 3.1; How does the framework perform? SQ 3.2; What recommendations can be made? And finally SQ 3.3; Is the framework applicable to different chains in different sectors regarding generalisability? The framework captures the different viewpoints and is complementary to each other. In the literature, there was not a high-level overview available of the declaration chain. With this research, such a model is created that can be used in practice to explain to health professionals why registration is essential and what the process is. The interviewees have identified different points on which the models can be improved. Since mental healthcare consists of almost the same structure as medical specialist care, it can be easily transformed into that sector in terms of generalisability.

# 7 Discussion and Limitations

This chapter assesses the limitations of the research. In Section 7.1, the different threats to validity in Section 7.2 and finally, Section 7.3, highlights the contributions in perspective for the healthcare sector and academia.

#### 7.1 Limitations

First of all, during the last three months of this research, the COVID-19 crisis is happening in the Netherlands. This results in multiple limitations for this research. To start with, the guidance of the internal and external supervisors is more difficult. For validation of the models, it was harder to get in touch and to conduct the validation interviews because it is hard to present the models via a computer connection instead of showing the models on paper in person.

In the Netherlands, there are two types of hospitals; hospitals that use salaried employment for medical specialists and there are hospitals that use a partnership model (Dutch: maatschap or Medisch Specialistisch Bedrijf) for a medical specialist (Schoten, Wagner, and Erp, 2016). In such a hospital, the specialist receives money for every treatment conducted with their name on the DTC. This structure can cause that specialist is better in registering healthcare activities while the specialist in a salaried environment is less focussed on registering. In this research, we interviewed two hospitals that use salaried employment. The partnership hospitals are not in this context of this study and therefore, these hospitals can differ from our created models.

In the research methodology, we had identified several interview prospects to capture practical and academical perspectives of chain thinking. Interesting enough is that all the health-related organisations responded favourably to the interview requests, while the academia, did not respond. This is a limitation in the academical background, since we could not interview experts in that area.

#### 7.2 Threats to Validity

In Section 2.6.5, we mentioned four types of validity namely: construct validity, internal validity, external validity, and reliability (Runeson and Höst, 2009; Yin, 2017; Wohlin et al., 2012). In this subsection, we reflect on the possible validity threats that originated with this research, related to these validity types.

#### 7.2.1 Construct Validity

To prevent this research from construct validity, all the organisations within the declaration chain are interviewed. By using multiple sources, validity will increase. Every designed artefact in this research is at least validated once by multiple experts.

For the validation interviews, an earlier interviewed organisation was contacted, and the interview protocol was sent. However, when the interview protocol was returned, it was not filled in. Only two comments were made regarding the framework of the perspective of the questioned company. Therefore, only two validation interviews are used instead of the three that were intended. This highlights the problem within the chain as well; the organisations only look at what is relevant for their organisation and not chain-wide.

#### 7.2.2 Internal Validity

In this research, our methodology protocol is followed and all the interviewees received the same questions regarding the ownership and responsibility part. Therefore, the instrumentation is the same for all the interviewees; they have seen the same models and the same tables. We assumed that they are all knowledgeable in this area of expertise. During the interviews, first, an introduction to the problem was presented, and all the participants understand what was happening. In the next set of questions, they were asked to give their view on the declaration chain and who is responsible for the data. Mortality of this research was only applicable to the final validation interview, in which the participant did not have enough time to meet the requirements of the interview.

#### 7.2.3 External Validity

As stated in the framework validation section, the framework can easily be adapted to the mental healthcare sector. A threat regarding generalisability is that this only works for healthcare in the Netherlands, and healthcare in other countries are organised differently (Busse et al., 2013). The selected population for the declaration chain is fully covered by all the interviewed organisations what strengthens this research. However, as we discussed on the limitations section, a partnership model in hospitals can cause that it is different for registering healthcare activities. This financing model can cause a threat to external validity.

#### 7.2.4 Reliability

Other researchers can reproduce the conducted research because the interview protocol is uniform for each organisation; however, some adjustments are made per organisation. Questions regarding the chain and the responsibilities are the same, but for hospitals, additional questions are added to get a better understanding of their processes. The different interview protocols are listed in Appendix B.1. When changes are made by the NZa on how registration should be performed, the results from this research will differ. If new guidelines change the process, hospital staff and specialists should make modifications in their way of working, and new regulations can have consequences for the different organisations in the chain.

