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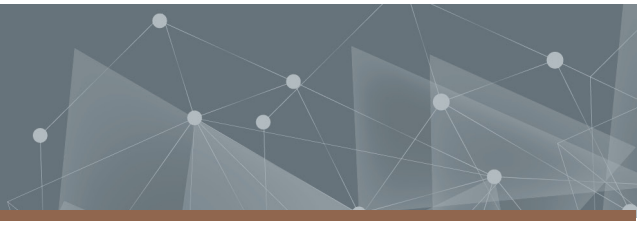

Organising for Data Accessibility

Standardising and Improving Access to Public Healthcare Data in Region Västra Götaland

Master's thesis in Quality and Operations Management

SIMON RUTSTRÖM
WILLIAM JÖRNELIUS

DEPARTMENT OF TECHNOLOGY MANAGEMENT AND ECONOMICS
DIVISION OF SERVICE MANAGEMENT AND LOGISTICS

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Report No. E2023:022
Department of Technology Management and Economics
Chalmers University of Technology
SE-412 96 Gothenburg
Sweden
Telephone +46 (0)31-772 1000

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SUMMARY
External healthcare data access is essential for improving healthcare quality. It is provided to: researchers, public health organisations, and private organisations. However, there is a balance between data accessibility and patient integrity. Together with the Centre of Registries (RC) in Region Västra Götaland (VGR), data accessibility is investigated and given learnings that can be applied to improve processes and organisation.

This thesis investigates and maps the current process for healthcare data withdrawal within VGR in order to deepen the knowledge of healthcare data accessibility and make recommendations from new learnings. The thesis work has used a qualitative approach where semi-structured interviews have been conducted with people with various backgrounds and hands-on experience in healthcare data accessibility. The collection of data and interviews were understood through relevant guidelines and thematic grouping. Parallel to the data analysis a rigorous literature review has been done to fit the research agenda and connect with the findings.

The findings show aggregated themes and implications from the interviews that answer the setting of how data accessibility looks like today in VGR. Along with the theoretical framework the findings have been connected and discussed to understand learnings that could improve the current process.

Firstly, streamlining the data withdrawal process and implementing a digital portal can improve efficiency. Secondly, ensuring patient integrity and data confidentiality through cross-scientific reviews is essential. Lastly, expanding beyond research can benefit other stakeholders. The thesis offers practical recommendations towards RC to help improve external data accessibility in VGR.

Keywords: healthcare data, accessibility, research, patient integrity.

Acknowledgement

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Additionally, we would like to extend our gratitude towards all interview respondents who generously shared their time, expertise and experience. And finally, we would like to thank family, friends and loved ones for their support, understanding and encouragement throughout this spring.

Simon & William
Gothenburg, May 2023

Contents

List of Figures

List of Tables

List of Abbreviations

Abbrevaition	Written out
VGR	Region Västra Götaland
RC	Centre of Registries VGR
H&C review	Harm and confidentiality review
EPM	Ethical Review Authority

1

Introduction

This chapter outlines the background to the master's thesis with information about the healthcare setting in Sweden and development and also information about the organisation that the thesis has been written in collaboration with. Moreover, the aim, research questions, and delimitation of the study are presented.

1.1 Background

Today, healthcare data is essential for improving healthcare quality. Healthcare institutions generate vast amounts of data through journals, medical histories, treatment plans and laboratory results (Solberg et al., 1997; Castellani et al., 2016) It is possible to leverage this data for analysis and research by providing controlled access to external entities, such as researchers, public health organisations and private organisations. The potential benefits are manifold, but at the same time, it is a delicate balance between improvements and maintaining the patient's right to privacy (Hansson, 2019). Healthcare data is highly sensitive and wrongful handling can result in serious implications for the patient. From the European Union, there is a new healthcare data structure called European Union Health Data Space (EHDS) underway (Directorate-General for Health and Food Safety, 2022). The goal of EHDS is primarily to empower the individual but also to enable a common ground for secondary data usage, i.e. innovation and research (Directorate-General for Health and Food Safety, 2022; Hebenstreit, 2020).

Although, data accessibility receives much attention at both a European and national level, approaches and methods are not consistent at a local level. Healthcare data within Region Västra Götaland (VGR) is fragmented between all administrations, that naturally own their own journals (Svensk författningssamling, 2008). This means collaborations and exchanges face inherent bureaucratic resistance. Today, it is possible to apply for external access to healthcare data at an administration, in what is called a data withdrawal. Applications come from scientists, researchers, hospitals, industry, media, and other governmental bodies. However, applicants seeking data from multiple

administrations within VGR must apply at each and every one individually. Depending on the applicant there are different legal possibilities, for example, the patient data law easily transfers over to research projects whilst others might not have the same possibilities for individualised journal data. Due to the strict privacy required by regulation, all applications go through a review regarding harm and confidentially (H&C-review). The purpose is twofold, firstly to determine if the patient will take harm from someone accessing the data, and secondly, to determine if the applicant has the possibility to keep the data confidential.

Within VGR there is an ambition to develop a common digital portal for applicants to gain access to healthcare data. Centre of Registries VGR (RC), has initiated a project called *Dataport* with the goal of developing one way in to access healthcare data within the region. Firstly, a common digital portal for incoming applications and secondly the solution could provide automation in repetitive administrative steps. And based on this project, how should the region organise for data accessibility. Thus, the problem formulation of this thesis stems from the Dataport project. RC wants to map how the different administrations are handling applications for external data withdrawals and what volumes of applications they receive as of today. Identifying challenges and opportunities going forward.

1.2 Aim and Research Questions

The aim of this master's thesis is to investigate external data accessibility to healthcare data within VGR. Through, mapping current processes and organisation, draw insights, and present improvement suggestions to the Dataport project. Considering the aim, the thesis sets out to answer the following three research questions:

1. *How are VGR working and organising for external data accessibility today?*
2. *What key learnings can improve external data accessibility at VGR?*
3. *What are the recommendations towards RC?*

1.3 Organisational context

Sweden is today facing great challenges in many fields and healthcare is no exception. The demand for healthcare is increasing, and the resources are limited. By 2026 it has been estimated that the Swedish welfare needs to increase the number of employees by approximately 200 000 and that 300 000 will be retired by then (Sveriges Kommuner och landsting, 2018). In healthcare,

it is also estimated that the demand increases with roughly 1800 people per year, and retirements with approximately 4000 per year (Sveriges Kommuner och landsting, 2020b). Moreover, there will be a gap in funding and difficulties to find new people to replace the ones that retire (Myndigheten för digital förvaltning, 2020). The gap between public spending with the current tax rates and the additional resources needed to maintain the level of quality measured in 2019 beyond 2026 is 90 billion SEK (Myndigheten för digital förvaltning, 2020). One of the main drivers for the increasing demand for healthcare is due to an ageing population. A macro-demographic trend will increase the number of people over 80 years old by 47 % until 2029 (Sveriges Kommuner och landsting, 2020a). With old age, naturally comes chronic illness, which in turn accounts for 80–85 % of total costs for Swedish healthcare (Socialdepartementet, 2016). Thus, resource efficiency needs to increase in order to ensure that proper healthcare can be delivered to everyone in need.

The healthcare system in Sweden is decentralised and equally divided between the state, 21 regional councils and 290 municipalities and its goal is to provide healthcare on equal terms for all citizens (Sveriges Kommuner och Landsting, 2023b). Every local authority, county council or municipality is responsible for managing their own healthcare service and resources which leads to the available service of healthcare might differ (Socialstyrelsen, 2023).

In Region Västra Götaland (VGR) the different care-giving facilities and administrations, such as hospitals, Närhälsan, Folktandvården, Västarvet and Koncernkontoret, are administered by the political decisions taken by elected politicians in boards and authorities (Västra Götalandsregionen, 2023). This means that each administration and facility have ownership over their own data.

One of the most critical tools for self-evaluation within the Swedish public healthcare system is the National Quality Registries (NQR). These registries contain individualised data about medical interventions and outcomes (Sveriges Kommuner och Landsting, 2023a). These registries enable the development of world-leading procedures, for example, the registries regarding hip replacements and diabetes (Sveriges Kommuner och Landsting, 2023a).

The master's thesis is written with the Centre of Registers within VGR and is one of several centres in Sweden that support the development of NQR. The Centre of Registers in VGR has around 25 registers, such as the Swedish Hip Arthroplasty Register. The registers help to gather information about certain procedures and treatments of patients in Sweden (1177, 2023). In addition, does the register also administrate and handle the IT structure and statistical processing, including the help of measuring the patient's experience of their care outcome (1177, 2023). With this data, representatives from other registers are provided with know-how and information about quality development and access to improvement factors(1177, 2023). The registers make it possible

to make certain interventions, medicine and products of medical care and ultimately remove those that do not work. It is also possible to see if healthcare is equal for everyone in need of healthcare (Västragötaland, 2023).

1.4 Delimitation

Healthcare data accessibility is intricately linked to both judicial and legislative factors. Compliance with legal requirements and regulations is crucial when providing external access. Moreover, the secure management of healthcare data relies heavily on the field of informatics, encompassing various technological solutions and practises to ensure confidentiality and integrity.

This thesis is within the realm of quality and operations management and focuses on exploring how administrations within VGR handle external data withdrawals. Examining the processes and operational aspects involved in the administration's interactions with external applicants. Hopefully finding challenges and opportunities associated with healthcare data accessibility.

Moreover, there is no intent to investigate outside of the major public administrations in VGR. Meaning municipal and private healthcare providers are not meant to be covered.

