Innovation as emergence in healthcare: Unpacking change from within

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Abstract

The contemporary healthcare literature suffers from a disproportionate focus on ‘given’ externally created innovations, and belief in ordered, planned and well-funded implementation processes. As an alternative, the present paper highlights the potential of emergent change processes, using the continuous invention and re-invention of the Rheumatology Quality Registry in Sweden as an example. This 19 year long process, which is still ongoing, does not exhibit the sequential steps that are allegedly determinants of success in the innovation and implementation literature. Yet, it has produced system-wide improvements. We draw on more than 100 informal and formal meetings with practitioners involved in the process studied, observations, documentation analysis and quantitative registry-data. A total of 67 interviews with registry-users and external stakeholders were also performed. The dissipative structures model (complexity theory) was used to analyze the data. The studied process illustrates an ongoing, practice-driven improvement process, which was sparked by abstract and indirect energies that interacted with more concrete innovations such as new drugs. For example, participants tapped new information technologies, changing perspectives and governmental priorities to challenge current ways of working and introduce new ideas. Ideas were realized and spread through various self-organized processes that involved the re-arrangement of existing resources rather than acquisition of new resources. Taken together, these processes brought Swedish rheumatology to new levels of functioning 1992–2011.

An important implication of our work is that incremental and practice-driven change processes can significantly transform care systems in the long run. Policy makers need to acknowledge and foster such ongoing innovation processes at micro-level, rather than focusing exclusively on innovations as externally created ‘things’ that await ‘implementation’.

Introduction

A major concern of today’s policy makers is that a majority of improvement efforts in the health care sector fail to result in sustained impact (see e.g. Länsisalmi, Kivimäki, Aalto, & Ruoranen, 2006). Numerous articles in the health care innovation literature address this situation, suggesting ordered and sequential models for “optimal implementation processes” that underline the need to define the innovation, secure managerial support, and funding. The typical lack of fidelity to such ordered models in practice may, from this perspective, explain the difficulty to achieve long-term improvement (Becker, Dumas, Houser, & Seay, 2000; Castle, 2001; Cohen et al., 2004, see also review by Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004; Länsisalmi et al., 2006).

Is it not possible, then, to achieve large-scale changes without managerial support? Without a clear strategy from the outset? With an innovation that has not been subject to randomized controlled trials? Is it possible to achieve change through messy and diverse rather than ordered processes?

Readers informed by the nascent healthcare literature inspired by complexity theory would probably answer yes to this question. This literature emphasizes that health care systems consist of a large number of interconnected agents that can self-organize in highly unpredictable ways (McDaniel & Driebe, 2005; Plsek & Greenhalgh, 2001). There is however still a lack of studies applying complexity theory to empirical cases in ways that highlight the potential of and flesh out the mechanisms involved in self-organized innovation.

The present paper seeks to begin to fill this gap by analyzing the nationwide spread of and continuous re-invention of an IT-based ‘quality registry’ and associated re-invention of rheumatologist...
practice in Sweden. The process started with an idea about measuring results in a new way among a few practitioners in 1992, an idea, which has not only been materialized in the form of an IT-system implemented in all 64 rheumatology clinics in Sweden. It has also evolved into a multi-professional and cross-sectorial model for health care innovation and improvement. The 19 year long process, which is still ongoing, does not exhibit the sequential steps that are allegedly determinants of success in mainstream innovation or implementation studies. Yet, its results are remarkable in terms of the reach and range of changes achieved.

We use the dissipative structures model (DSM) (Chiles, Meyer, & Hench, 2004; Plowman et al., 2007; Prigogine & Stengers, 1984), a branch of complexity theory, to conceptually unpack this incremental and ongoing process of innovation and change. At more practical level, our empirical material shows how significant health care improvement can be achieved by practitioners that do not wait for policy changes or directives, but rather find ways of making do with resources at hand. This suggests that 1) organic change, which starts out small, can escalate into system-wide changes within the healthcare structures that prevail today. This is important as the repeated mantra that ‘policy changes’ are needed creates a passive mentality. However, 2) much can be done at structural level to facilitate and boost such practice-driven innovation, rather than, as is too often the case today, impede it.

Limitations in the health care innovation and implementation literatures

Innovation can be defined as “ideas, processes, products or procedures, new to the relevant unit of adoption, designed to significantly benefit the individual, the group, or wider society” (West, 1990: 309). A large share of the contemporary health care literature focuses on the implementation of readymade innovations, trying to provide a “prescription” for achieving sustainable implementation and adoption of innovations. The theory developed by Rogers (1983) has had a pervasive influence in this context, suggesting five “innovation attributes” effect adoption: relative advantage, compatibility, complexity, trialability and observability. While these are important aspects, the mere application of Rogers’ (1983) theory tends to generate rather obvious conclusions rather than arguments that bring implementation science forward. For example, Scott, Plotnikoff, Karunamuni, Bize, and Rodgers (2008) conclude: “...if a potential user sees no advantage in using the innovation it will not be adopted.” (pp. 6). In general, many recent studies repeat the need to conform to previously listed success models. For example, Glaser (2009) emphasizes the need for having clear strategies, objectives and plans, managerial support, efficient IT governance in place; and measures of performance of the implementation process. Further, van Achterberg, Schoonhove, and Grol (2008) apply a stepwise approach and model for “effective implementation”, which include a series of rational and deliberate steps in order to accomplish practice improvement.

