Appendix 1.1:

The Swedish e-Health Landscape Surrounding the SRQ Registry

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Abstract

The purpose of this appendix is to provide: (a) an overview of the Swedish national e-health landscape and the legal infrastructure that supports it, (b) an introduction to the Swedish quality registries and a technical description of the Swedish Rheumatology Quality (SRQ) registry, and (c) a summary of the SRQ integration with electronic health records (EHRs) and other health information systems.

Sweden has a well-developed health information technology infrastructure with 100% EHR use in primary health care, hospitals, and psychiatry; more than 90% e-prescription rate; and around 104 national quality registries, among which the SRQ leads in terms of innovative e-health services, patient-centeredness, decision support functionalities, information technology (IT) development, and integration efforts.

The SRQ registry is comprised of three modules (patient, clinical, and national) that reflect the underlying IT and legal infrastructure, and most importantly the different needs of the end-users (patients, providers, researchers, and decision makers). The SRQ registry is integrated with one of the six leading EHR systems operating in Sweden, covering 24% of the Swedish population.

Many of the developmental and integration challenges that the SRQ registry has faced are applicable to the context in the United States. It is therefore worthwhile to explore the Swedish national and local efforts for having a modular approach in building registry services, the use of standards, defined information structure and terminology, and using service platforms for vendor-independent integration.

After reading this appendix, we invite the reader to consult Appendix 2, in particular Exhibit 2.6 and Exhibit 2.7 where the challenges and opportunities for adoption of the SRQ approach in the United States are elaborated along with the priority areas for advancing the existing health information technology infrastructure.
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1. National E-Health Landscape

Sweden together with the neighbouring Nordic countries lies in the forefront when it comes to using informational technology (IT) in health and social care. The use of EHR in primary health care, hospitals and psychiatry has reached 100% coverage in 2012\(^1\), the rate of e-prescribing is more than 90%\(^2\), there are 104* national quality registries and the government is seriously committed to providing citizen oriented e-health services (access to electronic health records, national health care contact portal, personal health account, etc.). Knowing the national e-health landscape is paramount to understanding the context in which the quality registries in Sweden function and advance.

Sweden is administratively divided into 21 county councils and 290 municipalities; and the healthcare system is decentralized and organized on three levels: national, regional and local. The municipalities (local level) are accountable for the social services and elderly care whereas the county councils (regional level) are primarily responsible for planning and organizing healthcare including e-health services. They rely on county taxes and government grants for funding. The central government can, by deciding on financial incentives, promote and support important activities that aim to overcome Sweden’s main challenge in the e-health area: providing interoperable solutions between different care providers and across regional borders. Accordingly, the National Board of Health and Welfare (NBHW) and Swedish Association of Local Authorities and Regions (SALAR) have agreed on a National Strategy for e-health.

1.1. National Strategy for E-Health

The National Strategy for E-Health (first published in 2006 and revised in 2010) is a key document which formulates Sweden’s vision for IT development in health care and social services. The strategy\(^3\) aims to create visible and concrete improvements for three main target groups: the individual, the health care and social services professionals, and the decision-makers. Six action areas were also identified as requiring strong national commitment:

- Bringing laws and regulations in sync with increases in data exchange.
- Creating common information exchange rules for data interoperability in health care and supporting CEN/ISO EN13606\(^4\) standard to create a European standard similar to HL7 (HL7 v3)\(^5\).
- Creating a common technical infrastructure for communication, an electronic directory of users and organizations, identification of health care providers, and infrastructure for security and access control.

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* 79 quality registries in routine operation and 25 in planning or pilot phase; both types received government funding in 2014.

† The CEN/ISO EN13606 is a European norm from the European Committee for Standardization (CEN) also approved as an international ISO standard. It is designed to achieve semantic interoperability in the electronic health record communication.

‡ The Health Level Seven Version 3 (HL7 v.3) Normative Edition represents a new approach to clinical information exchange based on a model-driven methodology that produces messages and electronic documents expressed in XML syntax.
• Implementing interoperable IT systems for exchanging/maintaining the nationwide EHR framework, administrative support, and drug prescription support.
• Developing the national infrastructure for access to health information across organizational boundaries.
• Making information and services easily accessible to citizens via the web.