2

Methodology

In this chapter, the methodology used in the research is described to give the reader an overview of the thoughts and considerations behind the decisions. According to Bell et al. (2019), there are three integral parts of research; research strategy, research design and research method. Namely, the strategy explains the general orientation of the business research, whilst the design is the framework for both collection and analysis of data. Lastly, the method is how data is collected. Within these individual subjects there are many considerations to keep in mind as there for each individual part are different models and techniques according to Kothari (2004). This study incorporates interviews as the source of primary data which is subsequently analysed. At the end of the chapter, research quality and ethical considerations arising in the context of conducting the thesis are discussed.

2.1 Research strategy

At the beginning of the study, the research setting had to be both understood and scoped properly. Thus, there was a need for an exploratory phase where the work was iterative. Both the research questions and theoretical framework had to be adjusted several times and Bell et al. (2019) suggest the following criteria for good research questions to be: clear, reachable, connected to established theory and research and appropriately scoped. Moreover, at the beginning of the project, it is possible to have a wide initial scope and to ask the easy questions early in order to be more flexible with focus and directions with the project.

As the strategy includes interviews as the primary source of data Bell et al. (2019) recommend using a qualitative structure which in the thesis work has been designed to fit the research agenda and problem description connected to the healthcare sector.

2.2 Research design

The research design is adopted by Maxwell (2012) and illustrated in Figure 2.1 with the concepts: *Goals, Conceptual framework, Research question, Validity and Methods*. The author suggests that it is important to let the different parts of a qualitative study influence each other. If one individual component changes it could simultaneously also affect another component. The framework helps to structure the study and plan the parts that are meant to be carried out. In addition, this research design has been helpful when finding connections between the analysed data and the theoretical framework. This thesis is abductive in nature.

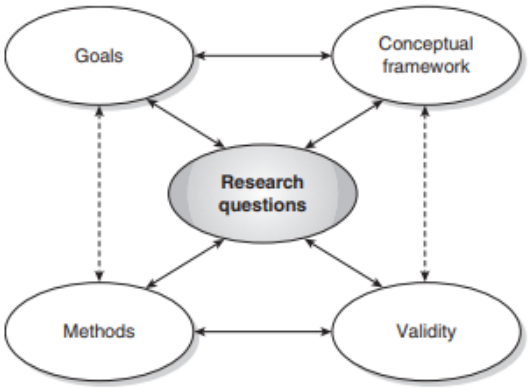

Figure 2.1: Research design for the thesis work, from Maxwell (2012)

To begin with, the aim of the thesis is to investigate external healthcare data accessibility. Thus, the conceptual framework connects to all research questions where the first question connects with the theoretical framework and the agenda for understanding the characteristics of research in healthcare. Similarly, the second research question is to find perspectives and learnings that could give value to the project with the use of frameworks by looking at the quality dimensions in healthcare, improvement factors and business model. These insights will ultimately be used to answer the third research question and give recommendations to the RC. During the thesis work, it becomes important to maintain the validity and trustworthiness of the findings, and for that reason, the method agenda and analysis followed the necessary guidelines. The methods used, such as having semi-structured interviews and collecting data have been chosen to answer the research question, as well as following the ethical considerations discussed in Section 2.6.

2.3 Research method

Bell et al. (2019) explain that selection of research design influence what methods for data collection are appropriate. Moreover, the authors state that the research method guides the execution of data collection and also subsequent

analysis. This thesis is abductive and to gain qualitative data in-depth interviews are appropriate.

2.3.1 Primary data collection

The collection of primary data was done through interviews. Since the research method calls for in-depth qualitative data, interviews are a suitable method to use as it helps to explain the setting more and understand the respondent's opinions and experiences.

2.3.1.1 Interview characteristics

Bell et al. (2019) highlights the importance of capturing the opinions and perspectives of the respondents in qualitative research. For this purpose, semi-structured interviews have predominantly been used. This type of interview structure provides sample guidance whilst still allowing respondents to develop on certain topics, and thus combines structure and openness. Moreover, Bell et al. (2019) explains how semi-structured interviews allow for making sure that important things are covered whilst at the same time not becoming locked by a prearranged format.

For the agenda preparing and structuring the interviews and questions the steps are two-phased. In the first phase for mapping questions to the interviews, some potential questions with connection to the project scope and topic have been asked the supervisor at the RC. This allowed to gain deeper knowledge and input to feel more confident when entering the interview sessions. After the questions have been iterated and mapped to fit the problem space it was possible to begin the second phase and the interviews with participants recommended by the RC supervisor.

In the second phase, the aim was to conduct interviews with the participants. The interviews were semi-structured with questions open to gauge the opinion of the respondent. Meaning, some questions would open up to more discussion whilst others were more specific. One challenge, that requires active effort, is to stay open-minded and stay away from assumptions in order to keep the interviews unbiased. However, in some cases, it was required to take a more active role and perhaps project assumptions from previous experiences to gain relevant data. Particularly in questions that were of a more specific nature.

Interviews in this study were held with respondents both internal and external to VGR. Table 2.1 depicts the respondent's background and whether they are internal or external. To keep the anonymity of the respondents, information about their exact background and organisational belonging is not disclosed. However, all respondents in the interviews are experienced with external healthcare data withdrawals. Respondents' backgrounds are an indication of their primary field and are deliberately broad. For example, respondents

with a judicial background have extensive experience in this field and so forth. Administrative respondents are oftentimes in management positions. What is worth detailing is that respondents with a research background oftentimes are dissertated and thus have experience in medical research. Additionally, the internal respondents are from the 17 major healthcare institutions within VGR, namely: Angered's Hospital, Biobank, Data and Analytics department, Folktandvården, Gothia Forum, Health and Habilitation Center, Innovation platform, Närhälsan, NU-Sjukvården, Centre of Registries, Regianal Cancer Centre, Regional Vårdanalys, Södra Älvsborgs Sjukhus, Sjukhusen i Väst, Skaraborgs Sjukhus, Insitute of Stress Medicine, and Sahlgrenska University Hospital.

Table 2.1: Respondent backgrounds

Background	Internal	External	Total
Judicial	5	2	7
Researcher	12	2	14
Analyst	6	1	7
Administrative	3	2	5
Statistician	3	0	3
Grand total	29	7	36

Interviews with internal and external respondents were held in parallel and injected more information that helped shape the questions towards other stakeholder groups as time progressed. This also added additional perspectives which gave even deeper knowledge of external data accessibility.

Snowball sampling was used in the study. A first list of respondents was drafted with the RC supervisor. Many of these accepted to be a part of the project whilst others instead recommended other respondents to take their place. Additionally, in interviews many suggest to further pursuing contact with other prominent people, which lead to external participants.

The structure of the interviews was held in a virtual and remote setting to ease the communication with the respondent. The interviews were in addition held in Swedish to avoid misinterpretation of questions as well as to understand the answers. The invitation to the participants through mail included a background and explanations on the project and questions that would be asked in order to prepare the participant as well as not giving deceptive information. Bell et al. (2019) also emphasises the importance of preparing respondents in advance.

During the interviews, the participants were asked for permission to record the session.Recordings made it possible to go back and listen and complement notes taken during the interview.Both Trost (2010) and Bell et al. (2019) suggest

recording the interview in order to listen through it later for details one might miss whilst in the heat of the interview. However, no complete transcription of interviews was done.

The majority of interviews were held for a duration of 45 minutes, meanwhile, others were longer when a larger joint group of respondents were participating. In some cases, one respondent participated in another session to clarify some questions further and give more details.

In every interview, one author was asking the questions whilst the other one was taking notes. However, this was only a guideline as Bell et al. (2019) mentions it is hard to listen actively and take notes at the same time. Moreover, it can be hard to be able to filter what is relevant and ask questions. Thus the authors sometimes asked questions as note taker or passed a note to the main interviewer with suggestions on what to talk about next or ask follow-up questions.

2.4 Secondary data collection

The secondary data is gathered to support and understand the organisation even better as well as further providing depth in the master thesis. Interviews provide essential data when mapping the problem space. However, to get more data, information has also been collected from websites, documentation, presentation material and relevant literature on the topic. Especially materials describing the current process and elements that have to be considered going forward when finding recommendations for the project. With knowledge gained from secondary data material, it was also possible to better prepare the interviews.

2.5 Data analysis

As there is much data provided during the interviews it could be difficult to navigate through the information, which is emphasised in Bell et al. (2019). In cases where the study is qualitative Bell et al. (2019) mentions that the analysis requires an iterative approach. For that reason, much data collected from the interviews were analysed parallel to new findings in secondary data and literature review. This is also in line with the abductive approach, going back and forth, in thesis work.

With the vast amount of data and information from interviews, it became necessary to order the information within themes. With guidelines and structure inspired by Gioia et al. (2013) have enabled the thesis work to organise around the data analysis and themes collection. Conducting the interviews and then going back to the recorded material led to the coding of statements from the respondent. Making codes allowed for tracking who said what, still

maintaining the integrity and anonymity of the respondent, as inspired by Gioia et al. (2013). Figure 2.2 below illustrates the coding and original data points from the interviews, which have been reviewed by the thesis authors.

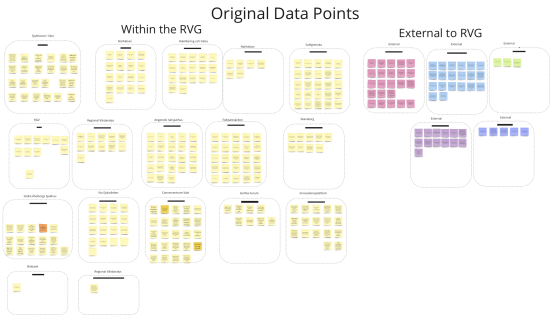

Figure 2.2: The image shows the coded statements from interviews with internal and external participants to VGR.