This focus on orderly implementation processes has been questioned. For example, authors have suggested that successful implementation involves the unpredictable interaction between various forces at multiple-level, and that local champions are as important as the manager. Scholars further underline that the innovation-system fit is a more useful construct than Rogers’ (1983) “innovation attributes” (Greenhalgh et al., 2004; Ovretveit, 2002).

The mainstream literature has also been criticized for its short-term and single-level focus (Greenhalgh et al., 2004; Länsisalmi et al., 2006), which is associated with the focus on the implementations of specific programmes (e.g. Dixon-Woods, Bosk, Aveling, Goeschel, & Pronovost, 2011) as opposed to longer-term studies of how programmes are renewed and replaced over time. Finally, an important critique against the literature is the predominant view of innovations as proactively developed in external, formal research programs. However, as argued by Greenhalgh et al. (2004: 604), “many innovations in service delivery and organization occur as “good ideas” in local services”. The innovations produced through such embedded processes of adapting practice differ from innovations as envisioned in the evidence based medicine framework in that they are not finished “products”. Rather they can be viewed as improvable ideas. The question is: How do you implement an improvable idea — a possibility that others can use and further develop?

The present paper seeks to begin to answer this question. We do not separate the generation of innovations from their implementation. In the process studied, these dimensions were inextricably interlinked to each other.

A framework for studying change from within

Indeed, what was salient in the process studied was the need to focus on innovation as an ongoing activity embedded in everyday practice, rather than a thing awaiting implementation. Previous work on complexity theory in health care helped us approach this case. Works by McDaniel and Driebe (2005) and Pisek and Greenhalgh (2001) suggest that health care systems should be viewed as complex adaptive systems (CAS), characterized by diverse agents who can learn, self-organize, and co-evolve with their environment in non-linear ways. Order and progress can emerge naturally from the interactions within a CAS, they do not need to be imposed centrally or from outside.

What dynamics may be involved in such self-organized processes? The extant literature on health care as CAS does not provide empirical elaborations on this issue. Hence, the present paper draws on the dissipative structures model (DSM) (Prigogine & Stengers, 1984), which posits four interacting dynamics of emergence that have been confirmed inductively in several empirical studies of social settings (Chiles et al., 2004; Plowman et al., 2007). Building on this framework our proposition is that change processes can be triggered by fluctuations, the injection of energy in terms of a new idea, technology, product, policy or other event that interrupt the existing order — “way of doing things” — create disequilibrium, and catalyze the emergence of a new order. Amplifying Feedback Dynamics fortify the initial fluctuations, helping the emerging new order to take hold and gain momentum. There is no central agent controlling how the energy is repeatedly channeled through these self-organizing feedback-loops. Deviation is amplified until a threshold is reached, where the system has reached the limits of its capacity. At this threshold, the system can collapse or reorganize through recombination dynamics in which the system’s existing elements are reused, rearranged, reconstructed, re-leveraged, and re-created. Finally, stabilizing dynamics constitute a “quasi-permanent, invisible substructure” that, unlike many observable structures, remains intact during major transformations, takes the form of basic social rules that comprise fundamental organizing principles. Stabilizing dynamics dampen the non-linear process and institutionalize the change. This process repeats itself, generating a continuous evolution of new orders that replace previous orders. That is, emergent processes can disrupt existing orders or norms, in a self-organized or from within manner.

Drawing on the DSM, it is possible to situate acts of innovation and implementation in a process of emergent change that involves the continuous interaction between the enabling and constraining mechanisms at micro- and macro-level, producing results that may drift from the original intention of the inventors, implementers and users. Hence, in contrast to conventional views that describe attempts to deliberately spread a “finished” innovation in order to
reach a given end, the model above suggests that users depart from and recombine available means and gradually learn what aims are possible (cf. Orlikowski, 1996). It is difficult to foresee the result of such practices.

Method

The invention and nationwide spread of the Swedish Rheumatology Quality Registry constitutes the process (case) studied. This is a multi-level process that spans over 19 years, during which the registry has expanded vertically (in terms of the range of services offered) and horizontally (new user-groups) in an unpredictable and incremental manner. Hence, the process was chosen for theoretical reasons in the sense that it could enable the elaboration of theories about non-linear, bottom-up change (theoretical rather than representational sampling (Eisenhardt, 1989)).

Data generation

Informants. A total of 67 interviews with process participants were performed in Sweden in 2010–2011. All (150) physicians, physician secretaries, nurses, physical therapists, clinical managers who attended the yearly rheumatology registry seminar in 2010 were asked for an interview. 25 accepted. In order to access regions and positions not represented by those, 15 additional practitioners were identified through the registry administration and they accepted. The final set of 40 interviewees covers all regions in Sweden. 21 patients were interviewed (17 face-to-face, 4 via phone, 15 female, 6 male), the majority in the Stockholm area for convenience. Finally, 6 peripheral process participants representing Carmona, the IT-firm developing the registry, health IT consultancy firms, the National Health Technology Assessment Agency, the life-science industry, ministry of health, the county council-level, and the Swedish Association of Local Authorities and Regions were interviewed.

Interviews

The duration of the 67 interviews ranged between 60 and 130 min and included open-ended questions in order to allow for unexpected issues to emerge. A brief interview guide was used with questions concerning: 1) professional/patient background, view of own position and daily situation; 2) use or view of the registry and its development. The majority of interviews was recorded, transcribed and certain parts translated (Swedish to English) by the primary author. 17 interviews were performed by another researcher also studying the registry development.

