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Digital innovation platforms in healthcare: What we can learn from the Swedish Rheumatology Registry

CURRENTLY, THERE IS large focus on digitalization within the Swedish healthcare sector. This raise the question of what we can learn from earlier digital healthcare initiatives. The report summarizes research about the self-organized development and implementation of the Swedish Rheumatology Quality Registry (SRQ). The SRQ is an example of a digital platform that has survived for more than two decades. Therefore, it constitutes a unique opportunity to learn from an early digital innovation process. In the report, the dissipative structures model is applied to the development of the register. The SRQ is treated as an example of a digital innovation platform and not a single system. A platform provides a common interface, functionality and data that the users can share in order to advance the development of different services. Therefore, the SRQ shows how digital platforms can serve as a common resource and promote a living health system.

AUTHOR
Anna Essén, Assistant Professor at Stockholm School of Economics, House of Innovation. E-mail: Anna.Essen@hhs.se

THE DEVELOPMENT DID NOT EXHIBIT success factors that organizational change models often list. A professional community drove the development of the SRQ by improvising with the technological, medical and organizational tools available, thereby realizing what strategies were possible

THE SRQ PROCESS SHOWS THAT SYSTEM-LEVEL change is possible when individuals create action space within existing legal frames and resource constraints. This is important given the "we-have-to-wait-for-regulatory changes" or "we-need-more-resources-first" attitudes that permeate the debate about healthcare system transformation today.

STRUCTURAL CHANGES CAN FACILITATE and strengthen self-organized innovation and innovation platforms. Attention needs to shift from specific and predefined e-services to platforms that private and public actors can use. There is a need for long-term efforts to establish frameworks for new ways of making data accessible and for being more open to unpredictable service innovation.

Graphics: Patrik Sundström. *Original:* Gabriella Stjärnborg.

SNS RESEARCH BRIEF | The objective of the SNS Research Brief series is to make research accessible for decision-makers in politics, business and the public sector. Financial support has been granted from the Jan Wallander and Tom Hedelius Foundation. Responsibility for the analysis and the conclusions in the research briefs rests with the authors alone.

This report[1] summarizes research about the self-organized[2] development and implementation of the Swedish Rheumatology Quality Registry (SRQ)[3] from 1993 to 2013. I treat the SRQ as an example of a digital innovation platform rather than a specific e-service or system and I focus on what we can learn from the development process rather than the specific data the registry contains.

Many future scenarios of healthcare describe how we will be able to deliver more preventive and individualized care by analyzing and learning from data. One implicit assumption underpinning these scenarios is that vast amounts of data will be available to users and producers of e-health services through some kind of digital coordination structure—what one may call a digital platform.[4] In contrast to a specific e-service or function, a platform provides shared resources that many different actors can reuse and build on to refine and develop their e-services quicker. For instance, a platform can provide developers access to data and shared development resources. Network effects characterize successful platforms because the platform's value increases with the number of users (both producers and end-consumers). The question is: What can we expect in terms of the development of platforms that enable and facilitate such accumulation and use of data? What can the innovation of such platforms look like, and how can such processes be facilitated?

Digital platforms make it easier to learn from data and improve future healthcare.

The SRQ is one of Sweden's several national quality registries (see Facts 1). It was introduced in 1995 and is still used and relevant in 2019. It continues to accumulate data, amounting to 75,000 patients in 2019.[5] A majority of rheumatologist specialists in Sweden and other healthcare professionals, such as occupational therapists, physiotherapists and nurses, use the SRQ. Further, patients, researchers, clinical managers, governmental authorities and pharmaceutical firms access the registry. Thus, the SRQ ties together all these actors and enables them to develop new services based on the registry as a common resource. This has produced system-wide changes in rheumatological clinical practice, research and governance. Studies have shown that the SRQ use has produced new interaction patterns between patients and physicians; new care planning and delivering methods; new ways to organize, execute and implement research; and new ways to monitor and compare rheumatology care at aggregated levels.[6] The SRQ can therefore be understood as an early and successful example of a digital platform for service development, successful in terms of its user loyalty, degree and scope of use and the change it has produced.[7]

This report is based on qualitative studies of how one of Sweden's quality registries (i.e., the SRQ), has been developed and used over

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[1] Thanks to Andreas Hager and Staffan Lindblad, initiator and previous registry holder of the SRQ, for helping me to critically evaluate the research results in relation to today's development projects. Elin Lindblad, project leader with experience in leading projects tied to the SRQ, Anna Krohwinkel, research manager, Leading Health Care, Ralph Nisell, the SRQ's current registry holder, Sofia Ernestam, Manager, academic specialist center in Stockholm county, and previous registry holder of the SRQ, the SRQ administration members and the SNS reference group have also contributed valuable insights. Thanks also to Gabriella Chirico Willstedt for excellent help in clarifying the messages.

[2] I use the term *self-organized* to emphasize that individuals organized themselves "voluntarily"; they created coordination structures without orders from higher levels in the organizational hierarchy (e.g., through policy interventions). However, the term *self-organization* does not mean an actor does everything "herself." I also use the term *distributed* to show that many groups participated in the innovation process over time, again illustrating that it was about something other than centrally controlled processes, which is typical for digital innovation of greater scale (Yoo et al., 2012).

[3] The SRQ was initially labelled "the Rheumaregistry."

