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The internationalization of new technology within an organization with unclear ownership

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Abstract

The internationalization of new technology within an organization with unclear ownership

Alexandra Eriksson and Sofia Piccolo

This master thesis was done at Uppsala Clinical Research Center (UCR). UCR have recently developed the technical platform QReg 5 for managing quality registries. UCR have been in contact with several international organizations interested in collaborating with UCR because of their expertise within quality registries as well as their technical competence. UCR have a complicated owner structure as well as organizational structure, as they are owned by Uppsala University and Uppsala County Council. The purpose of this master thesis was to present how QReg 5 could be commercialized under UCR's preconditions. In order for the internationalization plans to be successful, it was shown that the shared ownership of UCR needs to become clearer. By taking advantage of the possibilities with the new development section at UCR, the management of the contacts will be more efficient. Potential competitors for UCR are registry centers that have created their own technical solutions, large software companies, Life Science related organizations (e.g. hospitals), the organizations that UCR license QReg 5 to, as well as software companies creating electronic medical records. The most interesting customer segment for UCR are organizations with technical competences, which are placed in countries were quality registries are not yet in use.

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Populärvetenskaplig sammanfattning

Detta examensarbete har utförts på uppdrag av Uppsala Clinical Research Center (UCR). UCR arbetar med kvalitetsregister för förbättrad hälsa hos människor världen över, och de har nyligen utvecklat den tekniska plattformen QReg 5 för hantering av kvalitetsregister. UCR har varit i kontakt med flera internationella organisationer som är intresserade av att påbörja ett samarbete med dem. Organisationerna vill ta del av UCR:s expertis inom området för kvalitetsregister samt deras tekniska kompetens. UCR har både ett invecklat ägarskap och organisationsstruktur, då de är en centrumbildning mellan Uppsala Universitet och Uppsala Landsting. Syftet med detta examensarbete var att presentera hur ny teknologi, såsom QReg 5, kan internationaliseras med de förutsättningar som UCR:s organisation har. De frågor som skulle besvaras var; 1. Hur kan UCR hantera organisationsprocessen avseende internationalisering av QReg 5? 2. Vilken typ av konkurrenter finns det för UCR och QReg 5? 3. Vilka olika internationella kundsegment finns för QReg 5?.

Genom bakgrundsstudier, teoretiska koncept och intervjuer med nyckelpersoner inom UCR:s verksamhet skapades en referensram. Via referensramen konstruerades frågor inför kvalitativa intervjuer med jurister från Uppsala Universitet och Region Uppsala, representanter från övriga nationella registercentrum i Sverige samt med representanter från de internationella organisationerna som UCR tidigare har varit i kontakt med. Tack vare de svar som erhölls från de kvalitativa intervjuerna, så har frågeställningarna för examensarbetet besvarats.

Sammanfattningsvis så resulterade arbetet i riktlinjer för UCR:s fortsatta arbete med internationaliseringen av QReg 5. Till att börja med så konstaterades det att möjligheten att arbeta med organisationer världen över inte bara är en möjlighet för UCR, utan även för Sverige. Därför gavs rekommendationen att UCR fortsätter med sina internationella planer.

Det konstaterades även att det delade ägarskapet mellan Uppsala Universitet och Region Uppsala medför att internationaliseringen av QReg 5 blir komplex. Ägarskapet är inte tydligt för UCR, och därmed inte heller för QReg 5. UCR behöver ett tydligare ägarskap, med avsikten att skapa tydligare riktlinjer för hela organisationen och dess medarbetare. Ett avgörande beslut för UCR:s organisation är att de introducerat en utvecklingsenhet, som är ansvariga för internationella samarbeten. En rekommenda-

tion är att kontakterna i framtiden ska inkomma till denna enhet, som kommer att vara tydliga i sitt internationella arbete genom att leverera rimliga och genomförbara projektplaner. UCR bör även se till att QReg 5 får mer fokus av internationella kontakter, redan innan de kontaktar UCR.

Av de intervjuade registercentrumen så hade två skapat egna tekniska lösningar för kvalitetsregister, dessa två organisationer hade även fått internationella förfrågningar. Dessa registercentrum kan därför betraktas som potentiella konkurrenter. Andra potentiella konkurrenter pekades ut som stora mjukvaruföretag, Life Science relaterade organisationer (exempelvis sjukhus) som redan arbetar med eller planerar att arbeta med kvalitetsregister samt de organisationer som UCR licensierar QReg 5 till. Ifall kvalitetsregister kan implementeras i elektroniska journalsystem, så kan även de mjukvaruföretag som skapar dessa vara potentiella konkurrenter för UCR.

Det mest aktuella internationella kundsegmentet för UCR har pekats ut som kunder med tillräckliga tekniska kompetenser, samtidigt som kvalitetsregister inte ännu används i det land som organisationen befinner sig i.

Abbreviations and definitions

- ACS = Acute Coronary Syndrome
- AMI = Acute Myocardial Infarction
- BCIS = British Cardiovascular Intervention Society
- BMC = Business Model Canvas
- CDT = Care, diagnostics and treatment
- CPDC = Central Personal Data Controller
- CPUA = Centrally Personal Data Responsible
- CRCS = Clinical Research Center for Stroke
- MINAP = Myocardical Ischaemia National Audit Project
- NCIS = National Cardiac Information System
- NDR = The Swedish National Diabetes Register
- NICOR = National Institute for Cardiovascular Outcomes Research
- Open QReg 4 = Older version of UCR's technical platform
- PCI = Percutaneous Coronary Intervention
- QReg 5 = UCR's latest technical platform for quality registries
- RCSO = Registercentrum SydOst
- RRCT = Registry-based Randomized Clinical Trials
- SALAR = The Swedish Association of Local Authorities and Regions
- UCL = University College London
- UCR = Uppsala Clinical Research Center
- USP = Unique Selling Point
- UU = Uppsala University

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1 Introduction

1.1 About quality registries

Quality registries are a way of collecting patient data in structured databases. Each quality registry focuses on a specific disease or health condition, for example heart disease or obesity. Patients with the concerned disease or condition have personal data collected in the appropriate quality registry. The data is inserted in the registries by healthcare professionals, such as medical doctors or nurses. The purpose of quality registries is to improve national healthcare, by being able to follow up and attribute effects of medical treatments over time. Researchers that are interested in data from specific registries can apply to access the data, and thereby be able to use it in their research. Each quality registry is managed by a registry holder group that is constituted of researchers or medical doctors. The registry holder groups are the clients of registry centers, such as Uppsala Clinical Research Center (UCR). UCR's quality registry section's responsibilities include the management of the technical aspects of the registries, since the registries are created upon UCR's own technical platform. The newest version of this infrastructure is called QReg 5, and the internationalization of QReg 5 will be the focus in this study.

1.2 Problematization

UCR have been contacted by numerous international organizations. These organizations have shown interest in UCR's work with quality registries, and they want to take part of UCR's know-how as well as discuss potential collaboration possibilities. The contacts have not directly addressed the technical platform QReg 5. However, several of the contacts have quickly realized that QReg 5 is the key in order to create functional quality registries. As mentioned, the purpose of this thesis is to act as a foundation for UCR's internationalization of QReg 5.

In order to define the questions to answer in this thesis, there is a need to observe UCR's situation from different aspects. This is a crucial step to realize and assess the potential risks with an international expansion. There are several aspects to consider such as economical, organizational and theoretical. The mentioned aspects are important not

only for UCR, but they also apply to the stakeholder's situation.

As UCR is a research center created by Uppsala County Council and Uppsala University (UU), this implies restrictions such as economic ones since UCR is a non-profit organization. One possibility could be investigating the opportunity to export the business concept regarding QReg 5 into a separate company. However, being a non-profit organization connected to healthcare and research, there is a certain credibility and market position associated with this. The attained credibility and market position could possibly be lost if the business concept would be exported in order to profit economically.

The organizational difficulties refer to UCR being restricted as a direct consequence of them having a shared ownership between the university and the county council. To what extent can UCR do business, and what degree of freedom do they have? It seems as this might also affect the ownership of the technical platform QReg 5. Further organizational difficulties are concerned with UCR and the potential growth of the organization. To welcome new employees and restructuring the organization requires carefulness, as UCR need to meet the challenges that a larger and more developed organization faces. For example, if UCR manage to expand by signing with several international clients, and if this happens too quickly, there could perhaps be a risk of UCR outgrowing themselves. Might there be a lack of business management competence within UCR as an organization, that is needed in order to expand internationally? The question is, is UCR ready to grow as an organization?

Thirdly, regarding the theoretical aspect, this intends the technical part of UCR's internationalization plans, namely the technical infrastructure QReg 5. How should UCR protect the software in order to maintain control of it when licensing it to international clients? Should UCR open source the code for the technical infrastructure, in order to be able to develop healthcare in the world in a higher frequency? An important aspect is how UCR should package the business concept for QReg 5, could there for instance exist different versions of QReg 5?

The internationalization plans for QReg 5 do not only involve UCR, but the counter part in the business relation as well. When it comes to the nature of the stakeholder, there might also be technical and political obstacles depending on the national structure of the country the organization is in. The business concept of QReg 5 needs to be individually adapted concept for each organization since it is not a software that can be downloaded

and used instantly. It is also common for nations not to have an unique identifier for every citizen, such as in Sweden, and this problem must therefore be solved for each country. Finally, in order to understand the potential market, who are the possible competitors to UCR and the technical platform?

1.3 Aim of the thesis

The aim of this thesis is to present how new technology can be internationalized, considering aspects such as an unclear ownership. Having considered the mentioned aspects in the problematization, and made certain delimitations, three questions have been formulated.

The questions that will be answered in this thesis are:

- How can UCR manage the organizational process in a profitable way, regarding the internationalization of QReg 5?
- What kind of critical competitors are there for UCR and QReg 5?
- Which different international customer segments could be identified for QReg 5?

By answering the questions mentioned above, we will bring value to us as students but also to UCR's plans to internationalize QReg 5, in order to contribute towards UCR's mission to improve healthcare globally.

2 Background

2.1 The origin of quality registries

Quality registries origin from Sweden. The first quality registry in Sweden was up and running in 1975 in the city Lund, and it was initialized by a Swedish orthopedic professor called Göran Bauer after he returned back home from Harvard. The first registry was a collection of data concerning knee surgeries. A few years later his colleagues started a hip surgery registry. The reason why these two registries were the first ones, is because the technique concerning the replacement of damaged hip and knee joints was new at that time and initially there were many complications. These registries became

national, and thanks to all collected data it was possible to create statistics in order to draw conclusions regarding how to improve within the field. These registries made Sweden world leading within knee and hip surgery. In the beginning of the 1990s the interest in evidence-based medicine and quality work within healthcare increased, which lead to the formation of the decision-making unit for national quality registries in 1993. The unit laid the principles for how quality registries are structured today (Nationella kvalitetsregister, 2016).

The turn of the millennium and the fact the web technology facilitated the data input procedure making it possible to insert data with the help of the Internet, led to a breakthrough for quality registries. Every hospital and its personnel were able to insert information directly into the registries, instead of using floppy disks and send them to an intermediator who then would insert data into the registries for them. This brought a significant rise in the number of quality registries, at the same time as they were becoming more complex since they contained more data than ever before (UCR, 2017b).

2.2 Sweden's venture at quality registries

In 2011, the Swedish Association of Local Authorities and Regions (SALAR) decided to invest in quality registries. Today, it is optional to create new national quality registries, and the registry centers are self-governed while being indirectly controlled by the funding of the registries donated from SALAR. In 2015, a website called "Healthcare in numbers" became active for the public, allowing anyone to inspect the results of quality enhancing work in Swedish healthcare. There is a mutual opinion in the political climate in Sweden that quality registries are valuable for improving the healthcare in the country (Götaland, 2017).

Today, Sweden is a leading country when it comes to collecting patient data in quality registries. The purpose is to deliver the best possible care for all patients in Sweden, regardless of gender, ethnical background or geographic location. The collected data is intended to be useful in research studies for several years to come. If data is collected during a long period of time, and if it is highly diverse, it is more reliable and therefore more valuable for studies. The national quality registries systematically collect data from almost all patients in the group of interest from all care units in Sweden. The qual-

ity registries contain information at an individual level including background factors, diagnoses, treatments, outcome of treatments etc. With the help of registries it is for example possible to determine which interventions, medications and medical technology devices that have given the best results. Thanks to quality registries it is also possible to analyze whether the same quality of healthcare is offered all over the country. Some registries are, however, still in the early stages and it is necessary to collect more data before being able to make qualified conclusions based on the data(Götaland, 2017).

The structure of the Swedish system is highly beneficial in order to be able to collect personal data, as every person has a unique social security number and is registered in a national population registry.

2.2.1 Results of quality registries

An example of how healthcare has been improved by the use of quality registries is shown in the well-known article published in The Lancet from 2014. The article presents outcomes from different methods of care for acute myocardial infarction (AMI), and represents a comparison between Sweden and the UK with data collected between year 2004 and 2010. Sweden and the UK were chosen because these were the only two countries worldwide that had national clinical registries for acute coronary syndrome at that time. Unlike the UK, Sweden had a more efficient system for reporting and evaluating the quality and outcomes from healthcare. The national registry concerning AMI in Sweden is called SWEDEHEART and is managed by UCR, and the registry from the UK is called Myocardical Ischaemia National Audit Project (MINAP).

The effectiveness of different treatments was compared and the findings were that 30-day mortality of patients after having suffered from an AMI was 7% in Sweden and 10% in the UK, this corresponded to 11 263 excessive deaths in the UK. These deaths could possibly have been prevented, if the patients had experienced their care in Sweden and not in the UK. Thanks to these discoveries, it was possible to determine that it is crucial to study clinical differences between countries, in order to improve healthcare and prevent deaths (Chung et al., 2014).

Thanks to the well established use of quality registries in Sweden, in particular SWEDEHEART mentioned in the article above, different methods for care are continuously evaluated which results in well proven methods and better healthcare.

2.2.2 The management of quality registries

There are more than 100 national quality registries in Sweden. As can be seen in Figure 1, there are different actors involved in the management of quality registries. For each quality registry there is a management group that is responsible for the registry, this is called a registry holder group. In this group there is maximum one registry holder, and this person is usually a doctor that is responsible of a registry during his or hers research time. Therefore, the registry holders and the other members of the registry holder group (generally 5-6 people in total) do not work full-time with the registry they are managing. For a quality registry center such as UCR the client will therefore be the registry holder group and it is them who pay UCR for their services. Except the registry holder group there is a Centrally Personal Data Responsible (CPUA) for each registry, for the registries that are managed by UCR and thereby Uppsala County Council, this person is the county attorney. Once a registry holder group has chosen a quality registry center, depending on what technical platform the center offers the registry will be created with that platform. Thereafter, it is almost impossible to change platform since it requires a lot of work and is expensive. The registry holder groups are financed by SALAR, there are however criteria such as enough technical excellence that have to be fulfilled before SALAR decides to invest in the quality registry. If researchers want to take part of the information that is included in quality registries they have to be granted ethical vetting before they can send their applications to the registry holder groups (Brodén, 2017).

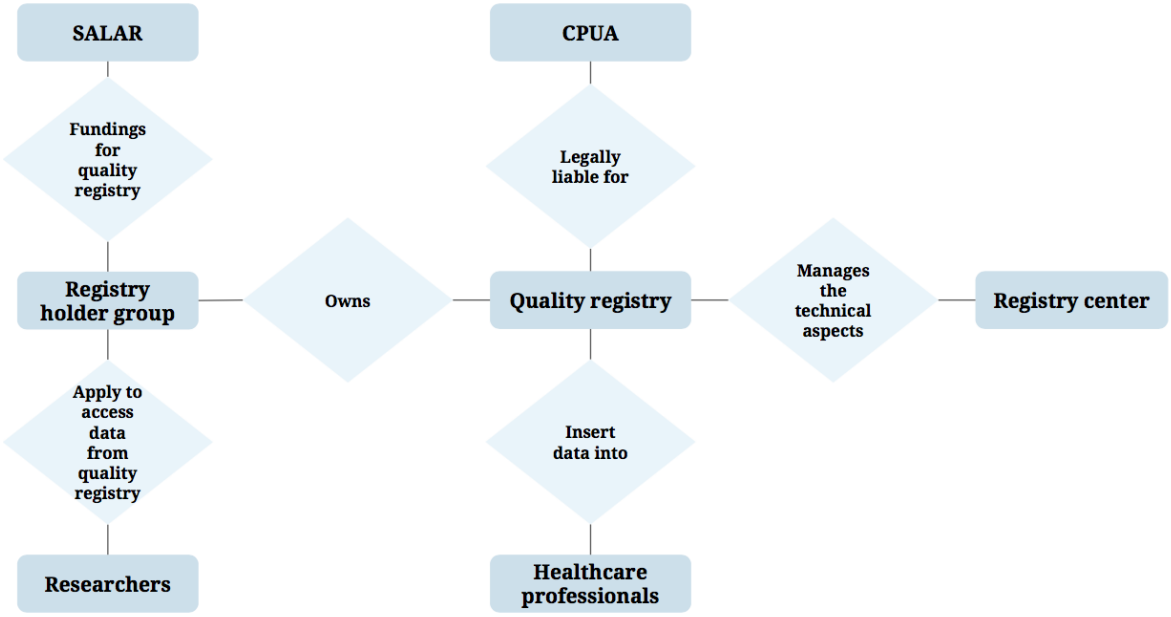

Figure 1: Relational diagram for quality registries. SALAR provides funding to the registry holder group, in order for them to manage a quality registry. The registry holder group chooses a registry center to manage the technical aspects of the quality registry. A CPUA is responsible for all the quality registries in a region. Healthcare professionals insert data into the quality registry. Researchers can apply to the registry holder group to access the data.

2.3 Uppsala Clinical Research Center

UCR is organized in three main sections; clinical research, biobank and quality registries (see Figure 2). The clinical research department offers complete services for clinical trials, such as initiation, planning and implementation of the project. They work both with academic institutions and pharmaceutical companies (UCR, 2017a). Uppsala Biobank contains research samples and sample collections intended for care, diagnostics and treatment. UCR Laboratory, that is integrated in Uppsala Biobank, offers analytical and other laboratory services for companies and other research purposes (UCR, 2017c).

The section for quality registries manages the technical aspects of several national quality registries. UCR is one of the registry centers in Sweden, which are all working towards the mission to improve healthcare set by the Swedish National Quality registry Unit. UCR is the largest quality registry center in Sweden, and except support and

development of quality registries, they also work with research registries and registry based randomized clinical trials (RRC-T). Today the quality registry center at UCR supports 22 national quality registries, and Sweden's largest as well as UCR's most famous registry is SWEDEHEART which contains data regarding cardiovascular diseases. There are 20 software developers in the quality registry section that work with the different registries that are supported by UCR. Their responsibility is maintenance and support of existing registries, as well as developing new solutions for the technical platforms managing quality registries. They have recently developed a whole new version of the platform called QReg 5. The platform is developed based on feedback from scientists and hospitals using the data for research (UCR, 2017b).

