Architectural Constraints on the Bootstrapping of a Personal Health Record

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Abstract. During the last decade we have seen a proliferation of electronic personal health record systems (PHRs) aiming to change the way people manage and receive healthcare. However, many of these initiatives have failed to take-off. We inquire into such unsatisfactory outcomes by drawing upon the perspective proposed in the information infrastructure (II) literature. This literature views the value of PHRs as dependent on the number of actors using them. This poses a challenge for designers (referred to as ‘bootstrapping’): how to persuade users to adopt a PHR when the user base is still small. To address the bootstrapping challenge, II literature suggests starting with a simple solution that creates immediate user value and enables users to enrol gradually. This paper seeks to explore how PHR architecture can hinder PHR bootstrapping through a longitudinal case study on the implementation of an integrated PHR. Our case analysis identifies four architectural constraints: poor data quality; coordination across heterogeneity; privacy and control; and re-configurability. This paper concludes by discussing the implications of the findings for the literature on personal and electronic health records and on the design of information infrastructures.

Keywords: personal health record, architecture, feedback loops, bootstrapping, electronic health record, information infrastructure.

1 Introduction

There is mounting interest around the world on how electronic personal health record systems (PHRs) can improve the effectiveness and efficiency of healthcare delivery, and enhance a patient-centred care (Epstein et al. 2010). According to the American Journal of Medical Quality a PHR is: “a person-centered system designed to track and support health activities across one’s entire life experience; not limited to a single organization or provider.” However, many of these
PHRs have failed to take-off despite the high stakes and interest in PHRs by health providers, national health services, and citizens (Archer et al. 2011; Nazi 2013; Wang et al. 2012). For instance, Google justified the discontinuance of its Google Health service on January 2012 by stating: “There has been adoption among certain groups of users like tech-savvy patients and their caregivers, and more recently fitness and wellness enthusiasts. But we haven’t found a way to translate that limited usage into widespread adoption in the daily health routines of millions of people.” (Brown and Weihl 2011). Similarly, the British National Health Service closed its HealthSpace service in March 2013 arguing that “the service was not as popular as we would have liked” (Connecting for Health 2012).

In an independent evaluation of HealthSpace, Greenhalgh et al. (2010) identify four main possible explanations for the limited success of HealthSpace: (1) flawed concept—HealthSpace was conceived as a data container rather than a component in a socio-technical network; (2) flawed product design—HealthSpace did not align well with patients’ self-management practices, information needs, and preferred styles of communication; (3) flawed implementation and embedding—policy makers assumed that intended users would need no persuasion, training, support, or incentives to use HealthSpace; and (4) flawed timing—people were not ready for this type of PHR. In a similar vein, Nazi (2013) notes: “despite high consumer interest in PHRs and growing availability, a paradox exists in that adoption remains relatively low overall”. Nazi (2013) argues that the consumer (patient) perspective on PHR is insufficient to understand this paradox. Accordingly, Nazi (2013) conducts an in-depth case study of My HealtheVet, a PHR developed by the US Department of Veterans Affairs, from the perspective of care professionals. The authors identify several key factors explaining the outcomes of the implementation, adoption, and use of My HealtheVet: namely, perceived relevance; perceived value; education and training; integrated with existing technology; alignment with workflow; incentives; access to information; and communication.

An alternative perspective to the study of PHR outcomes is proposed in the information infrastructure (II) literature. This literature defines an II as a shared, evolving, open, heterogeneous large-scale socio-technical system compromising an installed base of IT capabilities and their users, operations, and design communities (Hanseth and Lyytinen 2010; Tilson et al. 2010). The II literature develops an alternative approach to the design of large-scale complex system such as PHRs. This literature suggests viewing II design as the bootstrapping of the socio-technical installed base (Hanseth and Aanestad 2003). In particular, bootstrapping involves starting with a simple, cheap, and flexible solution that addresses specific user needs and enables users to enrol gradually. Hence, the bootstrapping of an II leads to the generation of self-reinforcing dynamics that feed on the installed base and enable the II to grow. For example, as the installed base of users (e.g., doctors and patients) using a PHR grows, more value will be created for existing users (feeding on the installed base) and more users will find adoption worthwhile (growing the installed base). Accordingly, some II studies propose a set of design principles and rules for II bootstrapping (Aanestad and Jensen 2011; Hanseth and Lyytinen 2010). At the core of these design principles is the idea that certain aspects of II architecture can spur the generation of positive feedback loops involved in II bootstrapping. Drawing upon insights from this literature, the goal of this paper is to explore the constraints that PHR architecture can pose on bootstrapping.

We approach this research goal by conducting a longitudinal case study of the genesis, design, implementation, and evolution of a PHR (which we have termed RegPHR) that was im-
implemented in a Spanish regional public healthcare system. RegPHR is an integrated PHR (Tang et al. 2006) that interconnects health data from multiple providers. In 2013, four years after it had gone live, RegPHR still had a marginal user base and there was only limited evidence of positive feedback loops. The question that guided our empirical study was: which aspects of the RegPHR architecture constrained the generation of positive feedback loops and ultimately inhibited the bootstrapping of RegPHR?