[4] On a technical level, a digital infrastructure can be defined as the underlying hardware functionality—server, storage and network—that provides power to a platform. A digital platform is defined as the software functionality the various modules that are built "on" the platform share. Shared functionality can include programming and exchange services, such as libraries, application program interfaces (APIs) and service development kits (SDKs). The platform thus also includes the interfaces through which the modules interact. The platform and its modules together form an ecosystem. I use a broader definition, wherein the platform refers to common resources that, in addition to software, include accumulated data and legal/regulatory agreements, as well as shared norms and values. Modules can here be seen as user groups/app developers who develop new components, services and working methods that use the common platform functionality and contribute to the expansion of the shared capacity (Tiwana et al., 2010).

[5] The SRQ was used by 150 employees at 65 clinics in all Swedish county councils/regions in 2018. The cumulative number of patients who used the patient's sElf registration (PER) to enter health data in 2017 was 54,880.

[6] For more details of the consequences of the SRQ, see Essén and Lindblad (2013); Essén and Sauder (2017); Ovretveit et al. (2013); and Edenius et al. (2012).

[7] Compared to other digital innovation platforms such as Google, the SRQ has evolved slowly. I leave it to the reader to judge whether that is positive or negative.

Fact box 1: National quality registries in Sweden

The SRQ is one of many Swedish national quality registries. A national quality registry “includes individual data about problems, measures taken, and their result in health care. A national quality registry is reviewed and is certified by the national steering committee for quality registries.” [1]

In 2017, 96 national quality registries and 12 registry candidates received financial support from the Swedish state and regional governments. All registries send reports and renewed applications for financial support each year to the national steering committee for quality registries. In return, the committee provides suggestions about how to improve the registry.

Sweden also has a number of other local, regional and national quality registries that are not financed by the state.

The national steering committee for quality registries in Sweden has defined a vision of national quality registries as “to save lives, achieve equal health and they are to be used actively for monitoring, and quality development.”[2]

Much medical, epidemiological and health economic research uses data from quality registries in combination with other registries. Registries are also used to conduct observational studies, monitor long term effects of treatments and capture nonspecific adverse and side effects. These studies have high external validity because they are conducted in the clinical context and routine practice rather than in controlled environments. However, quantitative research about the effects of quality registries on patient health and costs is scarce. It is difficult methodologically to evaluate what changes are attributed to the quality registries per se, not least because it is difficult to find control groups. This challenge ties to investments in new documentation and data-generation initiatives generally. [3]

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1. www.kvalitetsregister.se [author’s translation]
2. See further http://kvalitetsregister.se/tjanster/omnationellakvalitetsregister/framtidenskvalitetsregister. 3239.html [author’s translation]
3. Thanks to Thomas Schneider for suggesting this aspect.

time. I focus on the SRQ’s innovation process rather than its attributes in comparison with other registries. The SRQ’s development, however, exhibits patterns found in other registries as well—in particular, in registries used not only for research, but also by different actors to develop multiple stakeholders in healthcare systems. Just like the SRQ, those registries have moved from offering a certain service (for instance, access to data for research) to providing a platform that can be used to develop multiple services.

This report discusses the results of several studies on how health professionals in Swedish rheumatology (hereafter referred to as *health professionals*), in collaboration with other actors, developed the SRQ in a self-organized and distributed, rather than top-down, manner. I focus on the innovation process rather than strengths or flaws in the SRQ system’s functionality. The study builds on previous research about complex adaptive systems. This research stream suggests that societies and communities can organize without the governance of one central controller or manager in a traditional sense.[8] In Section 1, I account for how the SRQ was developed and implemented, drawing on published research. In Section 2, I discuss implications for the future development of digital platforms in healthcare.[9]

The innovation process of the SRQ is the focus in the report, not strengths and weaknesses of its functions.

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[8] Chiles et al. (2004); Plowman et al. (2007); Prigogine and Stengers (1984).

[9] Essén and Lindblad (2013). The paper builds on interviews ($N = 67$) with individuals who developed, used or funded the SRQ (e.g., rheumatologists, occupational therapists, government and business representatives); observations from more than 100 formal or informal meetings and seminars where the SRQ was presented and discussed; and document (minutes from the SRQ’s steering committee and annual reports 1995–2013) analyses. More detailed method information can be found in the article.

The innovation and implementation process

The development and implementation of the SRQ did not involve implementing an external or off-the-shelf informational technology (IT) system. Nor did the process exhibit success factors that organizational change models often listed, such as:

- Begin with a clearly defined aim,
- Anchor your aim and get support and financing from your organization's top management,
- Operationalize how to attain the aim in terms of a sequential plan, and
- Execute the plan and monitor the degree to which your initial aim was attained.

The development of SRQ did not exhibit traditional success factors.

The SRQ process did not correspond with the ideal or golden standard model for how to implement new medical innovations, which is performing randomized controlled studies that test predefined hypotheses about what effects a certain innovation will generate and for whom. According to that model, innovations would be implemented only if there were proof of their superiority. My point is not that these implementation models are wrong—rather, that there may be additional ways to consider implementation in the context of digitally enabled organizational innovations.

A distributed and unpredictable innovation process

The SRQ can be viewed as an innovation that was continuously created during the implementation process in an unpredictable way. One article refers to the process as emergent and as an example of change from within.[10] This is because a few rheumatologists initiated the SRQ and initially used it on a small scale at the clinical microlevel. The registry, however, then was reshaped continuously, which resulted in comprehensive changes at the system-wide level thanks to vertical and horizontal interactions between several healthcare stakeholders over time. The interactions were neither initiated by—nor initially receive financial support from—formal management levels at hospitals and regional governments. Rather, the interactions resulted from several individuals and groups creating agreements about how to use and contribute to the SRQ.