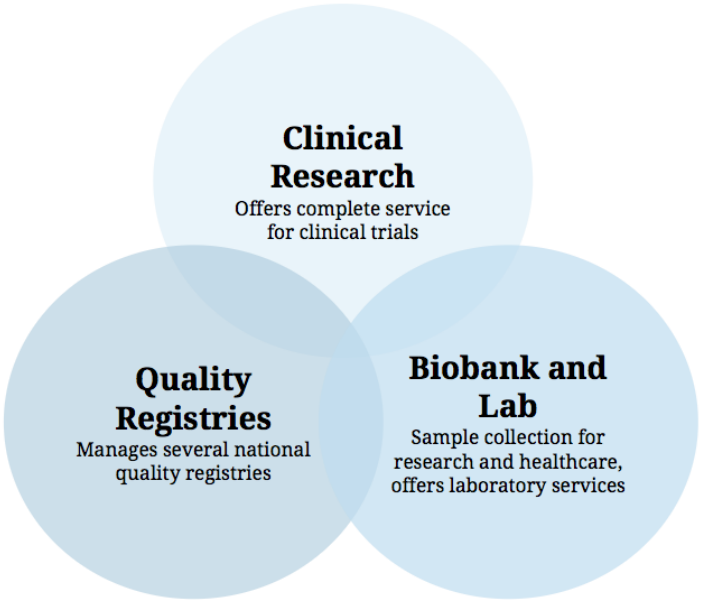

Figure 2: The main sections of UCR. The main sections Clinical Research, Quality Registries and Biobank and lab, perform their activities independently from each other.

2.4 The technical platform QReg 5

In the early stages, the quality registries at UCR started out as simple sheets with information. The sheets later developed into a technical platform called Open QReg. The platform was extended with more features leading to several generations of the platform. The last version of that platform was called Open QReg 4. However, in time Open QReg 4 became outdated and several problems could not be resolved which resulted in misleading statistics.

QReg 5 is the latest platform developed by UCR. The aim of the developers has been to make the platform user-friendly and easily adaptable to different registries. The platform is constituted of modules that are replaceable. If any technology becomes outdated for a component, the concerned module can be replaced, and thereby the risk of the whole platform becoming outdated is avoided. This would otherwise have been a large risk in today's society, where the development of technology moves at rapid speed (Mickelsson, 2017).

3 Theory

3.1 Internationalization of new knowledge and new technical solutions

How can new knowledge from scientific research, that possesses commercial potential, be turned into an economically valuable business?

According to Witt and Zellner (2005), different categories of knowledge from scientific research are transferred in different ways. Propositional knowledge that can be stored by information media (as for example written documents), which requires no personal contact with those who created the knowledge, has a fairly easy transfer process. However, other forms of knowledge that are hard or even impossible to transmit to recipients by information media, require an entrepreneurial transfer process. Scientists or engineers that migrate from academia to the private sector can commercialize the knowledge, which is one of the reasons why it is necessary to recruit scientifically trained personnel to companies. The transfer of the scientific knowledge is triggered by someone seeing

the business opportunities in the new scientific knowledge, which is an entrepreneurial achievement, who then creates a concrete business concept. Another entrepreneurial task is to integrate the new technology into, if applicable, an established organization. The most efficient way this can be successfully exploited by a company, is if the new knowledge can be made complementary to already existing organizational capabilities. Sometimes this requires major organizational restructuring (Witt and Zellner, 2005).

3.1.1 Understanding clients from a value perspective

Business Model Canvas

In order to launch the internationalization process, it is crucial to know who the potential clients are. The first step is to understand the clients from a value perspective, and thereby understand how to position UCR's organization and their technical platform QReg 5. The Business Model Canvas (BMC) is a concept created by Osterwalder and Pigneur (2010), and a BMC was to be created for UCR. The very essence of a business model is to describe how an organization creates, delivers and captures value. In the BMC, there are nine building blocks which are the following; Customer Segments, Value Propositions, Channels, Customer Relationships, Revenue Streams, Key Resources, Key Activities, Key Partnerships, Cost Structure.

The first block is Customer Segments, which in UCR's internationalization work stands for the international organizations that they have been in contact with. The organizations are different types of customers, that UCR might aim to reach and serve. The Value Proposition block describes the products and services that create value for a customer segment, namely the technical platform QReg 5 and its USP. Channels describes the way UCR reach and communicate with their clients, from how they raise awareness of QReg 5 to how clients are able to sign a licensing agreement in order to gain access to it. The Customer Relationships block describes the relationship that UCR have with each Customer Segment. The Revenue Streams block represents the revenues that UCR generate from each Customer Segment. Key Resources stands for the most important assets for UCR. In UCR's case there are many Key Resources, thanks to their complex organization, for instance the know how of the people working at UCR and their expertise regarding quality registries. The Key Activities block describes the most important actions for UCR, for example the development and support of QReg

5. Key Partnerships represents UCR's network and partners, such as the other registry organizations in Sweden. Lastly there is the Cost Structure, a block that describes all costs that are involved for UCR. The Cost Structure for UCR is could be described as value-driven, rather than cost-driven, as they are not concerned with focusing on minimizing the costs wherever possible, instead they deliver a high quality product and support with the associated costs (Osterwalder and Pigneur, 2010).

A visualization of UCR's Business Model Canvas can be seen in Figure 3.

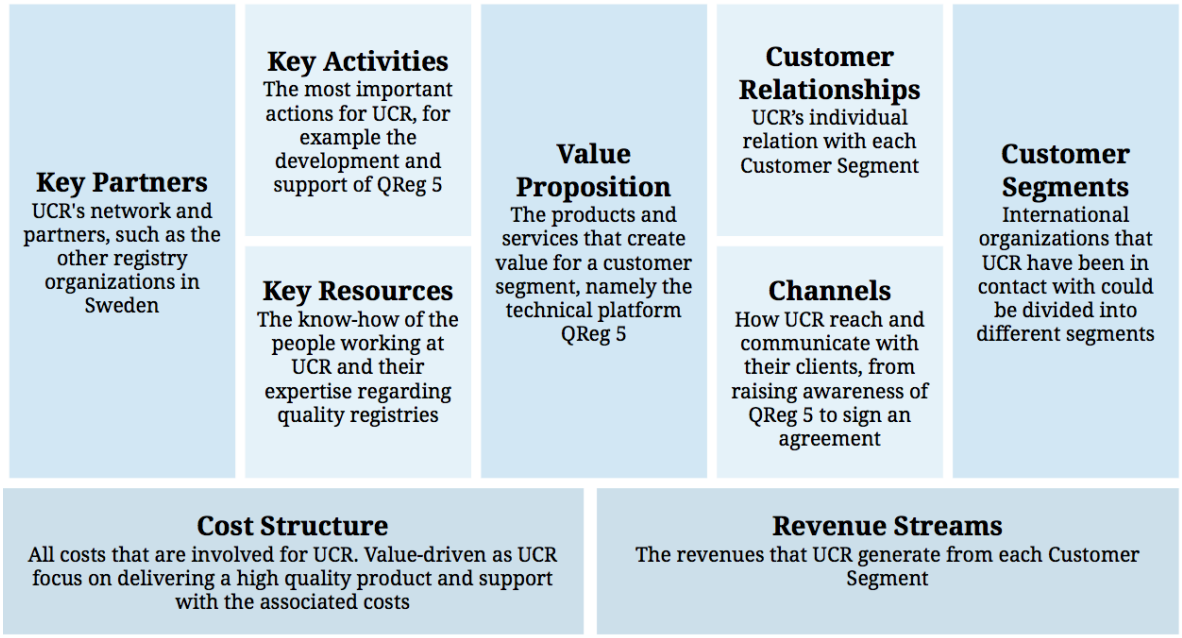

Figure 3: Business Model Canvas. The applied BMC on UCR, from the theory by Osterwalder and Pigneur (2010). Explaining how UCR as an organization creates, delivers and captures value. In the BMC, there are nine building blocks which are the following; Customer Segments, Value Propositions, Channels, Customer Relationships, Revenue Streams, Key Resources, Key Activities, Key Partnerships, Cost Structure.

3.1.2 Evaluating UCR's internal and external elements

The SWOT analysis

Continuing in the understanding of the internationalization process, after having created a BMC, the next step was to evaluate UCR's internal and external elements. In order to do this, a SWOT analysis was created for UCR. This was the first tool to be used in the creation of the frame of reference, as described in 4.2. SWOT stands for Strengths, Weaknesses, Opportunities and Threats, and it is a common tool that can be used to evaluate an organization or a product. Strengths and Weaknesses are internal elements, whereas Opportunities and Threats are external from the environment (Dyson, 2004). The aim of a SWOT is to exploit the strengths and opportunities, while the weaknesses and threats should be dealt with.

UCR hold multiple strengths. For instance there are organizational ones, as there are different sections within the organization. The different sections have specific expertise, which creates the possibility to collaborate between the sections, thereby enabling a beneficial sharing of the know-how within the organization. Thanks to UCR's long experience and mission to improve healthcare, they have a good reputation, making them credible on the healthcare market. UCR publish a large number of articles every year, creating positive publicity for the organization. Having the technical platform QReg 5, a superior platform for quality registries, is also an important strength for UCR.

Moving on to the weaknesses, a main one is that it is difficult for UCR to exploit new innovations because of their high daily workload. There are also organizational challenges, as UCR has a shared ownership, meaning that for instance the costs and revenues are highly regulated. UCR do not have the right to make profit that will not be reinvested into the organization. Another weakness is that there are different visions regarding UCR's future and mission within the organization, complicating the creation of a business strategy.

As for UCR's opportunities, one is that the market for quality registers is growing. International organizations all over the world have become increasingly aware of the benefits of quality registries. The technology has developed rapidly in the latest years, enabling this kind of soultions within healthcare. When a quality registry is created with a technical platform, there are low chances for a client to change the technical

solution as this would be both time consuming and costly. Therefore, when clients sign an agreement with an organization in order to use their technical solutions, they are looking for an ongoing relationship which results in customer loyalty. Today, the quality register market is still new, and there is still low competition for UCR and QReg 5.

Finally there are the threats for UCR. As the quality registry market is a new market, it might attract competitors, such as for example large software companies that have not yet discovered the potential of this market. Furthermore, there is a potential threat that another solution becomes more relevant than quality registers. For example, the market for electronical medical records is rapidly evolving, and in the future it might be possible to integrate quality registers within them. Politics are also a threat, as the introduction of new legislations could restrict the use of quality registers.

A representaton of UCR's SWOT can be seen in Figure 4.

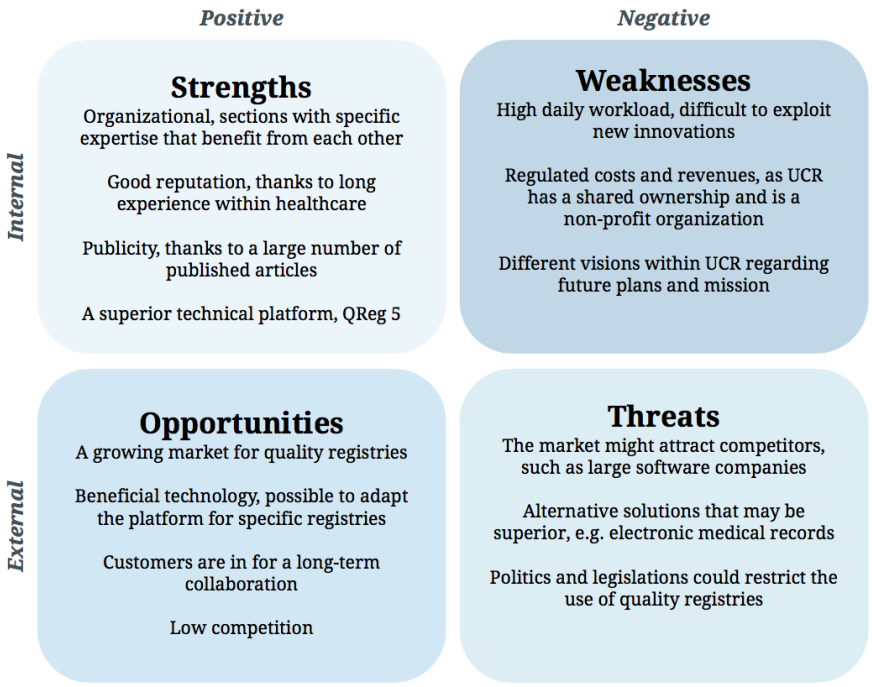

Figure 4: SWOT-analysis for UCR. When analyzing UCR's position on the market, there are several strengths, weaknesses, opportunities and threats to consider.

3.1.3 Describing a client's sequential steps in the purchasing process

The AIDA model

The last step in the internationalization process, after the clients have been studied from a value perspective with BMC and UCR's internal and external elements have been evaluated with a SWOT analysis, involves the AIDA model. This was the second tool to be used in the creation of the frame of reference, as described in 4.2. The AIDA model is used to describe a client's sequential steps in the purchasing process, starting from the first contact with a product, up until the moment when the client makes a decision and takes action, for example by signing a license agreement in order to get access to QReg 5. AIDA is a simple yet effective tool, and it stands for Attention, Interest, Desire and Action (Priyanka, 2013).

Firstly, comes the word attention. Attention is usually brought by different marketing strategies, such as internationals. However, UCR is not a traditional business, and does not work with any marketing strategies. UCR has regardless of this, successfully been able to draw multiple organizations' attention to UCR and QReg 5. For instance through key people at UCR, namely their professors, who spread the word about UCR. Another source for publicity is existing well-known registries, such as for instance SWEDEHEART. Thanks to UCR's registries, UCR publishes articles in credible journals, which are read by people all over the world, showing the potential benefits when working with quality registries.

The second part of AIDA is interest, the international organizations have become increasingly interested in UCR because of their strengths. UCR's strengths are presented in 3.1.2. It is not up until this moment that the stakeholder generally realizes that UCR hold a superior technical platform. The client sees the possibility of a collaboration with UCR, which adds to their interest.

Thirdly, comes desire. A client's desire is augmented when all opportunities with the potential collaboration with UCR have been presented. The stakeholder sees the opportunity of gaining access to QReg 5, in combination with the expertise of UCR. The client feels the desires to adapt the UCR and QReg 5 solution.

Finally, the action part of AIDA is reached. In order for the potential clients to stay updated in the continuously changing society, there is a pressure to keep up with the

newest technology. This is where the stakeholder proceeds to an agreement, about initiating an cooperation to develop their own quality registries with QReg 5 as the technical platform, and UCR as a collaboration partner.

See Figure 5 for the applied AIDA-model on UCR.

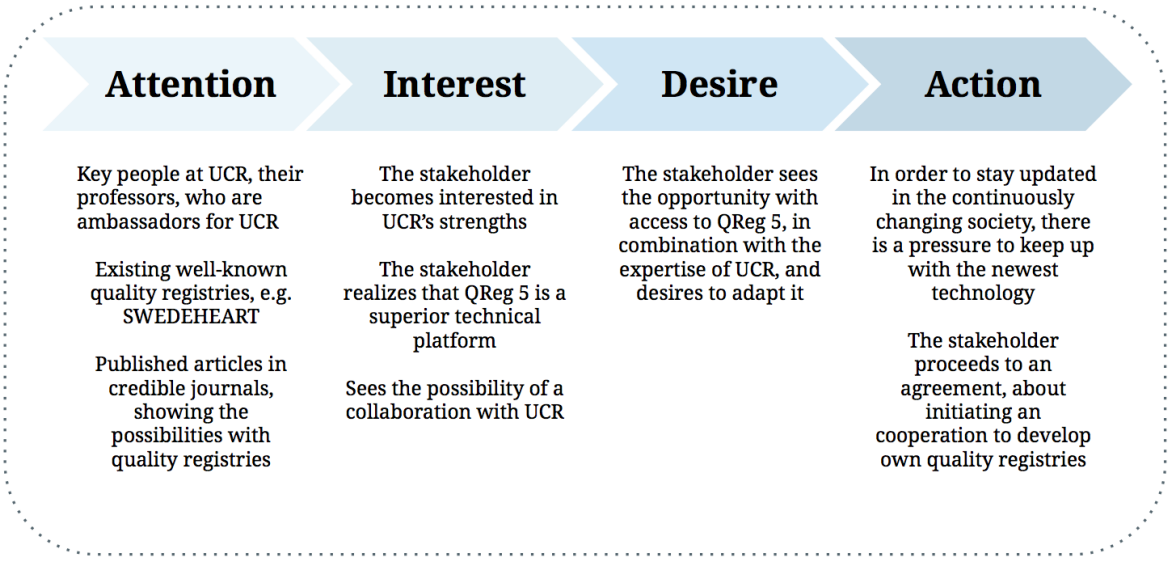

Figure 5: AIDA-model applied on the stakeholders of UCR. The AIDA-model analyzes the process of stakeholders becoming clients.

3.2 Overcoming organizational challenges

As UCR is an organization that is not only working with the development of new technical platforms such as QReg 5, but is also an organization managing older versions of the platform as well as daily tasks such as the management and support of registries, there are organizational challenges that need to be managed.

3.2.1 Exploring new possibilities while exploiting old certainties

As mentioned by Witt and Zellner (2005) in 3.1, the most efficient way a new technology can be exploited by a company, is if the new knowledge can be made complementary to already existing organizational capabilities. This is also explained by March (1991), who deduces that two different concepts exist in organizations. Namely the exploration

of new possibilities and the exploitation of old certainties. These two concepts compete for the same resources in an organization, and a good balance between them is required in order to create a successful organization. If the organization favors exploitation rather than exploration, that is by refining already present competences and knowledge, this leads to increased efficiency in the short run. In the long run the same relation is destructive as it leads to the organization being trapped in an equilibrium state, where it does not take on any new knowledge and thereby stops developing. If the organization favors exploration rather than exploitation, the organization ventures at new possibilities and experiments. It is then common to end up with many undeveloped new ideas, resulting in suffering costs of the experiments as well as a lack of competence, without gaining many of its benefits.

March introduces the model *Mutual learning*, which presents a strategy to be used in order to achieve a good balance between exploration and exploitation in an organization. An organization's code contains the stored knowledge in procedures, norms, rules and forms. The knowledge increases over time as the organization learns from its members, meaning the code adapts to the beliefs of the individuals. At the same time individuals modify their beliefs when socialized into an organization. The beliefs of an individual and the code will converge at some point, and an equilibrium is achieved that will remain indefinitely. This will result in the organization being stuck in exploitation. To achieve exploration, a turnover can be provided by recruiting new individuals. If replacing individuals with recruits that are close to the current organizational code the efficiency is decreased. Instead, the recruits should deviate from the code in a favorable way (March, 1991).