### 7.3 Contributions

#### 7.3.1 Scientific Contributions

This research results in multiple scientific contributions. First and foremost, the goal of this research is to identify what is a suitable framework that can be used in the context of assigning responsibilities and ownership to data elements in a chain computerisation perspective for the declaration chain in the Dutch hospital healthcare sector. An attempt is made to visualise the information flows based on interviews within the computerisation chain on three different levels. First, an overview of the activities and data elements in a BPMN, followed by a CRUD matrix to identify which party can mutate what data, Finally, at attribute level, we classified who is responsible for the attribute and the source (ownership). These models did not exist yet, but with this research, it filled a gap in the literature that we identified in Section 7.3. During the validation interviews, it became clear that the constructed models add value. The Dutch Declaration chain is an area of a lot of debate in politics and among health institutions.

In the literature review, multiple definitions for interorganisational collaboration are discussed, which chain computerisation provides a good definition for our research. In the literature, chain computerisation is not used that often; however, it provides us with a correct corresponding definition. This is a contribution to science to investigate the term chain computerisation in collaboration with the healthcare declaration.

Furthermore, we created a real patient journey which the attributes contain data that is used in daily practice. No such journey exists for the declaration chain in the Netherlands. This can give a better understanding to patients how the process goes of their medical treatments towards eventually, their health receipt. In the interviews, the hospitals say that they receive a lot of questions of patients of what their is receipt saying and how the process of declaration works. This gap is filled with this research by explaining all the steps in the declaration process and how it is translated to a receipt.

For the scope of this research, the impact of GDPR on this chain is hard to identify, since all the chain collaborators only look at themselves and have not chain-wide vision. A formal data governance structure in the chain is missing as well. Some organisations have a processing agreement between each other, but that is not the case among all the organisation. There should be more constructive collaboration

and a clear understanding of the roles of all the participants, so they know what the purpose is of every organisation within the chain. Unfortunately, since it was not possible to get in touch with the academic interview prospects, an academic validation of the framework is not conducted, what could yield into new insights.

#### 7.3.2 Practical Contributions

The practical contribution of this research is that it creates a clear overview of the declaration chain for medical specialist healthcare. There was not such overview available, but now it can be used as a global picture for participants within the declaration chain or people who are exploring this. During the validation interviews, one important key finding came up, and that is with the created model, the doctors can get an understanding of how the administrative side of their work is functioning. Doctors do not want to do administrative work, but it is important to register all the health activities correctly; otherwise, there is a chance that the hospital will receive less money for the diagnosis. What can result in losing money, which can eventually result in financial problems.

This research is conducted at KPMG within the IT Assurance & Advisory department. They provide companies with IT assurance reports. The contribution of this research for KPMG is that they can explore how to offer assurance chain-wide in this declaration chain. The framework offers a high-level basis what the information flows are between the organisations, which is useful to examine possibilities for a large assurance report. The grouper is audited by KPMG, and if a chain of evidence can be established through the whole chain, less auditing is needed.

During the interviews, it became clear that the current financing scheme is not sustainable for the future. The focus is now on production instead of the quality of healthcare. The interviewees made comments about this topic and suggested that the focus should shift to prevention and keeping people out of the hospital. Change is needed to keep healthcare affordable and of high quality.

#### 7.3.3 Personal Reflection

While I started this research eighth months ago, I have some preliminary results in mind. Those results are partly confirmed, but also new findings shed light on this research. To start with, I thought that the organisations within the chain knew what the other organisations are doing. This was the case, but they only had a vague high-level understanding. That indicated clearly to me that this was not a very smooth collaboration between the companies. Furthermore, I was not aware of the frustration in hospitals between medical specialists and administrative workers, and that with this research, an understanding between both parties can be realised.

# 8 Conclusions

#### 8.1 Conclusions

This research proposed a framework to identify who is responsible and owner of different data elements in the declaration chain of medical specialist care. This chapter presents the conclusions of this research in regard to the research questions.