For this reason, it is difficult to identify who is to "blame" or "thank" for the SRQ. Some groups and individuals certainly had more influence over and insight into the process than others. A few individual rheumatologists played a key role by driving the process, particularly in its early stages.[11] However, overall, the process was far too distributed and complex for a single actor to control or micromanage. This includes me as a researcher: The portrayal I provide here is but one among many possible ways of summarizing the SRQ story.

What, then, caused more actors to join and then contribute to the maintenance and continuous refinement of the SRQ? From my view, the motivation to use data included the strive to understand rheumatoid disease and better treat it (by patients, different professions within the rheumatology specialty and researchers), strengthen individual and the specialists' status (by rheumatology professionals), sell more effective pharmaceuticals (by the life-science industry), and assume responsibility for equal and safe rheumatology care (by governmental authorities at national and regional levels).

At a more general level, I believe the inherent strive among human beings to do their jobs as well as possible, build their careers, show progress and take care of their health continuously a little more and a little better each day, and the fact that technical, legal and social structures are flexible, changeable, and usable[12]—if only we treat them as such, drove the process. Against this background it is relevant, if difficult, to articulate how such change poten-

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[10] Essén and Lindblad (2013).

[11] The rheumatologists who introduced the register and were the register holders played a critical role in the beginning by strenuously traveling and talking about the register to mobilize interest in it and raise funding for its initial development. This confirms the importance of a change champion, which research often emphasizes. Note, however, that this is not enough. The SRQ shows not only that the initial creator spurs an innovation to gain momentum and start living its own life, but also points at the importance of the followers, who in turn recruit more followers. This is critical for the momentum to survive over time.

[12] The assumption that normative expectations can be treated as "resources" is discussed in several research streams, for instance, about institutional logics (Thornton et al., 2012).

Fact box 2. Complexity theory

It is widely agreed that healthcare systems are complex.[1] Among the many streams of complexity theory,[2] the majority emphasize that complex systems (sometimes called complex adaptive systems) contain many agents (e.g., individuals, organizations, technicians) who interact unpredictably. One may describe a complex system metaphorically as a house with many doors between the rooms that open and close in unpredictable ways—sometimes leading to permanently opened, removed or new doors. It is further impossible to close the main door between the house and its surroundings. This makes it difficult to control the creation of new structures and behavior patterns in complex systems ”from top to bottom”—that is, from a central function outward into every agent and relationship. Instead, all levels of complex systems are characterized by a self-organized, emergent order (pattern or structure) that results from individual activities and interactions at lower aggregation levels. Individual agents, acting in accordance with their aims and local knowledge and adapting to what others do, create the order.

I use a certain self-organization model—the dissipative structures model[3]—that I refer to as the Model. The Model was developed through studies of the emergence of structure and order in several disciplines and in different empirical contexts.[4] According to the Model, order in complex systems can be seen as a structure that emerges when the system is far from equilibrium (balance, rest) and when energy is constantly injected into it (compare: the doors must open).

According to the Model, self-organization takes place through four mechanisms. First, fluctuations (shocks, changes outside the norm or the usual) inject energy into systems by triggering interactions between individuals and organizations (running through the doors). These activities move the system towards new directions that deviate from the existing order. Second, activities amplify deviations that bring the system closer to a new order. New structures emerge as the many agents react to what others are doing. This is possible due to all the links among the agents. Third, the agents and resources in the system are recombined and coordinated in a way that stabilizes a new order and increases the system’s overall capacity. Fourth, this type of coordination is based on deep structures—what I call values—that control the activities of the collective. They slow the amplifications and prevent the system from going into total chaos.

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[1] Plsek and Greenhalgh (2001).

[2] Bedau and Humphrey (2008).

[3] Chiles et al. (2004); Plowman et al. (2007); Prigogine and Stengers (1984).

[4] Prigrione developed important parts of the theory about dissipative structures. He was awarded the Nobel price in chemistry 1977 thanks to his work about how order emerges in thermodynamic systems that are far from equilibrium. The theory has been used in many disciplines, including control theory, quantum mechanics, etc.

tials are used and realized or manifested in different concrete activities, methods or interactions that carried the innovation process over time.

How can we describe the innovation mechanism actualized more than two decades ago (and that still exists)? In this report, I use complexity theory (Fact Box 2) to highlight four aspects—I refer to them as *drive forces*—that characterized the process, according to my research. The four forces, identified in previous research about what mechanisms drive self-organized processes,[13] are fluctuation, amplification, recombination and stabilization. This is obviously a brutal simplification of the process.[14] However, I argue that these forces are

Four aspects – or drive forces – that characterised the innovation process.

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[13] Chiles et al. (2004); further see Plowman et al. (2007) and Prigogine and Stengers (1984).

[14] See further Ovretveit et al. (2013) and Edenius et al. (2012).

relevant to discuss because, although research has shown they are fundamental to self-organized innovation processes, they are not given enough attention in today's policy discussions.[15]

I refer to these four mechanisms as *driving forces* and show how they can be interpreted in the case of the SRQ in the first part. In other words, I apply the Model and its abstract theoretical concept in a certain empirical context in the following sections.

1. Absorbing fluctuations

The initial innovation and how it produced additional innovation over time. The idea to develop a national registry in rheumatology was initially presented by a rheumatologist physician and researchers at a national meeting for the Swedish Society for Rheumatologists (SSR), the professional association of rheumatologists, in 1993. The idea came from a local research initiative but had a national ambition. The aim was to achieve a standard way of documenting results among rheumatologist physicians, which in turn would generate a common data resource useful for research and thereby extend knowledge about new forms of therapy. The SSR approved the idea, and the rheumatologists collaborated with a small IT firm to develop a digital system for health outcomes documentation from 1995 onwards. Development funds from the Swedish Association of Local Authorities and Regions (SALAR) financed the initial development of the registry.[16]

New forms of therapy were crucial for initiating the innovation process.