3.2.2 Managing both daily tasks and innovation

When a company work with both daily tasks as well as innovation, there is a substantial risk that one or the other takes over. It is a complex business situation to manage, and the difficulty lies in handling future tasks while managing existing capabilities, products and/or clients of the past. This description is a common problem for many companies today. However, it has been shown by O'Reilly III and Tushman (2004) that cross-functional teams may well be the actual reason to groundbreaking innovations. Keeping the exploratory units separated from the exploitative ones, while keeping the strong link between the units on the executive level might be the key to success. Companies that

do this have been named “ambidextrous organizations” by O’Reilly III and Tushman. The ambidextrous organizations are proven to be more successful in launching their groundbreaking innovations, while keeping a steady or improved result for the existing products.

There are some factors to focus on in order to achieve a well-functioning ambidextrous organization. Firstly, it is crucial to have senior management executives with enough experience so that the different needs of the separate units can be fulfilled. The management team needs to be open towards the idea of ambidexterity, even if the team members show resistance. Lastly, the vision and plans for the whole organization need to be communicated by the management team to all members of the personnel. While working in separate but united teams in the same organization, it is possible to let exploitation and exploration coexist side-by-side (O’Reilly III and Tushman, 2004).

3.3 Software protection

3.3.1 Copyright and open source

According to the Swedish law about copyright, a written computer program is the property of the author. The computer program, or source code, cannot without an agreement be changed, sold or be used in a way that is not accepted by the author (Riksdagen, 2017).

As described by opensource.com (2017), a source code that is distributed on open source is publicly accessible. Products and projects on open source promote collaboration and sharing. This means that anyone can inspect, modify, enhance and share the code. LibreOffice is an example of a software that is open sourced. Users must accept a licence when accessing the open sourced code, but the legal terms are very generous compared to closed source. In general open source allows users to use the code for whatever they want. However, open source is not free of charge and open source programmers can charge money for the open source software they have created or contributed to.

The opposite of open sourced software is proprietary software or closed source, that only the person, team or organization that created it can modify. Only original authors may legally copy, inspect or alter that software. Microsoft Office and Adobe Photoshop are examples of proprietary software, the users of this software must sign a license before

using it, consenting to that they will not do anything with the software that the authors do not permit.

Open source has an impact on science, education, government, manufacturing, health, law and organizational dynamics. The choice of open source rather than closed source, could be made because it gives the feeling of more control over the software as it is being examined by others which will result in that the code works properly. Open source also leads to that the code can be updated faster than if it would have been a proprietary code. Open source allows people to become better programmers as they can study each other's code, and thereby avoid future mistakes (opensource.com, 2017).

4 Methodology

4.1 Explorative approach

In this project, an explorative approach is the starting point, since there is a desire to discover opportunities for a new product. According to Lekvall and Wahlbin (2001), the purpose of an explorative survey is to collect an overflow of data in order to generate explorative results. In the overflow of data, theoretical concepts can be searched for, both pre-considered and new ones which results in the survey being able to generate explorative results. Prior to a study, a frame of reference with existing knowledge, theories and models needs to be set. However, in order to collect an overflow of data, the data collection can be performed with a loose connection to theoretical concepts. This is why the questions should not be too well-structured before the interviews, and asked openly. Furthermore, variables are not to be used and a strict operationalization of concepts does not need to be decided in advance. Instead, operationalizations are tested against the collected data, which could generate new concepts. It is important to emphasize that this method does not lack theoretical concepts, it is actually quite the opposite since these studies contain a frame of reference with more theoretical concepts than the surveys with exact operationalization (Lekvall and Wahlbin, 2001).

4.2 Developing a frame of reference

According to Lekwall and Wahlbin (2001), a frame of reference is to be used as a guideline when creating studies. In this thesis, the frame of reference was used in the structuring of the interviews and questionnaires that were conducted with the Swedish registry centers and the international organizations respectively. With the help of a well-defined frame of reference it is possible to examine and analyze problems in an efficient way. A frame of reference is developed through the thesis writers' knowledge, other peoples' knowledge as well as existing models and theories (Lekvall and Wahlbin, 2001).

These mentioned information sources were all used in several steps in the creation of the frame of reference. Information was obtained through browsing the Internet, formal and informal interviews with people in different areas of expertise, business models such as SWOT and AIDA as well as literature and articles.

4.3 Qualitative method

4.3.1 Validity and reliability

According to Lekvall and Wahlbin (2001), before conducting a survey or an interview, it is important to ensure that an adapted method is chosen in order to ensure a high quality of the results. By avoiding measurement errors, the conducted survey will end up being trustworthy. This is enabled through the two concepts validity and reliability. Before executing a survey, it is necessary to conclude why the specific measurement method is chosen, why the questions are asked in a specific way and in which order, as well as determine how measurement errors affect the survey, that is in what extent the survey is reliable or not.

The concept validity is used both to evaluate whether the measurement method assesses the qualities it was supposed to measure, and to evaluate the relevance of newly obtained knowledge. According to Lekvall and Wahlbin, there are different categories of validity that can be used in order to conclude if all the qualities are measured correctly. These categories cover that the questions are reasonable, that the measurement results agree with theory, that the study has a good ability to predict the success of a product

when it is launched on the market, as well as that the measurements do not deviate from the original concept. If measuring something complex, for example the image of a business, many aspects need to be studied to result in an overall image (Lekvall and Wahlbin, 2001). According to Alvehus (2013) there are alternative concepts regarding the validity of newly obtained knowledge. These concepts cover that results and conclusions are founded by a continuous review of the material, that obtained knowledge is communicated to external people in order to test its reasonability, and the way the knowledge might affect society (Alvehus, 2013).

The concept reliability intends in what extent the results are repeatable. If a survey is reliable, the survey should generate the same results every time when repeated. In other words, reliability is the ability of the measurement method to resist coincidences. For example the interviewees mood and motivation, other distractions, or the interviewers way of asking questions and related unclearness. In order to achieve high reliability it is essential to use clear questions that do not have several ways of interpretation (Alvehus, 2013) (Lekvall and Wahlbin, 2001).

No matter how well-defined and executed a survey is, the respondent could cause measurement errors as well. This occurs if the respondent:

1. Feels forced to answer something they do not have an opinion on.
2. Guesses an answer that they are not really aware of or have forgotten.
3. Adjusts the answer depending on what he/she believes is a desired answer.
4. Answers questions that are asked in a directed manner.
5. Is tired, or if the survey is of low interest to the respondent. This is avoided with an opening letter to the respondents, asking them if they would want to participate.
6. Tells general opinions instead of personal experiences.
7. Is affected by the interviewers age, gender and/or behavior.

(Lekvall and Wahlbin, 2001)

4.3.2 Qualitative interview

When studying the Swedish registry centers and the international organizations, the qualitative method intervew was used. Interviews are a way to get to know more about the interview participants' points of view, and personal experiences regarding a topic. There are different ways that an interview can be designed. It can be kept rather informal, general or standardized.

According to Turner (2010), an informal interview means that the questions are not predetermined, instead they are created as a reaction during the interview. Questions are based on what is going on in the moment, and the driving force is the interaction between the participant and the interviewer. This kind of qualitative interview is beneficial because it is a flexible way of working. However, it has been criticized for being a too unstructured way of performing an interview, resulting in inconsistency in the questions and answers, and it is therefore harder to analyze the obtained data. The second interview option is to have a more general approach, which is more structured than the previously mentioned informal interview. The general approach means that questions are predetermined and therefore structured, however, they can be adapted during the interview depending on for example the interviewees' answers. As for the first informal interview, there is a risk that this interview type lacks in consistency. Lastly, the third interview version is the standardized one. This kind of interview has a clear structure, and the interviewees are asked exactly the same questions. What is kept flexible in this interview design is that the participants have the possibility to answer the questions as detailed as they prefer. This can be seen as the benefit with a standardized approach, the weakness is the risk of data being difficult to interpret because of the openness of the participants' answers. It is a hard task to determine what is interesting in the data, because of its exhaustive qualitative nature.

Turner mentions that except choosing one of the different ways that the qualitative interview can be performed, there are other factors to consider as well. The first factor is to be prepared for the interview. It is obviously crucial to the interview situation that the interviewer has properly prepared in advance, so that the interview(s) result in the best possible benefit to the study. Parameters to the interview preparation are for example the setting where the interview will take place, preferably a calm and quiet one, but also that the interviewer is clear when it comes to the purpose and format of the interview. Furthermore, it can be of interest for the participant(s) to

know priorly how long the interview usually takes, and to give instructions on how the contact between interviewer and interviewee(s) will take place after the actual interview. Another important factor is to select the best suited participants for the interview, it is crucial for the study to try to find participants that are sufficiently qualified to answer the questions in a credible and honest way. The last factor to mention is to construct effective interview questions, which is probably the hardest and most important step. The goal is to gain maximum data with clear and precise questions. The interviewees should be able to answer on their own terms, the questions should be kept neutral to not influence the participant's judgment and the questions should be clear to reduce misunderstanding. An interesting and helpful tool is to add follow-up questions later on in the interview (Turner, 2010).

4.3.3 Qualitative questionnaire design

According to Krosnick and Presser (2010), when using a questionnaire as a qualitative method, the most important part of it is the questionnaire design. In order to assure an optimal questionnaire design, there are factors to consider. The factors include e.g. the formulation of the questions, the order of the questions, as well as the structuring of the questionnaire.

The formulation of the questions is particularly important as to ensure that there will be as few mistakes or misunderstandings as possible, and that the answers will be easier to analyze and evaluate. Firstly, when formulating the questions, it is recommended to use simple words and avoid too technical terms. To further make the questions easy to understand and hard to misinterpret, the formulation of them should be with words that can only be interpreted in one specific way and a question should only regard one subject. Questions that are somewhat loaded or sensitive should be avoided, however, if they need to be asked they should be asked towards the end of the questionnaire.

Furthermore, Krosnick mentions recommendations to follow when it comes to the order of the questions in the questionnaire. For example the questions in the beginning should be undemanding and engaging. By keeping the tone light in the early questions there is a relation build up between the interviewer and the interviewee, and the early questions influence the interviewee's willingness to answer the questionnaire. Early questions should have a close relation with the original theme of the questionnaire. If

there are different topics addressed in the questionnaire, it creates a more clear structure and a flow if these questions are grouped together. There is a risk that questions in the beginning as well as towards the end of the questionnaire are not answered, because of the interviewee being tired or simply bored which results in mistakes as well as shorter and less detailed answers. Lastly, filter questions should be included so that the interviewees do not need to answer questions that do not concern them.

When deciding upon the structure of the questionnaire a decision must be made between open or closed questions, whereas open questions permit the interviewees to answer in their own words while closed questions intend that the interviewees choose an answer from a set of predetermined choices. The risk with open questions is that they are harder to analyze, to facilitate this the questions can be grouped into a few different categories. There are also drawbacks when using closed questions, for example the use of them can produce error. Open questions add another dimension to the survey, rather than closed ones, so it is beneficial to include at least some open questions to a questionnaire (Krosnick and Presser, 2010).

According to Lekvall and Wahlbin (2001), another factor is whether the correspondent has the opportunity to overlook the form from the beginning. If the respondent does not see the whole form, there is a risk that the respondent misjudges the time scale, which increases the risk for the respondent to not answer at all. However, if the respondent gets to overlook the whole form from the beginning, there is a risk that the respondent's standpoint is affected by later questions (Lekvall and Wahlbin, 2001).

4.4 Analyzing qualitative data

According to Turner (2010), the final part in the interview design is how to interpret the data obtained from the qualitative interview. The key is to try to find themes and patterns in the data set that has been collected. The themes can be expressed as phrases, or the way the interviewee has expressed or formulated certain ideas (Turner, 2010).

When analyzing qualitative data, Yin (2010) has defined this as a five step process. The steps are; 1. Compiling data, 2. Disassembling the data, 3. Reassembling, 4. Interpreting, and 5. Concluding. The first compiling step includes sorting out all of the collected data, which may result in some kind of database. When continuing to analyze

qualitative data, the next step would be to create fragments of the structured data from the first compiling step. In this step it is possible to accord different labels or codes to the fragments. Coding is a useful tool throughout the analysis that can be used to facilitate the search for pattern in the found data. Thirdly, the fragments need to be reorganized and thereby new groupings and clusters than the ones from the beginning are created. When reaching the fourth step where the acquired data will be interpreted, situations that require re-clustering might appear. If this is the case, previous steps of fragmenting and reassembling the data need to be done all over again. The final phase is the concluding one, during which all conclusions from the study can be drawn, based on the interpretation made in the fourth step of the analysis (Yin, 2010).

4.5 Research ethics

When conducting research and studies such as this thesis, the ethical perspective is of great importance. According to Bryman and Bell (2013), topics concerned by ethics are e.g. how to treat participants in a study, and how to present the collected material in a way that does not fool the people taking part of the study. Other aspects concerning the participants in a study are that the people participating in the research do this voluntarily, that their integrity and anonymity is respected, as well as that the study is conducted in a confidential manner. There are also ethical aspects that concern researchers in Sweden, such as that the researcher has to inform the participants of the purpose of the study, and that the participants need to be aware of that they participate of own free will. Furthermore, that the information regarding the people in the study is treated with confidentiality, that information collected in the study will only be used for research purposes as well as that the researcher shall not give any misleading information regarding the study to its participants (Bryman and Bell, 2013).

5 Course of action

5.1 Creating a frame of reference

In order to be able to analyze the market for quality registries and QReg 5, a frame of reference was created. As described in 4.2, the frame of reference is a basis for the

development of interviews, such as the interviews and questionnaires created for the market study in this thesis. When developing the frame of reference, a systematic approach was used to analyze the market for quality registries and for the technical infrastructure QReg 5. The creation of the frame of reference started off by focusing on key peoples' expertise and experiences. This information was obtained through several formal and informal interviews with key people at UCR, both through e-mail conversations and meetings. Thereafter, models such as SWOT and AIDA were created and analyzed for UCR as an organization.

Therafter, the market was divided into actors on the market and potential clients. The existing actors on the market were considered being the other registry organizations in Sweden, and the potential clients were the international organizations that had previously contacted UCR. Firstly, research was performed to get to know more about both the registry organizations as well as the international organizations. It was decided that interviews would be conducted for the registry organizations, and questionnaires for the international organizations, which would be created based on the previous research and information attained from key people.

5.2 Interviews

After creating a frame of reference, the interviews could proceed. When conducting the interviews/questionnaires in this thesis, the ethical aspects that had been previously discussed in 4.5 were all respected. All the participating interviewees had existing relations to UCR, and it was important to care for and respect these relations. The interviewees were all well-informed that the project was conducted on behalf of UCR and its new infrastructure QReg 5. The interviewees from the registry centers are to be kept anonymous, since their answers reflect the values of the organizations that they represent and the individuals are not important in the context. The same thing goes for the interviews conducted with the legal officers at Uppsala University and Uppsala County Council. The answers from the representatives from the international organizations are not anonymized, since they do not necessarily represent an organization, and their names are important for further contact.

5.2.1 Interviews with legal officers

Interviews were performed separately with both a legal officer from Uppsala University and a legal officer from Uppsala County Council. The separate interviews enabled that the legal officers shared their individual perspectives and opinions regarding the business activities of UCR, and the matter of UCR's shared ownership. Both interviews were conducted through the semi-structured interview method, as described in 4.3.2. This implied that predetermined questions were used, which were thereafter adapted during the interview depending on the interviewees' answers.

5.2.2 Interviews with registry centers

Interviews conducted by phone were used to interview representatives from registry centers. The aim of the interviews was to cover the market for technical platforms used for quality registries in Sweden, and know more of their experiences and opinions concerning international collaborations. The interviews were semi-structured, as for the interviews with the legal officers, described in 4.3.2. The questions were constructed after conducting background studies on the registry centers. The questions could thereafter be targeted for each registry center based on the specific expertise within the organization, and thereby an overflow of data could be collected as an explorative direction was chosen, as described in 4.1. The risk of a lack in consistency between the interviews with the different registry centers was handled by setting up clear goals with the interviews, for instance through the definition of common parameters that were to be collected in order to be able to compare the registry centers with each other. The questions were of the same nature, even though they were individually adapted to the registry center in focus. The interviews were well prepared in advance, and effort was put into choosing the most adequate person to interview from the organization. This resulted in an efficient interview situation for both interviewers and interviewees. After conducting phone interviews, the noted answers to the questions were sent to the interviewees for approval.

5.2.3 Interviews with international organizations

Questionnaires were used to interview the international organizations that UCR had previously been in contact with. The first interviewed organization was NICOR, an organization in England that UCR already had signed an agreement with. The remaining international organizations that were interviewed exist in the following countries; Finland, Italy, Korea, The Middle East (through a Swedish consulting firm), Norway and Uganda. The diversity among the countries enabled the possibility to map different potential customer segments for UCR.

Prior to interviewing the international organizations, background studies were performed by searching the Internet as well as questioning concerned personnel at UCR. The purpose of the background studies was to better understand the nature of the different international organizations, and thereby be able to group them into categories so that different customer segments could be determined for UCR. All contact with the international organizations was performed by e-mail. This was in order for the interviewees to be able to carefully consider their answers, and thereby be aware of what information they would share. Written answers also implied that multiple people could answer to different sections, which enabled more accurate answers. Furthermore, verbal interviews would have implied a higher risk for misunderstandings.

The questionnaires were constructed by the help of mentioned design guidelines in the section qualitative questionnaire design, see 4.3.3. The questionnaires were constructed by using only open questions. By taking this decision, another dimension was added to the interview and some answers contributed with more information than what was expected from them. Before sending the questionnaire, an introductory e-mail was sent which explained the reasons behind the interview and it also included some example questions. Thereby, the interviewees had the opportunity to get an overview of the questionnaire. In the e-mail which contained the questionnaire in its whole, the questions were grouped regarding their nature, and the interviewee could see all the questions at once. This was a conscious choice, which was supposed to encourage the respondent to read all questions from the same topic before answering.

6 Results

6.1 Legal officers

Two interviews were perfomed in order to learn more about UCR's legal situation and its implications when it comes to UCR's shared ownership between Uppsala University and Uppsala County Council.

6.1.1 Uppsala University

Firstly, a legal officer at Uppsala University was interviewed. During this interview the legal officer stated that UCR had not been in contact with the Legal Affairs Division at UU concerning the new technical platform QReg 5, for instance regarding intellectual property issues or their internationalization plans. According to the legal officer, UCR is equally a part of the university and the county council. However, the officer continued by stating that UCR consider themselves as owned by Uppsala County Council, and not by the university, when doing business and signing agreements. It seems as if UCR alternate between acting as the university and the county council, depending on what is beneficial for them in the specific situation. An example is demonstrated as UCR use the county council's legal organizational number when signing international agreements. The university legal officer stated that because of this, it might be up to Uppsala County Counil to take decisions regarding for instance which organizations UCR have the right to sign agreements with, and what price the license of QReg 5 should have. The university does not have any clear policies when it comes to which countries they favor to collaborate with, except that one should cooperate with all people regardless of their nationality.