The data points collected from the interviews were then arranged in a first-order concept, as illustrated in the figure below, see Figure 2.3. The data points were grouped together with matching themes and duplicated if necessary as some were similar to other statements. Finalizing the arrangement, each matching category was given a descriptive sentence to clarify the statements for the first-order concept.

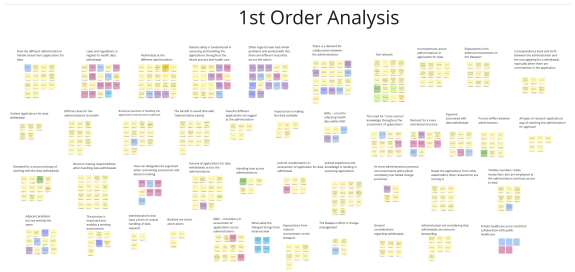

Figure 2.3: First-order concepts from the original data points arranged and given a descriptive sentence to clarify its meaning.

Within the second and last order concept, the arrangement of data points was grouped into new categories and themes and then put into an aggregated heading. With the project and theoretical framework in mind, the initial coding for the statements was shifted to group the first-order concepts into categories and themes that would allow the thesis authors to answer the first research questions. Grouping the data this way implicated thorough discussion between the thesis authors to not miss any details and increased analysis as Gioia et al. (2013) also imply. In the findings chapter, an aggregated description of the themes constitutes the headings. The second-order themes constitute the subheadings as the first-order concept themes will be displayed in bold. The results of the second-order analysis are illustrated below, see Figure 2.4

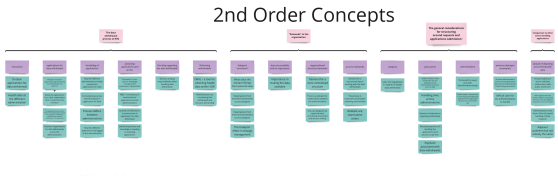

Figure 2.4: Results from the aggregated themes from first-order concepts.

2.6 Literature review

To have a rigorous and comprehensive text as well as ensuring that the research provides valuable insights to the topic is according to Bell et al. (2019) to have an abductive approach as it is suitable when a set of observations determines and identifies possible explanations or hypotheses to the topic. It enables the study to work towards developing new theories. It is sought that the literature review will demonstrate new ideas and enable the authors to broaden the understanding of the topic and research.

As the literature review occurred parallel to the interviews the knowledge and understanding of the issue became better which ultimately helped when gathering relevant theory for the thesis work. As the concept and considerations circulated around having an improved process to give more value as well as maintaining quality, from the interviews the search for relevant theory was opted for that. When doing a literature search Yin (2014) mentions that much information seems to be relevant at first hand. However looking closer and evaluating the information shows that it is not relevant, which makes it important to be able to compare literature to get the most relevant.

2.7 Research Quality

As this thesis is a study with qualitative research characteristics Lincoln and Cuba (1985) in Bell et al. (2019) suggest trustworthiness as a criterion with the following four aspects: credibility, transferability, dependability, and confirmability in order to achieve it.

2.7.1 Credibility

Credibility is the outcome of whether the research has been done with the best efforts to ensure that the findings are accurate and correct (Bell et al., 2019). As the thesis builds on data analysis from interviews and secondary data, our roles as researchers and authors have to represent the data best way possible. Lincoln and Cuba (1985) in Bell et al. (2019) mentions that triangulation of facts and sources of data is a method to increase the credibility of the research as the data is verified across the different sources. For instance, the conducted interviews were held in Swedish to avoid misinterpretation and the answers have been compared to other sources.

When accessing data and sources of facts this way there is usually a risk that there are parts being left out and fragmentation of data (Bell et al., 2019). To avoid this during the collection of statements from the interviews and knowing who said what, the statements were coded in order to trace back.

2.7.2 Transferability

With the collected material transferability is the aspect described by Bell et al. (2019) to be one way of seeing how much the information is overlapped or matched with another source. In a qualitative study, it becomes necessary to get data that will represent the information. As the interviews were conducted with representatives from similar roles but in different administrations, it became valuable to compare and match information.

2.7.3 Dependability

Measuring many aspects during the process is concerned with the dependability aspect as the data and results should be consistent and reliable (Bell et al., 2019). Therefore the thesis work has been utterly documented in a work log and the information collected as well as the process method has been checked with the supervisor at Chalmers.

2.7.4 Confirmability

As it is sought after to ensure objectivity in the research, Bell et al. (2019) suggests that the researcher should act in good faith in order to minimize influences from own thoughts. The thesis work strives to achieve a high level of objectivity as it strives to give understanding from perspectives on both sides within the thesis work topic.

2.8 Ethical considerations

In the research work, several interviews have been conducted. Much of the information and data collected from the interviews is a big part of the research and source answering the research question which makes it immensely necessary to secure that the statements followed by the interviews are not to be tracked back to the respondent. The thesis work has therefore considered the following ethical principles by Bell et al. (2019): informed consent; no harm to participants; no invasion of privacy; and no deception.

When interviewing the participants for the thesis work it is necessary to give all the details and information about the research in which the answer could come to be used. This is what Bell et al. (2019) calls to ensure informed consent of the participants. All the participants were asked to participate with information about the project and the structure of the interview. Before the interview, the

participant was also told that the study would be anonymous and that the recording of the interview would be deleted before entering into the discussion.

In the next principle of no harm to participants Bell et al. (2019) empathise that harm could include that participant feel, stress och harm of future development and career or even physical harm. For that reason, all records and interviews have been anonymous and deleted at the end of the report. Bell et al. (2019) also mentions that confidentiality is more critical in qualitative research as it could be easier to trace a statement back to the respondent if there is only one person from that specific organisation in which the interview has been conducted.

With the principle of no invasion of privacy, it becomes necessary for the researcher authors to ensure that the participant's privacy is not invaded (Bell et al., 2019). That means that the participants and respondents should feel that the questions are not too intrusive. The participants were therefore allowed to rephrase or withdraw from the questions.

When conducting a research project the researcher might present it in another way than it actually is which could be misleading or deceptive according to (Bell et al., 2019). Thus the information presented for the research had been given to the participants both before and during the interview, aiming to be as transparent as possible.

3

Theory

This chapter describes the relevant theory applied in the study. To begin with, the chapter starts with the different use cases of healthcare data. Secondly, the quality dimensions used in healthcare are explained. Thirdly, why it is necessary for improvements in healthcare. And lastly, the business model framework and how it can be valuable in implementing changes. Even though the business model framework is used more in business literature it could give some valuable insight into how it is possible to design and show the value of establishing a project in the healthcare setting, thus it is put in this theoretical framework.

3.1 Use cases of healthcare data

Measurements in healthcare are necessary for improving the process of medical care and healthcare for all according to Solberg et al. (1997). It shows how well current processes are performing, if the process has lived up to expectations, if there is variation in the current processes, showing a small test of changes and if the change has resulted in an improvement as well if the change has been sustained (Solberg et al., 1997). Doing measurements in healthcare require a lot of data and Solberg et al. (1997) explains that there are three aspects to consider when collecting and understanding the data that will be used when measuring in healthcare as well as understanding the data. These are: *judgement*, *research* and *improvements* and will be explained in the following sections.

3.1.1 Judgement

In the judgement aspect, the collected data is evaluated to see outcomes and results. It is a component of the decision-making on how good the results from the data are. In this aspect, there is no set hypothesis on what the data will show and also no pre-defined specifics on what kind of data to collect. The judgement aspect in the data for improvement efforts is merely to understand if the data could be used to improve healthcare (Solberg et al., 1997).

3.1.2 Research

The research-based aspects as a tool for improvement efforts in healthcare is a way to gain more knowledge on how previous work around healthcare topics have been used (Solberg et al., 1997). The data collection method in this aspect is to get as much data as possible and to get the “just in case” data that will be used in statistical tests as well as eliminating unwanted variation in the data sets. Typically, the research aspect approach has a pre-defined hypothesis on what the research should achieve and for what reasons when measuring the data and seeing results that would ultimately lead to seeing that a change in the healthcare process is an improvement.

3.1.3 Improvement

The improvement aspect is considering the aim of improvement. The measures of data in the improvement aspect are to identify the problems, and see the opportunities and need for attention (Solberg et al., 1997). This aim is a way of collecting only the data necessary and keeping things simple. The hypothesis on what the data should show is changing and rather than using statistical tests as in the research aspect, run charts are used to see the variation as a tool to see the change and unexpected events over time.

3.2 Healthcare quality dimensions

Developing and implementing new systems in health care is necessary to continuously improve the quality of operations. There are several quality dimensions to consider in healthcare and the Institute of Medicine (IOM) mentions that the dimensions for good care in healthcare are: *safety*, *effectiveness*, *patient-centred*, *timeliness*, *efficiency* and *equity* (Agency for Healthcare Research and Quality, 2022).

The *safety* dimension in the IOM research paper states that healthcare should be delivered without causing harm to patients or the one working with the patient (Institute of Medicine, 2001). It is also emphasised to use safety in every setting and for all patients (Institute of Medicine, 2001). In a safe system, information is not lost nor forgotten in transition and all knowledge about patients is available, with assurances of confidentially to all who need to know it (Institute of Medicine, 2001). Oftentimes the organisational complexity in health care causes processes and routines to be flawed and time-consuming, risking patient safety as well as challenging pressure from legislation (Institute of Medicine, 2001).

Effectiveness in healthcare is defined as the best-acquired evidence to achieve the desired outcome of an intervention among alternatives, including the alternative of doing nothing (Institute of Medicine, 2001). It is providing services based on scientific knowledge to all who could benefit as well as providing the

right care at the right time and avoiding unnecessary or harmful interventions (Institute of Medicine, 2001).