Why did the idea emerge in 1993? Rheumatology care then faced a paradigmatic shift due to introduction of new medical evidence that could potentially produce radically improved health outcomes. New aggressive forms of therapy in the 1980s generated both hope and uncertainty regarding the consequences of the new therapies. The registry initiators presented the SRQ as a concrete way to respond to the new possibilities. Thus, they tied the registry to a vision that attracted the rheumatologist community.

Multiple medical, technological, financial and political events and developments beyond the daily practice of rheumatology created instability within the rheumatology specialty over time. Note that the rheumatologists *used* or transformed these fluctuations to introduce changes in the functionality of the SRQ. For instance:

- The introduction of new biological drugs fueled the development of new functionality allowing documentation of side effects in the SRQ. This turned the SRQ into a valuable resource for the life-science industry, which needed to report such effects to national and international authorities. Thus, the life-science industry provided financial support to develop the new functionality.
- Internet technology was used to develop a web-based solution for the SRQ in 2001. The new version enabled real-time interaction between physicians and registry data. Physicians received a longitudinal overview of the patient's disease during the patient encounter. The registry thereby was extended with a decision-support module for daily care (complementing the previous research functionality).
- Ideas and rhetoric about patient as a co-producer, patient empowerment and patient involvement were operationalized in the development of the Patient sElf Registration (PER) service. The PER allowed patients access to their health results over time and enabled them to participate in the formal documentation of their own treatment results. The SRQ thereby gained yet another module and purpose: to enable new ways of patient interaction.
- The debate about Sweden's declining rank in global research investments and patent comparisons were transformed into a problem the SRQ could partake in solving. The SRQ received the formal assignment and funding to develop organizational, technical and legal arrangements to collaborate with industry and to develop general modules of rheumatology-specific functionality. It thereby was extended with new modules allowing industry collaboration and scale across specialties.

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[15] Chiles et al. (2004); Plowman et al. (2007); Prigogine and Stengers (1984).

[16] More specifically, this was then the county council association, which later has merged with municipalities. Together, they today form the Swedish Association of Local Authorities and Regions, SALAR.

The SRQ process illustrates how practice drives change, triggered by concrete innovations (new drugs, new technology) that interact with more abstract or intangible energies (new ideas, theories and political visions). By transforming these external fluctuations into new functionality in the SRQ, the registry maintained its relevance over time.

2. Self-organized amplification: Focusing and expanding the innovation

The innovations that the fluctuations initiated were allowed to develop and scale further in various ways. Following are examples of how rheumatologists extended the innovations in a distributed and decentralized way, which *extended* the innovation process (*pull)*:

- New measurement instruments and a variety of tools to analyze and present information. Rheumatologists and other professionals, such as physio- and occupational therapists, initiated self-organized research that identified new measurement instruments and a variety of tools to analyze and present information that could be used to evaluate new dimensions of patients' health. At first, the instruments were used locally in research and care improvement, but then were incorporated into the national registry.
- New ways of using the SRQ and new service process designs. Health professionals, who identified new ways of making decisions at individual patient meetings, locally discovered new ways of using the SRQ and new service process designs. One example is the rheumatology clinic in Gävleborg, which on its own initiative started using the SRQ to monitor patients remotely and thus save staff time. The clinic also changed their remuneration practices for nurses so that nurses could replace doctors in the new healthcare model, which led to increased access for patients.
- Exchange of knowledge about new instruments, functions and ways of using the SRQ occurred through voluntary meeting forums, such as local rheumatology meetings and other informal forums.
- Work-arounds and work-in-parallel with regulations. In an example of work-arounds, it had been considered illegal for patients to submit self-reported data into medical records when the PER was introduced in 2003. Some rheumatologists solved that problem by allowing patients to record data in a separate module, which the doctors then imported. Thus, PER became "legal."

Factors that focused and extended the innovation process.

The rheumatologists also deliberately incorporated certain forms of centralized control. Such activities strengthened the process by *focusing* rather than expanding it (*push*):

In 1995, SSR members voted for a *central coordination function*—that is, a steering committee and registry holder who would be responsible for the SRQ's maintenance and development.

- The steering committee created incentives to increase the number of users. They succeeded in encouraging the Dental and Pharmaceutical Benefits Agency to make it mandatory for rheumatologists to document their use of new biological drugs in order to receive a license to prescribe them. Because the registry was a documentation tool, this requirement became an incentive to use the SRQ.
- The steering committee also facilitated SRQ use by offering courses in the SRQ for rheumatology staff (doctors, nurses, secretary, occupational therapists, physiotherapists, etc.). The pharmaceutical industry financed the courses through innovative but regulated contracts; thus, the courses could be offered free of charge to the clinic. The courses were conducted at the clinics, which made it easy for staff across the country, regardless of their location, to attend. The courses were also accredited by IPULS (a formal course accreditation agency), which provided the staff additional incentive to participate.
- The steering committee focused on users, leaving non-users be. They centered on the early users (early adopters) to create an early majority, allowing the remaining rheumatologists to join the SRQ when they were ready.

The combination of activities that both expanded and focused the process helped a majority of Sweden's rheumatologist health professionals to start using the SRQ over time. They used it as a database in their research to contribute to new insights and guidelines at the macro level. The rheumatologists also registered—and let their patients register—data into the SRQ and used the SRQ to support decisions during individual patient encounters. This, in turn, meant a continuously growing amount of data, which increased the platform's value for research. The different modes of use—that is, different user groups—thus created conditions for each other. This scenario is typical of platforms that have two markets—service developers provide services based on the data, and service users contribute data and consume the services.