1.2. National Technical Infrastructure and Basic Services

As mentioned in the National Strategy for E-Health, one of the most essential precursors for developed e-health is the common technical infrastructure. The infrastructure enables collaboration between counties, municipalities, public or private healthcare providers, and ensures information exchange in a consistent and safe manner. To date, there are six basic national infrastructure services that allow healthcare providers to securely access essential patient data. They are:

1.2.1. Secure IT in the Healthcare Sector (SITHS): Identification Service

SITHS is a national security solution for electronic and physical identification for secure and authorized communication of information. By using the SITHS ID-cards, providers can identify themselves and verify their authorization, independent of organizational and geographical boundaries. In this manner the identity and the legal responsibility of the health service provider during patient data transfer at any time point is guaranteed. SITHS was successfully introduced in all county councils in 2010.

1.2.2. Sjunet: Dedicated, Quality-Assured Network

Sjunet is a robust, dedicated IP-based broadband network that enables electronic communication between Swedish hospitals, primary care centers and many other health care providers. This quality-assured network allows secure communication and transfer of data for more than 100 services such as e-prescriptions, medical images, patient data transfer, etc. Sjunet is built up of nodes connecting the firewalls in the 21 county councils and regions separate from the Internet\(^4\) and supplied by only one service provider that permits a high level of demand. Sjunet’s wide availability forms a basis for the national services for secure communication across organizational boundaries and geographical distances.

1.2.3. Basic Services for Information Management (BIF): Security Services

The security services consist of various services that cooperate in a service-oriented architecture (SOA) to give a uniform secure handling of information transfer between different IT systems in health care. This means full cooperation between services for authentication, authorization, logging, consent and blocking handling and access control. In that manner the legal requirements, especially from the Patient Data Act can be implemented in practice.

1.2.4. HSA Directory Service

The HSA (Hälso och Sjukvårdens Adressregister) is an electronic directory containing quality-assured information about people, their profession and workplace in Sweden’s: municipalities, county councils,
public or private health care organisations. Most of the national security solutions are linked to the HAS service thereby enabling only authorized people to get the information they are entitled to.

1.2.5. Video and Long Distance Meeting: Teleconsultation
This service supports secure, video conferencing that health care providers use in both clinical and administrative situations. In clinical situations it enables teleconsultation for diagnostic or therapeutic decisions involving experts from more than one county council at a time.

1.2.6. Common Service Platform
The service platform represents a pivotal national integration response to the diversity of IT systems and fragmentation of health care data. It is a national technical platform that simplifies, ensures and streamlines the integration between different IT systems in health and social care.

In the last 20 years, the 21 county councils in Sweden have purchased and used many different IT systems. That diversity, the use of proprietary systems, and the lack of standards have impeded the interoperability and made the integration costly and unbelievably complicated. As a response, the central government is building a service platform that will serve as an interlayer to which all systems will connect in a standardized way. Every actor/service that wants to be connected with the platform has to sign a “Service Contract” based on the technical instructions from the Regulatory Framework for Information Interoperability in Healthcare.

1.3. National Information Structure and Terminology

1.3.1. National Information Structure (NI)
The National Information Structure (NI) specifies on a general level what type of information is needed in health and social care documentation. Additionally, it describes how the information should be structured in order to be used in different contexts, for different purposes, in the health and social care process and for monitoring and managing activities³.

The aim is to increase patient and legal security by having necessary and quality assured information available for decision-making and for providing the best health and
social care for individuals carry out follow-ups and comparisons of health and social care interventions and results develop evidence-based knowledge and practice.

NI consists of a process model, an information model and a concept model. The models are prerequisites that all healthcare and social service’s providers use the same information structure in their IT systems. It also serves as the basis for requirements elicitation, development, procurement, adaptation and extension of IT systems.