Healthcare should be tailored to meet the needs and values of the patient, hence it is necessary to be *patient-centred* (Institute of Medicine, 2001). Patients are involved in the decision-making, able to address their concerns and given respect for their autonomy. The Institute of Medicine (2001) research paper mentions the following dimensions of patient-centered care:

- Respect for patient's values, preferences, and expressed needs.
- Coordination and integration of care.
- Information, communication, and education.
- Physical comfort.
- Emotional support – relieving fear and anxiety.
- Involvement of family and friends.

Timeliness is an important characteristic in any service and valued focus in improvement of health care and process flow (Institute of Medicine, 2001). Risking to miss timeliness sends signals and lack of attention flow and lack of respect toward the patient, thus time in Healthcare should be delivered without delay or waiting, including appointments, test results and treatments (Institute of Medicine, 2001).

Efficiency in healthcare systems is directed to maximize the use of resources and minimize waste, to get the best value for money spent (Institute of Medicine, 2001). The IMO research paper mentions two ways to improve efficiency, either by (1) reducing quality waste, and (2) reducing administrative or production cost (Institute of Medicine, 2001, p.52).

Lastly, the *equity* dimension in healthcare means that healthcare should be delivered fairly, without discrimination or bias (Institute of Medicine, 2001). This includes addressing disparities in access, outcomes, and quality of care based on factors such as race, ethnicity, gender, socioeconomic status, and geography (Institute of Medicine, 2001).

3.3 Improvements in healthcare

Considering that the organisation is making improvements is what Langley et al. (2009) mentions; for an organisation to be successful at improvement it needs the will to improve. Acts of making changes that result in improvement could also lead to the will for change in an organisation (Langley et al., 2009).

Further is improvement the outcome of actions when developing, testing and implementing changes (Langley et al., 2009). Langley et al. (2009) also suggest the following questions to be asked in improvement processes are:

- What are we trying to accomplish?
- How will we know that a change is an improvement?
- What changes can we make that will result in improvement?

The first question is about constructing a clear aim statement for the change. The second clarifies choosing the right measures and planning of how to collect the right information in the improvement efforts. The last question clarifies the measures in how to improve the current state.

Improvements have to be seen as an inspiring part of the daily life in an organisation as well as the improvement efforts in the organisation's drive for change (Bergman et al., 2015). However, even though all improvements lead to change, not all changes are improvements (Batalden and Davidoff, 2007). Improvements need much planning and knowledge from human factors, and those that interact, to redesign the processes (Varkey et al., 2007).

Making improvement efforts could also be very demanding as the organisation has to be able to use knowledge, capabilities and capabilities when delivering value to the customers (Bergman et al., 2015). It includes seeing new ways of working with improvement and using more innovative ways of doing that (Bergman et al., 2015). The ways of working with improvement efforts could also make it easier to adopt more improvements which lead to new innovative changes (Bergman et al., 2015).

3.3.1 Why are improvements important

As there is an increase of new knowledge and technology along with having an updated healthcare system that has to perform, to keep acceptable levels of patient safety and need, there is a demand for understanding the reasons for improvement (Varkey et al., 2007). The improvement in healthcare could be derived from the conviction that in order for it to reach its full potential the change making has to become the intrinsic part of everyone's job in all parts of the system (Batalden and Davidoff, 2007). In addition, to define improvement in healthcare Batalden and Davidoff (2007) uses the definition as "the combined and unceasing efforts for everyone-healthcare professionals, patients and their families, researchers, payers, planners and educators - to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development (learning)." Following this definition Batalden and Davidoff (2007) illustrate this definition with the figure below, see Figure 3.1.

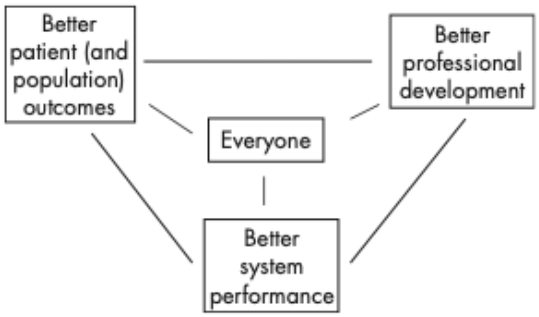

Figure 3.1: Linked aims of improvement, cited from Batalden and Davidoff (2007)

Another reason why improvement is needed is mentioned by Dixon-Woods (2019) where healthcare processes and systems use improvement as a way to use available resources. The improvement factors and research when making efforts in improvement help to scale learning and prevent the improvement process from reinventing solutions that already exist or for things that do not work (Dixon-Woods, 2019).

3.4 Business model framework

To get a better understanding of the approach when assessing the problem description and aim in an organisation a business model framework can be used. In business literature, the business model has been used to understand the goals of organisations and how they are aligned (Fredriksson et al., 2017). Zott and Amit (2010) defines the business model as "a system of interdependent activities that transcends the focal firm and spans its boundaries. The activity system enables the firm, in concert with its partners, to create value and also to appropriate a share of that value". The business model captures the business logic and helps managers to find alignment in what the organisation offers (Fredriksson et al., 2017).

The business model concept is about how it identifies and creates value for customers and captures value as the organisation profits in the process (Casadesus-Masanell and Ricart, 2010). To design a business model Casadesus-Masanell and Ricart (2010) mentions that designers will consider *design elements*, which describe what the system's architecture look like and *design themes*, which derive the elements that are sources of value creation.

A typical business model could look like the one in the figure below, see Figure 3.2. It is a business model canvas that is proposed by Osterwalder and Pigneur and widely used as a tool to describe, visualize, evaluate and innovate business models (Li et al., 2019). The blocks in the canvas are customer segments, value proposition, channels, customer relationships, revenue streams, key resources,

key activities, key partnerships, and cost structure. Osterwalder's canvas is stakeholder focused and intended for who does what in the business (Rayna and Striukova, 2016).

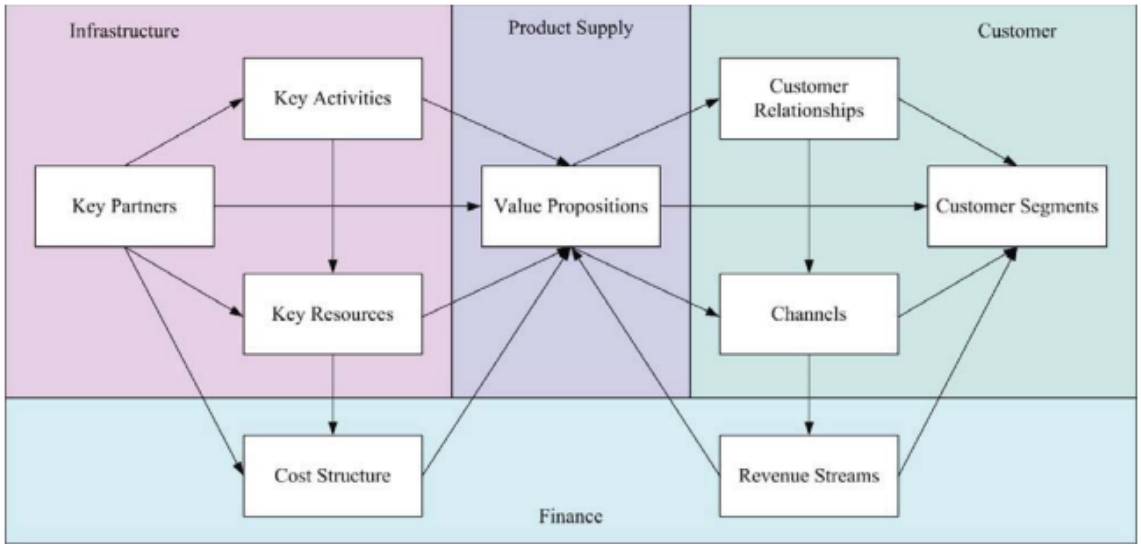

Figure 3.2: Cited from *Study on the business model of a virtual power plant based on Osterwalder Business Model Canvas* (Li et al., 2019, p. 1843).

3.4.1 Business model innovation in health care

In growing challenges of the healthcare system Fieldston et al. (2013) suggest using business model innovation as a strategic framework for improving the delivery of healthcare. Doing so could also help to unify the quality dimensions mentioned in section 3.2 (Fieldston et al., 2013). Business model innovations are the match between a solution and need that in the end create value (Fieldston et al., 2013).

In Teece (2010) *Business Models, Business Strategy and Innovation* the business model is adapted to technological innovations when new opportunities arise in the market to meet new customer needs. A business model can both represent innovation and facilitate it. In addition, does the business model analysis create questions about established and accepted roles in healthcare which opens up new possibilities of organising services within as well as helping healthcare organisations to innovate (Fredriksson et al., 2017).

A business model in Sorescu (2017, p. 692), innovation is also defined as "a change in the value creation, value appropriation, or value delivery function of a firm that results in a significant change to the firm's value proposition.". Value creation is the manufacturing firm's resources and process that develop the products and services. Value delivery refers to where the products and services of the firm are delivered and sold. The firms' cost and revenue functions are also referred to the value appropriation. A business model innovation can reinvent the delivery for the product or service that exists (Sorescu, 2017).

3.5 Summary

The healthcare setting is complex and means of improvement are inevitably a high priority but as mentioned, even though all improvements lead to change not all changes are improvements. Healthcare organisations and systems need the will to improve and doing so can look different. In means of having the right approach, the right data and measurement methods along with several other factors such as maintaining quality aspect are difficult. One way of understanding the value an improvement could bring is by utilising the business model framework which illustrates how to see the bigger picture which the change of process could bring. The idea of this theory is to enhance the understanding of value creation along with improvement efforts and how to see the change when establishing a new project in the healthcare setting.