3. Recombination

Technical recombination. The continuous development and diffusion of the SRQ could potentially lead to an endless need for new resources. However, the rheumatologists managed to create resources by integrating the SRQ with existing services and systems and making it available through channels that already existed. In this way, they succeeded in scaling up the SRQ with limited resources. That is, they made the SRQ useful in new ways and for new user groups without dedicated investments from hospitals, county councils or national units. Some examples of how the rheumatologists created leverage on the SRQ's modules include:

The SRQ was integrated with existing systems.

- Integration between the SRQ and the Take Care electronic medical record (EMR) system in 2010 enabled physicians to export data from the SRQ to the EMR. The integration was funded by Karolinska Hospital, Take Care and SRQ.
- Integration between PER and the regional/national patient portals, "My healthcare contacts," and later the citizen portal, "www.1177.se," enabled patients to use PER from home. The integration was financed by SRQ, which had funds from SALAR and applied for other project funding as well as funds from business partnerships.
- Integration between the SRQ and other Swedish databases (e.g., the national drug registry and national patient registry) was made possible technically. Procedures to allow researchers access after the patients' informed consent and ethical committees' approval were also developed. The integration was financed by research funding and commission payments from pharmaceutical companies.
- Compilation of results for managers at the clinic level was funded by SRQ.
- Opening parts of group-level SRQ data for the pharmaceutical industry through innovative but regulated contracts avoided any industry impact on the research. Research funding and commission payments from pharmaceutical companies (QRDF Quality Register Drug Follow-up) funded the release.
- Opening parts of the SRQ data for National Board of Health and Welfare (NBHW) and SALAR, who incorporated the aggregated results in the Open Comparisons (which compare regional performance across Sweden) was financed by SRQ through funds received from SALAR.

The above examples imply that the SRQ became increasingly accessible to clinically active and researching professionals and their patients. Because the SRQ's functionality and content were divided into different modules and layers, which could then be recombined, the SRQ could also become a resource for new user groups, such as clinical managers, the pharmaceutical industry and national authorities.[17] An important prerequisite here was the data-sharing agreements—new user groups received access only to aggregated data. These carefully drafted contracts with the pharmaceutical industry further implied that the industry could not affect data collection and research.

Expanded use of the SRQ meant that the overall innovation capacity in Swedish rheumatology grew because more users and new partnerships meant more data analysis, discovery of multiple relationships and new input on how rheumatology could improve from the medical and organizational perspectives. Collaboration with external stakeholders, such as the IT firm, the pharmaceutical industry and national

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[17] Lindblad et al. (2017).

authorities, were key for this multi-actor learning.

*Redefinition.*The SRQ administration and various users also re-created the SRQ linguistically over time. Several definitions of the register existed at the same time—some in conflict with each other. However, the multiple SRQ users could shape their own view of what the SRQ was; thus, they could be attracted to, contribute to, and use SRQ data, which in turn enabled the SRQ's expansion. Examples of different SRQ definitions include it as a:

- research database
- decision-making system
- tool for reorganizing healthcare
- monitoring system for national authorities
- self-care system
- patient safety system
- "post-marketing drug surveillance service package"
- collaborative platform
- register-based learning network
- resource to strengthen Sweden's competitiveness and create jobs
- system for value-based healthcare
- new rheumatology
- new standard for cross-sectorial collaboration and innovation
- fast-acting (instant) and slow-acting quality register

Some rheumatologists also used the power of rhetoric strategically by intentionally presenting the SRQ in different ways to different target groups.[18] The SRQ's services, for example, were introduced in some contexts as tools to provide "safe, traditional, evidence-based medicine," and, in others, as tools to achieve "patient involvement and radical change of roles in care." The SRQ was thus sometimes presented as a means to continue working as before, just a little better and safer, as well as a means to work in completely new ways, as a new model of care—depending on what the rheumatologists thought would attract the audience. This, in turn, led many actors to perceive the SRQ as legitimate and worthy of support and attention over time.

4. Values: Providing stability and continuity

In 1993, the SRQ's initiators did not predict the way in which the SRQ would be developed and implemented (see the overview in Figure 1 , p. 10). However, shared values stabilized the process over time. Those shared values contributed a foundation,[19] served as reference points and provided a sense of continuity. Some values, such as the beliefs in change from within, preserving professional autonomy and strengthening the profession, were preserved. The idea of creating improvement at the micro *and* macro levels was also important over time: The goal was to create more knowledge to improve patient health at every patient encounter *and* to advance rheumatology research in the long term (see Figure 1 for both clinical and research perspectives). Other values moved over time. Fundamental assumptions about what roles patients and the pharmaceutical industry could and should play in healthcare, what evidence actually was, how quality improvement should be defined and what is included in the rheumatologist's professional responsibility began to expand.[20] This suggests that the development and use of the SRQ not only shaped, but also was shaped by, an institutional change—namely, a change in what was considered proper, justifiable and worth pursuing.

Some values had a stabilizing effect, while other values changed over time and led to further development.

Lessons for the future

The SRQ's development shows how a practice-driven, self-organized innovation process can be scaled up to a platform that provides common resources for a large number of different actors in healthcare. What can we learn from it in relation to the future development of digital platforms in healthcare? In this section, I present some implications from the results reported in the preceding section.

What does the SRQ tell us about development of digital innovation platforms, and how can we facilitate such processes?