1.3.2. The National Interdisciplinary Terminology (NF)
The National Interdisciplinary Terminology for health and social care (Nationellt fackspråk, NF) includes nationally agreed concepts and terms as well as international classifications. The National Board of Health and Welfare has identified five integral parts:

- concepts and terms that have been agreed on a national basis and published in the Board’s terminology database,
- statistical classifications and coding systems that have been agreed on a national and international basis,
- the clinical terminology SNOMED CT,
- methods for developing, managing and administering the interdisciplinary terminology, and
- rules for use of the interdisciplinary terminology.

The national efforts around the informational structure and the interdisciplinary terminology have a tremendous importance because they provide the indispensable quality and organization of the information. The efficient and effective information supply in health care and social services relies not only on the technical interoperability of the IT systems, but on relevant, unambiguous, and structured high-quality data. There are several regional and national projects assessing the data from the Swedish quality registries and the compliance to the recommendations from the national information structure and the national interdisciplinary terminology. This work of assessing data before integration with other systems is considered critical.

1.3.3. The National Architecture and Framework

The national architecture and framework for health and social care services deals with a high-level description of which solutions are needed, and how they should be constructed to enable information exchange, regardless of who has access to it or who the information provider is. This requires compliance to several international standards such as ISO/IEC 27001, CEN standard EN13940, ISO/EN13606, HL7, W3C/IEEE, OASIS, IHE, etc. The architecture is delivered in a form of reference architecture and best practices that govern the development of common solutions. There is a Regulatory Framework for Information Interoperability in Healthcare (Regelverk för interoperabilitet inom Vården, RIV) which provides the specifications for design and communication of services to achieve interoperability to enable service-oriented architecture in healthcare in Sweden at national level.
Citizen-oriented e-health services also exist, including a secure national portal for patients to access scheduling, referrals and prescription refill requests (My Health Care Contacts), their medical records (Case Records on the Net) as well as other services which are under development.

1.4. The Unique National Patient Identifier: The Swedish Personal Identity Number

Swedish health care and all national health registers depend on the presence and usage of the national unique identifier: the Swedish Personal Identity Number. It is comprised of the date of birth, a three-digit birth number, and a check digit.

The usage of the Swedish personal number is not limited to routine health care, but rather it is widely used in all public administration, population statistics, education, taxation, passports, income, social security services, etc.

From a health IT perspective, the existence of the personal number greatly streamlines the tracing of patients and their medical records, reduces the risk of duplication errors, and makes referrals and coordination of care much easier. Furthermore, it enables linking of valuable data across the entire national population for research, treatment outcome evaluation and quality improvement. Large-scale, cross-registry data linkages give researchers material to examine a range of questions on, for example, long-term disease consequences, outcomes, direct and indirect treatment costs, associations between medical events and human behaviour, as well as estimations of morbidity and mortality\(^9\).

Of course, registry research has to fulfil the legal and ethical requirements before it is considered from the special authorities that handle register-linkages for health research purposes. The two main authorities are Statistics Sweden and the National Board of Health and Welfare that match and anonymize the data returning it with unique serial numbers instead of personal numbers.

1.5. Important Laws and Regulations

1.5.1. Patient Data Act (2008:355)

The latest update on the Patient Data Act (Patientdatalagen)\(^10\) in 2008 established clear rules designed to ensure secure and efficient handling of personal data while improving patient safety and strengthening personal privacy. The act enables digital access to a person’s EHR by care providers on different levels in the health system, but at the same time, strengthens citizens’ privacy by enabling citizens to determine, upon mutual consent, who is to be given access to their medical records. In addition, the act stipulates the citizens’ right to directly access to their own digital information or electronic record, currently available only in a single county.

Chapter 7 from the Patient Data Act\(^10\) addresses specifically the national quality registers, their goal and safe handling of personal data. The patients control their data in any quality registry and they may opt-out at any time from participation, requesting their data to be removed from the national registry. The
nationally aggregated data may be only used for three purposes – analysis of health care quality, for statistics and research upon permission from the Ethical Review Board.