The organisations in the declaration chain are mainly focusing on their direct partners in the chain. The organisation are not aware of the roles of the other organisations in the chain. They have a vague understanding of what is happening. We would suggest to first understand the chain completely as an organisation and then focus on your own specific goal. To improve chain collaboration, a better understanding of the participating organisations is required. Companies need to know how information is flowing throughout the chain what can result in a more uniform set of data. Many mutations are done on the declaration data and flowing around. Based on the interviews, a suggestion is to have a central data storage where the declaration data is stored. This lowers the chance of mistakes in the data and it is accessible for all the organisations. This, of course, raises a lot of questions about security and privacy. There is only one party that has influence about this and that is the government, and more specifically, the Ministry of Health. Different parties identified that the Ministry of Health should be the chain director since they have power and can make decisions and policy. In the current situation, the Ministry has to say it simple 'outsourced' the declaration chain to different organisations and is not actively participating in it. They should come back in the game and be the chain director, discuss with the organisation how collaboration can be improved. This will eventually drastically lower the costs in this process, so more money is available for actually providing healthcare.

SQ1: What is the state-of-the-art of the literature about chain computerisation in relation to healthcare?

- 1.1 What is chain computerisation?
- 1.2 What are the major flows in the healthcare sector and how can a patient journey be created?
- 1.3 Which data elements exist in the patient journey within the healthcare chain computerisation flow?

We used the definition by Grijpink (2010) for chain computerisation and provided an understanding of what this principle is. An overview of the different disciplines of healthcare is given based on the research by Kroneman et al. (2016). We zoomed in on medical specialist care, and for this, a patient journey is created of wrist problems. This patient journey provided real-life examples of how the declaration information is created, derived and transformed to a receipt. Finally, the Entity-Relationship Diagram (Figure 4.2) provided an understanding of which data elements exist and how they correlate to each other. The corresponding attributes of the data elements are used to assign who is responsible for them. The interviews confirmed that it captures the most important elements of the declaration chain.

SQ2: What are the requirements for a framework for responsibilities and ownership of data elements?

- 2.1 Which concepts occur in the context of data governance and what is their definition?
- 2.2 What current frameworks exist for assigning ownership and responsibilities concerning data elements?
- 2.3 What is the current situation of assigning ownership and responsibilities to data elements?
- 2.4 Which parties are responsible and accountable for which data elements within the healthcare sector?

Section 3.3 is devoted to providing a brief introduction to the different concepts of data governance. The GDPR caused mainly troubles internally in the organisations, but between organisations, the impact was not experienced. In the chain, there is not a clear understanding of the current situation of assigning ownership and responsibilities throughout the chain. Internally, organisations know who is responsible for the in-house data, but chain-wide, there is a grey area. The existing frameworks that are identified in the literature for assigning responsibilities are the Responsibility Assignment Matrix, Responsibility Assignment Modelling and the CRUD Matrix.

Derived from nine interviews with all the participants of the declaration chain, we have identified who is responsible and accountable for the data elements that we presented in the ERD. The medical specialist holds one of the critical positions since they are responsible for many registration obligations. The HIS registers a lot of necessary attributes automatically so; it is important that the HIS is functioning correctly. To assure this, auditing of the HIS is an important aspect. The tables of health products and activities fall under the NZa as well as many source attributes like health types, declaration codes and health activity codes.

SQ3: How can the framework be applied in a case study?

- 3.1 How does the framework perform?
- 3.2 What recommendations can be made?
- 3.3 Is the framework applicable to different chains in different sectors regarding generalisability?

Based on the validation interviews, the framework provided an easy practical understanding of something difficult. It presented the correct situation how information is flowing between the organisations and the responsibilities are correctly assigned.

The interviewees proposed different recommendations for the models to improve the level of detail and correctness. These improvements are added to the models what for the current situation of the declaration chain, provides a correct high-level overview.

Within the healthcare sector, the framework can easily be adjusted for mental healthcare since the base structure is almost the same. Other parts of the healthcare system in the Netherlands have a different structure, and therefore, the framework does not apply to those parts.

**MRQ**: What is a suitable framework that can be used in the context of assigning responsibilities and ownership to data elements in a chain computerisation perspective for the declaration chain in the Dutch hospital healthcare sector?

The main research question of this study has been answered by researching the subquestions. First, we looked at the state-of-the-art of the literature about chain computerisation in relation to healthcare. This is followed by specifying the requirements for a framework for responsibilities and ownership of data elements. Based on interviews with eleven people who are working for organisations in the sector, we have established an understanding of what the role of the organisations in the chain is, and responsibilities lie. Three different viewpoints are required to correctly present the responsibilities and ownership of data elements within the declaration chain of medical specialist healthcare. A general overview of the activities and data elements in the form of a BPMN is present. For the second perspective, we looked at the different CRUD mutations for each data elements. Finally, an overview concerning the responsibility for registering the data and the source of the data is presented. These models are validated by conducting two validation interviews and are confirmed that it provides a good overview of the problem at hand and can help people understand the complicated declaration situation.