Field work and focused observations

The primary author worked part-time with members of the registry steering committee 2009–2011 (writing annual reports and providing feedback from users). This provided access to informal conversations and formal meetings (N = >100) such as workshops, seminars, steering committee meetings and other meetings where the registry was discussed. Field notes from these numerous occasions (>100 pages in total) constitute important background material. The primary author also conducted observations at two different clinics in Sweden (convenience sampling). Observations of in total 10 patients using the PER service in the waiting rooms and of their subsequent meetings with the physician/nurse were performed. Notes were taken and summarized the same day.

Quantitative registry data was used to illustrate increase in users and data volumes, e.g. to summarize number of patients included in the registry over time.

Secondary sources include rheumatology guidelines, diagnostic criteria documents; the registry website (www.swerre.se); the Swedish rheumatology association website (www.svenskreumatologi.se); registry applications, annual reports, agreements and user contracts, articles in trade press, and protocols from the registry steering committee meetings 1995–2011 (about 90 pages in total).

The ethical committee in Stockholm approved of the methods used.

Data analysis

The empirical illustration presented below resulted from a repeated process of interrogating the data, consulting the theory and creating sub-categories and returning to the data (abduction) (Alvesson & Sköldberg, 2000; Miles & Huberman, 1994).

Creating a basic timeline. We used registry data and secondary data to create a rough chronological overview of the new functions added to the registry and the parallel growing number of clinics using/patients included in the registry between 1992 and 2011 (see Table 1).

Creating a narrative. A 17 page long narrative summarizing the change process as experienced by participants was then created based on an analysis (in Vivo) of the interview transcripts, field notes and observational notes. The narrative was then read through and sentences and paragraphs were coded inductively with labels as e.g. collective decision, peer-to-peer support, unexpected events, external financing, lack of interest from top-managers, etc.

The resulting network of themes (recurring topic of discussion that captured an issue expressed by an interviewee or visible in an observation, Miles & Huberman, 1994) indicated the incremental and contextually driven nature of the process and lack of top-down power. To relate our analysis to existing theory, we hence delved into the literature on emergence and identified the dissipative structures model (DSM) as a fruitful tool for organizing and making sense of the vast material generated. We applied the model in a new round of coding of our own material, coding sentences, paragraphs and old themes as fluctuation, amplifier, recombination or stabilizing dynamic.

Abduction. Working recursively between the narrative and DSM theory, we arrived at a first version of the empirical account of the process that highlighted the emergence of three orders (see Table 1). We then reorganized the empirical account to disaggregate each dynamic. This enabled us to provide an extended conceptualization of the DSM, with inductively identified sub-categories. For more empirical examples, see Supplementary file available online.

Validity checks. Several working papers were presented to process participants and peer scholars and critical feedback was received. In general, we triangulated data obtained from interviews and documents wherever possible to check the validity of our narrative.

Limitations. This study relies partly on interviewees’ post-hoc accounts, which may reflect impression management, post-hoc rationalizations and memory errors. To reduce this bias, we asked the same questions to multiple participants and supplemented interviews with secondary data to corroborate facts. The account presented here includes only data substantiated over multiple information sources. Further, we do not claim that we have gained access to the local and tacit forces present throughout the process. However, our conceptualization illustrates some of the patterns involved in the process, in a way that makes sense to the practitioners involved.

Change from within as the continuous emergence of new orders: the case of Swedish rheumatology 1992–2011

While it is not clear-cut when the process studied “starts”, we begin our illustration with the emergence of an idea to develop an
IT-based quality registry among a few rheumatologists in the early 1990s. As we will show, the idea was not only realized and the registry successively implemented, its use also disrupted the pre-existing ways of delivering chronic care services by contributing to the re-invention of the registry engaged in the collective project of monitoring certain pre-defined health aspects, thus contributing to a shared knowledge bank.

**Table 1**

<table>
<thead>
<tr>
<th>Year</th>
<th>No of clinics using SRQ</th>
<th>No of patients included in SRQ</th>
<th>The emergence of new orders in Swedish rheumatology (1992–2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>0</td>
<td>1.047</td>
<td>1st New order: Making results transparent &amp; comparable</td>
</tr>
<tr>
<td>1993</td>
<td>0</td>
<td>1.066</td>
<td></td>
</tr>
<tr>
<td>1994</td>
<td>0</td>
<td>3.091</td>
<td></td>
</tr>
<tr>
<td>1995</td>
<td>7</td>
<td>4.625</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>20</td>
<td>6.270</td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>27</td>
<td>7.797</td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>32</td>
<td>10.479</td>
<td></td>
</tr>
<tr>
<td>1999</td>
<td>40</td>
<td>13.188</td>
<td>2nd New order: ‘Seeing’ patients in a new way</td>
</tr>
<tr>
<td>2000</td>
<td>40</td>
<td>16.131</td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>41</td>
<td>19.918</td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>41</td>
<td>24.184</td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>42</td>
<td>27.951</td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>43</td>
<td>31.094</td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>44</td>
<td>33.094</td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>45</td>
<td>37.164</td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>49</td>
<td>41.344</td>
<td>3rd New order: cross-sectorial and multi-level health care innovation</td>
</tr>
<tr>
<td>2008</td>
<td>51</td>
<td>45.344</td>
<td></td>
</tr>
<tr>
<td>2009</td>
<td>52</td>
<td>49.344</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>58</td>
<td>53.164</td>
<td></td>
</tr>
<tr>
<td>2011</td>
<td>58</td>
<td>57.344</td>
<td></td>
</tr>
</tbody>
</table>

The idea of developing a Swedish rheumatology quality registry (SRQ) was introduced & accepted by the Swedish Society for Rheumatology (SSR). Negotiations about what measures to include.