1.5.2. Other Laws and Regulations

Other important legal regulations are the Personal Data Act (Personuppgiftslag 1998:204)\textsuperscript{11} which deals with protection of personal integrity during personal data processing, and the Public Access to Information and Secrecy Act (Offentlighets- och sekretesslag 2009:400; chapter 25)\textsuperscript{12} which gives provisions on both document secrecy and the duty of confidentiality in health and social care.

2. Quality Registries in Sweden

Quality registries are one of the main drivers of health systems improvement in Sweden. The Swedish association of local authorities and regions (SALAR), the member organization of county councils and municipalities responsible for all care supports the development and maintenance of national quality registries through direct funding and through six Regional Register Centers supporting quality registries with common competencies and infrastructures to increase cost efficiency. They provide services such as patient participation and reporting of PROs, technical consultancy, certification consultancy, analytical work and sharing of best practices in using registry data for clinical quality improvement.

The Swedish government has made an agreement with all care providers through SALAR to invest a total of 220 million USD in the national quality registers during 2012 – 2016. A number of effect goals have been set, amongst them a significantly improved health in 10 large disease groups at the end of the period. A certification system has been set up to increase the standards of quality registries detailing what competencies and deliveries the registries should attain on a scale from 1 – 3.

Among the 104 national quality registers in Sweden, the SRQ registry leads in terms of innovative e-health services, patient-centeredness, decision support functionalities, information technology (IT) development, and integration.

2.1. Technical Description of the SRQ Registry

The Swedish Rheumatology Quality registry can be presented as three modules (patient, clinical, and national) that reflect the underlying IT and legal infrastructure and point to the different core elements and functionalities used by different end-users (see figure 2: SRQ’s three modules)
Appendix 1.1: The Swedish e-Health Landscape

Patient Module

The patient module PER (In Swedish: Patientens Egen Registrering, or Patient Self-Registration/Reporting) is an e-health service that enables patients to:

a) report PROs and PROMs relevant for their disease (e.g. HAQ, EQ-5D, self-assessment of swollen and painful joints, working capability assessment and smoking status).

b) follow their disease activity longitudinally (graphical display of a disease activity over time, as well as particular variables gathered at every clinical visit).

The PER’s graphical user interface (GUI) with accompanying explanation is provided in Exhibit 1: The patient module.

Core features/functionalities of the patient module:

- Enables structured gathering, storing, analysis and visualization of patient reported data. It uses both standardized questionnaires and self-assessment metrics that are generic as well as disease specific for several of the diagnoses in the SRQ.
- Serves as a feed forward system used before visits to the provider.
- Enables longitudinal visualization of the disease activity scores and variables.
- It is built to be generic and it can be adjusted to any disease of interest. The adjustment consists of defining the relevant PROMs and PROs and selecting indicators or disease activity scores of interest.
- Access: the patients can access the PER module via the national secure web portal called My health care contacts (Minavårdkontakter.se) or through a web service on a computer/tablet in the...
waiting room in the clinic. If the patient does not want to, or is not able to enter the data electronically, they are offered a paper version.

- Patients have the freedom to use PER as much as they want between visits to help the self-manage their disease.

**Clinical Module**

The clinical module is comprised of a local SRQ database and a clinical decision support system. It enables organized collection, storage, and analysis of uniform care generated health data in order to inform, evaluate, and improve rheumatology care and outcomes for individual patients and clinical populations. The module is designed to be used actively by health care providers (both physicians and nurses) during a clinical encounter with the intention of supporting outcome evaluation and decision-making (See Exhibit 2). Additionally, the clinical module enables the clinic to have an overview on its care results at the group level and implement continuous quality improvement initiatives locally.