The legal officer continued stating that when it comes to software as QReg 5, the university should have full rights to use it for free, if they find it useful for the university's activities. However, the university has no interest in QReg 5 or any other innovations of UCR if they do not find them useful, and will therefore not interfere with the internationalization plans of QReg 5. When the open source possibility of QReg 5 was mentioned, the legal officer said that the academic culture implies that knowledge should be shared and spread, as an act of altruistic behavior. The whole academic system is founded on that discoveries and results are published. The university would

therefore not support a decision which would implicate that QReg 5 would be kept exclusive.

6.1.2 Uppsala County Council

Secondly, a legal officer at Uppsala County Council was interviewed. During this interview the legal officer stated that UCR actually belongs to the county council, and should be more clear about this, instead of identifying themselves as a separate organization which occurs today. When asked questions concerning UCR's internationalization plans for QReg 5, the legal officer stated that UCR had regularly been in contact with the Legal Affairs Division at the county council regarding this. However, the legal officer was not aware of the fact that the written agreement between NICOR and UCR was written and designed by an external legal firm. The legal officer mentioned that even though there are no requirements for UCR to get advice from any instances, the county council would prefer that UCR seeks their advice in the future. This way UCR could use already available resources at the county council to ensure that the governments body's interest are taken into consideration when UCR write agreements in the same organizational number as the county council.

As UCR have shared their internationalization plans with the county council, the county council have discussed which countries UCR could work with. For instance there had been a discussion regarding The Middle East, since it could have been a sensitive matter because of political reasons. However, UCR received the county council's approval to proceed with the business negotiations. The legal officer pointed out that when it comes to UCR working with developing countries, the county council shall not in anyway sponsor this kind of collaborations. The funding for projects with developing countries must be proven not to originate from the citizens of Sweden. The revenues of UCR truly belong to their owners, the county council, accordin to the legal officer. If sponsoring or any kind of aid would be applied for by UCR, this would actually be as if the county council applied for sponsoring, and thereby any eventual sponsoring would belong to the county council. Consequently, UCR could not apply for sponsoring and directly apply them into collaborations with developing country (such as Uganda). If UCR would manage to get the equation right, that is to answer that the citizens of Uppsala County Council did not finance the cooperation with a developing country, it may be possible to work with such countries.

As UCR's internationalization plans progress, the legal officer stated that there could be a possibility for the development section at UCR to be exported into becoming its own organization, independent of the university and the county council. However, the officer continued saying that this would require a thorough process as all investments made from the county council in order for UCR to become the organization that they are today would need to be inspected. Uppsala County Council would then urge UCR to pay back all the summarized investments to the County Council.

The legal officer continued stating that when it comes to software, as e.g. QReg 5, the county council fully owns QReg 5. However, if the university would like to use QReg 5 for free, the county council would not have any issues with this. The great difference between the university and the county council is that the county council's policies depend on the present political climate, as it always acts on behalf of its citizens and the political parties they have democratically voted for.

6.2 Registry centers

All registry centers have a common mission, namely to improve healthcare in Sweden by developing competences surrounding quality registries. The latest years, SALAR have invested in quality registries and the registry centers. All of the registry centers belong to a specific region, or county council.

At QRC Stockholm, the interviewee was a technical project leader. QRC Stockholm is a cooperation between Stockholm County Council and Karolinska Institutet. They do not have their own technical platform, instead they use several external suppliers to design individual adapted technical solutions for QRC Stockholm's clients. The external suppliers also provide support. QRC Stockholm do not have any plans on developing their own technical platform, since they do not consider it to be profitable for them. Developing their own platform would require another type of organizational structure than QRC Stockholm has today, and there are already several good suppliers on the market. When the interviewee was asked about QRC Stockholm's opinion on cooperating internationally, the interviewee stated that *"Of course we do not close the door for good and rewarding cooperations"*. They are especially interested cooperation internationally if this would enable them access to information/data that is not available in Sweden, such as data from certain diagnostic groups. QRC Stockholm have been in

contact with one international organization, namely a software development company, but did not proceed with a cooperation.

At RC Syd there were three interviewees; a unit director and a registry coordinator at the RC Syd Lund, as well as a unit director at RC Syd Karlskrona. RC Syd is a part of Skåne County Council, and it is constituted by two joined units, namely Lund and Karlskrona. The different units provide their own technical platforms to their connected quality registries. There are in total four platforms in use. The Lund unit have their own platform 3C, and the Karlskrona unit have their own platform Pharos. 3C and Pharos are said to be quite similar to each other. ECP and Eurocrine are the other two platforms in use, however, these will not be used in the future since a decrease of the number of different platforms would be more cost effective for RC Syd. The future plan for RC Syd is for the two units Lund and Karlskrona to have a common technical platform, however, since it would be costly, today's situation is not a bad option. RC Syd have been in contact with international organizations, as contacts have been forwarded from the quality registries connected to RC Syd. They received inquiries about forming a common European quality registry, where RC Syd would provide knowledge and experience to develop the registry. As of today, there is no ongoing activity to proceed with a cooperation with the international organizations they have been in contact with. The unit director at RC Syd Lund stated that *"It should not be forgotten why Swedish quality registries exist - that is to improve the quality within the Swedish healthcare"*.

At Registercentrum Norr there were two interviewees; a project leader and a person from the management team at the registry center. Registercentrum Norr are a part of Västerbotten County Council, the project leader stated that *"It can not be said that Västerbotten County Council own Registercentrum Norr"*. Registercentrum Norr provide the technical platform INCA, that is owned by SALAR, to its connected quality registries and they manage all the technical aspects. Some of the connected registries use other technical solutions than INCA, since the quality registries decided what technical solution they want to use. Registercentrum Norr provide technical support to the registries on these other platforms as well. Registercentrum Norr do not have any plans regarding a common technical platform for all the registries, or regarding the development of a new technical platform. They find that the technical situation that they have today is sufficient. Registercentrum Norr have not been in contact with

any international organizations. In the future they could be interested in international collaborations.

At Registercentrum Västra Götaland, the interviewee was an IT Strategist. Registercentrum Västra Götaland are a part of Region Västra Götaland. They use their own developed technical platform called Stratum, and the technical platform INCA delivered by Cancercentrum Väst. They do not manage any aspects of INCA, and they consider INCA as a supplier. The interviewee stated that *"It is more complicated to work with a supplier, and more comfortable to be working with an own platform"*. Stratum was developed by Registercentrum Västra Götaland as a result of their evaluation of different already existing technical platforms. Registercentrum Västra Götaland have been in contact with international organizations, and the requests were forwarded from various different registries. Often the requests have not been followed through, because of conditions predetermined by other countries legislations regarding data storage in other systems. Some organizations were also technically weak, as they did not have the resources to receive the technical solution, and they lacked competence concerning the development of quality registries. In the future, international collaborations could be of interest to Registercentrum Västra Götaland, even if they do not consider it to be in line with the mission from SALAR.

At RCSO, the interviewee was working within IT. RCSO is a part of Kalmar County Council. RCSO is a relatively small organization compared to the other registry centers in Sweden. RCSO do not offer a standard technical solution for quality registries, and some of the connected quality registries have their technical solution at other registry centers. The interviewee stated that *"In general, we mostly work with the information that has been inserted into the registry, and not that much with the underlying technical solution"*. When the interviewee was asked about whether working with suppliers for IT-solutions affects RCSO, the answer was *"If you have several systems it easily gets incoherent, however, it seems to work fine as it is today"*. RCSO have not excluded the opportunity to develop their own technical platform. However, this is not something they are anticipating, as there are already several technical platforms on a national level in Sweden. The interviewee did not know if RCSO have any international cooperations, but supposes it could be interesting in the future.

See Figure 6 for the summarized results from the interviews with the registry centers.

	Organizational structure	Description	Own technical platform	Technical development	International cooperations
QRC Stockholm	Stockholm County Council and Karolinska Institutet	Customized technical solutions for every registry	No. Uses several external suppliers of technical solutions	No plans on developing their own technical platform. It would require another organizational structure, and they are satisfied with today's suppliers	Not yet. Open for it in the future, especially in order to access data that is not available in Sweden
RC Syd	Kalmar County Council	Two registry centers, Lund and Karlskrona, were merged into one. The two units are fairly independent of each other	Yes. 3C at the Lund unit, and Pharos at the Karlskrona unit. External platforms in use are ECP and Eurocrine, but they are to be replaced	Transfer of all quality registries to 3C (Lund) and to Pharos (Karlskrona). Possibly one common platform in the future, however, this option is not cost-effective today	Has received inquiries, no cooperation yet
Registercentrum Norr	Västerbotten County Council	Supports the use, management and development of quality registries	No, manages INCA that is owned by SALAR. They also provide technical support to the connected quality registries on other platforms	Today's technical situation is sufficient	Has not received any inquiries, is open minded about international collaborations
Registercentrum Västra Götaland	Region Västra Götaland	Provides support in all areas concerning quality registries. Quite similar to UCR. Is a relatively young organization, has young connected quality registries	Yes, Stratum, and INCA which is delivered by Cancercentrum Väst	Stratum is a relatively newly developed technical platform, which is still being developed	Has received inquiries. All requests so far have been interrupted, either because of the stakeholder being technically weak or because of a lack in quality registry competence
RSCO	Kalmar County Council	Small organization	No. Uses several external suppliers of technical solutions	Other technical solutions may become relevant in the future. Are not planning to develop their own platform	No

Figure 6: Results from interviews with representatives from all the national registry centers in Sweden. Organizational structure describes the ownership of the registry center. Description gives a brief description of the registry centers. Own technical platform states whether the registry centers provide their own technical platform, or use suppliers. International cooperations shows the registry centers' attitute and experience with international collaborations.

6.3 International organizations

In total eight international organizations were interviewed, the only existing client for QReg 5 among these organizations was NICOR. Of these eight organizations, two are organizationally structured approximately as UCR (NICOR, Helse Nord IKT), four are hospitals (Heart Hospital Tampere University Hospital, Cork University Hospital, Seoul National University Bundang Hospital, Uganda Heart Institute), one is a non-profit association (The ANMCO Emilia Romagna) and one is a consulting firm (Global Pharma). The two organizations that are structured in approximately the same way as UCR, namely NICOR and Helse Nord IKT, already have existing agreements with UCR, even if it is for Open QReg and not QReg 5 in Helse Nord IKT's case. Out of the eight organizations, six of them focus on cardiovascular diseases in one way or another (all except for Global Pharma and Helse Nord IKT).

Regarding the use of quality registries, all organizations have worked with quality registries in one way or another. Almost all organizations mention that there are one or a few registries that have been, or are currently in use at the organization. Two out of the eight organizations have developed their own technical infrastructures for registries (NICOR and Heart Hospital Tampere University Hospital), in these two countries (England and Finland) quality registries are well known and used. Global Pharma have worked with the export of a registry managed by Registercentrum Västra Götaland to the MENA region. Helse Nord IKT use UCR's technical infrastructure Open QReg, the precursor for QReg 5, for 17 registries.

Prior to the contact with UCR, the organizations knew of UCR through different channels. One of the organizations (Heart Hospital Tampere University Hospital) mentions that they became aware of UCR through searching the Internet, another organization (Seoul National University Bundang Hospital) became aware of UCR through colleagues, and yet another one (Helse Nord IKT) through a registry conference approximately 10 years ago. Four of the organizations knew of URC through their largest registry SWEDEHEART and/or published research (NICOR, Cork University Hospital, the ANMCO Emilia-Romagna and Global Pharma). A special case was Uganda Heart Institute, who were contacted by Professor Stefan Thelin.

Before the organizations came in contact with UCR, there was only one organization that knew of QReg 5, namely Heart Hospital Tampere University Hospital. Helse Nord

IKT are using Open QReg today, and have therefore received some informational talks and demos regarding QReg 5. Remaining six organizations (NICOR, Cork University Hospital, the ANMCO Emilia-Romagna, Seoul National University Bundang Hospital, Global Pharma, Uganda Heart Institute) did not know of QReg 5 prior to their first contact with UCR.

The reason for the contact with UCR was very alike between the organizations. The organizations wanted to know more about quality registries and UCR's way of working with these, as well as assess the possibility of creating a collaboration with UCR. The person that the organizations chose to contact at UCR differed. NICOR contacted Peter Hedman (the manager of the development section), Heart Hospital Tampere University Hospital contacted Professor Stefan James, Cork University Hospital contacted Professor Lars Wallentin (before coming into contact with Professor Stefan James), Helse Nord IKT contacted Professor Bertil Lindahl, the ANMCO Emilia-Romagna contacted Professor Bertil Lindahl who introduced him to the registry holder for SWEDEHEART, namely Tomas Jernberg and Global Pharma also contacted Tomas Jernberg. As mentioned, Uganda Heart Institute were contacted by Professor Stefan Thelin.

Concerning the communication between UCR and the organizations, it was possible to find similar answers as well. The organizations mention that the communication has been good and professional. However, Helse Nord IKT which is an organization that has already been working with UCR said *"As people move around to different projects it's harder to get a personal and/or timely support, but now there's better system support. Some steps forward, and some backwards."*. A quote from NICOR, the only international organization working with QReg 5 today, was *"We had realised quite early in the collaboration that communication was an area we needed to get right from the onset primarily driven by the geographical dispersion. We have come up with several communicative methods...which has ensured this never became an issue."*. One organization (Cork University Hospital) mentioned that UCR seem to have a commitment overload, and they recommended UCR to commit to and deliver a reasonable and manageable project plan. Four organizations (the ANMCO Emilia-Romagna, Seoul National University Bundang Hospital, Global Pharma, Helse Nord IKT) mentioned the frequency of UCR's answers to be insufficient.

When it comes to whether the organizations had considered working with other organizations than UCR concerning quality registries and technical infrastructures, this

differed. Three of the organizations (the ANMCO Emilia-Romagna, Seoul National University Bundang Hospital, Uganda Heart Institute) had not contacted any other organization than UCR. Remaining five organizations (NICOR, Heart Hospital Tampere University Hospital, Cork University Hospital, Global Pharma, Helse Nord IKT) had contacted either software companies, hospitals, or other registries.

In the future all interviewed organizations want to progress with their collaboration plans with UCR concerning QReg 5. Four of the organizations (Heart Hospital Tampere University Hospital, the ANMCO Emilia-Romagna, Seoul National University Bundang Hospital, Uganda Heart Institute) envisage to use QReg 5 as the technical infrastructure for their own planned or existing cardiovascular registries. NICOR are planning on migrating all their current quality registries and audits into QReg 5. Global Pharma want to export the whole concept regarding QReg 5 to the MENA region. Helse Nord IKT are interested in working with QReg 5 instead of Open QReg, however they are not because of a lack of support on a managerial level, a lack of resources as well as Helse Nord IKT being understaffed.

The representatives were asked freely about final comments. One final comment stated that QReg 5 is complex technical infrastructure, that requires high initial costs and a lot of time for implementation (as mentioned by NICOR). Another mentioned the lack of either financial funding (Uganda Heart Institute) or a lack of technical expertise (the ANMCO Emilia-Romagna) as the main challenges for the potential collaborations. Some organizations also mention that they see Sweden as a benchmark for their own country when it comes to quality registries (Heart Hospital Tampere University and Seoul National University Bundang Hospital).

See Figures 7 to 14 for the summarized results.

	England - NICOR
Organization	Part of the National Center for Cardiovascular Preventions and Outcome at the University College London. Similar to UCR
Use of registries	NICOR have several quality registries. Had own-developed technology for quality registries, but it had limited scalability, flexibility and architecture
Awareness of UCR	SWEDEHEART and published research from UCR
Awareness of QReg 5	NICOR did not know of QReg 5
Contact reason & person	NICOR needed to replace their current technology, and wanted to assess the feasibility on developing a collaborative relationship with UCR. NICOR contacted Peter Hedman
Communication	A drawback was that it was not clear how the contact should progress after the first meetings. They have a good daily communication today, as they have signed with UCR
Other possible collaborations	IBM, Oracle, Microsoft, Monitor Deloitte and Aridhia. UCR were chosen because they matched NICORs business requirement
Future plans	NICOR plan to migrate all their current quality registries and audits into QReg 5
Comments/ Suggestions	High initial costs to implement QReg 5, including staff, hardware and software. QReg 5 is complex, demands learning curve. Underestimated the time to implement the first registry; it was originally set to six months, took nine months

Figure 7: Results from questionnaire with representatives from NICOR in England. The interviewees were Fabian D'Souza - Technical Project Lead, Peter Ludman - Consultant cardiologist, and Nadeem Fazal - National Clinical Audit Services Manager. For more information from the questionnaire, see B.2.1

	Finland - Heart Hospital Tampere University Hospital
Organization	University Hospital, focusing on cardiology
Use of registries	They have developed their own quality registries and technical infrastructure. Quality registries are well known in Finland
Awareness of UCR	Through searching the Internet
Awareness of QReg 5	Dr. Markku Eskola already knew of QReg 5
Contact reason & person	Create a collaboration in the field of cardiology registries. Dr. Markku Eskola contacted Professor Stefan James
Communication	The contact with UCR was described as very professional
Other possible collaborations	Other hospitals in Finland regarding quality registries and technical infrastructures, namely Oulu University Hospital, Jyväskylä, Pori and Hämeenlinna Central Hospitals
Future plans	Use QReg 5 as the technical infrastructure for quality registries regarding invasive cardiology
Comments/ Suggestions	According to Dr. Markku Eskola, quality registries are suboptimally used in Finland

Figure 8: Results from questionnaire with a representative from the Heart Hospital Tampere University Hospital in Finland. The interviewee was Dr. Markku Eskola. For more information from the questionnaire, see B.2.2

Ireland - Cork University Hospital	
Organization	University Hospital (Dr. Peter Kearney is a Consultant Interventional Cardiologist)
Use of registries	Familiar with the general nature of quality registries, through component registries and reports generated by SWEDEHEART
Awareness of UCR	Dr. Peter Kearney heard about UCR several years ago, through Professor Lars Wallentin
Awareness of QReg 5	No
Contact reason & person	Learn more about quality registries, and to develop a collaboration in order to develop their own system of registries. Dr. Peter Kearney contacted Professor Lars Wallentin, before he came in contact with Professor Stefan James
Communication	The communication is described as good, however, a possible threat according to Dr. Peter Kearney might be their mutual commitment overload
Other possible collaborations	The British Cardiovascular Intervention Society (BCIS), and chaired an IT-company for an Irish version of SWEDEHEART
Future plans	-
Comments/ Suggestions	For UCR to commit to, and deliver, a reasonable and manageable project plan

Figure 9: Results from questionnaire with a representative from Cork University Hospital in Ireland. The interviewee was Dr. Peter Kearney. For more information from the questionnaire, see B.2.3