Use of fluctuations

Policy interventions, deliberately introduced

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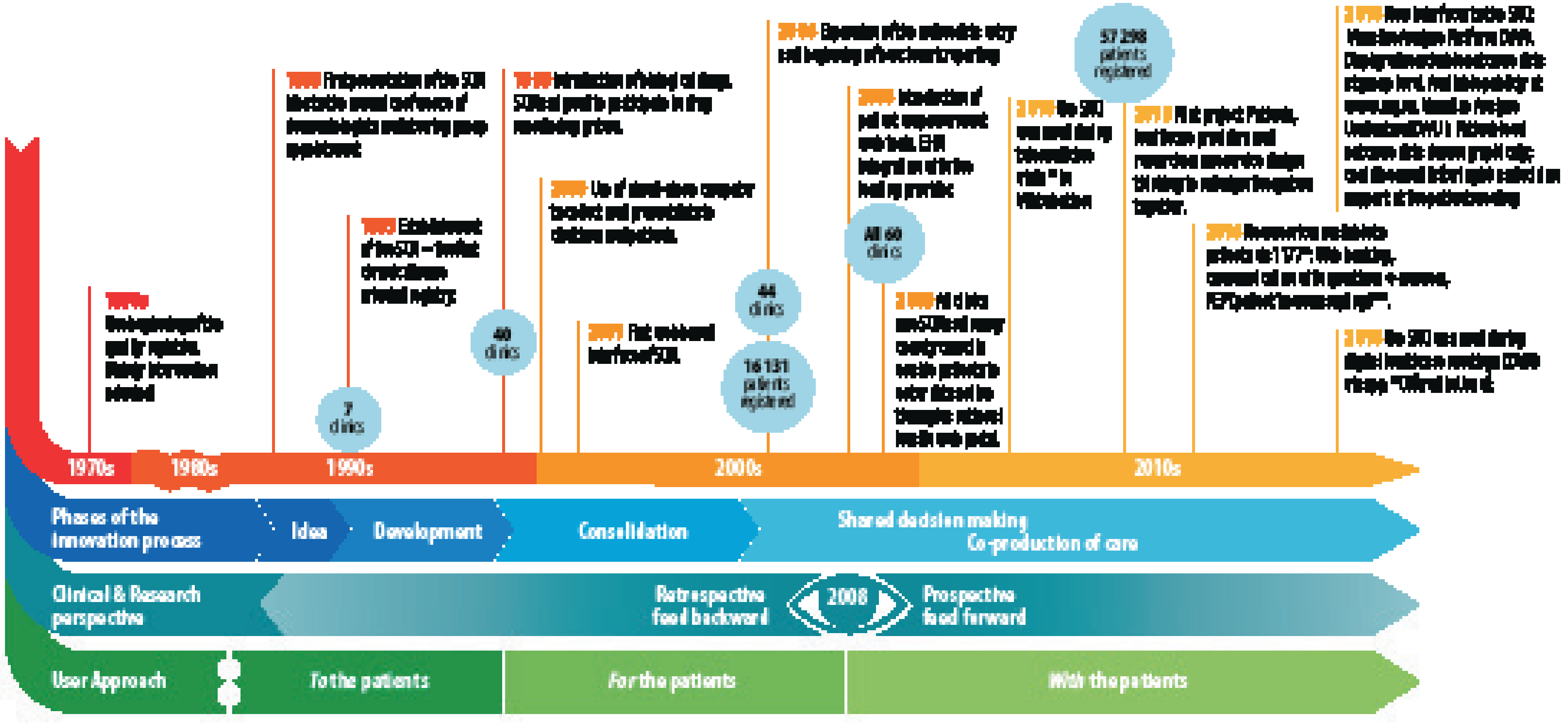
[18] Essén and Winterstorm (2018, 2019).

[19] Normann (1993).

[20] See also Essén and Winterstorm (2018, 2019).

The Evolution of The Swedish Rheumatology Quality Registry Approach



*Service was not offered via the SRQ.
**PEP was introduced in the county of Stockholm. It is however a generic service that can be used in other counties and for other specialities than rheumatology.

Figure 1. Selective overview of the SRQ’s development over time.
Note: Elena Eftimovska developed the image of the SRQ in 2015. The SRQ Office helped with updates of the picture with the events after 2013. Many new instruments and modules have been added to the registry; thus, this accounted for only a sample. Also note that some e-services after 2013 (marked with *) are not offered via the SRQ but are used in combination with the SRQ.

to influence the SRQ, such as earmarked funds or new IT-related goals at the clinic or regional levels, did not trigger the SRQ's developments primarily. Rather, fluctuations, such as new medical and technical opportunities, triggered the innovations. By combining new medical opportunities with technological and organizational innovations, rheumatology succeeded in reaching new capacity levels. This was possible thanks to the cross-sectorial but regulated contact areas, not least to the pharmaceutical industry, that individuals created.

The SRQ was initiated when rheumatology care was facing a paradigm shift similar to what is happening in many more diagnostic areas today: the introduction of biological drugs that create new possibilities for radically different disease trajectories. New technological developments, including smaller sensors, batteries, better analytics apps and new infrastructure and platform technologies such as 5G and blockchain, further create new opportunities to collect, share and learn data today. The SRQ and other quality registries in Sweden are attempting to use such fluctuations to speed the safe introduction of new drugs and create new medical evidence. Patients are further struggling to develop their own platforms—patient-driven registers—for data collection and learning.[21]

However, transforming medical and technological opportunities into concrete new e-services is not easy. It requires interdisciplinary knowledge and the rotation of individuals across medical, organizational, legal and technical worlds. The convergence between mechanical, digital and medical technologies also will create new demands on interdisciplinary expertise. It is difficult to imagine that such competence can develop in ways other than collaborative forms, such as coalitions or alliances involving various public and private actors in the healthcare system. Cross-sectorial digital platforms that offer common resources to develop new digital services could accelerate innovation here.