The SRQ clinical decision support system’s interface with accompanying explanation is provided in *Exhibit 2: SRQ Clinical Decision Support System*

Core features/functionalties of the clinical module:

- Graphical longitudinal display of clinical and self-reported variables, lab values, radiology reports, pharmacological and non-pharmacological treatments.
- Contains current and updated diagnostic criteria, guidelines and treatment protocols.
- Allows pulling of data from the patient module: PER.
- The clinical module is integrated with the EHR from the leading provider (EHR name: Take Care; company: CompuGroup Medical) and enables double entry avoidance.
- The clinical module is integrated with other research databases that have specific, more narrow research interest (e.g. TIRA, a study of early rheumatoid arthritis in 11 centres of the SRQ gathering extra research variables at the study visits of patients included after obtaining informed consent.)
- Enables comparison and benchmarking of local performance against regional or national performance.
- Contains a reminder system that alerts the provider when a patient is eligible for biobank sampling. The reminder encloses both an informed consent and a biobank blood test referral.

**National Module**

This national module is a national quality registry database that collects, stores, and analyses individualized data concerning patient problems, health interventions, and treatment outcomes from every rheumatology clinic in the country. The data is used for performance benchmarking, quality of care assessment, public reporting as well as for research and for analyses commissioned by the industry.
2.2. Integration

2.2.1. Integration with the Electronic Health Record (EHR)

The SRQ registry is integrated with the EHR system from the leading provider (TakeCare, CompuGroup Medical-CGM) since 2007. The TakeCare EHR is used in counties of Stockholm, Dalarna and Gotland and it serves 24% of the Swedish population. The integration eliminates the need for double entry and the health care professionals are more willing to use the clinical module for its true purpose: as a decision support tool during the clinical encounter.

In the rest of the country the health care providers have to do a double registration of the clinical visit. There, it has been of paramount importance that the providers see the added value of using the SRQ registry. That added value is the real-time decision support functionality of the clinical module that fosters discussion and optimal decision-making during the visit. Instead of using the registry as a retrospective audit of care it should be used for real-time decision support and continuous quality improvement during clinical visits.

Challenges and national initiatives

It is worth mentioning that there are serious efforts on national and regional level for refining the information structure in the EHRs, in order to secure data quality when a technical integration with other systems is made. The Structured Health Care Documentation project (Strukturerat Vårddata, SVD) in Stockholm gives good directions on how the data in the TakeCare EHR can be structured in templates (following the recommendations from the national interdisciplinary terminology), to be collected and validated before exporting it to the quality registries. On the national level there is the National Program for Data Collection (Nationella programmet för datainsamling, NPDI) that develops methods for more rational transfer of patient data from the EHRs to the quality registries. The goal is to reduce the local technical dependence on IT providers and use the common service platform with a service contract for “reading” of health care data.

2.2.2. Integration with the other health information systems

One of the most important success determinants for a quality registry is its integration with other health information systems (e.g., electronic health records-EHR, personal health records-PHR, laboratory information systems-LIS, radiology information systems-RIS, biobanks, specific research databases, etc.) that results in seamless data exchange. The integration is a crucial contextual factor that can significantly enhance or limit the possibility of harvesting full benefits of the registry-supported care. By integrating the services from all three modules (patient, clinical and national) in the digital ecosystem a synergistic effect is created. Figure 3 illustrates the recommended integration between the SRQ's modules and other health information systems.

The Biobank function is fully integrated with the clinical module.
Currently the SRQ registry is not directly connected with the laboratory information systems (LIS). In the county councils where there is an EHR integration the laboratory results are pushed from the EHR to the SRQ clinical module. Getting the laboratory data is central when making the diagnosis, following the disease activity or making treatment decisions, therefore integration with LIS is highly recommended. Similarly, the integration with the radiology information systems (RIS) for automatic access to radiology reports on joint erosion due to rheumatologic disease is highly desired and not yet available in SRQ. On national level this is planned to be done using the regional or the common service platform.

In 2013, SRQ started a pilot integration between the registry and a biobank in order to stream-down research data (genes and biomarkers) with proven clinical value to both the patient and the clinical module from the registry. The aim is to contribute to individualization and optimization of the care provided. In the same time patients are able to receive their own data, initially donated for research purposes, to be used now for their own care.

Another important direction for the integration efforts is the personal health record. In late 2014, the SRQ will be the first registry in Sweden allowing patients to download all of their registry data (from the patient and the clinical module) into their new nationally provided personal health record (PHR) called HealthForMe (HälsaFörMig).