**Assumptions (previous order) being challenged in the transition:**

Rheumatology is something ‘between the doctor and the patient’, a ‘private’ rather than collective endeavor.

**Assumptions being challenged in the transition:**

Rheumatology tasks cannot be commoditized or ‘inscribed’ in measures, and thus not delegated to non-specialists. Nurses should deal with ‘soft’ aspects and not deal with medical parameters. Patients are recipients rather than co-producers of care. Patients’ self-rated health is subjective, mood-dependent, unreliable, and cannot be used as evidence. Doctors’ assessments are objective, replicable and good evidence (this view was held by patients too). Rheumatology involves building long-term relationships with patients, following them through hard and good times, thus getting the satisfaction of seeing patients one has ‘succeeded’ with.

In 2009–2011, a new norm for innovation in care emerged, building the continuous accumulation of evidence enabling future research questions impossible to predict in advance. In this new order, several professional categories and patients feed data into the registry and the data is utilized as ‘evidence’ by (fed-back to) patients, health care practitioners, managers, life-science industry, researchers, authorities to evaluate care, make micro and macro level decisions and perform research.

**3rd New order: cross-sectorial and multi-level health care innovation**

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**Assumptions being challenged in the transition:**

Evidence is gathered by researchers at discrete events, based on certain hypotheses and research questions. Evidence is not the ongoing documentation from day-to-day practice. Research is clinical trials performed in controlled environments, rather than evaluations of data generated in the messy reality constituted by daily praxis. Innovation is based on external research in labs, not the task of practitioners and patients.

How new medical evidence and pharmaceutical products created instability 1980

In the 1980s, new medical evidence suggested that aggressive combinations of certain drugs could really make a change in patient health outcomes. Rheumatologists were happy about these new potent medical possibilities, as they historically had little to offer their patients beyond symptom relief. But there was an uncertainty regarding the long-term consequences of using such powerful pharmaceutical combinations.

The emergence of an idea

This produced an idea among a group of rheumatologists to develop a national ‘quality registry’ for systematically evaluating the results of the drugs in use. The idea of a national follow-up system with standardized measures was presented and accepted at a meeting for rheumatologists in 1993 where a development group, consisting of a few rheumatologists was formed. An arduous process now started, aiming at an agreement on what measures should be used. After two years of discussions involving multiple professional categories and the rheumatic patient association, a set of measures that could be used to evaluate the health outcomes in rheumatology was accepted by the Swedish Society for Rheumatology (SSR). Measures concerned therapies prescribed, patient data such as results from lab-tests, X-rays, and symptoms such as pain and signs such as number of swollen and tender joints. The
development group received a small grant from the National Board of Health and Welfare to develop a first version of the registry in 1995. The development occurred in close cooperation with Carmona, an IT-firm with experience of registry development.

In sum, the interaction between intangible energies in terms of new knowledge and uncertainties regarding the application of this knowledge, moved Swedish rheumatology to an unstable state, which triggered the innovation and development of a tangible, concrete IT product (the quality registry). As described in the amplification section below, the infusion of the registry into rheumatologist practice was leveraged by various self-organized processes, which brought Swedish rheumatology into a new order and level of functioning with an increased capacity to evaluate new procedures and drugs (the 1st new order in Table 1). This 1st new order was however challenged by further fluctuations in the 2000s.

**How new technology and new theoretical perspectives created instability in 2000**

The ubiquity of information technology in 2000 fueled the development of new ideas among rheumatologists, which in turn moved Swedish Rheumatology to a second state of disequilibrium. In 2001, Internet technology was utilized to create a web-based version of the registry, allowing for real-time interaction between physicians and the registry data. For example, an overview service that displayed a longitudinal summary of the patient’s drugs and health outcomes was now added to the registry and available to physicians in real time. The overview saved physicians the time previously needed to browse through paper based journal notes from years of visits. It motivated physicians to enter data into the registry when meeting the patient (as opposed to post-hoc, or making the nurse enter the data), as they could use the overview to make better decisions during the patient encounter. Hence, the new functionality triggered existing users to deploy the registry in new ways, and motivated previous non-users to start using it (see amplification).

At this time, research and policy movements emphasizing the importance of consumers as innovators, patient involvement, quality improvement and cost containment in health were further fluctuations utilized by rheumatologist professionals to introduce ideas about registry-services for patients. A rheumatologist, who had seen a self-rated health service at the Dartmouth Hitchcock Medical Center in the USA, figured that a web-based, improved version of this service could be valuable in rheumatologic care by saving physicians the time previously needed to enter data about patients’ subjective health status. The rheumatologist, a few recruited patients, and the IT-firm Carmona received funding for an IT-development project and designed the prototype for an e-service asking patients to assess their functional ability, quality of life health and rheumatic symptoms. The e-service was labeled PER (Patient Self Registration) and was later added as a function in the national registry thanks to grants from a Swedish health agency.