Amplification

New functionality and new ways to use the SRQ emerged because a large number of nursing staff, patients, researchers and pharmaceutical players had access to a shared resource: They could experiment with and contribute to the functionality and the increasing amount of accumulated data in the SRQ. This experimentation, however, was not without permission; there was a careful division between local, regional and national units and nodes, and projects aiming for improved care and research were distinguished. Data use and data additions were regulated not only through legislation, but also through supplementary agreements and voluntary standards,[22] which can also be seen as an important common platform resource typical of national quality registers.

There were also channels for the voluntary dissemination of knowledge about new innovative functions and working methods across clinic and regional boundaries. The cohesive power of the rheumatological specialty and the professional association was important here. The SRQ administration—continuously trusted to serve as a central function coordinating which local improvements would be upgraded to system-wide improvements in the rheumatological specialty—was also important.

Individuals and groups involved in the national quality registries in Sweden continue to use and create leverage on the data they collect thanks to self-organized coordination functions, channels and agreements.[23] Learning and innovation, however, occur primarily *within* rather than *across* specialist boundaries. Patients' ability to add, donate, share or learn from the data—for example, developing new self-care processes based on the data—and combining register data with record data and sensor or self-generated data, is still very limited. Again, we see the emergence of self-organized patient-driven registries and other networks of individuals who collect and experiment with biological samples and data, even in areas that cannot really be located within a particular specialty or even in healthcare.

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[21] See, for example, Nelson et al. (2016); https://arbetsyta.wordpress.com/om/.

[22] Essén and Sauder (2017).

[23] See examples at www.ringla.nu.

However, for different actors within and outside the formal care system to safely use and contribute to learning from such data, to share and disseminate learning from the individual level and beyond, and to involve actors directly at the system level requires new platforms and coordination functions, new dissemination channels for lessons learned and, above all, new legal frameworks and standards of action for how agreements between new and old players can be entered. The interrupted work on the development of personal health accounts by the Swedish e-Health agency (eHälsomyndigheten) is one such example.[24] There, ambiguity regarding its rigor, utility and purpose through a citizen's perspective was a decisive reason for the sharp backlash from the supervisory authority and administrative court.

Recombination

The SRQ managed to bring about change without major investments in new technology. In place of developing new functionality, the SRQ linked to existing digital resources (web interfaces, medical records, databases) that other actors in Sweden already had developed.[25] However, there were no standard solutions to speed up its integration; rather, the work required customized technical interfaces between the SRQ and other systems.

Reusing, recombining and adding to existing resources is a successful strategy.

Today, an increasing number of patient networks and health tech players want to re-use and build on the digital functionality and data that already exist in Sweden's quality registries, medical records and other health databases. However, no common platform allows these players to combine and create new links between existing modules to create new knowledge and new e-services. The entry barriers are many.[26] Projects linked to Inera's national service platform have partly aimed to create the conditions for third-party actors to offer apps via the national platform. However, Inera has encountered obstacles, and the priority of this service in the future is uncertain.

Thus, structures that facilitate, speed up and lower costs for integration between and recombination of existing healthcare systems could indeed be expanded. Examples of such structures are platforms that offer shared software resources in the form of APIs, SDKs, standards for semantic, technical and organizational interoperability,[27] and, again, clear legal approaches. This is worth emphasizing because research on information systems underlines that the opportunity to recombine existing modules is a success factor in innovation processes based on digital technology.[28] Digital innovations in the form of software are, in some respects, more editable than, for example, hardware such as medical devices and established procedures. Thus, there is an unrealized potential to accelerate introduction of, for example, new medical (and, in the future, biogenetic/cybergenetic) innovations in daily practice—if the recombination of digital resources can be accelerated.

Underlying values

Thanks to the SRQ's official support from SSR—a reliable player with members who uphold certain fundamental values, such as good research ethics and the pursuit of better patient health—users dared to join and participate in the SRQ. This points to the importance of social cohesion and ideology behind digital platforms to attract and retain users over time and says something about what we can expect from digital platforms in the future. This means, for example, that we *cannot* expect individuals or organizations to donate their data to different platforms just because the opportunity exists. Rather, we can expect a global influx of users into associations of individuals who have

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[24] https://www.ehalsomyndighet.se/nyheter/2018/nytt-om-halsa-for-mig

[25] Recombination of existing resources also applies at the organizational level. However, it would require that healthcare organizations have greater flexibility in using their resources. This indicates a need for the county council to introduce more flexible follow-up and compensation models, a work in progress. But it is also about being a caregiver—to think more creatively about how to combine resources given *today's* models.

[26] Essén and Ekholm (2018); Vimarlund (2014).

[27] For common definitions of information shared and exchanged (semantic interoperability), technical ability to exchange information securely and with the agreed quality (technical interoperability) and agreements between organizations on how information is shared and used to meet certain results (organizational interoperability), see www.kunskapsguiden.se

[28] Yoo et al. (2012).

a clear smallest-common denominator and who can gather around digital platforms to create knowledge of something for a particular purpose. Such communities can form the basis for data platforms that survive for decades and thus can constitute a significant resource for future learning within and outside of the formal care system.