#### 8.2 Future Work

This section is devoted to future works. We make the distinction between the healthcare industry and academia for future works because both domains face different types of challenges.

#### 8.2.1 Healthcare challenges

This research provides a lot of different directions for additional research. In light of the current COVID-19 crisis, the health system is under high pressure. Intensive cares are full, and many transportations of intensive care patients to other hospitals are occurring daily. For future research, it is interesting to see what is the impact of the COVID-19 crisis on the registration process. Do doctors still register all the products or are they only concerned with helping patients? This can have consequences on the money coming in for hospitals which result in more financial pressure. A possible research question in this area is:

How did the chain collaboration change in the healthcare sector focusing on intensive care due to the impact of the COVID-19 virus?

For this proposed research, a pre and post-analysis of the collaboration in the intensive care sector are required.

In this research, we only looked at hospitals that have a standard salary system for doctors. However, in the Netherlands, some hospitals work via a doctor buy-in system. In such a system, a doctor gets paid for each patient treated. Therefore, registration is more important; if the patient is not registered on the doctors' name, no compensation will be paid. This can lead to that registration is better organised in such a system within the hospitals. However, this is a hypothesis that needs more research.

Furthermore, the focus was on medical specialist care, while, as we identified in Section 4.1, there are more different disciplines. Each has its declaration procedures that are different from our investigated medical specialist care. For these disciplines, their chain collaboration and data elements can be analysed to conduct analyses over the whole Dutch healthcare sector eventually.

#### 8.2.2 Academia

More research is needed in the development of frameworks for ownership and responsibilities in different contexts. The literature provided us with some directions, but concrete models and guidelines are missing. This can be applied in an interorganisational setting or a chain collaboration. Furthermore, the impact of the GDPR in a chain computerisation perspective is so far unknown. Companies mitigated the GPDR regulations with measures internally, but GDPR measures between companies is an unknown area that could lead to potential future research.

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# A Consent form

# Informed Consent

We have asked you to participate in a research about ownership and responsibilities within the Dutch healthcare sector. This research is conducted by Philippe van der Voorn, under the supervision of Nico Brand and Sietse Overbeek. The interview will take approximately one hour and shall be recorded.

- 1) I voluntarily agree to participate in this research.
- 2) I have been given the opportunity to ask questions about the research.
- 3) I understand I can withdraw at any time without giving reasons and that I will not be penalized for withdrawing.
- 4) I agree that the interview will be recorded and transcribed.
- 5) I agree that the researcher can make notes during the interview.
- 6) I understand that the results from the interview will be used for the research.

For any questions afterwards, you are able to contact Philippe van der Voorn by emailing p.l.f.m.vandervoorn@uu.nl

I have read this informed consent and I agree,

#### Participant

Name:

Date:

Signature:

Researcher

Name:

Date:

Signature:

# **B** Interview Protocols

## **B.1** Interview Protocol Vecozo

- 1. Introductie (circa 5 minuten)
  - a. Zelf voorstellen (achtergrond, studie, stage et cetera).
  - b. Ondervraagde laten voorstellen (achtergrond, functie, loopbaan et cetera).
  - c. Omschrijving van het onderzoek.
  - d. Doel van dit interview.