Italy - The ANMCO Emilia-Romagna	
Organization	The ANMCO is a non-profit association constituted by Italian cardiologists, Dr. Filippo Ottani is president of the regional section Emilia-Romagna
Use of registries	Quality registries are not used in Italy as they are in Sweden. The region Emilia-Romagna had the Percutaneous Coronary Intervention (PCI) registry during 10 years, it is no longer used since two years back, because of economic and political decisions
Awareness of UCR	Scientific papers reporting on data produced and managed by UCR
Awareness of QReg 5	No
Contact reason & person	To understand how to set up a permanent registry in Emilia-Romagna. Dr. Filippo Ottani contacted Professor Bertil Lindahl, who introduced him to Professor Tomas Jernberg who is the registry holder for SWEDEHEART
Communication	Dr. Filippo Ottani visited Professor Tomas Jernberg. This was a personal initiative as well as an initiative from the former regional president of the ANMCO Emilia-Romagna and the top managers of the regional health system
Other possible collaborations	No
Future plans	Use QReg 5 for regional quality registries, and not at a national level for the moment. The priority would be a cardiological registry
Comments/ Suggestions	Very useful communication. Because of ANMCO's lack of quality registries experience, there is a large gap before they will be able to cooperate usefully with UCR. When Dr. Filippo Ottani came back to Italy after his visit to UCR, the contacts had suddenly ended

Figure 10: Results from questionnaire with a representative from the ANMCO in Emilia-Romagna, Italy. The interviewee was Dr. Filippo Ottani. For more information from the questionnaire, see B.2.4

Korea - Seoul National University Bundang Hospital	
Organization	Professor Hee-Joon Bae represents the Epidemiologic Research Council of the Korean Stroke Society and the Seoul National University Bundang Hospital
Use of registries	Quality registries are just at the starting line in Korea, e.g. there are The Clinical Research Center for Stroke (CRCS) and AMI registries
Awareness of UCR	From his colleagues
Awareness of QReg 5	No
Contact reason & person	To visit UCR with colleagues from the CRCS and AMI registries. Representatives were medical doctors (cardio-cerebrovascular) and government officials
Communication	It would improve the contact if the correspondence would be without delay
Other possible collaborations	No
Future plans	His institution uses several quality registries, most of which are developed and managed by the academic societies of Korea. QReg 5 could be used for these
Comments/ Suggestions	Professor Hee-Joon Bae sees quality registries as a self-motivated continuous quality improvement for which Sweden is a good benchmark for Korea

Figure 11: Results from questionnaire with a representative from Seoul National University Bundang Hospital in Korea. The interviewee was Professor Hee-Joon Bae. For more information from the questionnaire, see B.2.5

	The Middle East - Global Pharma
Organization	Swedish consulting firm that works with both Swedish and international pharmaceutical, medical devices and other life science companies that want to establish a business in the Middle East/North Africa (MENA region). Contact was Global Pharma's CEO Paula Hassoon
Use of registries	Global Pharma had worked with export of know-how from The Swedish National Diabetes registry (NDR) to the MENA region, a Registercentrum Västra Götaland registry
Awareness of UCR	Through SWEDEHEART
Awareness of QReg 5	No
Contact reason & person	Know more of how they could export Swedish know-how regarding quality registries to the MENA region. Tomas Jernberg who is the registry holder for SWEDEHEART
Communication	Very good and professional, even though it has sometimes taken some time to get answers to e-mails because of UCR being busy
Other possible collaborations	Except NDR and UCR, Global Pharma have been in contact with other organizations regarding quality registries and technical solutions
Future plans	In the future Global Pharma believe that the whole concept with the know-how from UCR, a well developed IT-system and support make QReg 5 interesting for many countries in the MENA region, especially the Arab states of the Persian Gulf
Comments/ Suggestions	-

Figure 12: Results from questionnaire with a representative from Global Pharma working with The Middle East. The interviewee was the CEO Paula Hassoon. For more information from the questionnaire, see B.2.6

	Norway - Helse Nord IKT
Organization	Helse Nord IKT is a main operations and support organization for one of the four regional healthcare organizations in Norway. They offer quality registries and small applications for regional support, and a team dedicated to an integration infrastructure
Use of registries	Helse Nord IKT use Open QReg, the precursor to QReg 5, for quality registries on a local, regional and national level, in total 17 registries
Awareness of UCR	At a registry conference called “Kvalitetsregisterkonferensen” approximately 10 years ago
Awareness of QReg 5	Using Open QReg 4 today. They received some informational talks regarding QReg 5, and some demos.
Contact reason & person	Perform a general inquiry regarding UCR’s work on medical quality registries (not the technology behind it). The first contact person was Professor Bertil Lindahl
Communication	Frequent communication regarding the technology in the beginning of the collaboration. The informal nature of the collaboration might have hindered the collaboration. Today it is harder to get personal and timely support, however there is a better system support
Other possible collaborations	They had one or two registries on the platform MRD from Hemit IT. This platform was abandoned in favor of Open QReg
Future plans	Interested in working with QReg 5 instead of Open QReg 4. Because of a lack of support on a managerial level, a lack of resources, as well as Helse Nord IKT being understaffed, this has not been followed out
Comments/ Suggestions	Regular meetings, in order to not find out about critical releases too late. It seems that UCR either forget or are too busy to talk to Helse Nord IKT. When UCR are present it usually works well

Figure 13: Results from questionnaire with representatives from Helse Nord IKT in Norway. The interviewees were system developers Are Edvardsen and Ketil Holden. For more information from the questionnaire, see B.2.7

	Uganda - Uganda Heart Institute
Organization	Uganda Heart Institute (UHI), a National Heart University in Uganda
Use of registries	The centre is a part of the Paediatric International Quality Improvement Collaborative (IQIC) online registry, an initiative at the Boston Children's Hospital
Awareness of UCR	Professor Stefan Thelin contacted UHI
Awareness of QReg 5	No (nor prior to the visit, or after the visit at UCR)
Contact reason & person	Professor Stefan Thelin contacted UHI
Communication	Good, however sporadic. The collaboration is still in its infancy, and is a work in progress
Other possible collaborations	No
Future plans	Probably institutional registries at first, thereafter national ones in the far future. A birth and death registry is needed nationally. Start off with a heart registry.
Comments/ Suggestions	A possible threat to the collaboration is the lack of funding, this is the main challenge as funding is needed in order to create the registries

Figure 14: Results from questionnaire with a representative from Uganda Heart Institute. The interviewee was Dr. Michael Oketcho, a consultant cardio-thoracic surgeon. For more information see B.2.8

7 Analysis

7.1 The opportunities with QReg 5

The attention surrounding QReg 5 has originated from several international organizations, and it is practically impossible to not consider it to be a potential economically valuable business. However, when conducting interviews with the registry centers in Sweden, some of these centers expressed concern regarding UCR's potential internationalization plans. They argued that the aim for registry centers is to develop healthcare in Sweden. As mentioned earlier, UCR's mission is to improve healthcare all over the world and not only in Sweden. Quality registries have been proven to be significantly beneficial for the healthcare in a country, and by improving healthcare in the rest of the world this would also ameliorate healthcare in Sweden. If quality registries would be used to a larger extent globally, it could implicate that there would be larger amounts of patient data available, and thereby it would be possible to conduct research with larger and more diverse patient populations. Sweden is a rather small country, and with the possibility of having access to much larger populations and amount of data, even more accurate studies would be possible. This could be enabled by the use of QReg 5 globally, and it would result in an improved quality of healthcare in the world.

7.2 The organizational structure

The integration of the new technology QReg 5 into the established organization UCR has been a challenge for UCR, as they have continued with the older version of the technical platform at the same time. However, efforts have been made in order to let QReg 5 complement the older version of the technical platform (Open QReg 4). Some organizational restructuring has also been made, by the creation of the development section which is now responsible for the international work, including the collaboration with NICOR.

7.2.1 Exploitation and exploration within UCR

UCR is a typical example of an organization where it is important to have a balance between exploitation and exploration, as described in 3.2. UCR have managed to ex-

plore new possibilities, while exploiting existing capacities. An example of this is the creation of QReg 5. UCR as an organization has personnel with different backgrounds, such as from academia, from state-owned institutions or from the private sector. By using the model *Mutual learning*, the organization has benefited from the personnels diverse backgrounds. To achieve exploration, UCR have recruited individuals to management positions that did not have a background within the organization. Thereby, UCR have worked with their weakness, and they have avoided the risk of a decreased efficiency, as the recruits have deviated from the organizational code in a favorable way.

7.2.2 UCR is an ambidextrous organization

UCR have faced organizational challenges following the new technical platform and its potential. Since UCR is an organization that works with both daily tasks and innovation, the risk is that one or the other takes over, as described in 3.2. However, this situation has been managed by letting Open QReg 4 continue to be used for some quality registries, while the new platform QReg 5 has been developed. What has been crucial for UCR, is that the organization has kept the relatively new exploratory unit called the development section separate from the exploitative one, that is the quality registry section. Even though the two sections are separate, a strong link has been kept between them, which might have been UCR's key to success so far. UCR is therefore a so called ambidextrous organization. A challenge for UCR is that the visions and plans for the whole organization need to be communicated by the management team to all members of the personnel. Even the people that are not directly involved in the exploration of the new technical platform should know about the progresses made by it. The unclear visions concerning the internationalization and internationalization of QReg 5 affect the personnels motivation and engagement in the project.

7.2.3 UCR as an organization with shared ownership

UCR has a shared ownership as two parallel organizations, Uppsala University and Uppsala County Council, have been integrated through their ownership of UCR. Since this kind of cooperation is rather unique, there is no standard legal frame of reference for this kind of organization that UCR can use as guidelines when running its activities. Instead, UCR needs to constantly communicate with the legal officers from both the

county council and the university.

As can be read in 6.1, the interviewed legal officers from Uppsala University and Uppsala County Council had different views on UCR's ownership situation. The legal officer from the university stated that UCR is equally a part of the university as the county council. However, the university legal officer continued by stating that UCR consider themselves as owned by Uppsala County Council, and not by the university, when doing business and signing agreements. The legal officer from the county council, on the other hand, said that UCR actually belongs to the county council, and that UCR should be more clear about this. The two interviews revealed two different point of views concerning UCR's ownership. This ambiguity leads to uncertainties regarding for instance the ownership, pricing and software protection of QReg 5, as well as how UCR should present themselves when cooperating with other organizations, and what ethical guidelines to follow when choosing clients.

When UCR approaches agreements with clients, the question arises whether legal officers from the university or the county council should advice UCR and design written agreements. In the case of the written agreement with NICOR, this was designed by an external legal firm. Even though there are no requirements for UCR to get advice from any instances, the interviewed legal officer at the county council stated that they prefer that UCR seeks their advice in the future. This way they could use already available resources at the county council to ensure that the governments body's interest are taken into consideration, as UCR write agreements in the same organizational number as the county council.

The legal officer at the county council mentioned that there could be a possibility for UCR to be exported to become its own organization, independent of the county council. This could be interesting if UCR choose to focus on the internationalization of QReg 5, as it would be easier to do business. However, this would require a thorough process. There would be a need to inspect all the investments made from the county council in order for UCR to become the organization that they are today. The county council would thereafter urge UCR to pay back all the summarized investments to the county council.

7.3 QReg 5

7.3.1 Ownership of QReg 5

As can be read in 6.1, the interviewed legal officers from Uppsala University and Uppsala County Council also had different views on the ownership of QReg 5. This is a consequence of the unclear ownership of UCR. Today, QReg 5 is mainly protected by copyright. This implies that the organization where the employees that have developed the code are hired, owns the code. At UCR, employees are either employed by the university or the county council, or possibly by both. This has created an unclear copyright ownership. The legal officer at the university stated that when it comes to software, as QReg 5, the university should have full rights to use it for free, if they find it useful for the university's activities. However, the university has no interest in QReg 5 or any other innovations of UCR if they do not find them useful, and will therefore not interfere with the internationalization plans of QReg 5. The legal officer at the county council said that the county council fully own QReg 5. However, if the university would like to use QReg 5 for free, the county council would probably not find any issues with this. Summarized, there are no obstacles for the county council and the university regarding Qreg 5's ownership. However, concerning the matter of open sourcing the code, this situation could change.

7.3.2 Open sourcing QReg 5

If QReg 5 would be open sourced, the code would be available for others to distribute it, including the university. However, if QReg 5 would be kept exclusive in order to internationalize it, it would become a more delicate matter as the ownership of QReg 5 could become an issue. This needs to be considered when deciding whether or not to open source QReg 5. The academic culture implies that knowledge should be shared and spread, as a kind of altruistic behavior. The whole academic system is founded on that discoveries and results are published. As can be read in 6.1, the legal officer from Uppsala University stated that the university would not support a decision which would implicate that QReg 5 would be kept exclusive.

Open sourcing or not becomes an ethical question as well. When choosing whether to open source the technical infrastructure QReg 5 or not, a point of view would be that

open sourcing it would inevitably make QReg 5 more widespread, therefore, this might be more ethical in this aspect.

7.3.3 Integration with electronic medical records

A future possibility could be integrated quality registries in healthcare systems, such as electronic medical records. If it would be possible to use QReg 5 as the technical infrastructure enabling the merge between quality registries and electronical medical records, then all suppliers of electronic medical records could be potential clients for UCR creating a new market for QReg 5.

However, the integration with electronic medical records could also implicate a possible risk for QReg 5. If the suppliers of electronic medical records would create a solution for the integration of quality registries into the medical records, there would not be any need for QReg or any other platform used for quality registries today. If only one system existed instead of two, this would also imply less work for the healthcare professionals, saving them from inserting data two times. There are about a few different electronic medical records systems primarily used within healthcare in Sweden today, and these are differently constructed. This solution could therefore be more technically advanced than expected.

It is also possible that countries that do not yet have quality registries nor electronic medical records, start off with only aquiring the medical records and could therefore be more interested in finding integrated solutions. In Sweden where well-functioning quality registries already exist, the need for the two systems to merge might not be as urgent.

7.4 Competitors for UCR

Potential competitors for UCR regarding their internationalization plans with QReg 5 could for instance be software companies or other quality registry centers that develop their own technical platform, but it could also be other Life Science related organizations (e.g. hospitals) that already work with or plan to work with quality registries. Any organization that sees the potential in creating quality registry platforms is a potential competitor. Now that UCR has signed with NICOR in England, there is also a certain

risk that they become better at using quality registries and the platform than UCR is. England is a significantly larger country than Sweden, and by using QReg 5 this might give them a lot of attention from for example researchers (if NICOR publishes a lot of articles for instance) that they decide to move on and develop their own technical platform. Since UCR is a relatively small organization, the largest risk is that a big company with better finances take over the market. No market shares left for UCR would be devastating for the internationalization of QReg 5.

There are large software companies that have become increasingly interested in healthcare. If such large actors enter the same market as UCR it might be difficult for UCR to distinguish themselves and their technical platform. Large global companies have infinite larger economies that they are able to use in order to develop the ultimate technical platform for quality registries. When interviewing international organizations, NICOR mentioned that they had considered the following companies; IBM, Oracle, Microsoft, Monitor Deloitte and Aridhia. These are all to be considered as competitors for UCR. However, there are aspects that would complicate large companies to enter the quality registry market. To be able to build well-functioning quality registries, a combination of knowledge, culture and product is needed.

7.5 Analyzing registry centers

The registry centers in Sweden have been analyzed in order to identify how they manage their respective organizations, compared to UCR. The analysis is based on the results from the interviews with representatives from all registry centers in Sweden, as described in 6.2.

7.5.1 Organizational structure and similarities with UCR

Firstly, the focus is on the registry centers' organizational structures and their similarities with UCR. Since RC Syd and Registercentrum Västra Götaland have their own technical platforms and they both possess technical competences within the organizations, they are independent of third parties. This is also the case for Registercentrum Norr, as they manage all technical aspects for their associated quality registries, even though they use the platform INCA which is owned by SALAR. Being independent im-

plies that the organizations are able to plan their activities more efficiently, diminishing supplier-related risks. Consequently these registry centers have reduced the risk of not being able to deliver the promised product and support to their clients.

Since QRC Stockholm and RSCO both use external suppliers for technical solutions for their connected quality registries, they are dependent of the suppliers to also deliver support. This implies the risk that QRC Stockholm and RSCO are unable to deliver the promised support to their clients because of incapable suppliers. In this eventual situation, the registry centers would be put in a position to answer to their clients, while being unable to take action. However, there are benefits with working with external suppliers. For example the workload within the organization is reduced, hence they can focus on doing what they do best. These organizations might have a better possibility to achieve a balance between exploration of new possibilities and exploitation of existing competences within the organization.

QRC Stockholm is the only other registry center, except for UCR, that has shared ownership with the academia. This implies certain benefits, e.g. opportunities to apply for funding, trustworthiness in the eyes of the clients, as well as an extended network. However, it also complicates the ownership of both the organization as well as of the innovations created within the organization, as in the case for UCR.

7.5.2 The development of different technical platforms

Secondly, the registry centers' development of different technical platforms was analyzed. The registry holder group for a quality registry may choose what technical platform they prefer to base their registry on. It is not common for the registry holder groups to possess technical knowledge, therefore the easiest choice for them is to choose the technical platform that is delivered by the registry center that they are connected to. As it is both complicated and expensive to transfer between technical platforms once a registry is already up and running, it is not likely that a registry holder group changes technical platform once they have chosen one. This reduces the opportunity for competition among technical platforms and registry centers in Sweden, since only new quality registries are to be considered potential clients. This does not create a market upon which technical platforms are competitors, since there are not clients enough in Sweden in order for it to be considered a profitable market. In combination with this

reason, there is also the strict funding from SALAR, which both limit the conditions of the market.

The reason for developing a new, more advanced, platform is when the precursor becomes insufficient. This was the case with Open QReg 4, which was the precursor to QReg 5. This was also the case for Registercentrum Västra Götaland, that developed Stratum even though they used INCA. Except for Registercentrum Västra Götaland, there is only one more registry center that have developed their own technical platform, namely RC Syd. Remaining registry centers are not using their own technical solutions, nor are they planning on developing their own platforms.

7.5.3 Possibilities for international collaborations

There is a potential global market for the technical infrastructures developed in Sweden. As international organizations realize the benefits of quality registries, there has been an increased demand of UCR's expertise and technical know-how.

Regarding the other registry centers, two of them have received inquiries concerning international collaborations. The two other registry centers who possess their own technical platforms (RC Syd and Registercentrum Västra Götaland) have received proposals from international organizations. However, no other registry centers besides UCR have signed any international agreements.

In general the registry centers are rather positive when it comes to working internationally, however, it is not a priority for them as SALAR's venture indicates that their mission is to improve healthcare in Sweden. It is important for the registry centers that the internationalization does not in any way interfere with their given mission by SALAR. As SALAR's venture ends, the registry centers might need to look around for other business management strategies for their organizations. This could imply that international collaborations become of higher priority than they are today.