4

Findings

In this chapter the findings from the study's primary data collection are presented, these stem from interview statements and provide a deeper understanding of the process, considerations and other factors that helps to answer the first research question: *How are VGR working and organising for external data accessibility today?* The collected data are grouped into four themes: the nature of healthcare data within VGR, the data withdrawal process, general considerations, and lastly an external outlook. Statements marked in bold corresponds to the grouped theme that refer to first-order concepts, see section 2.5.

4.1 Nature of healthcare data within VGR

The overall insights are provided in this section before going into detail about the various aspects that are affecting data withdrawals.

4.1.1 Overview

To begin with, findings show that all respondents consider patient data access an important topic. However, at the same time, many consider it an area where the administrations are able to improve. What a majority mention as part of the root cause for the issues is that the area is heavily dependent on laws and regulations. An area considered tricky for both administrative and clinical personnel by all respondents – even the ones specialised in judicial matters.

Thus there is a bottom-up demand for help with the legal complexities. But also to create a consistent process across the region to make it internally efficient. Moreover, such efforts are deemed to create value for applicants as well as for those that handle the applications.

All respondents express how maintaining patient integrity is always important and of the highest priority. About half of the respondents from administrations consider it important and are actively working on improving to work with internal efficiency when working with data withdrawals. On the other hand, a third consider it important to be able to deliver data timely towards the

applicant.

Throughout the region, there are inconsistencies in how applications are handled, such unclarities create risks for mismanagement and thus patient data getting exposed. In the end, this leads to very long lead times for applicants.

One respondent explains that real value is created when there is a fast way through the entire system. A researcher contests to this as it took over two years to get access to data and also expresses that colleagues have cancelled research projects due to long waiting times.

However, another respondent elaborates that the tardiness today is not in favour of researchers and that: “real value is created when a researcher can go from question to having access to data within a short amount of time and not in year’s time”.

4.1.2 Importance of data accessibility

All respondents have expressed that there is a unique opportunity for improvements in healthcare thanks to the availability of health data. Many highlight that there of course is no meaning in collecting large amounts of data, oftentimes at the cost of clinical personnel, if it is not used. Considering the value that data has for improvement it should be easy to access and one respondent in one of the administrations in VGR argues: “I am of the belief that we should use the data we generate in order to improve the healthcare.” Additionally, two other respondents from different administrations in VGR mentioned that: “patient data should be used to develop healthcare.” and “we want our databases to be used for research.”. One external opinion lifted towards industry and life science is that it is equally important to access healthcare data used to improve healthcare products or services, i.e. medical products, drugs and procedures.

However, the drawbacks of inconsistent data withdrawals have led to delays in research projects and one applicant who is also employed at VGR, mentions how it took almost two years from conceiving the idea of a research project to gaining access to health data.

4.1.3 Types of applications

Patient journal data is sought after by many parties. These different parties are interested in the data for a myriad of different reasons and all have different use cases. Thus, the requests are not all the same. For example, RC mentions how requests can come from researchers, media, industry, private persons or improvement projects. Important to mention is that these different request purposes are applied differently within the space of law.

The general tendency is that the number of research applications coming

from within VGR is much larger than external research. Consequently, the process for research requests is the only one with a clear process across all administrations. It has been expressed different views on the varied types of applications and requests for patient journal data.

4.1.4 Laws and regulations

Research projects are in a different field of laws than, for instance, improvement projects with the purpose of operational development, and research is for external distribution and thus needs to be more strict. One respondent with judicial background mentioned that the government premier's research and thus the laws are generous. Another respondent with a research background said that the research agenda considered with laws have had technical problems before and is today a juridical dito. Nevertheless, all the rules that follow in healthcare data access are mentioned by a respondent, with a research background, needed to be in place to make sure that the integrity of the patient is preserved.

4.2 The data withdrawal process

First and foremost, findings show the important steps that characterise the process for data withdrawals within the region. In this section, these steps will be elaborated on between the different administrations and examined. The process is characterised by six main steps:

1. Data discovery – before applying for data, one must know what data is available.

2. Incoming applications – once an applicant knows what data they are interested in they can apply to access it.

3. Handling and assessment of applications – an administration receives the application and has to examine it and prepare it for decision-making.

4. Decision-making – after applications are prepared, decisions regarding admitting or denying access to the data in question are made.

5. Data collection – if an application proceeds this far the administration is tasked to extract the data and prepare it to be submitted to the applicant.

6. Delivering withdrawals – prepared data is handed over to the applicant.

4.2.1 Data discovery

Health data availability. Across the different administrations within the region, health data is available from a variety of sources. The sources range from internal research databases, patient journals, lab data, the National Quality Registries etcetera. Moreover, different administrations can use different patient journal systems. Some of the variations originate from that the region previously has been divided into five sub-regions, whilst different types of administrations contribute; dental care versus "regular health care". Moving over to the types of data available there are: patient data, HR data, economic data (such as cost per patient), internal healthcare, biological samples, amongst others. Not all of these data types are subject to requests for data withdrawals.

Unclear applications for data withdrawal. Respondents from various backgrounds mention how incoming applications sometimes get held up as the one requesting the data has little insight into available data. One respondent with a research background in the region mentioned that towards Gothia Forum, are many companies reaching out and expecting to get data to train AI networks immediately.

One important note is that metadata, the type of data that makes up for collecting the data requested in an application could be very scarce, which causes unclarities on what type of data that is needed. Applications for a research project could be requested without having any insights into if the data really exists.

4.2.2 Incoming applications

The way in for applications. Many respondents express that there is no clear way in for requests and that applications can be sent to various places within each administration. Sometimes this leads to applicants getting "bounced around" in the organisation before reaching the right receiver. In some administrations, there are websites dedicated towards applications, but these are an exception within the region. The majority of administrations receive their applications through a department mailbox, a general e-mail address for the entire administration. This means someone has to forward the application towards the right department in the administration. Generally, this is the R&D department.

Once an application arrives, only a few administrations are numbering and log these. Logging the incoming applications is essential for being able to keep track of the number of withdrawals that are conducted, according to RC. It is noteworthy that one of the larger administrations is not aware of the number of research projects that receive data but only the total amount of journals that are handed out. One respondent from an administration in VGR with administrative background argues that: "it is hard to maintain control over the process at our administration as it is possible to contact the deciding manager

directly. This application does not become logged properly centrally, and it is impossible to know if everything has been handled centrally correctly".

Moreover, one respondent explains that at their administration there is a general tendency not to record and follow the requests if the application is thought to be approved in the end.

Back and forth correspondence. A majority of respondents in the VGR administrations explain that it is not uncommon for incoming applications to be incomplete or erroneous. Such application can not proceed without the applicant correcting them and thus a back-and-forth correspondence is initiated. These respondents proceed to explain that more often than not iteration is needed as some faults persist from the first rounds of correspondence.

This means incomplete or erroneous applications risk getting held up in the process. One respondent with a research background from an administration said: "cases can be pending for several months as correspondence goes back and forth due to the researcher not knowing what data is available or what data they have the right to ask for.". This in some parts connects back to the poor availability of information about how to apply for data withdrawals as mentioned that there are difficulties with entering the information for the documents that constitute the application. Those that request data more often are better at filling the information out.

Volume of applications. In total, across all administrations within the region, there are about 800 incoming applications for data withdrawals towards research projects each year. Many express that the current volume is doable but not "with ease", and that current volumes are expected to grow looking into the future.

The volumes for other types of applications are a little bit more vague. Comparing the administrations, other types of applications do not always take the same way in. However, counting other types of applications the number is indeed much larger and the agenda in this research has covered the research projects and therefore it is not possible to say how the coverage for other applications looks.

For example, one administration receives 20 times as many applications for improvement projects as research projects. Another example is how the volume of journals handled within research projects constitutes a maximum of 10% for the applications.

4.2.3 Handling and assessment of applications

How applications are handled. First off, findings show that there is no general process applicable to all administrations. Although, at RC the incoming

applications are logged and assigned to a person responsible for looking into the details and preparing them for the next step which is decision-making. The applications need to be thorough with information about the research plan and admittance from EPM.

In some administrations there are personnel with researcher experience looking at these applications and then recommending the operational manager in the administration to make a decision, these recommendations are generally followed. Oftentimes such recommendations are based on how well the proposed research method aligns with EPM testing.

Only a minority of administrations describe that they have this process “dialled-in” as they wish. Respondents from both small and large administrations, and also with different backgrounds explain how handling can be challenging. Subsequently, the time spent by the different administrations at this stage varies a lot and can take anywhere from one hour to several. The time spent might not be continuous, but rather spread out and thus the throughput time also varies a lot.

The need for "cross-science" knowledge throughout the assessment of applications. All respondents describe a situation where there is a large demand for a cross-science perspective as the H&C process touches upon different fields. Particularly legal perspectives are oftentimes the most demanded skills throughout assessing applications.

At RC for instance, there are meetings bringing together statisticians, doctors, professors, administrators and researchers. These assessments are in collaboration with several administrations. This process sticks out as the one bringing together the whole spectrum of fields for knowledge on data withdrawals.

There are several examples of when the responsibility lies on a single person, this situation is described as sub-optimal. In some cases, this person could be a statistician or operational manager at the administration making the decision.

One respondent mentions one of the risks of having a dependency on a single person as it is possible for the deciding manager to premiere research of their choice by denying competing projects access to data – although this is a speculation it is still a risk and a showcase of that there is no transparency at certain administrations.