SRQ has been traditionally connected with many research databases (TIRA- early RA, BARFOT-better anti-rheumatic pharmacotherapy, ARTIS-anti-rheumatic therapies in Sweden, etc.) and thereby, has enabled longitudinal observational studies and frontline rheumatology research that Sweden is famous for. Vollenhoven and Askling provide a good illustration of how the Swedish RA inception cohorts and registries interrelate. The drug cost-effectiveness research and postmarket surveillance is enabled by connecting the registry with the Quality Registry Drug Follow Up (QRDF) health information system. QRDF contains important analyses on number of started and ongoing anti-rheumatic biologic drug
treatments classified per drug product and diagnosis, as well as outcome measures such as mean values of DAS28 and HAQ. It is possible to do search queries on different patient characteristics, prescribed drugs and treatments results with disease activity scores and PROs as endpoints. This service is of extreme importance for the collaboration with the research-driven pharma industry.
Works Cited


**Exhibit 1: Patient module – PER**

In this exhibit we present the graphical user interface (GUI) of the PER module focusing on the most important patient-PER interaction points.

Figure 4 shows the screen where patients using a visual analogue scale (VAS) report their perception of pain, fatigue and global health in the last week.

![Visual analogue scale in PER](image)

*Figure 4: Visual analogue scale in PER*
Figure 5 shows the screen where patients fill in one of the standardized PRO instruments: the Health Assessment Questionnaire (HAQ).

Figure 5: Health assessment questionnaire in PER

Figure 6 shows the screen where patients after performing joint self-assessment indicate which joints on the hands are swollen and/or painful.

Figure 6: Figure 6: Self-assessment of swollen or tender joints on the hands
Figure 7 shows the screen where patients can report other joints that swollen and/or painful.

Figure 7: Self-assessment of swollen or tender joints in the rest of the body

Figure 8 shows the screen where patients fill in one of the standardized PRO instruments: the EQ-5D

Figure 8: EQ-5D in PER
Figure 9 shows the screen where patients see a longitudinal graph of their disease activity (DAS28) score. By using traffic light colors it is easy to interpret if the disease activity score is high, intermediate, low or the patient is in remission. This overview is available after the patient has filled in all the PRO data.
Figure 10 shows the screen with a tabular view of all patient data (self-reported, clinical or lab) gathered on various clinical encounters. Patients have access to the same information that the providers see in the SRQ clinical decision support system.
Figure 11 shows the screen with a tabular view of all prescribed medication type and dosage. Patients have access to the same information that the providers see in the SRQ clinical decision support system.

Figure 11: Provider’s overview of drug treatment in PER
Exhibit 2: The SRQ Clinical Decision Support System

In exhibit 2 we present the graphical user interface (GUI) of the SRQ Clinical Decision Support System (SRQ CDSS) focusing on the most important provider - SRQ CDSS interaction points.

Figure 12 shows the initial screen that can be divided in three areas. Area 1 contains the basic information as patient’s name, diagnosis, disease length and appointed rheumatologist. Area 2 gives a tabular view of relevant patient data gathered before and during a clinical encounter. It contains PROs, lab data (C-reactive protein – CRP and sedimentation rate – SR), clinical joint examination data, medications and calculated disease activity scores (DAS28 and DAS28CRP). The provider can switch from tabula to graphic view (see figure 13). In area 3 there is a window-like menu of additional options: detailed view of treatment, clinical studies, biobank results, adverse drug event reporting etc.

Figure 12: Table view of patient data in SRQ CDSS
Figure 13 shows the graph view of area 2. The provider selects which type of information (HAQ, VASPain, DAS28, DAS28CRP, GRIPPIT) to be graphically displayed and for which time period (6 months, 1 year, 2 years etc.). Under the graph there is a visualization of which medications (i.e. Methotrexate, NSAID-COX1, Prednisolon, Enbrel, Humira etc.), were taken in the same period. In this way the provider and the patient have a cognitive support when evaluating the results from the current treatment and making future treatment decisions.