7.6 Analyzing international organizations

7.6.1 NICOR as a departing point

To be able to understand the way QReg 5's potential clients think and act, NICOR acted as a departing point. With the help of the AIDA model, the collaboration between NICOR and UCR would serve as a template for UCR's international business relations. The analysis is based on the results from the interviews with NICOR representatives, as can be read in B.2.1.

NICOR's attention was drawn to UCR because of UCR's largest register SWEDEHEART and through published research. NICOR did not yet know of the technical platform QReg 5's existence, instead it was UCR and their registries that initially were of interest to NICOR. NICOR's interest in UCR was based on the potential collaborative relationship that could be created with UCR, including to learn and understand UCR's approach in registry based quality improvement from a technical perspective. Another factor that fueled NICOR's interest in QReg 5 was the platform's technical potential. NICOR's desire in UCR and QReg 5 increased following the two first meetings when NICOR visited UCR in Sweden. What made UCR and QReg 5 appealing to NICOR were multiple factors such as the potential benefits of working with a similar experienced organization, that UCR could bring a combination of expertise, experience and knowledge in a collaborative manner as well as UCR having technologies designed for high volumes of data adapted for running national quality improvement registries for extended durations. In conclusion, the desire was based on a combination of UCR as an organization as well as the technical benefits of QReg 5. The final part of the AIDA-model is action, that occurred when UCR licensed the technical platform QReg 5 to NICOR. See Figure 15 for the AIDA model applied on NICOR.

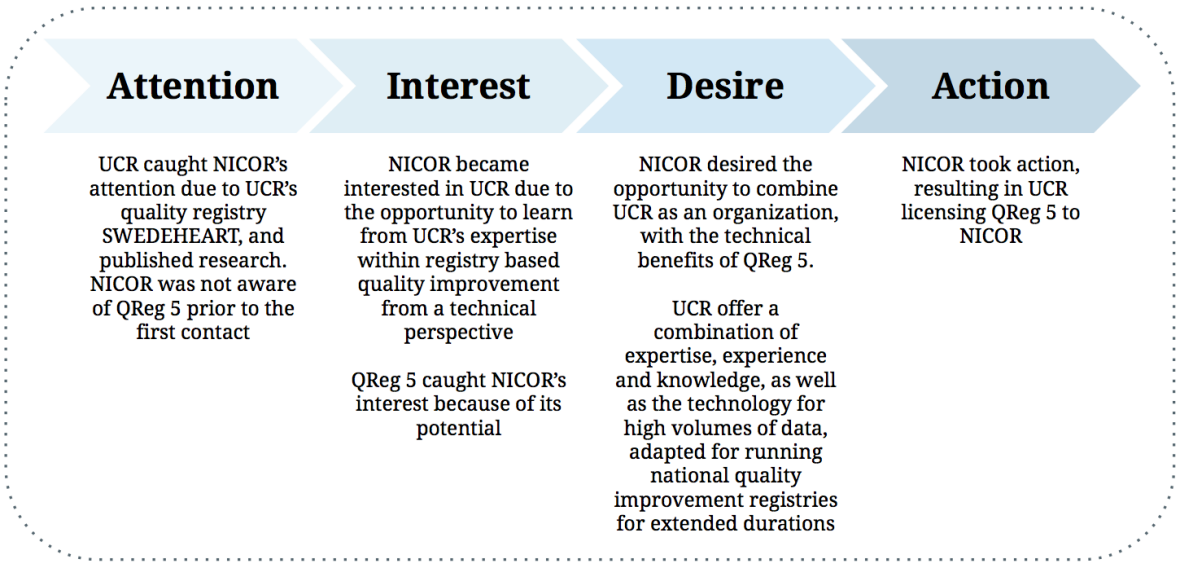

Figure 15: The AIDA model applied on NICOR The four steps in the AIDA model are Attention, Interest, Desire and Action.

7.6.2 General patterns among the international organizations

When studying the international organizations' answers to the questionnaires, which are summarized in 6.3, general patterns could be pointed out.

Concerning the organizational structures, all organizations except two focus on cardiovascular diseases, and four out of eight were hospitals. When organizations with similar structures to UCR contacted UCR (e.g. NICOR and Helse Nord IKT), collaborations were created. This might imply that it is crucial for the organizations to possess technical knowledge within the organization. It is likely that this is the reason that contacts from other kinds of organizations, such as hospitals, have not lead to any collaborations. The cardiovascular focus is coming from the SWEDEHEART registry, however, it does not seem to be crucial for UCR when creating collaborations.

The awareness of UCR for the international organizations was mainly thanks to UCR's largest registry SWEDEHEART, and/or published research, as this was the answer of four out of eight organizations. When asked about the organizations awareness of QReg 5 prior to the first contact with UCR, only one organization knew of it. Raising awareness of QReg 5 prior to the contacts would imply that the organizations would be more well-informed when contacting UCR with collaboration requests.

A common pattern was found for all organizations regarding the reason for contacting UCR. All organizations stated that they wanted to know more about quality registries and UCR's way of working with these, as well as assess the possibility of creating a collaboration with UCR. The first contact person was usually one of UCR's professors or in two cases, the registry holder for SWEDEHEART. The professors are therefore to be considered the key people for the organizations' contacts. In the future, the development section that work with the international collaborations should be the first contact for the organizations, this could be more clear, for instance on UCR's website.

The communication was mostly described as good and professional between UCR and the international organizations, however, it seems that UCR have not been clear when it comes to the progression of the contacts. One organization recommended UCR to commit to and deliver a reasonable and manageable project plan. UCR also seem to have a commitment overload, and therefore there is either a delay in their answers or there are simply no answers at all. In order for the communication to work between the organizations and UCR, UCR need to increase their degree of answering to the contacts. This might be enabled by a more structured way of following-up the contacts. For instance by logging all organizations that have been in contact with UCR, as well as the progression of the contact. This should be managed by the development section.

Three out of the eight organizations had not contacted any other organization than UCR concerning quality registries and technical infrastructures. Remaining five organizations had contacted either software companies, hospitals, or other registries. UCR appears to be a strong alternative on the quality registry market. However, UCR should not sign agreements with too many clients at once. This would make it impossible for UCR to be able to deliver the technical solutions and support, at least with the business structure they have today. Even if many organizations have been in contact with UCR, only one has signed a licensing agreement, NICOR. NICOR seem pleased with the collaboration with UCR, however, they also pointed out delays in the implementation process and that it was hard to understand QReg 5. In order to avoid this when working with other international organizations in the future, better education and structure plan for the implementation is needed from UCR.

In the future all interviewed organizations want to progress with their collaboration plans with UCR concerning QReg 5. Most of the organizations envisage to use QReg 5 as the technical infrastructure for their own planned or existing cardiovascular registries.

The representatives were asked freely about final comments. This resulted in interesting themes that have been noted, and a few common patterns have been identified. One is that QReg 5 is complex technical infrastructure, which requires high initial costs and a lot of time for implementation. The main challenge may therefore be the lack of either financial funding or a lack of technical expertise, depending on the organizations' conditions.

7.7 Ethical guidelines and factors

Because of UCR's shared ownership, both the university and the county council need to be present in the future internationalization plans for QReg 5. The university and county council have different policies regarding which countries their respective organizations should collaborate with. Uppsala University does not have any clear policies when it comes to which countries they favor to collaborate with, as can be read in 6.1, except that one should cooperate with all people regardless of their nationality. Uppsala County Council's policies depend on the present political climate, as it always acts on behalf of its citizens and the political parties they have democratically voted for. The county council have partaken in discussions with UCR, advising UCR which countries to work with. There was for instance a discussion regarding The Middle East, since it could have been a sensitive matter because of political reasons. However, UCR got the county council's approval to proceed with business negotiations.

As UCR's mission is to improve healthcare globally, one could argue that it would be ethical to work with countries that need it the most. The interviewed legal officer at the county council pointed out that when it comes to UCR working with developing countries, there are not to be any kinds of sponsorships from UCR, as can be read in 6.1. The funding for projects with developing countries must be proven not to originate from the citizens of Sweden. If sponsoring or any kind of aid would be applied for by UCR, this would actually be as if the county council applied for sponsoring and thereby, any eventual sponsoring would belong to the county council. Therefore UCR could not apply for sponsoring and directly apply them into a developing country (such as Uganda), or any other country which mentions financial issues to be the main challenge for a potential collaboration. If UCR would be able to prove that the citizens of Uppsala County Council did not in any way finance the collaboration, it may be possible to work with such countries. It is crucial for UCR to make thorough risk analyses concerning

cooperations with financially weak countries, to ensure that it would be approved by the county council.

As for the use of quality registries there are also cultural and ethical factors involved. For instance the citizens in a country need to have enough trust in the government, as in Sweden, to be willing to share private data with the purpose of improving healthcare. In Sweden, there is a strict legislation controlling who can create and own a quality registry and for what purpose. In other countries where this is not the case, there might for example be a risk of hospitals using quality registries in order to appear more successful. Such hospitals could modify the data to achieve more appealing results. Some countries have insurance companies involved within healthcare and quality registries, creating an interest of making profit. This factor decreases the trust among patients and makes it more difficult to persuade patients to share their data. It is easier to earn the trust of citizens if the healthcare is public and not private, since interest of making profit could lead to setting aside the best care for patients.

8 Conclusions

Conclusions have been drawn for the internationalization of the new technology QReg 5 for UCR. The conclusions regard the management of the organizational process for the internationalization of QReg 5, the different kinds of competitors for UCR and QReg, as well as the different potential customer segments for QReg 5. The following conclusions are to be considered as guidelines for UCR's continued work with the internationalization of QReg 5.

It is clear that there has been attention surrounding QReg 5 originating from several international organizations. Clearly, this is a potential economically valuable business for UCR. The internationalization plans align with UCR's mission to improve healthcare all over the world, and Swedish healthcare would benefit from QReg 5 being used globally. Therefore, the internationalization of QReg 5 is definitely something valuable that UCR should continue exploring and working with.

The shared ownership of UCR between Uppsala University and Uppsala County Council implicates complications for the internationalization plans for QReg 5. The consequences for the management of the organizational process have been considered in this

thesis. The ownership of UCR is not clear, and this leads to uncertainties regarding for instance how UCR should collaborate with international organizations, and what ethical guidelines to follow when choosing clients. The unclear ownership of UCR creates an uncertainty in the whole organization. On the contrary, a clear ownership and distinct visions would create a functional organization with direct goals.

The unclear ownership of UCR also results in an unclear ownership and software protection of QReg 5. However, it has been concluded that there are no obstacles concerning the ownership when it comes to the internationalization plans for QReg 5. As for the eventual open sourcing of the code, the legal officer from Uppsala University stated that they would not support a decision where QReg 5 is not shared with the academia.

It has been challenging for UCR to integrate the new technology QReg 5 into the established organization. However, by balancing exploitation and exploration within the organization, as well as working as a ambidextrous organization, UCR have managed to explore the new possibilities with QReg 5. One crucial part of this has been the introduction of a development section, which is responsible for the international collaboration with NICOR today. This is a step in the right direction, as more business competence is needed within the organization. Thanks to the development section, there will be key people focused on only caring for and keeping track of the progress with the international contacts. The contacts from the international organizations should therefore be directed to the development section, and not the professors at UCR. Furthermore, UCR need to be clear when it comes to the progression of the contacts, and deliver reasonable and manageable project plans. In the new development section, UCR will have to be more structured in order to be able to answer contacts without delay. In order to keep their focus, UCR should not sign agreements with too many clients at once. Instead the internationalization of QReg 5 will have to be an organically growing process. As for the implementation of QReg 5, a more thorough educational and structural plan for the implementation is needed. Another conclusion that can be drawn is that the organizations should be aware of QReg 5 prior to their contact with UCR, if the organizations are more well-informed when contacting UCR, it is more likely that there will be a successful collaboration.

UCR's management need to communicate with all the personnel, in order to keep everyone updated on the progress of the internationalization plans of QReg 5. This way, the personnels motivation and engagement in the project will augment.

In conclusion for the management of the process, UCR will not be able to continue with their internationalization and internationalization plans of QReg 5 as long as the ownership is as unclear as it is today. The legal officer from the county council mentioned that there could be a possibility for UCR to be exported to become its own organization, independent of the county council. However, this seems as a very complicated process, as the county council has been heavily involved in UCR's work until this point.

When the registry centers were analyzed, it was shown that the main differences between the centers were the possession of technical competences/technical platforms within the organization, and the use of suppliers. UCR's independence from suppliers imply that the supplier-related risks are decreased, however, because of their independence they also have a higher daily workload. As UCR internationalize QReg 5, it is beneficial that UCR do not have to rely on suppliers, instead they can ensure successful implementations of registries thanks to their expertise and know-how within the organization.

As long as the other registry centers are not planning on entering the international market, they are not to be considered competitors for UCR. Since most of them have not developed their own technical platforms, nor have they planned to do so, they do not have a product to internationalize. When asked about their thoughts on international cooperations, this did not seem to be the top priority for the registry organizations. However, the two other registry centers who possess their own technical platforms have also received proposals from international organizations, but have not signed any international agreements yet. These two organizations could therefore be considered as potential competitors for UCR and QReg 5.

Other potential competitors for UCR are large software companies, Life Science related organizations (e.g. hospitals) that already work with or plan to work with quality registries, as well as organizations that UCR license QReg 5 to. A future possibility for quality registries could be the integration, or merge, of quality registries in electronic medical records. This could be both a possibility and a threat for UCR, depending on whether UCR or the companies creating the electronic medical record's software create a solution for this. If the electronic medical records companies find a solution for the integration before UCR do, these are also to be considered competitors.

As for the potential clients, there are different kinds of customer segments to be found

among the international organizations. The international organizations could be clustered into organizations with a similar structure as UCR (with technical competences within the organization) as well as with different organizational structures than UCR (e.g. hospitals). When organizations with similar structure to UCR contacted UCR, collaborations were created. Thereby, a conclusion can be drawn, namely that it is crucial for the organizations to possess technical knowledge within the organization in order to create successful collaborations.

The optimal international clients for UCR would be organizations with enough technical competences in order to run and setup the quality registries with only some guidance for UCR, placed in countries were the use of quality registries are still not fully developed. This way, if a successful collaboration would be initiated with an organization, QReg 5 could be spread within the same country, as other technical solutions would not yet have been explored.

When choosing the international organizations to work with, UCR will need to be clear in their communication with Uppsala University and Uppsala County Council, as they have different policies. Especially the county council's policies are important, as they depend on the present political climate. If UCR proceed with their plans to work with financially hindered organizations, the funding for projects must be proven not to originate from the citizens of Sweden.

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Appendices

A Technical specification of QReg 5

This technical section, appendice A, is written by Alexandra Eriksson.

QReg 5 consists of several merged functionalities. The core idea for QReg 5 was to create a loosely coupled infrastructure, meaning that the parts can be replaced if superior technology is developed. It also needed automated testing, to be adaptable to different quality registries, no allowance of data loss, and the registrations needed to be traceable. These are all features of Qreg 5. Healthcare professionals can input data through registration forms via a Web application, that is rendered from multiple definitions and rules. QReg 5 can also input data through web services and other potential sources.

Other organizations using Qreg5 will either use the same services as UCR, or use their own infrastructure and write their own custom adapters for it. There are multiple possibilities to adapt QReg 5 to the potential clients organizations, depending on the organization's needs and the country that the organization is in. As QReg 5 is constructed through a merge of different blocks, it can be requested to only use desired functions.

A.1 Hardware and software requirements

In order to run the technical platform QReg 5, there is a requirement for both hardware and software:

- A Java Persistence API (JPA) compliant database. MySQL/MariaDB/H2 is used at UCR, and is therefore recommended
- Java 8 or later version, since the program code is written in Java
- Apache Tomcat 8 or later version. A web application server that responds to call, which the quality registry runs at. This enables data input for quality registries through the Web

There are also recommended software, in order for facilitated usage of QReg 5 and

constructing of quality registries:

- A Java-8 compliant Integrated Development Environment (IDE) for developers, it provides facilities for software development, such as source code editor, building automation tools and debugger
- Apache Maven 3+ or later version, or similar software. It is recommended in order to effectively construct quality registries

A.1.1 Downloaded dependencies

The package constitutes of several dependencies, which contains reusable code libraries. They are used via Apache Maven, which downloads the dependencies one by one from UCR's Sonatype nexus server. As mentioned earlier, QReg 5 is adaptable to different kinds of quality registries. Therefore, what dependencies are downloaded depends on what kind of quality registry that is going to be constructed. Different quality registries demand different rules for how the data should be stored. Every dependency constitutes of three different JAR-files. A JAR file contains compressed data, which is necessary for saving storage space and rendering files through the web. More importantly, a JAR file allows lossless data compression, meaning that the original data is fully recovered after the unpacking (The Java™ Tutorials, 2017) (ETHW, 2017). The first of these three mentioned JAR-files contains the binary code, which is the compiled Java code. The compiled code is computer readable and therefore runs directly in the server. The second one is the source code, that is the human readable version of the code. It has to be compiled in order to run, however, it is very useful for the clients developers in order to understand the infrastructure and develop new quality registries. The last one is the Javadoc, which contains the source documentation for every dependency.

A.2 The infrastructure

QReg 5 consists of four major parts:

- Registration Application Programming Interface (API) - data definitions of registrations, validation rules, data persistence, registration audit trail, registration process support and tools for generating documentation of the registry data definitions.

- Registration forms - a library for rendering dynamic web forms based on the data definitions created using the Registration API
- Data exchange - a library for data export from persisted registrations, and for import of exported data into Statistical Analysis System (SAS) analytical environment
- Developer tools - for making it easier to get started on creating registry applications, and for maintaining them.