4.2.4 Decision-making

Decision-making As mentioned in the process from RC it is possible for all participants to be present and also voice their opinion during data withdrawals. For instance, the professors may not participate in all meetings but when research is within their field they are inclined to participate. Albeit, throughout

VGR the administrations are organised differently to tackle the same problem. External interviewees in other regions mention that they do this differently as they have stated to organise data requests and withdrawals centrally. In region Halland the organised responsibility is under the IT officer where a cross-scientific board prepare and organises the cases for that person.

H&C – consistency in the assessment of applications across administrations. Due to looking at the application from different perspectives or the lack thereof in some cases the outcome can be, and is different.

Every administration has the legal right to accept or deny applications to their data. Moreover, is it allowed for everyone to reach different conclusions, albeit when they do so one starts to wonder if everyone has looked at it from all relevant angles.

Judicial considerations in decision-making. For example, it is not good to look at the wrong things. One example is if one would be judging the quality of the research itself with the method used or anything similar. Consequently, it could result in situations where the judgement belongs to a single individual.

Oftentimes respondents with backgrounds in research express that one of the areas where the need for assistance in handling applications is within the judicial experience. And respondents with a judicial background express how they would appreciate the opportunity for more collaboration.

4.2.5 Data collection

Administration are considering data collection are resource demanding. In almost all administrations, respondents have said that the most resource-demanding part is administering the handouts themselves. One respondent with a research background, now working in an administration within VGR, has also claimed that data withdrawals are stealing time from something else. On the other hand, one of the larger administrations has a department of about 50 persons dedicated to withdrawals from journals and other sources. In addition for data withdrawals one system named GRAL has been said to be structuring data that is already available within the region. This is said to allow that applications also could have one way out which one respondent has expressed importance to complement the handling process to reach full effect.

4.2.6 Delivering withdrawals

Possible methods. There are some main methods considered when delivering the data to the applicant: physical papers by mail or encrypted drives. There are other initiatives within the region to create new digital ways of delivering healthcare data to external entities.

Handover on paper. As mentioned there are different methods to deliver the data to the applicant. Although with regards to doing this by paper is empathised by one respondent with a researcher background as: “Delivering papers is not something that is reasonable in today’s day and age.”. – In addition, it also is a matter of safety and one respondent with administrative background in the VGR region expressed that doing this through mail might also have issues: “I do not know how these persons with insights into the legalities have arrived at the conclusion that sending sensitive health data by mail is the safest way to handover data to researchers.”.

4.3 General considerations

Firstly, there are some issues described that do not fall into a single step within the withdrawal process. Secondly, some respondents themselves have expressed thoughts about how to address certain issues within the process.

4.3.1 Overarching problems

Apart from the ones previously brought forward these are additional problems that exist today.

“Hidden statistics”. When researchers are also employed clinically at VGR they of course have data access within their clinical role. Many respondents are aware of this problematic situation as it can be hard for clinical practitioners to navigate the surrounding laws and regulations and access data directly. One respondent with a research background in VGR explains how it can be confusing as the research project is admitted by EPM and as the researcher has access – why should they not be able to use it?

This is an issue the administrations are working on, for example, one respondent with an administrative background describes: “after we had informed researchers about how to properly apply for data withdrawals, the number of applications coming in the right way rose.”. It is also a matter of knowledge causing difficulties in the administrations as one respondent from one administration states: “there is a large gap in knowledge within our organisation”

Processing time across administrations. The time elapsed from sending in an application until the applicant receives data varies greatly within the region. For example, in research projects, it could take anywhere from 30 days to 2 years.

As not all administrations keep thorough records, there are no readily available statistics for how long it could take to receive data in general.

One respondent who is a researcher explains how there amongst the colleagues

is a view that it can take a very long time and be fatiguing to request data. It is not unheard of that projects are cancelled due to the troubles in gaining access to data. In a project conceived in 2019, access to data was not gained until the end of 2021. This project required journals from different administrations and their subdivisions. Compared to other regions it is easier to access data and the respondent mentioned that there might be an issue with the fragmentation of journal systems within VGR.

Payment associated with data withdrawals. RC explain how being a public organisation there is no possibility to earn money on selling access to data. Moreover, although there is a possibility to cover costs coupled with the administration and work required to deliver data. However, as of today, there is not a commonality across the region in regard to payments for data withdrawals. One respondent with an administrative background in VGR describes the situation as problematic since VGR: “is both understaffed and underfinanced and our administration is at best ill-equipped to handle data withdrawals.”. Today, only a few of the administrations within the region are covering the costs associated with data withdrawals.

All respondents agree that since it is allowed to cover costs, this should be the practice as well. Moreover, one respondent with a research background in VGR reasoned along the line that: “researchers are not unfamiliar with having to pay for their data, this is the norm with other governmental bodies”.

Moreover, at one administration, they have been forced to take a cut from the whole research budget and give internal researchers the possibility to apply for data withdrawals for free, to the administration’s own data.

4.3.2 Organisational demands

Some respondents directly address issues, they touch upon the application process, aspects of change management, awareness of inconsistencies and collaboration.

Improving application process. There are opinions on how to create a more digital and automated handling of applications. In this aspect, the sentiment is that the administrations feel that data withdrawals for research projects are resource-demanding. One external researcher explains that there is no self-fulfilling purpose in sitting with admin for either side. Therefore it should be important for the applicant that the Dataport can have an overview that is providing all information when entering information about the research. One external research respondent claimed that it should be clear to send in an application for research and not having to wait several months to get correspondence that there was information missing in one field in the document when requesting data. A system like Dataport could have avoided this and it would have been much appreciated.

Change management One respondent answered on change in current processes and managerial aspects that:“people will always be reluctant to change, however, in practise this might not be a problem when change is properly anchored in the organisation”.

When respondents are asked about potential challenges for such a project the responses mainly focus on challenges concerning change in the organisation and people’s reluctance to change within. This is almost always the case and the respondents also believe that all types of projects face these challenges but that if anchoring the project it would be no problem to change the process from today.

Process inconsistencies. Some respondents are aware of how the process for handling applications differs between the administrations. These respondents request more structure and consistency. It is not efficient to be uncoordinated in such a large region. One respondent with an administrative background in VGR also states: “we need one process that is mature and all in all professional”. Moreover, this respondents also state: “that the way we are working with withdrawals today is immature for a region of our size´´. In addition, it is important to coordinate and integrate perspectives within the region, one administrative respondent expresses: “it is essential to build a common structure and process”.

There is a demand for collaboration between the administrations. The respondents claim that collaboration in the region would be beneficial when working with applications. One respondent with a research background in an administration wants rules that apply for everyone. Or mentioned by another respondent external to VGR, to have a policy that everyone can use.

Some respondents, mainly working administratively and quite high up in their respective administration note how a centralised structure could be helpful in order to achieve: “an efficient and consistent handling and assessment.”. These respondents request central handling of applications.

4.4 External outlook

Here, respondents external to VGR are primarily presented with statements on how their respective regions are workings with healthcare data withdrawals.

4.4.1 Other regions

Halland. The respondent from Halland explains how there is a centralised structure for handling applications for external data withdrawals within research projects. A central committee prepares and examines the applications and provides the basis for a decision that the IT Director has a delegation to make. For retrieval of data for the hand-out itself, there is a sort of “data-lake”

making it possible to collect data from several administrations simultaneously.

Östergötland. The respondent from Östergötland explains how there is a centralised structure for handling applications for external data withdrawals within research projects. A central committee prepares and examines the application. Moreover, they have started to collaborate over the geographical regions in what is called healthcare regions. The respondent considers their ability to meet demands from applicants over time to have established Östergötland as a stable provider of healthcare data.

Other regions. According to the respondent from Östergötland, Närke and Västmanland have made considerable progress on the issue of external data accessibility. Moreover, highlighting how the topic is discussed in virtually all regions right now. Respondents have mentioned that region Stockholm and Skåne are working centralised with external data accessibility.

One external respondent also believes that the case of data accessibility is much more of a problem than what decision-makers on a national level consider it.

4.5 Summary

The findings reveal a recognition among all participants regarding the importance of healthcare data accessibility. Furthermore, respondents stress the utilisation of generated data for healthcare improvements and research purposes. The general process for withdrawals can be outlined in six main steps. However, the existing processes exhibit inconsistencies between the administrations and thus room for improvement. The processes are heavily influenced by laws and regulations, leading to difficulties at the clinics. Inconsistent handling of applications poses a risk of mismanagement and also delays in data access.

In conclusion, this study underscores the criticality of enhancing processes, ensuring transparency, and improving efficiency in accessing external data for research and healthcare improvement within VGR.

5

Discussion

This discussion chapter the findings are combined with the theory. Most of all this will put focus on the second research question: *What key learnings can improve external data accessibility at VGR?*

5.1 Quality dimensions

Quality is an essential element of healthcare and has embossed this thesis work to a large extent towards understanding and learning about the healthcare setting within external data accessibility and in the end to give recommendations to RC. Technological developments and improvements of ongoing systems in healthcare are impacting the quality of healthcare in which the given healthcare becomes safer and more efficient. Much of the respondent's answers from interviews, internal and external, revolve around the quality dimensions presented in the theoretical framework and in the following subsections the most empathised dimensions will be discussed.

5.1.1 Safety

During the thesis work and data collection from interviewing much empathising has been toward keeping the integrity in data accessibility of healthcare data. In every interview, the respondent, both internal and external participants, has also highlighted that the integrity of the patient is of high priority and importance. This is connected to the safety dimension mentioned in the theoretical framework. The safety dimension is perhaps the most essential one in healthcare as it stresses that patients should be given healthcare without causing harm. Needless to say, is that the healthcare setting and in the case of healthcare data are continuously challenging this aspect. Although the safety dimensions are empathised with not harming the patient it still connects to maintaining the secrecy of, as well as the integrity of patients.