In summary, the interaction between concrete energies such as new information technology and intangible energies in terms of new views of patients fueled the development of new functions, which gave the registry new purposes (a decision support system rather than a simple documentation system) and new users.

**How national crisis rhetoric and local resource scarcity created instability in 2007**

A perceived crisis regarding Sweden’s declining position in clinical research rankings created instability in 2008. Several authoritative voices expressed concern about the decreasing number of pharmaceutical patents developed in Sweden. Rheumatologists in the registry board were sensitive to this rhetoric and figured that the rheumatology registry could be presented as a tool for attracting foreign research investments in Sweden as it was an infrastructure facilitating the execution of clinical research. As a result of various informal information loops, the Swedish Ministry of Enterprise initiated the CUR project (Clinical innovation Utilizing Registries), the purpose of which was to enhance Sweden’s competitive power by facilitating cooperation between health care practice, academia and the life science industry. The rheumatology registry development group was assigned to lead CUR and to develop generic IT-modules facilitating multi-level usage of registry data by using the Rheumatology registry as a role model. The assignment increased the interest in the registry within and beyond rheumatology. Note that this development interacted with other intangible energies. The persistent new public management movement and emphasis on evidence-based medicine also influenced authorities to seek accountability and ask providers to make their performance visible. Many publications argued for a shift toward measuring outcome rather than process, and Swedish national directives required Swedish regions to report data annually to the online “Open Comparisons” report, which is available to the general public. This fueled the interest in the idea of allowing various parties to add to and use registry data to continuously evaluate and improve care and health. In Swedish rheumatology and beyond, this model is increasingly regarded as legitimate although there is still resistance. Hence, the 3rd order, which is depicted in Table 1, is still open to re-definition.

**Amplifying and reducing dynamics**

The fluctuations depicted above were meaningful not in themselves but because they triggered amplifying reactions.

**Self-organized activities performed by voluntary users (pull)**

Consider the disequilibrium state following the initiation of the registry in 1992–1995. SSR then collectively elected a national registry steering committee and a central administration, which were independent from other clinical management structures. A limited set of rules and standards regarding e.g. license and support conditions were created. We refer to these self-organized events as the democratic creation of an administrative order, which facilitated the nationwide diffusion of the registry.

In parallel, a first group of rheumatologists started using the registry and acted their way into an understanding of its benefits. The perceived benefits varied and were often unexpected. We refer to this amplifying mechanism as purposes emerging through hands-on usage. Users shared their experience-based insights through annual rheumatology meetings and professional conferences. That is, they tapped on existing communication channels. As a result, the number of users increased, including new categories of rheumatologist professionals such as physiotherapists, occupational therapists and nurses. We refer to this dynamic as sharing emerging purposes through existing peer-to-peer channels.

From the late 1990s, various locally initiated and funded research projects utilizing the registry emerged in different regions, a dynamic we have labeled multiple local extensions and registry-enabled practices. This dynamic strengthened the role of the registry in rheumatologist practice across regions. For example, physicians, physiotherapists, occupational therapists and nurses developed new measures related to specific rheumatic sub-diseases in local research projects. Some of these measures were later made available nationally. Another example is the rheumatologist who introduced a so-called “Open Tight Model” at his local clinic. This care service delivery model utilized the registry to monitor the variability in disease activity over time to and create two different care delivery processes on this basis. More
specifically, patients with high disease activity were identified through their patient reported health outcomes in PER and were offered frequent physician visits and extended treatment ('Tight control'), while patients with low and stable disease activity were managed by the nurse at ‘nurse visits’. These patients were however free to initiate physician visits any time, ‘on-demand’ (Open). The delegation of power and tasks to the nurse regarding patients with low disease activity eliminated waiting times at the rheumatologist’s local clinic. Hence, the rheumatologist’s way of enacting the registry made it a tool for handling lack of resources, as nurses and patients performed some of the tasks that the rheumatologist previously did. Although clinical managers did not support the Open Tight service model, it began to spread to other clinics, again through peer-to-peer channels.

**Self-organized attempts to attract participants (push)**

Some enthusiasts also engaged in deliberate push-like efforts aiming at increasing participation at national level. For one, enthusiasts in the registry board engaged in creating new incentives. For example, in 1998, a few enthusiasts saw a possibility to attract more users by linking the registry to the new powerful biological anti-rheumatic drugs. Rheumatologists needed a license from the Swedish Medical Products Agency (MPA) in order to prescribe the new drugs. Working through informal, peer-to-peer channels, the enthusiasts managed to convince the MPA to make it mandatory for rheumatologists to document their prescriptions of the drugs in the registry in order to be given a prescription license. This was a powerful attractor that operated without any involvement of politicians or clinical managers. Second, enthusiasts engaged in creating facilitators. For example, the need for a registry course became evident to new and old users in the late 1990s. A few board members unsuccessfully asked clinical managers and several governmental health agencies to finance the registry courses. The board members hence approached the life-science industry, which was willing to finance the courses. This was controversial, but contracts made clear that the industry would not have any influence of the course content. A full-time course coordinator was employed and registry courses offered to users, on their clinic, for free. Members of the board later managed to make the course IPULS (Institute for Professional Education for Physicians in Sweden) certified, meaning it provided credits for continuing education for professionals. This attracted more participants and registry users.

**Dealing with resistance**

Another salient pattern involved the participants reactions to impediments encountered along the journey.