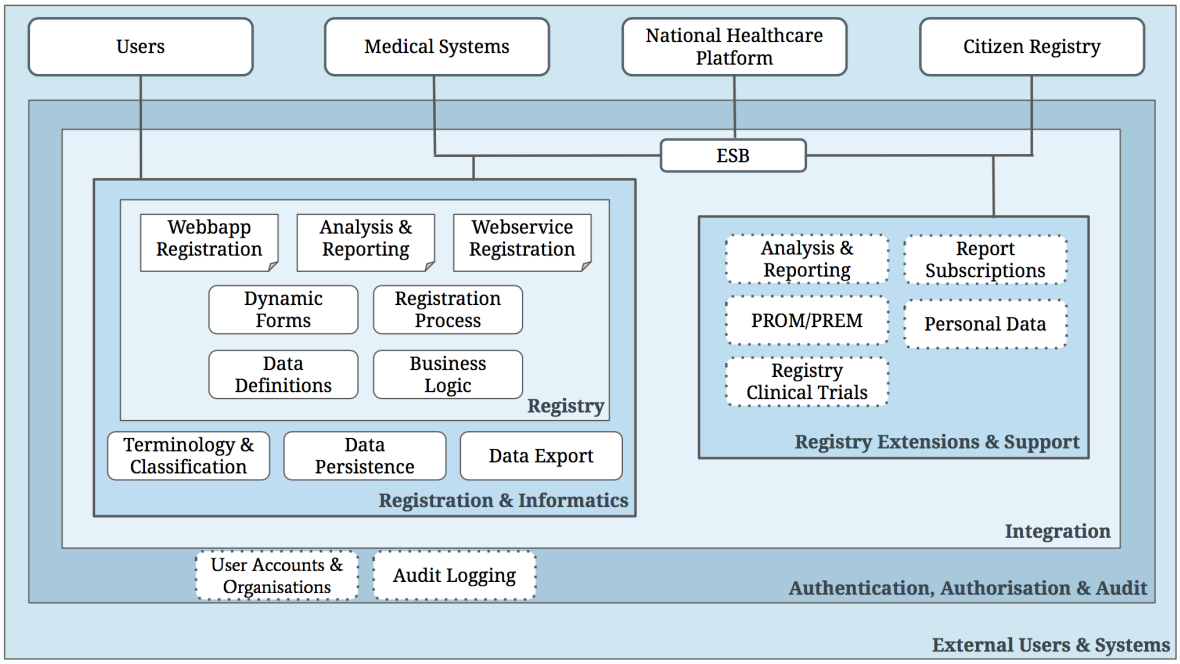

Figure 16: Technical Schema of Qreg 5 and connected functions. The Registry section contains the registration forms, its underlying code and functionalities provided through the Web to users. The Registration and Informatics section contains the functionalities for simplifies management of the collected data. The Registry Extensions and Support section contains support functions that QReg 5 can use. The Authentication, Authorization and Audit section contains the functionalities for distributing the data within the organization. The Integration section merges QReg 5 with the support functions. The External Users and Systems section shows what external systems that communicates with Qreg 5.

A.2.1 Database storage and data definitions

All the data input for a new registration ends up in a primary database, that is semistructured using MySQL and other relational database management systems. The

primary database is constructed to have data persistence (see Figure 16, Data Persistence), that ensures no loss of data. E.g. if a registration needs to be changed, a changed variable could cause connected variables to disappear, which is not allowed in the semistructured database. The database is driven by Axon Framework and Spring Data JPA. The stored personal data is separated from the identificator (such as name and social security number) via keys, in order to care for the integrity of the registered citizens. Testing of the stored data is executed through generating a fake key, making sure that there is no risk for the developers to recognize a registered patient.

The data definitions (see Figure 16, Data Definitions) contain rules for how the input data should be defined and collected into the database. It is all written in Java code. The data definitions offer several null flavors in order to improve traceability, that is necessary for using the data in research studies. *Empty* means that the user left no answer, and that they were allowed to do so because the variable was not required. *Not applicable* means that the variable was not filled out, as it was hidden due to data definition rules. *Answer no value* means that the user gave an answer but the value was not available for that specific variable, or, that the information was missing. For example, when a nurse can't find the answer to the question in the medical healthcare record system. The last one is *Not defined*, that means that the variable was not defined in the registration.

Every registration is also tagged with a reference and a version, which ensures traceability of how data was collected over time. Another highlighted benefit with QReg 5, is the standard coding functionality (see Figure 16, Terminology and Classification). By using established code systems within helthcare, such as ICD-10, KVÅ, SFAI and Snomed, a more structured collection of data is enabled.

A.2.2 User interface and registration form

The User Interface (UI) is built using Bootstrap, which is a web development framework for cross-browser support, developed by Twitter. The UI supports several devices. Users, with other words the healthcare professionals, can fill out the registration forms using both computer (Windows or Mac OS X), data tablets and cellphones (Android or iOS). The UI also supports several browsers; Chrome, Firefox, Internet Explorer, Opera and Safari. This flexibility regarding user devices means that healthcare personnel

may input data both using their workstation as well as via a mobile device while meeting patients outside of the office. The registration forms are based on Wicket MVC framework, and they are built using dynamic forms (see Figure 16, Dynamic Forms). Dynamic forms react on events from the user, they can re-ender several times during the fill-out (Adobe LiveCycle Designer ES, 2017), which allows for showing or hiding input fields which become applicable or not depending on data definition rules. This carries out the opportunity for the registration form to be constructed in a visually favorable way, in order to facilitate the process for the user to input data. The registration form is rendered from the Java code for the data definitions.

A.2.3 Registration process and validation

A registration process sets rules for how registration of data is executed in relation to the corresponding healthcare process (see Figure 16, Registration Process). It is all written in Java code. There are rules for how the user transfers between registration forms, that the developer choose to define in the process. Firstly, is that in the initial registration all variables must be filled out before moving on to the next step in the registration process. This to make sure that key information is stored. Secondly, there are rules for what fields to fill in in what order, if there is no possibility that a certain field could be filled out before another. Thirdly, a diagnosis can not be determined in the registration, without a certain lab result being filled out first. Lastly, there must also be possible to change information. However, if a question in a previous step is changed, then the following steps must be reconsidered. It must also be able to handle scenarios where changes need to be made to an already locked/signed registration. It can also track status for registrations. There are also rules that could exclude redundant variables in the registration form. This means that variables could be hidden depending on what is previously filled out, to facilitate the registration and remove redundant information. For example, depending on gender, some questions are not relevant to opposite sex. This is executed through eg. if variable A=1 and variable B=2, hide variable C.

The registration form also has validation and feedback functionality. Values that are filled out in the field could be marked with error or warning. This means that the form can directly give feedback to the user if a variable is filled out with an unlikely value. This to increase the reliability of the registry. For example, if a field is questioning about the participants weight, a high value is reasonable in a study about obesity, but

not in a study about toddlers. Developers can choose to accept a non-valid registration or not as saved. However, before a registration is signed, it must be valid. Also, there is a user registration assistance, extra descriptions for the fields can be provided, to help the user fill out the correct value. The registration API is fully testable - both rules, validation and feedback - through automated testing.

A.2.4 Data export for analysis and reporting

From the primary database, datasets could be exported for analysis (see Figure 16, Data Export). Datasets are defined by a developer in Java code. As part of this step, data transformation can also be defined, if the developer so chooses (for example if a score-value is to be calculated). The meta information about the dataset is exported, as well as the data that goes into dataset modifications. Between UCR registries, datasets can be joined on personal-data key, healthcare unit, healthcare issue ID or geographic codes. Between external datasets, datasets can be joined on personal number, healthcare unit or geographic codes. The choice of analytical tool for the datasets is flexible, as the exported format is flexible, e.g. CSV or Excel could be used. This functionality is a part of Qreg 5. Also, datasets can be exported to an highly structured export database for deeper analysis. From the export database an analysis could be done in any export destination that is implemented as a support function, e.g. SAS or JDBC datastores. Since the requests for the analysis environment could highly variate among organizations, the analysis and reporting function is up to the client to develop (see Figure 16, Analysis and Reporting).

A.2.5 Adaption of QReg 5

There are some functionalities that require individual adaption to the clients organization/nation, such as anonymization of personal data and business logic.

As mentioned above, personal data is separated from the identificator through keys, which also enables the developers to test the data without violating the patient's integrity. However, QReg 5 cannot provide any standard solution when it comes to the anonymization of personal data (see Figure 16, Personal Data), since the identification of citizens could be individual to each nation. In Sweden, we have social security number, meaning data could be easily anonymized using keys to separate the personal

identification from the data. In other countries, where this personal identity number does not exist, other solutions have to be considered to still make sure that each registered patient in the registry is unique.

The business logic is what describes the workflow of the data and how it is distributed to people or other systems. It needs to be integrated in QReg 5 (see Figure 16, Business Logic). There are some basic business logic encoded in the standard components. However, the majority of the business logic depends on the client's quality registry. The business logic could be very unique to an organization, therefore, this part is up to the client to develop.

A.3 Standard components and other support functions

The standard components are reusable components that are used for the quality registries functionality. These are imported into the registry web application (see Figure 16, Webapp registration). The standard components are for login/security, healthcare unit selection for user, registering and handling patients, system health function, browser filtering and browser detection and statistics. The clients can develop whatever functionality that they feel is a necessary standard component. The standard components uses support functions for extended functionalities. The support functions are not a part of the QReg 5 platform. Some of the support functions may not be useable for every organization, depending on their legal requirements and domain.

A.3.1 Data collection from external systems

In Sweden there is a registry over all the citizens, called *Befolkningsregistret*, providing social security number, name and contact information. QReg 5 can collect this data, for easier registrations of new patients (see Figure 16, Citizen Registry). Also, the support functions of Qreg 5 connects to the Swedish national healthcare platform, called *Nationella tjänsteplattformen* (see Figure 16, National Healthcare Platform). It is built by SALAR to facilitate the construction of quality registries. The platform improves the possibility for patients to communicate through SMS, e-mail, online guide via *Mina vårdkontakter, HSA-Katalogen* and *NKRR*.

There is a possibility for quality registries to collect already entered information from

medical systems, such as electronic journals (see Figure 16, Medical Systems). A solution where data from medical healthcare records can be imported into a quality registry, can reduce workload for healthcare personnel, since they don't have to enter all data manually. Qreg5 supports such solutions and allow for import/export solutions to utilize the same data definition with validation rules as data being submitted through online registration forms. However, in many cases the data is not provided in the right way, carrying out more workload from the beginning when half of the data needs to be entered manually anyway. There is a need for better integration between electronic journals and quality registries in the future to make sure that the data fits.

A.3.2 User services

One support function is the one for subscription service (see Figure 16, Report Subscription). This service is offered to users, that can subscribe to reports of their choice. Whenever an update occurs in the report of interest, a notification will be sent digitally to the user. For example, a registry holder could be interested to know the progress of a care section, and when updates occurs the registry holder will receive an e-mail.

Another support function is PROM/PREM (this is not in yet in function for QReg 5). PROM/PREM stands for Patient Reported Outcome/Experience Measures, it includes the patients point of view of the healthcare process. Patients can register their opinion of the healthcare they received, directly into the registries. Also, there will be a service to enable the patients to input certain data by themselves via electronical authorization. For example, a patient can insert data before meeting with a doctor, to facilitate the registration process and reducing the workload for the healthcare personnel.

A.3.3 Authentication, Authorization and Audits

There is a requirement for authorization function for quality registries, in order to control how the stored data can be accessed. Within healthcare in Sweden, hospitals that belongs to the same caregiver can share data with each other. For example Uppsala County Council is a caregiver, therefore, all the registrations made at hospitals within Uppsala County Council can be shared with all other hospitals within Uppsala County Council. Sharing of data between different caregivers, such as Stockholm County Council and Uppsala County Council, is restricted by legislations. An organizational schema

for authorization controls this distribution of data. It contains rules declaring the owner of the saved registrations in the database, and from which leverl a user is allowed to access the data. This access control is provided as a support function (see Figure 16, User Accounts and Organizations). Another support function is Audit Logging (see Figure 16, Audit Logging), that documents whenever personal data is viewed and by who. This enables keeping track of shared private information.

A.3.4 Randomized Registry-based Clinical Trials

Randomized Registry-based Clinical Trials (RRCT) is a totally separate framework that could be added to other technical platforms as well. This framework manages randomized clinical studies within quality registries. By combining the advantaged of randomized clinical studies with quality registries, a cost-effective alternative with broad population coverage is enabled. It is more cost-effective since patients of interest is identified in the quality register and could therefore more efficient be recruited to the study. There is no need of recruiting patients separately. However, this is only suitable for randomization between approved treatment strategies. Study-specific code needs to be created, utilizing the RRCT API, to define the business logic of the study. A RRCT-based solution can either be integrated with an Electronic Data Capture (EDC) system, which is a system designed for clinical data collection, or just use the RRCT study database, which is separate from the registry application's database.

B Interviews

B.1 Interviews with registry centers in Sweden

B.1.1 QRC Stockholm

QRC Stockholm is a cooperation between Stockholm County Council and Karolinska Institutet. They offer individually adapted IT solutions for national quality registries, regardless if the quality registry does or does not belong to QRC Stockholm. QRC Stockholm provide this service through their different suppliers. Today they have framework agreement with 13 different suppliers, amongst them Evry Healthcare Solutions AB, Omegapoint AB and Tieto Healthcare and Welfare AB (QRC Stockholm, 2017a) (QRC Stockholm, 2017b).

The interviewee was a technical project leader at QRC Stockholm. The interview was conducted by telephone on March the 21st, 2017. QRC does not have their own technical platform, and with every new client they develop individually adapted technical solutions. Their clients are both quality registries that are already connected to the registry center, as well as other quality registries that are not. QRC Stockholm create the requirement specification and place an order to one of their suppliers.

QRC Stockholm have chosen not to develop their own technical platform, as it would require another type of organizational structure than the one QRC has today. Their opinion is that there are already several good suppliers, which makes it not profitable for QRC Stockholm to develop their own technical platform. The client is affected by this solution both through the delivered technical solution, as different suppliers have slightly different directions and strengths, as well as the possibility for support, as the suppliers do not need to be available for providing support to the quality registries at any time.

QRC Stockholm have been in contact with one international organization, a software development company, but did not proceed with a cooperation. QRC Stockholm are positive about cooperating internationally, especially if they would be able to access information/data that is not available in Sweden such as data from certain diagnostic groups.

B.1.2 RC Syd

RC Syd is a part of Skåne County Council, and it is constituted by two joined units, namely Lund and Karlskrona. The different units provide their own technical platforms to their connected quality registries (RC Syd, 2017). The units of Lund and Karlskrona were merged when SALAR decided that there should only be one registry center in every county. As there were already two registry-based organizations in Skåne County Council, these where merged into one, named RC Syd. This is the reason why RC Syd has several technical platforms; 3C, Pharos, Eurocrine and ECP(RC Syd, 2017).

Two interviews were made with representatives from respective units of RC Syd. In the first interview, two interviewees from RC Syd Lund participated, a unit director and a registry coordinator. This interview was conducted by telephone on March the 23rd, 2017. At RC Syd Lund there are about 15 connected quality registries, and the competences among the personnel is a mixture of technical, statistical and mathematical competences. RC Syd Lund provide technical solutions, support and analysis of the information in the quality registries. The 3C platform is developed by an external company, but RC Syd Lund bought the full rights to it. 3C is a web based application for registration, storage, analysis and data report which is managed and continuously developed by RC Syd Lund.

In the second interview, the interviewee was a unit director at RC Syd Karlskrona. This interview was also conducted by telephone, on March the 28th, 2017. At RC Syd Karlskrona there are about 10 connected quality registries and they have an agreement with the IT-department at Blekinge County Council, which provides the technical management of the registries. The platform is named Pharos, and is very similar to 3C. However, RC Syd Karlskrona do not own this platform, instead an external consultation firm owns it. RC Syd Karlskrona have full right of disposal of Pharos, and are trying to become owners of the platform.

There are two other platforms that have been used at RC Syd except 3C and Pharos, namely ECP and Eurocrine. ECP is an previously developed platform that, and at RC Syd Karlskrona some registries are still located on the platform. However, the goal is to phase out the use of ECP during the years to come. The second older platform in use at RC Syd is Eurocrine. One or two registries are located on Eurocrine, and the platform is managed by a private company. Just like for ECP, the use of Eurocrine is

intended to be phased out. This will lead to RC Syd using only two technical platforms; 3C at the unit of Lund, and Pharos at the unit of Karlskrona.

Decreasing the number of used platforms would be more cost effective. As RC Syd completely own and distribute 3C, there is a possibility to migrate the registries on the platforms Pharos and ECP to 3C. Currently some registries are being migrated from ECP. In the future the units Lund and Karlskrona could have a common technical platform. However, because of the fact that this would be both costly and require a large amount of work, todays' situation where RC Syd aims at using two platforms is not a bad option. Especially not when the platforms are very similar.

RC Syd has been in contact with international organizations, however, there is no ongoing activity to proceed with a cooperation. The contacts have been transferred from the quality registries connected to RC Syd. One of the connected quality registries received a proposal to form a common European quality registry within the area of expertise, where RC Syd would provide knowledge and experience to develop the registry. Some of the quality registries already have participants from other countries, for example at an Icelandic hospital, data is inserted to the Swedish vascular registry. It is important to state why Swedish quality registry centers exist, namely to improve the quality within the Swedish healthcare as it is financed by the state.

B.1.3 Registercentrum Norr

Registercentrum Norr is organized into the research and education section of Västerbotten County Council. They support the continued work to use, manage and develop quality registries and secures the register competence in the north region. They offer the technical platform INCA to its connected quality registries. INCA is managed together with regional cancer center and Registercentrum Västra Götaland (Registercentrum Norr, 2017a) (Registercentrum Norr, 2017b).

There were two interviews, in the first one the interviewee was a project leader at Registercentrum Norr. The interview was conducted by telephone on May the 11th, 2017. In the second one, the interviewee was the head of the register center. This interview was conducted on May the 16th, 2017.

Registercentrum Norr provides the technical platform INCA, that is owned by SALAR, to its connected quality registries. Registercentrum Norr manages all the technical as-

pects around quality registries. However, some of the connected registries uses other technical solutions, the quality registries decides what technical solution they want to use. Registercentrum Norr provides technical support to the registries on these other platforms as well, therefor Registercentrum Norr is not tied to only INCA. They do not have any plans on a common technical platform for all the registries, or developing a new technical platform. The technical situation they have today is sufficient. Registercentrum Norr have not been in contact with any international organizations, however, they could be interested in international collaborations in the future.

B.1.4 Registercentrum Västra Götaland

Registercentrum Västra Götaland are a part of the Region Västra Götaland. They use the technical platform INCA, and their own developed technical platform called Stratum (Registercentrum Västra Götaland, 2017).

The interviewee was an IT Strategist at Registercentrum Västra Götaland. The interview was conducted by telephone on April the 3rd, 2017. Registercentrum Västra Götaland provide support in all areas concerning quality registries, for example expertise within the field of technology and law. This makes them quite similar to UCR. Registercentrum Västra Götaland is a relatively young organization, and connected quality registries are therefore principally young ones.

At Registercentrum Västra Götaland there is, except from their own developed technical platform Stratum, a platform called INCA. INCA is delivered by a third party, namely Cancercentrum Väst who are the technical administrative officer of INCA and handle all technical management. The reason for why Registercentrum Västra Götaland have quality registries on INCA is because of historical reasons. Having an external supplier of technical solutions is not optimal, as it is more beneficial to be independent from other organizations when developing their own platform. Stratum was developed as a result of Registercentrum Västra Götaland creating their own criteria list, when evaluating different already existing technical platforms. The core idea when developing Stratum, was being able to create the same validation logic for the client and the server. This was built on a model that executes a java script in a validation package. Stratum provides a flexible way of describing data models, as the addition of data to different tables can be adapted, which is why the database could be described as a hybrid.