#### 2. Declaratieketen laten zien (circa 15 minuten)

- a. Klopt dit figuur?
- b. Hoe kan dit figuur verbeterd worden?
- c. Wat zijn precies de werkzaamheden van Vecozo?
- d. Is Vecozo verantwoordelijk en/of eigenaar voor de Grouper?
  - i. Welke partijen auditen de Grouper?
  - ii. Hoe wordt de Grouper gecontroleerd?
  - iii. Hoe wordt omgegaan met foutieve data die uit de Grouper komt?
- e. Hoe wordt gecontroleerd of zorg ook echt geleverd is?
- 3. Data elementen van ERD laten zien (circa 15 minuten)
  - a. Ontbreekt er volgens u data elementen?
  - b. Wat is de huidige situatie met betrekking tot het aanwijzen van verantwoordelijk en eigenaarschap bij data elementen?
    - i. In verschillende papers staat dat het nu onduidelijk is wie verantwoordelijk is, hoe kan dit beter?
    - ii. Waardoor ontstaat deze verwarring?
    - iii. Gebruiken jullie een framework om eigenaarschap vast te leggen? Zoja, welke?
  - c. Van welke gegevens zijn jullie eigenaar?
    - i. Hoe is dat vastgelegd?
  - d. Voor welke gegevens zijn jullie verantwoordelijk?
    - i. Hoe is dat vastgelegd?
  - e. Zou u voor de overige data elementen kunnen aangeven wie u denkt dat eigenaar is en verantwoordelijk is voor elk data element?
  - f. Hoe denkt u dat de samenwerking binnen dit keten kan worden verbeterd?
- 4. Zorgnota (circa 5 minuten)
  - a. Voorbeeld laten zien van mijn zorgnota met foutieve zorgactiviteit, wie is hiervoor verantwoordelijk?
- 5. Algemene vragen (circa 10 minuten)
  - a. Heeft de AVG/GDPR nog invloed op dit keten?
  - a. Wat is denk u de grootste uitdaging binnen dit keten?
  - b. Hoe denkt u dat het opgelost kan worden?
  - c. Is er iets dat ontbreekt of nog wilt toevoegen?
- 6. Afsluiting (circa 5 minuten)
  - a. Bedanken voor de tijd en deelname
  - b. Vervolgacties toelichten

## **B.2** Interview Protocol CZ

- 1. Introductie (circa 5 minuten)
  - a. Zelf voorstellen (achtergrond, studie, stage et cetera).
  - b. Ondervraagde laten voorstellen (achtergrond, functie, loopbaan et cetera).
  - c. Omschrijving van het onderzoek.
  - d. Doel van dit interview.
- 2. Declaratieketen laten zien (circa 15 minuten)
  - a. Klopt dit figuur?
  - b. Hoe kan dit figuur verbeterd worden?
  - c. Wat zijn precies de werkzaamheden van CZ in het declaratieproces?
  - d. Ontvangen jullie alleen informatie uit de Grouper of ook van het ziekenhuis.?
    - i. Welke partijen auditen de Grouper?
    - ii. Hoe wordt de Grouper gecontroleerd?
    - iii. Hoe wordt omgegaan met foutieve data die uit de Grouper komt en bij jullie terecht komt?
  - e. Hoe wordt gecontroleerd of zorg ook echt geleverd is?
- 3. Data elementen van ERD laten zien (circa 15 minuten)
  - a. Ontbreekt er volgens u data elementen?
  - b. Wat is de huidige situatie met betrekking tot het aanwijzen van verantwoordelijk en eigenaarschap bij data elementen?
    - i. In verschillende papers staat dat het nu onduidelijk is wie verantwoordelijk is, hoe kan dit beter?
    - ii. Waardoor ontstaat deze verwarring?
    - iii. Gebruiken jullie een framework om eigenaarschap vast te leggen? Zoja, welke?
  - c. Van welke gegevens zijn jullie eigenaar?
    - i. Hoe is dat vastgelegd?
  - d. Voor welke gegevens zijn jullie verantwoordelijk?
    - i. Hoe is dat vastgelegd?
  - e. Zou u voor de overige data elementen kunnen aangeven wie u denkt dat eigenaar is en verantwoordelijk is voor elk data element?
  - f. Hoe denkt u dat de samenwerking binnen dit keten kan worden verbeterd?
- 4. Zorgnota (circa 5 minuten)
  - a. Voorbeeld laten zien van mijn zorgnota met foutieve zorgactiviteit, wie is hiervoor verantwoordelijk?
- 5. Algemene vragen (circa 10 minuten)
  - a. Heeft de AVG/GDPR nog invloed op dit keten?
  - a. Wat is denk u de grootste uitdaging binnen dit keten?
  - b. Hoe denkt u dat het opgelost kan worden?
  - c. Is er iets dat ontbreekt of nog wilt toevoegen?
- 6. Afsluiting (circa 5 minuten)
  - a. Bedanken voor de tijd en deelname
  - b. Vervolgacties toelichten