Accepting resistance to emergent changes. There was early resistance to the registry among rheumatologists. Documenting the results of the therapies in use was time consuming, and some rheumatologists perceived the registry as an external control system that reduced their discretion. There were no attempts to aggressively ‘convert’ these non-adopters. Use was voluntary and peer-to-peer loops rather focused on those interested in the registry. Making usage mandatory was beyond the power of the practitioners involved. Over time, enough physicians were however using the registry on voluntary basis, and they eventually generated peer-to-peer loops which created a critical mass that hung on to the ‘movement’, turning critiques into outliers. In a sense, the negative energies were out-crowded by the positive energies.

In some cases, resistance however led to enthusiasts to relabel & repurpose the emergent changes, to accommodate critics’ views. For instance, some rheumatologists and researchers were however skeptical toward the idea of using everyday documentation and patients’ subjective health assessments as ‘evidence’. A clinical manager explains: ‘...there has always been resistance among those who view evidence as data which is collected through questionnaires that is designed by researchers with a certain research question in mind. They do not view the daily documentation by patients and physicians as research data...’ (clinical manager, interview). The registry enthusiasts listened to these doubts among peers, referring to the registry as a “patient data bank” and emphasizing that the registry data could serve as an important complement rather than replacement to other research data.

**Working around and in parallel with regulations.** As noted above, a patient devoted registry service (PER) enabling patients to document their health outcomes was developed in 2003. The current Swedish legislation however prohibited patients to enter data into medical registries or records. Rather than waiting for these regulations to change, rheumatologists and the IT-firm Carisma invented a work around: don’t let patients enter data into the registry, but to a separate module, and let physicians then import the data into the registry. Building on this principle, PER was made ‘legal’. Similar patterns were observed in 2005, when new registry-enabled service delivery models such as the Open Tight Clinic clashed with prevailing reimbursement structures. Clinics were paid per visit, which discouraged the use of the registry to eliminate redundant specialist visits. Further, nurse visits were reimbursed less than physician visits. The few nurses working in this way in fact felt like ‘outside’ the formal system. As physicians deploying the Open Tight Model and offering Nurse Visits enjoyed being able to offer their patients improved accessibility, these models however remained and led a life ‘in parallel’ with the main system and currently spreads slowly across clinics.

**Recombination and repurposing dynamics**

The amplifying mechanisms above resulted in an increasing number of registry users and a continuous expansion of the registry database. Several re-arrangements prevented this growth from resulting in an uncontrolled state or chaos.

**‘Creating’ resources by re-combining existing ones**

The implementation of the registry software and hardware at clinics across Sweden occurred largely thanks to local acts of re-inventing existing resources, rather than the launch of new resources such as devoted budgets, personnel, facilities or computers. Our interviews provide numerous examples of how individual rheumatologists found ways of repurposing existing rooms, computers to the registry services, or convincing their manager to use existing funds or budget items to the registry rather than something else.

**Re-arranging the registry IT-platform**

The technological platform of the registry was restructured at several occasions to accommodate for the expanded demand among users. The technology originally required users to install a client on the local computer and save data on diskettes, which were subsequently sent to the central administration who imported the data into the national registry database. The online version of the registry created in 2003 enabled patients and professionals to add data from any computer with an Internet browser, and enabled them to identify trends in real-time, prospectively, at the point of service. In 2008, the registry board and IT-firm Carisma further decided to migrate the registry to a modularized platform to allow users more flexibility as regards what functions to
implement. The C.U.R. project developed several generic IT-modules for neurologic and pediatric diseases and template ‘contracts’ for industry collaboration by reusing the experiences from the rheumatology setting (see kurnet.se). This contributed to the emergence of a new view of registries in general, in which they was seen as platforms enabling a new cross-sectorial model of continuous health care innovation (see 3rd order, Table 1).

Efforts were also made to seamlessly integrate the registry with other health care information systems. For example, the registry was made interoperable with the most widespread electronic medical record system in Sweden in 2010, which minimized redundant documentation. Further, the patient service PER was made accessible through the regional and national healthcare portals 1177.se and minavardkontakter.se (my healthcare contacts), where patients could access other health care information services too.

Leveraging the utility of existing elements. The growing number of functions and data in the registry triggered efforts to make them accessible and relevant to a wider range of users. As noted above, rheumatologist professionals invented new sets of measures in small research projects. Many of these measure-sets were subsequently added as new modules in the registry (after decisions in the registry board) and thus made available at national level. As a result, the registry served as a tool for translating new evidence into practice. R & D grants covered the costs.

Re-structuring administration

The increasingly wide range of users called for the incorporation of new representatives in the registry board. In 2007, a rheumatologist in the board relocated resources (originally dedicated to other activities) to employ a patient as a salaried ‘care designer’ in the registry board. The patient was to participate in the reinvention and spread of the registry. A nurse, occupational therapist, physiotherapist and course coordinator were also represented in the board by 2011. This moved the registry to a new level by establishing its role as a tool also for patients. As a result, receiving grants for research and development became easier.