Registercentrum Västra Götaland have been in contact with international organizations, even though they were not the ones initiating the contact. The requests came through various different registries. Often the requests were not followed through, because of conditions predetermined by the law regarding data storage in another system. Some organizations were also technically weak, as they did not have the resources to receive the technical solution, and they lacked competence concerning the development of quality registries. There has been a common misunderstanding that Registercentrum Västra Götaland have encountered, and that is that building a quality registry only depends on technical solutions, however, there is much more competence required that is not technical. There have also been requests regarding Registercentrum Västra Götaland's system, and that an Icelandic or Dutch registry would be run with it. In the future international collaborations could be of interest to Registercentrum Västra Götaland, even if this is not in line with the mission that it has as a national organization.

B.1.5 RCSO

RCSO provide support in the whole process of the development of quality registries. RCSO is a part of Kalmar County Council (Registercentrum sydost, 2017).

The interviewee was an employee at RCSO working with IT, such as journal integration questions and technical solutions around output data. The interview was conducted by telephone on March the 23rd, 2017. RCSO is a quite small organization compared to the other registry centers in Sweden. RCSO does for instance not offer a standard technical solution for quality registries, and some of the connected quality registries have their technical solution at another registry center. Generally they work with the data in the registries and not the technical solutions. The interviewee could not specify whether the technical solutions provided today are delivered by a certain external company. Event though it easily gets incoherent having several systems, it works fine in today's situation. If more quality registries connect to RCSO, they have not excluded the opportunity to develop their own technical platform. However, this is not something they are anticipating, as there already are several technical platforms on national level. The interviewee does not know if RCSO have international cooperations, but suppose it is interesting in the future.

B.2 Interviews with international organizations

B.2.1 England - NICOR

NICOR is the only international organization that UCR has signed a contract with so far. NICOR are a part of the National Center for Cardiovascular Preventions and Outcomes (NCCPO) at the University College London (UCL). NICOR collects clinical information about cardiovascular patients from UK hospitals that is later inserted into registries. The data in the registries is shared with hospitals and healthcare improvements bodies, and for example external research groups can apply to get access to the data. The aim of NICOR's work is to improve the quality of healthcare (ULC, 2017). One could say that NICOR is quite similar to UCR as an organization.

The people that answered the questionnaire sent to NICOR were Fabian D'Souza - Technical Project Lead, Peter Ludman - Consultant cardiologist, and Nadeem Fazal - National Clinical Audit Services Manager. Based on their answers to our questionnaire, here follows a report of their collaboration with UCR. D'Souza, Ludman and Fazal had different answers regarding how they first heard about UCR, either because of UCR's registry SWEDEHEART (more specifically the SCAAR registry) or through published research. The purpose of their initial contact with UCR (in 2015) was to assess the feasibility on developing a collaborative relationship with UCR including; to learn and understand by adopting UCR's approach in registry based quality improvement from a technical perspective, research such as observational with linkage, big data, randomized trials, collaborative studies, application of Swedish Data collection and reporting structures to UK, and finally mutual further development and shared resources. When NICOR first contacted UCR, the person they chose to contact was Peter Hedman, the director of development at UCR. Prior to the first contact with UCR, NICOR did not know of the technical infrastructure QReg 5.

When NICOR first visited UCR in Sweden, the initial meeting was attended by NICOR's Chief Operating Officer, IT Services Manager and the Clinical Lead for the IT and informatics working group. The second meeting (March 2015) included clinical and technical staff, information analysts and statisticians as well as the director of NICOR, Professor John Deanfield. Following the first meetings, NICOR had a positive view on the collaboration. During the meetings the potential benefits of working with a similar experiences organization who had been using technology to transform innovative ideas

to improve the quality of healthcare provided to patients were highlighted, and opportunities for both organizations were in focus. A mentioned drawback from the initial contact was that there was no clear path that was agreed upon regarding how things would move forward from then on.

NICOR's decision to look for a new technical infrastructure was based on the fact that the current NICOR technical environment needed to be replaced as scalability, flexibility and architecture were limiting future requirements. The existing technical environment was developed by NICOR, and was an infrastructure based on IBM® Domino® that NICOR had developed and maintained over 17 years. When choosing the most appropriate IT platform for NICOR, other organizations than UCR had been considered as a part of a tendering process, which they are responsible for delivering by their commissioners. During this options appraisal process NICOR evaluated the following organizations and suppliers; IBM, Oracle, Microsoft, Monitor Deloitte, Aridhia and UCR. Later on IBM, Oracle and UCR were shortlisted. NICOR decided upon UCR as the preferred solutions provider because they closely matched their business requirements. UCR stood out by being able to bring a wealth of expertise, experience and knowledge in a collaborative manner as well as having technologies designed for high volumes of data designed for the task of running national quality improvement registries for extended durations. Furthermore, UCR use technologies that can reduce the burden of data collection having the ability to connect to other receptive systems.

NICOR could initially identify some possible threats to the collaboration with UCR. The main concern was the open source technology stack approach and the potential complexities with the QReg 5 framework. Moreover, NICOR did not already use most of the technology stack used in the framework, and the perceived gap was considered a risk. The UCR team noted this and initiated a structured learning programme.

Initially, NICOR considered QReg 5 to be a modern secure web based flexible platform designed by an experienced organization using current technologies. More importantly one which has been designed for the sole purpose of registry-based quality improvement. Other factors making QReg 5 appealing to NICOR were its scalability and that it has an adaptive architecture which reduces the effort needed. Now that NICOR have had the possibility to get to know QReg 5 better, they consider the benefits to be for example that it incorporate technologies designed for high volumes of data, it has single definition of datasets, it allows full traceability of collected data, it implements

an optimized structure where data linkage and extraction are used and finally extended modules within the framework such as randomization allows extended uses of the data. Drawbacks with QReg 5 according to NICOR are that the framework is complex, which means that there is a certain learning curve to understand the technicalities. There are also high initial costs such as set up and resources, including staff as well as hardware and software. Generally a drawback is the timescale of adoption, originally six months were estimated to be enough to develop and implement the first audit/registry, but nine months would have been more realistic.

Today the contact with UCR is positive, and NICOR think that considerable progress has been made to date. There is regular communication between the two organizations and there are continuous discussions regarding issues that arise, which are thereafter solved together with UCR. Methods of communication include e-mails, recurrent project review meetings and daily communications as well as direct contact via telephone if needed. By using these communication methods, the geographical issues are overcome. In the future, NICOR plan to migrate all their current quality registries and audits into QReg.

B.2.2 Finland - Heart Hospital Tampere University Hospital

The person that answered the questionnaire was Dr. Markku Eskola. Dr. Markku Eskola who has the profession Chief of Interventional Cardiology, contacted UCR as a representant from his organization, namely Heart Hospital Tampere University Hospital. Dr. Markku Eskola first heard of UCR through searching the Internet, and the purpose of the initial contact with professor Stefan James was to create a collaboration in the field of cardiology registries.

At the first meeting with UCR the organization was represented by Dr. Markku Eskola, his colleague Professor Kjell Nikus and Tommi Harakkamäki who represented IT. The contact with UCR was described as very kind and professional, and up to this point Dr. Markku Eskola does not identify any possible threats to the collaboration with UCR nor does he have any improvement suggestions regarding the contact so far.

Prior to the first contact with UCR, Dr. Markku Eskola already knew of QReg 5. Quality registries are well known in Finland, but suboptimally used according to him. The future plans for the organization would be to use QReg 5 as the technical infras-

tructure for quality registries regarding invasive cardiology. The organization has only contacted other hospitals in Finland regarding quality registries and technical infrastructures, namely Oulu University Hospital, Jyväskylä, Pori and Hämeenlinna Central Hospitals.

Heart Hospital Tampere University Hospital have developed their own quality registries and technical infrastructure.

B.2.3 Ireland - Cork University Hospital

The person that answered the questionnaire was Dr. Peter Kearney. Dr. Peter Kearney who is a Consultant Interventional Cardiologist at Cork University Hospital contacted UCR to learn more about quality registries and to develop a collaboration in order to develop their own system of registries. Dr. Peter Kearney heard about UCR several years ago, through Professor Lars Wallentin, which was also his first contact at UCR before he came in contact with Professor Stefan James. At the first meeting with UCR there were other participants except Dr. Peter Kearney, namely Brendan Cavanagh, administrative lead of Southern Acute Coronary Syndrome (ACS) Register, and Mike O'Regan, IT lead at Cork University Hospital.

The communication between Dr. Peter Kearney and UCR is described as good, however, a possible threat according to him might have been their mutual commitment overload. He thinks that a possible way to improve the collaboration and make more progress on their behalf, would be to commit to and deliver a reasonable and manageable project plan.

Prior to the contact with UCR, Dr. Peter Kearney was already familiar with the general nature of quality registries, through component registries and reports generated by SWEDEHEART. However, he did not know of QReg 5. Except UCR, Dr. Peter Kearney has been in contact with other organizations regarding quality registries or technical infrastructures such as the British Cardiovascular Intervention Society (BCIS), and he also chaired a ministerial committee that commissioned a technical report from an IT-company for an Irish version of SWEDEHEART. This was a decade ago for what was to be the National Cardiac Information System (NCIS), and he did not consider it to be useful.

B.2.4 Italy - The ANMCO Emilia-Romagna

The person that answered the questionnaire was Dr. Filippo Ottani. Dr. Filippo Ottani is a medical doctor working as a staff cardiologist in the Cardiology Department at the Morgagni Hospital in Forlì, Italy. His role at L'associazione nazionale medici cardiologi ospedalieri (ANMCO), a non-profit association constituted by Italian cardiologists, is president of the regional section Emilia-Romagna. Quality registries are not used in Italy as they are in Sweden, they formerly had a Percutaneous Coronary Intervention (PCI) registry on a regional basis during 10 years in Emilia-Romagna but unfortunately because of economic and political decisions it is no longer used since two years. He sees a future for quality registries in Italy, but thinks that it will be a difficult path.

Dr. Filippo Ottani knew of UCR because of the scientific papers reporting on data produced and managed by UCR. He came in contact with UCR through his contact with Professor Bertil Lindahl at UCR, who introduced him to Professor Tomas Jernberg who is the registry holder for SWEDEHEART. The purpose of the initial contact with UCR was to understand how to set up a permanent registry in his Italian region. He visited Professor Tomas Jernberg on his own, as a personal initiative as well as from the former regional president of the ANMCO Emilia-Romagna and the top managers of the regional health system.

Following the contact Dr. Filippo Ottani thinks that the communication has been very useful, however not so profitable for UCR at the moment since they are still in the beginnings of their experience with quality registries and there is therefore a large gap before they will be able to cooperate usefully with UCR. This gap is an identified threat to the collaboration according to Dr. Filippo Ottani. When he came back to Italy after his visit to UCR the contacts have suddenly stopped.

Prior to his visit to UCR, Dr. Filippo Ottani did not know any technical details regarding QReg 5. The goal for the ANMCO's Emilia-Romagna section would be to use QReg 5 for regional quality registries, and not at a national level for the moment. The priority would be a cardiological registry. The ANMCO has not been in contact with other organizations regarding quality registries or technical infrastructures.

B.2.5 Korea - Seoul National University Bundang Hospital

The person that answered the questionnaire was Professor Hee-Joon Bae. Professor Hee-Joon Bae from the Epidemiologic Research Council of the Korean Stroke Society initiated the contact with UCR after having heard about UCR from his colleagues. Professor Hee-Joon Bae also represents Seoul National University Bundang Hospital. Quality registries are just at the starting line in Korea, for example there is The Clinical Research Center for Stroke (CRCS) which has an International journal of stroke. Another example are the AMI registries. However, the most common pattern for improving the quality of care is external audit by the national health insurance review agency, which is causing several problems in Korea. Professor Hee-Joon Bae is enthusiastic regarding quality registries, and sees them as a self-motivated continuous quality improvement for which Sweden is a good benchmark for Korea.

The purpose of Professor Hee-Joon Bae's initial contact with UCR was to visit UCR with his colleagues from the CRCS and AMI registries. The representatives from Korea were medical doctors from the regional cardio-cerebrovascular centers designated by the government as well as government officials from the Korean Center for Disease Control and Prevention. The contact between Professor Hee-Joon Bae and UCR has been positive, and according to him no potential threats to the collaboration with UCR have been acknowledged so far. However, it would improve the contact if the correspondence would be without delay.

Prior to the contact with UCR, Professor Hee-Joon Bae did not know of QReg 5 and even after the visit to UCR he shared that he knows nothing of the infrastructure. His institution uses several quality registries, most of which are developed and managed by the academic societies of Korea, and he thinks that this might be a possibility for which QReg 5 could be used for. The institution has not been in contact with other organizations regarding quality registries or technical infrastructures.

B.2.6 The Middle East - Global Pharma

Global Pharma is a Swedish consulting firm that works with both Swedish and international pharmaceutical, medical devices and other life science companies that want to establish a business in the Middle East/North Africa (MENA region) (Pharma, 2017).

The person who answered the questionnaire was Global Pharma's CEO Paula Hassoon, who has been representing Global Pharma in the contact with UCR together with Raed Suhail also from Global Pharma. Global Pharma came in contact with UCR because of their contact Thomas Jernberg who is the registry holder for UCR's largest registry SWEDEHEART. They therefore knew of SWEDEHEART prior to contacting UCR, however they were not aware of that UCR is responsible for the running of the registry. Global Pharma's intention with contacting UCR was to know more of how they could export Swedish know-how regarding quality registries to the MENA region.

Prior to the contact with UCR, Global Pharma were already aware of that Sweden works with quality registries and that there are different registry centers. Global Pharma had worked with export of know-how from The Swedish National Diabetes registry (NDR) to the MENA region, a registry that Registercentrum Västra Götaland are responsible for, before contacting UCR. When contacting UCR, Global Pharma did not know of QReg 5. However, now that they know of the platform they appreciate that it seems to be working smoother than the system used for NDR. Except NDR and UCR, Global Pharma have been in contact with other organizations regarding quality registries and technical solutions. Global Pharma have not considered developing their own technical infrastructure for quality registries.

The contact between Global Pharma and UCR has been very good and professional, even though it has sometimes taken some time to get answers to e-mails because of UCR being busy, according to Global Pharma.

In the future Global Pharma believe that the whole concept with the know-how from UCR, a well developed IT-system and support make QReg 5 interesting for many countries in the MENA region, especially the Arab states of the Persian Gulf.

B.2.7 Norway - Helse Nord IKT

Helse Nord IKT is a main operations and support organization for one of the four regional healthcare organizations in Norway, they offer quality registries as well as small applications for regional support and a team dedicated to an integration infrastructure. Helse Nord IKT use Open QReg, the precursor to QReg 5, for quality registries on a local, regional and national level, in total 17 registries. The people that answered the questionnaire were system developers Are Edvardsen (no longer an employee at Helse

Nord IKT) and Ketil Holden.

At a registry conference called "Kvalitetsregisterkonferensen" approximately 10 years ago, Helse Nord IKT got to know of UCR. The purpose of the initial contact with UCR from Helse Nord IKT's behalf, was to perform a general inquiry regarding UCR's work on medical quality registries (and not the technology behind it). The contact was initiated by SKDE (Senter for klinisk dokumentasjon og evaulering), under which Helse Nord IKT worked as a partner. SKDE contacted Professor Bertil Lindahl as a first contact at UCR, and at the first meetings with UCR the representant for Helse Nord IKT was Are Edvardsen.

Soon after the first meeting in Uppsala, Helse Nord IKT were requested by SKDE to initate a collaboration with UCR. Helse Nord IKT had also contacted other organizations regarding quality registries and technical infrastructures, and they had one or two registries on another platform at some point. The contact was Hemit IT who had their own platform called MRD, however, this platform was abandoned in favor of Open QReg. They have never considered developing their own infrastructure.

In the early times of the collaboration, the technology became the main task, and there were regular workshops/conferences which were used to discuss the platform and plan for further development. The communication was quite frequent at that time, however, a lack of system support made most of the contact possible through e-mails and chat programs. Ketil Holden mentioned that concerning the communication today it is harder to get personal and timely support, however, there is a better system support.

Initially the collaboration worked out very well. The main threat was the informal nature of the collaboration, according to Are Edvardsen. However, this was also the opportunity and advantage of the collaboration initially. Later, the informal nature might have hindered their ability to collaborate.

The situation for Helse Nord IKT today is that they are using Open QReg 4, and since there has not been any regular contact they do not know much about the new platform. Helse Nord IKT have been shown some demos of QReg 5, and have had short informational talks but no more than that. Ketil Holden believes that this is caused by a lack of interest from managers from Helse Nord IKT, and he mentions that this might be the same situation at URC as well. It is hard to get the time without support from management both at Helse Nord IKT and at UCR. An improvement suggestion that

Ketil Holden mentions would be to have regular meetings, in order to keep everyone informed and not find out about critical releases too late. It even seems that UCR either forget, or are too busy to bother to talk to Helse Nord IKT, which is a shame since it usually works quite well when UCR are present.

Helse Nord IKT are interested in working with QReg 5 instead of Open QReg, and have talked with UCR about this on several occasions but because of a lack of support on a managerial level this has not been followed out. Except the lack of support, Helse Nord IKT have also experienced a lack of resources as well as being understaffed, and they have therefore been busy enough with existing registries. Another possibility for the collaboration mentioned from a technical point of view would be a cooperation for a common benefit, where Helse Nord IKT would not only receive help from UCR, but they could also develop the code on their own to some extent while UCR would remain in control.

B.2.8 Uganda - Uganda Heart Institute

The person that answered the questionnaire was Dr. Michael Oketcho, a consultant cardio-thoracic surgeon, Head of Paediatric Surgery at the National Heart University in Uganda. His centre is a part of the Paediatric International Quality Improvement Collaborative (IQIC) online registry, an initiative at the Boston Children's Hospital, which is a powerful data analytical tool.

Dr. Michael Oketcho has learned about the advantages of registries from his visit to Uppsala University/UCR. Nor prior or after the visit, did he know of QReg 5. He believes that the set-up of infrastructure/software may be a challenge.

Dr. Michael Oketcho describes the communication between the Uganda Heart Institute (UHI) and UCR as good, sporadic activity yet as the stage is set for more definite collaboration. He describes the collaboration between them as a work in progress, which is still in its infancy. A possible threat to the collaboration according to him would be the lack of funding, this is the main challenge as funding is needed in order to create the registries. Dr. Michael Oketcho has no improvement suggestions regarding the contact with UCR.

In the future Dr. Michael Oketcho sees the possibility of national quality registries in Uganda, however, he believes that they will probably be institutional initially and that

it will take a very long time for them to be established. National registries are likely to take a very long time, according to him. It would be easier to start with something like a heart registry, since there will not be many centres offering cardiac intervention for a while. He further indicates that a birth and death registry would be the easiest to start nationally, when the back bone of the national identity card is well set. The UHI has not been in contact with other organizations regarding quality registries or technical infrastructures.