In summary, the four driving forces continue to be actualized in the development of quality registers in Sweden, as well as in the emergence of digital platforms at the outskirts of today's formal and publicly financed healthcare systems. However, it is relevant to ask how a Swedish policy could support those driving forces more. Wouldn't it be great if more resources within and outside care could be coordinated to expand capacity in Swedish healthcare—similar to how the SRQ was developed but updated to today's possibilities?

Policy Implications

The SRQ's development shows how digital platforms can serve as a common resource for a learning health system. It is already used as a role model for other patient groups abroad.[29]

Decision makers at national and regional levels, as well as at development and research funding agencies, can contribute to creating national prerequisites enabling the emergence of new platforms that utilize today's technical possibilities and the expertise and commitment among patients, professionals and industry. The studies reported here provide no answer as to how policy should be designed or who should do what, but I discuss some general ways forward in the following section.

Encourage development of platforms

There is no "market" for cross-regional and cross-sectorial digital health platforms in Sweden. Investing in such platforms is not the formal responsibility of today's regional or local governments. National decision makers, therefore, can promote development in other ways. One way to "create" demand is to review today's research funding. Support is increasingly given to collaborations in projects related to healthcare and IT, which is a positive development. However, funding agencies tend to reward *specific, well-defined services* that target specific customer segments at the expense of developing platforms that could create *structural prerequisites* for safe use of the data and functionality by many different actors, which in turn can promote the innovation of many different services.

A clear ideology behind a digital initiative is crucial.

Encourage long-term perspectives

Development of shared platforms requires a long-term perspective and a vision that survives over time. Today, large sums spent on development projects stop after project completion because no actor assumes responsibility for ongoing management, financing or further development of the initial innovation. This applies to many government initiatives that the Swedish Association for Local Authorities and Regions (SALR) receives and several Vinnova (funding agency) projects that never commercialized. Innovation projects need a clearly specified actor—or coalition of actors—who will maintain the services over time. Such coalitions must commit to contributing to continuous refinement of the innovation in cooperation with end users. This is important to create among actors both trust in the underlying system and willingness to invest in it.

Encourage scalability

Decision makers should support initiatives that plan how to allow more actors to use and add functionality to the system in the long run. Platforms that can be decomposed and expanded modularly should be rewarded. Further, they should require organizational, semantic and technological interoperability at the ecosystem level.[30] This means encouraging knowledge exchange across today's industrial silos and collaborations outside of the formal organizational structure of care.

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[29] Lindblad et al. (2017).

[30] For examples of how the healthcare IT systems may start talking to one another via the semantic interoperability described, see Ingvar and Georgii-Hemming (2016).

Encourage entrepreneurial law

The EU's General Data Protection Regulation limits, but also creates, new opportunities. Policy makers should encourage local initiatives that invest in and disseminate legal knowledge and information on how existing laws and regulations can be *applied* in new specific digital contexts. They should allow local experimentation with how existing and new digital modules can be used within current legal frameworks to provide concrete examples that reduce public and private actors' prevalent fear of doing something "illegal." This would increase knowledge about what and how data accumulations, exchanges and analyses are possible to conduct legally. Doing so may require an entrepreneurial approach to law,[31] which may need to be purchased from the business community because lawyers within governmental agencies often specialize in areas such as procurement and public administration.

Support legal labs

Policy makers and research financiers should call for and provide financial support for the establishment of legal "labs." This would create opportunities for local actors to identify what regular barriers, after all, exist and cannot be avoided and what regulatory adjustments are justified at different legal levels. Doing so may prevent abrupt interruptions at the end of development projects, such as those that halted the "My Health Account" initiative. They should also encourage conceptual development of new legal frameworks for data exchange. In particular, the issue of digital integrity and identity is important in relation to the new forms of data provision for learning in new contexts.[32] Research projects can provide a safe environment for such development. It is important to delimit and define the legal domains in such projects so they do not risk interfering with other operating activities.

Embrace unpredictability

Today, funding agencies often require clear plans and a predefined aim; the assumption is that projects should be "evaluable" in the traditional sense. It is, however, difficult to predict the result of platform initiatives aimed at creating the *enabling conditions* for service innovation rather than a particular service.[33] The point is that that this kind of uncertainty is not necessarily negative. Information systems research has long emphasized that successful digital innovation platforms are characterized by *generativity*, that is, the ability to produce and incorporate innovations that were not initially intended.[34] This does not mean projects should not be evaluated—rather, new evaluation models are required. As an example, insights from agile working methods, which increase the capacity to adapt projects to unforeseen opportunities, such as unexpected ways of learning from data, could be applied.

In conclusion, I am convinced that Sweden has great opportunities to create digital innovation platforms with wider scale and scope than the SRQ example. Our tradition of building consensus provides a unique opportunity to create permanent digital forums for relevant stakeholders and jointly work towards goals we all value highly, including mutual learning for the creation of optimal patient health and, more generally, for maximizing value creation and ensuring a fair distribution of that value in our society.

The interest mobilized around value creation through digital innovation healthcare is significant. Actors that are able to invent stable but scalable structures for exploiting this momentum will reap great value. Many want to contribute and will—regardless of policy. There is great potential for public actors to provide trustworthy meeting places for these different actors and to leverage the interest in digital innovation for healthcare, rather than stand aside and watch the action. I look forward to following the continued development.

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[31] We use the term *entrepreneurial approach to law* to emphasize that it is about creating new opportunities and developing new frameworks and about expertise when it comes to evaluating whether a way to interact and exchange data "follows" laws and regulations.

[32] Essén and Ekholm (2018).

[33] This is particularly true of infrastructural and platform *technologies*, or so-called *general purpose technologies* (Bresnahan & Trajtenberg, 1995).

[34] Yoo et al. (2012).

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