Re-purposing the registry through new labels

Rhetoric efforts were important to encourage individuals to continuously adopt new registry functionality. Enthusiastic users played an important role here by emphasizing different aspects of the registry depending on the audience, and continuously assigning it new meanings and purposes that were related to more general movements in society. From having been referred to as a research database initially, it was increasingly referred to as a decision support system and a tool for reorganizing care. Various labels of the registry however emerged in the empirical data, including a national follow-up tool for authorities and government, a patient self-management service, a patient safety system, a new care logistics with task-shifting possibilities, a post-marketing drug surveillance service package, a research platform, a resource for boosting Sweden’s competitive power, a means for illustrating health outcomes and thus for legitimating high expenditures for bio drugs, a value based care delivery model and the new rheumatology. Along with the development of generic modules, people began talking about a new ‘model’ or ‘norm’ for cross-sectorial and continuous innovation in chronic care more generally. This new model rested on the assumption that the continuous documentation performed by patients and various health professionals provided a basis of ‘accumulated experience and evidence’, which various parties could learn from and use to innovate new, better ways of delivering care. Obviously, all users did not accept all these roles. Rather, patient, professionals and external actors used the registry based on the meaning they believed in. As a result, several, sometimes conflicting, views of the registry existed in parallel, leading to diverse usage patterns. The panorama of labels however enhanced capacity by encouraging new uses and understandings of the potential inherent in using a common platform and sharing data, which in turn increased adoption levels, data volumes and chances to receive funding.

Stabilizing dynamics preserving a core identity throughout the evolution

While the registry studied was continuously repurposed during its evolution, shared values provided continuity throughout the process.

Improving patient value by facilitating—and integrating—practice and research

One such common reference point was ensuring that the registry could bring concrete benefits in everyday practice. This implied a parsimonious approach to the number of measures included. Of course, the border between practitioners and researchers is blurred, as many rheumatologists divide their time between patients and studies. Hence, the aspiration to ensure the registry’s relevance in daily work was intertwined with the ambition to facilitate and improve research by embedding data generation and measurement in the daily flow of care. Bridging the distance between pharmacogenomic, clinical and translational research is an important aspect in this context. In general, the aspiration to demystify the cause and possible cure of rheumatoid disease was—and still is—a powerful drive force among users. These beliefs and ambitions preserved the overall identity of the registry as a tool for improving patient health outcomes.

Enabling change from within

Another persistent idea among registry users was to achieve improved patient health outcomes by encouraging a continuous re-invention of the registry: “… Some possibilities survive. Others are not attractive, and they are released, they die. It’s like evolution. The good ideas and services, those that actually contribute to health, survive…” (rheumatologist, personal communication). Unlike many other improvement projects that revolve around ensuring
adherence to guidelines and changing formal policies, the belief in the possibility to change care at micro-level, within the prevailing structures permeated the registry development: “...While health care improvement has often been viewed as a matter of smart planning, and top-down control, the registry builds on the belief in evolution and change from within...” (rheumatologist, interview). Ensuring flexibility at the technical level was thus a key value. As stated by the manager of the IT-firm: “…we see this as a living organism...that needs to be able to connect to other parts of health care...” (manager of IT-firm Carmona, conversation).

Professional freedom and medical professionalism are further deeply rooted values that persisted throughout the process. There was never any doubt regarding the fact that the rheumatologist association rather than e.g. clinical managers or policy makers or the life-science industry should determine the content and functionality of the innovation (i.e. what measures to include etc).

Values in movement

Some deeply rooted assumptions regarding the role of patients, evidence, how innovation should occur and who is a legitimate collaboration partner however began to shift as a result of the fluctuations mentioned above. A shift was also slowly emerging regarding the believed tight association between “face-to-face” meetings and “caring for a patient”. This view stabilized the view of the registry as a complement rather than replacement to human labor but more and more rheumatologists referred to the possibility of using registry-data during phone-consultations and allowing patients to monitor their own health-data via Internet, from home.

Conclusion

This study suggests that radical health care change and improvement can be achieved through other means than through the ordered implementation of ‘readymade’ or ‘given’ innovations. The development of the Swedish rheumatology quality registry and associated transformation of Swedish rheumatology rather illustrates a non-linear, emergent type of ‘internal’ innovation that is ongoing and a part of everyday practice. Note that this happened without managerial support initially—even in spite of managerial resistance—and without a predefined strategy. It was rather a matter of organizational members improvising with the tools available, thus gradually learning what strategies were possible. Referring to this as change from within, we seek to underline the self-referential drive characterizing the process. However, the process was far from closed from external energies. On the contrary, the interaction between external/macro and internal/micro developments was one of its major success factors.