The integrity of the patients and having their data safe is a difficult area in laws and regulations within the healthcare setting. Researchers that are employed clinically at VGR have access to the data within their role. Importantly, is

that accessing the data has to be aligned with the laws and regulations that can be difficult to navigate through. It is understood that there is a gap in knowledge of the judicial field of working with patient data in the region, which becomes an issue of patient secrecy and integrity if the process is lacking. Some respondents have also lifted that cooperation to share knowledge or access data is wanted to avoid mistakes.

5.1.2 Efficiency

Efficiency is also considered necessary when working with data accessibility. This dimension is perhaps more linked to the administration handling requests and approval of data that will be delivered to the requester. Efficiency in the healthcare quality dimensions means that healthcare should use resources that maximize the use of resources and minimize waste, which might not be the case in all administrations in VGR. Some participants feel that the request for patient data is causing an increased workload that takes time for other practices, or that the request is on such a scale the administration has to hire someone to manage the request. There are several aspects affecting efficiency in data accessibility. Few are mentioned in the findings but important to say is that the complexity of how to access the data without risking the patient's integrity is highly considered.

Although more resources of staffing could be one answer to manage efficiency dilemmas there is more to it, and this question does not seem to have a transparent and direct answer from participants in the interviews. Major administrations in the region seem to be able to deal with larger data withdrawals, meanwhile, the smaller ones are struggling. When the researcher wants to access data it has to be specified on what they want. Occasionally this information is lacking, causing the application for patient data journals to be complete, with more information than requested. In addition, this takes time for the person handling the application, which causes delays in other tasks.

5.1.3 Timeliness

Improving operations and quality in healthcare is one of the main topics for this thesis work. Accessing data for research is one way to do this as researchers or med-tech companies will use the data to measure conditions to see what works and do not. The timeliness dimension might not be the most highlighted aspect from respondents, albeit one of the most important. Timeliness means that patients should be delivered healthcare without delay, likewise, should not researchers be delivered data that will improve healthcare without delay.

Conditions causing delays in data application withdrawals can be applied in both perspectives, the researcher requesting data and the administration handling the request. From interviews with external researchers, everyone has pointed out that the time to access data is too long which has caused projects to

be halted for years or even cancelled. Meanwhile, the administrations mention that some applications are taking time to handle. Reasons for delays are incomplete requests or difficulties to follow up if it is not logged. As the application might not be logged it becomes person dependent, meaning there is someone handling the application. If that person is sick it becomes paused. If the application is not logged there is a risk that it goes around in the administration, as no one wants to take care of it or even knowing the request exists from the beginning. Sometimes, the requested data is difficult to interpret, and the person dealing with the application is unsure of what kind of data that should be delivered. Additionally, the researcher requesting data does not even know if there is any data for the proposed research.

5.2 Process

This section focuses on the process for external data withdrawals and the importance of having a standardised process. Firstly, the difference between different types of applicants will be discussed. Secondly, the inconsistencies within the process – mainly for research applications – will be investigated. Lastly, this leads to the consequences and gives details of where improvements are needed.

5.2.1 Types of applicants

First and foremost, the applications contain information about which healthcare data the applicant wants to have. The applications vary and the data will be used for different purposes. Utilising Solberg et al. (1997) description of the different purposes of healthcare data there are three main usages: research, improvement and judgement. Comparing these three with the ones from the findings, research, as well as improvement, are present in both, either for private organisations or research projects in institutes. On the other hand, judgement from the author's model is loosely translatable to the need of media; following up on outcomes and results without a scientific hypothesis. Essentially, the usage of healthcare data will be for different purposes, which also calls for different handling in the data withdrawals.

One of the main findings is that there is only a clearly defined process for research applicants. Other types of applications, meaning all the ones coming from other parties are handled with much lower commonality across administrations. Further, even within the group of research applications, a majority of applicants are internal to VGR. A possible reason for research applications mainly being internal to VGR is that these are oftentimes clinically employed and they thus have knowledge of the available data needed for their research.

In most projects concerning operations improvement, the requested data applications are also coupled with another judicial field. However, one respondent

expresses how it sometimes is accessing their own data already reported to the central department for data and analysis. This statement highlights the different ways applications can take within the region. Then applications coming from private individuals need to be very specific

Concerning media requests, mainly depending on the size of the administration, some have a press department whilst others barely have an assigned person for the task.

Additionally, it is here interesting to note how some respondents state that they consider that data generated and collected within publicly funded healthcare should not be the foundation for profit-generating activities in private companies without them properly paying for the access.

5.2.2 Inconsistencies between administrations

Looking at the generalised process for handling applications, described in the findings chapter, there are inconsistencies between administrations. Following the process as described, the most untactful inconsistencies is: logs, review and collection as well as payment and throughput time.

In keeping logs, numbering and also providing statistics the administrations differ. In some administrations, the ones managing the withdrawals manage their own logs in connection to the process whilst others utilise the common log-keeping department for their respective administration. Consequently, the details available are not the same and some administrations are unable to provide statistics on exactly how many applications that are being handled.

Perhaps most important is how the H&C review differs between the administrations. Many respondents express that a cross-scientific review is advantageous, however, few administrations utilise this in their reviews. In many administrations, there is oftentimes a single person handling assessments and then making recommendations to the one who makes the formal decision. A cross-scientific group handling the reviews ensures that different perspectives are present and accounted for. Laws and regulations surrounding data withdrawals are sometimes complex and additionally, they differ for the different types of applications. Many respondents express how they feel a need for more support with foremost the legal and judicial knowledge throughout the H&C review. Additionally, Of course, different administrations have different resources available to work with H&C review. and not all administrations can have a lawyer just for applications when they just receive a dozen applications per year. However, when there are fewer persons available for this assessment, the dependence on the individual is naturally high. This means the risk for misjudgement rises, for example through biases towards the applicant. Another type of bias could be promoting their own research or that of colleagues. Organising in a manner that enables a thorough H&C review is essential for

maintaining patient safety.

In the withdrawal step, healthcare data mainly from journals must be extracted/collected. Foremost the available resources at the different administrations vary and this leads to that sometimes it is clinical personnel having to read journals and transcribe them for the handout. For example at RC, the national quality registries are more easily available for withdrawals due to the structuring of data. The registries are not journals per see but rather data from journals organised to enable research.

Moreover, two other important things are payments and throughput time, but these are not coupled to an individual step in the process. Firstly, costs are not properly covered at all administrations or not having any cost structure at all for patient journals. Secondly, the throughput time varies a lot at the different administrations. which will be a consequence of the different types of applications and volume of data, or even specified information on what the data should be.

In summary, it is important to note that the administrations more or less regardless of size all describe issues with the process for data withdrawals. The commonality exists mainly in regard to research applications and here collaboration should be possible to a large extent.

5.2.3 Consequences

There is no inherent fault in working in different ways at the different administrations, each way of working is adapted towards the individual organisation's possibilities. However, in certain steps, such as the H&C review, it is critical to capture additional perspectives, because otherwise there is a large risk of making decisions that are not "legally secure". Naturally, patient safety and privacy are fundamental. Consequently, there is the possibility that outcomes are not the same. Again, there is no inherent problem with different outcomes either as each administration is the owner of their data and thus responsible for upholding the proper secrecy through laws and regulations. However, it raises the question of whether administrations actually are doing proper and consistent H&C reviews and still arriving at different conclusions. Overall, it is fundamental that the process must lead to enabling proper H&C review.

Moreover, being able to actually provide the data is essential and can influence decision-making. Hand-outs on paper are not preferred by anyone. Considering the work required to compile a data withdrawal it can be beneficial when the administrations are making these judgements themselves. At the same time, this means that applications are being processed in parallel at different administrations.

The digital portal solution in the Dataport project is meant to automate the log-

keeping and parts of correspondence. This is addressing parts of the inefficiency in the process. Moreover, not all administrations are covering costs associated with data withdrawals. Addressing payments should to some extent make it possible to assign resources without taking the costs elsewhere. Researchers in particular are not unfamiliar with paying for data access, this is the case at other public institutions. However, political decisions are needed to make it possible for everyone to make withdrawals against payments; and always at a cost-covering basis.

Additionally, without a proper working process in place, there is an inability to scale up if there are more applications for data withdrawals. Moreover, collaboration can be harder as the persons collaborating must have an understanding of the new context they are assisting in. This is essential in part due to new regulations and also a wish to include more types of applicants and make healthcare data more accessible.

5.3 Organisation

This discussion point entails how to organise to ensure knowledge is at the right place within the organisation. Firstly, by looking at how other regions have worked with the same issues and secondly, the needs within VGR.

5.3.1 External outlook

In the findings, how other regions are working with data accessibility, mainly concerning research applications, have been investigated. Two other regions have been contacted directly, Region Östergötland and Region Halland. Both are organising centrally in regards to research applications for external access to healthcare data.

Firstly, in Region Halland there is a central committee conducting the H&C review, they are preparing and discussing applications. Subsequently, decisions are made by the IT Director, A common IT infrastructure is described as essential. Moreover, the region is about one-fifth of VGR in terms of population.

Secondly, Region Östergötland is, much like Halland, centralised in research applications. Region Östergötland is actually starting to collaborate within their so-called healthcare region, meaning their geographically adjacent regions. The respondent explains how being able to meet demand over time also has increased the volume of applications coming from researchers outside of the region. Noteworthy is that Region Östergötland's population is about a fourth of VGR's.