## **B.3** Interview Protocol Hospitals

- 1. Introductie (circa 5 minuten)
  - a. Zelf voorstellen (achtergrond, studie, stage et cetera).
  - b. Ondervraagde laten voorstellen (achtergrond, functie, loopbaan et cetera).
  - c. Omschrijving van het onderzoek.
  - d. Doel van dit interview.
- 2. Declaratieketen laten zien (circa 10 minuten)
  - a. Klopt dit figuur?
  - b. Hoe kan dit figuur verbeterd worden?
  - c. Wat zijn precies de werkzaamheden van het ziekenhuis binnen dit keten?
  - d. Hoe werkt het HIS?
  - e. Wie is verantwoordelijk en/of eigenaar voor de Grouper?
  - f. Heeft het ziekenhuis ook een eigen/interne Grouper?
  - g. Hoe wordt gecontroleerd of zorg ook echt geleverd is?
- 3. Hoe gaan jullie in ziekenhuizen om met fouten in DBC's/EDPs? (circa 10 minuten)
  - a. Hoe waarborgen jullie dat de informatie klopt en juist en volledig in de systemen komt met de juiste koppelingen naar DBC's?
  - b. Wie is verantwoordelijk voor juist en volledig registreren van DBC? Ziekenhuis, arts of functionaris? Een persoon of een entiteit en hoe is dat intern gedefinieerd? Kan een arts het delegeren? Dan is de kans op fouten groter, hoe wordt dat gecontroleerd?
  - c. Wanneer denken jullie dat de registratie en facturatie compleet en juist is?
  - d. Is er onderscheid tussen hoofd en sub-DBC's?
- 4. Data elementen van ERD laten zien (circa 15 minuten)
  - a. Ontbreekt er volgens u data elementen?
  - b. Wat is de huidige situatie met betrekking tot het aanwijzen van verantwoordelijk en eigenaarschap bij data elementen?
    - i. In verschillende papers staat dat het nu onduidelijk is wie verantwoordelijk is, hoe kan dit beter?
    - ii. Waardoor ontstaat deze verwarring?
    - iii. Gebruiken jullie een framework om eigenaarschap vast te leggen? Zoja, welke? volgens u data elementen?
  - c. Van welke gegevens zijn jullie eigenaar?
    - i. Hoe is dat vastgelegd?
  - d. Voor welke gegevens zijn jullie verantwoordelijk?i. Hoe is dat vastgelegd?
  - e. Zou u voor de overige data elementen kunnen aangeven wie u denkt dat eigenaar is en verantwoordelijk is voor elk data element?
  - f. Hoe denkt u dat de samenwerking binnen dit keten kan worden verbeterd?

## **B.4** Interview Protocol Hospitals

- 5. Zorgnota (circa 5 minuten)
  - a. Voorbeeld laten zien van mijn zorgnota met foutieve zorgactiviteit, wie is hiervoor verantwoordelijk?
- 6. Algemene vragen (circa 10 minuten)
  - a. Heeft de AVG/GDPR nog invloed op dit keten?
  - a. Wat is denk u de grootste uitdaging binnen dit keten?
  - b. Hoe denkt u dat het opgelost kan worden?
  - c. Is er iets dat ontbreekt of nog wilt toevoegen?
- 7. Afsluiting (circa 5 minuten)
  - a. Bedanken voor de tijd en deelname
  - b. Vervolgacties toelichten

## **B.5** Validation Interview Protocol

# Framework Validation

- 1) Introduction (5 minutes)
  - a) Description of research.
  - b) The goal of this interview.
    - i) The goal is to validate the three models and the business rules. We want to check if it is complete or that some things are missing. The practical use will also be validated and check if this is something useful for the different participants in the chain.
- 2) Present BPMN (10 minutes)
  - a) Is it complete?
  - b) Does it represent a correct view?
  - c) Is the level of detail good?
  - d) How can it be improved?
  - e) Can this model be generalised for different aspects of the healthcare sector or other sectors in general?
- 3) Present CRUD (10 minutes)
  - a) Is it complete?
  - b) Does it represent a correct view?
  - c) Is the level of detail good?
  - d) How can it be improved?
  - e) Can this model be generalised for different aspects of the healthcare sector or other sectors in general?
- 4) Present attribute table (10 minutes)
  - a) Is it complete?
  - b) Does it represent a correct view?
  - c) Is the level of detail good?
  - d) How can it be improved?
  - e) Can this model be generalised for different aspects of the healthcare sector or other sectors in general?
- 5) General questions (10 minutes)
  - a) Do you think the figures are correctly corresponding to each other?
  - b) Are the different perspectives missing from these figures?
  - c) Do the business rules complement the models?
  - d) Do you think such an overview can improve the collaboration within the chain?
  - e) Do these models fill a gap in the literature or in practice?
- 6) Thank you for your participation!