Complexity theory and the dissipative structures model (DSM) (Prigogine & Stengers, 1984) helped us to unpack this process. Scholars have confirmed and used the dissipative structures model to study non-linear change in other social contexts (Chiles et al., 2004; Plowman et al., 2007). We extend these works by disaggregating the previously identified dynamics in DSM, based on an inductive analysis of our empirical material. Starting with fluctuations, we highlight that not only tangible innovations such as new approved drugs available on the market) but also intangible developments (e.g. medical evidence, new academic theories about consumers’ role) can create instability and thus trigger reactions that lead to significant change in service delivery systems. Needless to say, such abstract energies are far from ready to be implemented in health care according to a pre-defined script. Our case however shows that they can be transformed into concrete resources if they are used to challenge and introduce alternatives to existing norms. In general, fluctuations generate change only if they trigger amplifying reactions that leverage the initial energy. We identified two kinds of amplifying mechanisms that balanced each other in the studied process: dynamics that increase diversity/expand borders (e.g. the emergence of various local purposes through hands on usage, distributed innovation and the spread of services in the legal periphery) and dynamics that reduce diversity/limit borders by creating order and steering the process in certain directions rather than others (e.g. the election of a central administration, the provision of courses and the establishment of rules preventing misuse of registry-data). By emphasizing these two paradoxical but complementary mechanisms in the emergent process studied, we hope to transcend the classical dichotomy between grass-root movements that are characterized by unlimited tolerance and anarchy on the one hand, and planned top-down change processes that are steered by a pre-defined goal on the other (c.f. emergent and deliberate strategies (Mintzberg & Waters, 1985)). In their review of innovation studies, Greenhalgh et al. (2004) depict this contrast in prevailing models on a continuum, with non-predictable, emergent processes at one end, and predictable processes characterized by deliberate activities on the other. The “hybrid” process we studied cannot be readily located on this continuum. We thus agree with Dixon-Woods et al. (2011: 193), who conclude that quality improvement efforts “...should combine horizontal or “grassroots” momentum with a vertical integrating structure that can coordinate activity and manage potentially competing interests and motives”. In our case, the coordinating structure was represented by the registry-board and rheumatologist society, which in a sense represent ‘central agents’ in the otherwise scattered process. Their decisions regarding the spectrum of services made available through the registry, and their goal-directed efforts to attract and coordinate the participants, generate funding for the innovation’s further development and to make sense of local inventions distinguished their activities from the amplification activities of other users, who were happy with merely developing and using the registry for their own, local purposes.

The recombination dynamics further highlight how the process could remain in a state of bounded instability (Plowman et al., 2007) by mobilizing the skills and resources needed to maintain its new phase (Prigogine & Stengers, 1984). The process studied reached several thresholds as a result of the growth in registry-users and data volumes. At these thresholds, several kinds of re-arrangements were made to bring the system to a new level of functioning. Rather than acquiring new resources, employing more laborers, adding new servers — which would soon create an unsustainable cost explosion — the participants re-purposed and re-arranged existing facilities, labor time and budgets. At several points of time, they further re-arranged roles in the administration and migrated to new technological platforms that were more generic, flexible and interoperable with other existing health care information systems. This prevented the registry from becoming a separate system with its own resources as it was now inevitably integrated with existing systems and processes.

Finally, stabilizing mechanisms enabled and constrained the amplification and re-combination activities by providing common reference points and coherence throughout the studied process. This study highlights values that remained unchanged throughout the 19 year long process, for instance the belief in improving health care from within, the preservation of professional freedom, and always working to improve individual patients’ health. However, our material also indicates values in motion along with the emergence of new orders. Table 1 shows how fundamental assumptions regarding e.g. the role of patients and what is evidence are not immune to change. We see this as an example of how micro-level changes can amplify into institutional changes in terms of new ways of thinking and believing.
In summary, we position our study in the emerging literature challenging 1) the classic association between radical and episodic change on the one hand, and incremental and continuous change on the other, and 2) the association between intentionality and radical change (McDaniel & Driebe, 2005; cf. Plowman et al., 2007). Our work rather confirms that small, continuous changes can be amplified into system-wide changes, and we argue that the extended version of the DSM provided here is useful for studying such emergent change processes. Future research is warranted regarding the applicability of the extended version of the DMS in other health care and non-health care settings.

Practical implications

What can we learn practically from all this? For one, that changes initiated by practitioners rather than managers in professional organizations may have a relative advantage as regards their chances to succeed in the long run (e.g. Dixon-Woods et al., 2011; Waring & Currie, 2009). Users involved in the registry development further continuously updated the registry based on external developments such as technological opportunities, discursive trends, social and political movements, governmental priorities and new research streams. The participants ‘capitalization’ of these diverse and abstract sources of change ensured the relevance of the registry and provided the development process with resources, hence making the involved individuals less dependent on the support from managers and policy makers. This kind of environmental scanning requires practice members with interdisciplinary competence (boundary actors), enabling them to rotate between medical, technological and economical worlds and to transcend the strict borders between medical and organizational development. Indeed, while many decision makers appear primarily concerned with achieving change by speeding up the implementation of concrete medical innovations such as drugs, guidelines and apparatus, our case suggests that only when such innovations interact with more abstract new perspectives on how to organize everyday care can they realize their full potential to bring health care systems to a higher level of capacity.

Policy makers should however note that ‘imposed’ fluctuations such as new regulations or earmarked money will not automatically bring health care systems to a new level of functioning, if they are not accompanied by amplifications and recombinations. Imposed fluctuations are often rather subject to reducing reactions, thus producing only small or no effects (i.e. a reversed butterfly effect). Policy makers need to get better at monitoring, making sense of and supporting (amplifying) promising practice-driven changes rather than initiating and imposing grand changes from above. Assuming that continuous change and complexity is default in organization implies a need for managers and policy makers to develop feedback systems rather than prediction systems. Only with the establishment of more reliable measurement systems that continuously monitor the costs, outcomes and patient safety of various initiatives, will top-level actors feel comfortable with delegating more power and flexibility to self-organized, practice-driven initiatives.

Limitations

The conclusions presented here are based on a single case and are associated to the Swedish context with a decentralized health care delivery system and a strong rheumatologist society. Practice-driven changes however occur elsewhere in the world and the dissipative structures model is a valuable lens for studying and thinking about innovation and change in other health care contexts.

We hope that the rich empirical details about the case can provide insights that resonate with other contexts, and that it can serve as a springboard for discussions about the potential inherent in, and how to facilitate emergent change.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at doi: 10.1016/j.socscimed.2012.08.035.

References