Finally, both Region Stockholm and Skåne are working centralised and Västmanland is described as a front-runner. Findings indicate that there is some

national collaboration, but mainly between singular regions. There seems to be a tendency to centralise efforts. Anecdotally, one respondent working on a national level mentioned how “I thought VGR already had a process for this [central data withdrawal]”.

5.3.2 Internal possibilities

Based on the previous main discussion point, what remains unaddressed is how to enable collaboration. Some respondents express demand for central handling. As aforementioned, when an applicant request data from several administrations they have to work in parallel doing the same assessment. Findings point towards that even though a standardised operating procedure is made, the multiple perspectives needed for a thorough H&C review will not be possible to find at only a local level. Working centrally certainly addresses this issue and could thus reduce the throughput time. Moreover, having central handling makes it possible to organise in a cross-scientific manner whilst still inviting local representatives in order to not miss their knowledge of the specific organisation. Without central handling the risks of mismanagement increase.

The mapping shows that the total volume of research applications is about 800 per year within VGR. Considering the RC handles about 150 per year, the total volume is deemed to be possible to handle by a central organisation. Moreover, it is possible to organise centrally from a legal perspective. Moreover, other regions’ centralisation and the benefits therein also point in the same direction.

5.4 Increasing data accessibility

The Dataport project contains a new digital solution that is meant to help the administrations to handle the applications more efficiently and hopefully with fewer resources. This new digital platform enables applicants to save time by only applying once for data, even when it is from different administrations. This is of course a huge gain for applicants, not having to contact each and every administration if they want data from the whole region.

The business model canvas presented in the theoretical framework is an attempt to illustrate what the value is in implementing a system that would allow for more resource-efficient data accessibility. It also helps managers to find alignment in offerings towards the customer base. The business model is meant to meet new demands and adapt to new opportunities. It ultimately reinvents how the delivery is changed for a service or product.

Integrating the infrastructure of the canvas including; activities, partners and resources to the value proposition, here referred to accessing healthcare data in the region, and then the customers which are the researcher and the ones wanting to access the data, it becomes possible to see the whole picture

of value creation. How the researcher and other actors that want to access healthcare data are through the Dataport, which connects the request from the researcher to the administration. In the end, value is created for both sides of the healthcare data as one goal of RC is to give access to healthcare data and the researcher will with the data improve healthcare.

When giving value it is necessary to understand the enablers. This would be a need for more competencies and also a need for more discussion involving several parts of VGR, which will be needing to integrate other stakeholders to complement the view. With new knowledge, the process and also value proposition will be seamless. More administrations will see the value and then have more people on board with the project.

Looking at how applications are handled today there is much more commonality with research applicants, however, the other types do not take the same way in the organisation. Neither are their needs identical. Looking at face value, researchers want lots of data at once whilst pharmaceutical companies might want more aggregated data or statistics on a regular basis. Further, the media might want a single case, as it was mentioned that some were asking about statistics during Covid-19 to puzzle out the spread and give a picture. There is also a concern in investigations when the media suspects something starting with the “gold customer”, i.e. researchers, and going forward and accommodating this once more knowledge about their needs is gained.

Moreover, when creating accessibility to data, applicants beyond researchers, who mainly are within VGR, the first step in the process, data discovery becomes even more important. A possible reason for research applications mainly being internal to VGR is that these are oftentimes clinically employed and they thus have knowledge of the available data needed for their research.

5.5 Moving forward

To ensure improved external data accessibility at VGR, the findings and subsequent discussion has arrived at several insights and learnings. It is possible to improve the quality of service by providing external healthcare data accessibility. Foremost within safety, efficiency, and timeliness. Ultimately, benefiting both the healthcare system and external entities.

The process is a critical aspect that needs to be addressed. Currently, there are inconsistencies between administrations, especially for non-research applications. It is essential to establish a clear and unified process that can be followed by all types of applicants. This process should outline the necessary steps, requirements, and guidelines for data accessibility requests, ensuring transparency and efficiency for all parties involved.

The H&C review process is vital for ensuring the legality and ethical requirements are met when providing external data accessibility. Based on the expressed need for collaboration, It is then essential to incorporate cross-scientific perspectives during the review to capture diverse viewpoints and minimise biases. In turn, the multidisciplinary perspectives will help ensure the quality and integrity of decision-making. The result is a more robust evaluation of applications which will mitigate risks associated with subjective judgements.

Moreover, collaboration and knowledge sharing among administrations and to other stakeholders is essential for fostering an environment for efficient data accessibility. It would in addition be valuable to use a business model to integrate all the perspectives when implementing a central system where one can request healthcare data to see how value is created for everyone involved.

6

Limitations

The thesis work has been in tight collaboration with RC and the research questions established to fit the agenda and also answer the problem space. The back-and-forth communication with RC has influenced the thesis work to a large extent, both in finding suiting literature and interpreting the findings as well as understanding the current process of accessing healthcare data. The collaboration has in addition deepened the author's knowledge in the field.

The authors of the thesis work had a wide scope when approaching the project, however, as time proceeded the scope has become more narrow and limited the research to fewer aspects, as an effect to increase the trustworthiness of data and results.

The limitations of the thesis work have led to the focus on research work and not other external stakeholders such as industries or media. As many of the respondents spoken with had knowledge about researcher application and request of healthcare data the mapping of information has predominantly been towards accessing healthcare data through the researcher perspective. Nevertheless, brief discussions with representatives from industries wanting to access healthcare data for research and medical improvements highlighted interesting points that could be of interest to further investigation.

Healthcare in Sweden is a combination of state, regions, municipalities and private actors. What has not been covered in this thesis work are the private healthcare providers or actors, and naturally not all single administrations of healthcare in the region. On the other hand, could information from the private actors contribute to the research and is therefore an interesting aspect to consider in future research.

7

Conclusion

Healthcare data accessibility is essential for improving healthcare. In this thesis, the broad concept to access VGR's healthcare data in an external setting is investigated with an emphasis on accessibility in research projects. The study is conducted in the setting of RC's project Dataport. VGR is one of the biggest regions in Sweden and thus has healthcare data of millions of inhabitants. The healthcare setting is a sensitive area with regard to patient integrity. This has been highly prioritised throughout the thesis work and strongly embossed when giving recommendations towards RC on how to proceed.

The concepts utilised are broad and integrate multiple perspectives in order to understand the current situation and also synthesise with the empirical findings to form the recommendations. Concepts include, improvements and characteristics of healthcare research as well as quality dimensions within healthcare.Another valuable insight from literature has been through the business model canvas as it helps to illustrate the value proposition that is formed between applicants of healthcare data, and the administrations giving access to it. Not all quality dimensions given in the theoretical framework are discussed, however equally important in other settings to the healthcare context. For the sake of this report, only the dimensions: safety, efficiency and timeliness have been elaborated on, connecting findings with literature.

The findings in the thesis work present information on what has been said by respondents – both internal and external. It is from both sides empathised that accessing data is important and that it should be easy. Researchers that want to access data sometimes do not fully understand the process as they apply for data or even knowing if the data exists, causing the application to be unspecific. This dilemma causes inconsistencies from both directions of data accessibility and ultimately delays in research that will be used to improve healthcare. The process for handling applications for external data withdrawals is fragmented and without a clear common guideline. Moreover, it is considered a complex area where laws and regulationshave a large influence. Without the proper knowledge, there are risks in mismanagement of healthcare data. Consequently, findings show that there is a demand for collaboration between administrations.

Combining theoretical concepts with the findings provide three main learnings that are discussed to improve external data accessibility in VGR. Namely, process, cross-scientific review and expansion.

First and foremost, the process for data withdrawal can be more efficient. Having one way in for applications would provide clarity for both applicants and administrations. The proposed digital portal could also help administrations with necessary but labour-intensive steps such as log-keeping. Moreover, other aspects such as payments and how to collect requested data also need to be addressed.

Secondly, maintaining patient integrity and data confidentiality is essential. The challenge lies in navigating the complex legal and regulatory landscape surrounding external healthcare data access. To ensure patient integrity, all applications must go through proper H&C review preferably by a cross-scientific group. In regards to the organisation required by VGR to be able to provide a cross-scientific review. Both volumes and resource scarcity point towards addressing it higher up in the organisation. Moreover, other regions have worked with centralising external data accessibility. Therefore, a central group for H&C review seems most suitable and could also incorporate local collaborations to encourage knowledge sharing.

Lastly, expanding beyond the current focus on research applicants would ultimately provide more usage of generated healthcare data that will be useful for other stakeholders. Although this has not been covered to a large extent, the future investigation could provide more insight into how to proceed with integrating these types of applications.

The contributions of this thesis are argued to be relevant and of practical value thanks to the recommendations it provides. These recommendations have the potential to help RC in the Dataport project and in the end, improve external data accessibility within VGR. Moreover, although the learnings stem from the specific context of VGR, these are still general in nature and could be valuable for other regions working with external data accessibility. However, as always one should proceed with caution.

8

Recommendation

This chapter will, based on everything presented in previous chapters, present the recommendations towards RC and thus, unsurprisingly, answers the third research question: *What are the recommendations towards RC?*. The recommendations are:

- RC should firstly implement the Dataport as one common way in for research applications.
- Utilise the portal to help in the handling of applications (log-keeping, etc.).
- And with this foundation, look at a common process of handling applications throughout the region.
- Centralisation of assessment is needed to ensure a cross-scientific H&C review.
- If centralising, leveraging the existing H&C review at RC is beneficial. Local representatives from administrations can be invited.
- When having one way in, also having one way out becomes essential. This needs to be further investigated and developed.
- Healthcare data should be released digitally.
- Pursue political decisions needed for payments for healthcare data withdrawals.
- Lastly, to accommodate all types of applicants the value offering needs to be investigated. Other types can then be connected to the common way in – the Dataport.

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