In addressing this question, this paper contributes to the literature on personal and electronic health record systems in several ways. It explains the low uptake of PHRs by showing the potential constraining role of PHR architecture on the generation of positive feedback loops. It identifies a set of architectural constraints that concur and extend the list of factors inhibiting PHR adoption that has identified prior literature (Greenhalgh et al. 2010; Lafkin and Horan 2011; Nazi 2013; Noblin 2012). Moreover, since our case narrative tracks the changes of the architecture, our results account for the viewpoints of diverse actors. Our results also contribute to those studies that have analysed the relations between electronic health records and personal health records (Archer et al. 2011; Wang et al. 2012). We show how certain architectural features conditioned the behaviour of doctors and ultimately negatively impacted on the value of health records for doctors and patients. Finally, we draw some lessons from our analysis of the case results against the design principles for II bootstrapping (Aanestad and Jensen 2011; Hanseth and Lyttinen 2010).

The remainder of the paper is as follows. We begin by providing definitions of the central concepts of the paper. We then present the method, including the research approach and setting, data collection, and analysis. We then present the narrative for the case study. This section is followed by an analysis and discussion of the case results. The paper concludes with a reflection on the contribution of our findings.

2 Literature background

EU policymakers have defined the need for radical improvements in the way people manage and receive healthcare (EU 2012). The realization of such a vision requires a transition from provider-centred healthcare towards patient-centred care (Vikkelso 2010). A lever for that transition is the deployment of comprehensive, integrated PHRs (Steele et al. 2012; Tang et al. 2006) that give citizens access to their own health information stored in the electronic health record of health providers, or in the nationally-held summary care records. As Greenhalgh et al. (2010) comment: “personal electronic health records, managed by patients and interfacing with clinician held records, are seen as having a key role in the new care model, by facilitating storage and exchange of information, promoting engagement with self-management, and supporting continuity of care” (p.1). That is, PHRs are expected to empower patients and extend their role in the healthcare system (Pelzang 2010). Accordingly, PHRs as a subject of study is increasingly gaining the attention of researchers (Archer et al. 2011).

In line with some studies in the PHR literature (Greenhalgh et al. 2010; Lafky and Horan 2011), our paper is concerned with the relation between aspects of PHR design (e.g., architecture, functional capabilities, security) and the outcomes (e.g., adoption, use, outcomes, benefits)
of PHRs. However, unlike prior PHR literature, we explore such relation by drawing upon the information infrastructure (II) perspective (Hanseth and Lyytinen 2010). We conceive integrated PHRs as healthcare IIs. We broadly define integrated PHRs as shared, heterogeneous and open socio-technical systems that interconnect multiple electronic health and medical records, practices, actors, visions, interests, and so on. Integrated PHRs are complex because a given individual may have visited multiple health providers during the course of a lifetime thus health data is distributed throughout many different systems and usually under different formats. PHRs are open as they must support a number of care management tasks that have not previously been performed by most people; and so the services and communities that can be added to PHRs may evolve in unexpected ways.

A core characteristic of IIs, and in turn PHRs, is that they are not designed from scratch but from the socio-technical installed base. In that sense, Hanseth and Aanestad (2003) conceive the design of IIs as bootstrapping. They use the concept of bootstrapping to refer to the “design process taking as its starting point the challenge of enrolling the first users and then drawing upon the existing base of users and technology as a resource to extend the network [II]” (p.386). The concept of bootstrapping assumes that the design of IIs is path dependent and involves self-reinforcing dynamics that feed the installed base of the II—that is, bootstrapping involves positive feedback loops (Hanseth and Lyytinen 2010). For instance, as doctors publish health data and informational services that patients regard as valuable in the PHR, more patients are likely to adopt it, and this in turn will likely stimulate doctors to use the PHR to interact with patients—thus giving rise to a positive feedback loop process that will help the PHR to bootstrap.

Taking into account the relation between positive feedback loops and II bootstrapping, Hanseth and Lyytinen (2010) propose three design principles that specifically address the bootstrap problem: 1) design initially for usefulness; 2) draw upon existing installed base; and 3) expand the installed base by persuasive tactics. These three design principles help designers “to create a self-reinforcing installed base by drawing upon existing ones, and avoid being trapped by the force of the installed base” (p. 15). Aanestad and Jensen (2011) extend this theory by suggesting the principle of ‘modularize the II’ for the bootstrap problem because this approach facilitates the mobilization of stakeholders. In particular, they argue that “modular implementation strategies can bypass, or at least significantly reduce the challenges to stakeholder mobilization…, and can allow a decoupling of implementation activities so that actors can adopt partial solutions relatively independently” (p.173).

Despite the fact that II architecture stands at the centre of these design principles, existing studies that have drawn upon this four design principles in the analysis of their empirical results (Aanestad and Jensen 2011; Eriksson and Goldkuhl 2013; Jensen 2013) have not brought the II architecture to the foreground of their analysis. By architecture we mean the basic inner structure of the II – i.e., its technical components such databases, software applications, hardware, communications, and so on, how they interact to provide the overall functionality of the II, and the decision rights over them. In the context of PHR, the architecture broadly refers to how the technical components of the PHR address the storage, and access of health data and the management of the health practices (Steele et al. 2012; Tang et al. 2006). For instance, Steele et al. (2012) identifies five PHR architectures (portable storage-based PHR, smartcard-based PHR, mobile device-based PHR, remote server-based PHR, and hybrid PHR) based on two infrastructural drivers (the connectivity coverage, which impacts the physical location of data,
and ubiquitous technology, which deals with issues such as whether its storage device is fixed or portable, and the hardware requirements).

Henfridsson and Bygstad (2013) identify three positive feedback-loop processes of IIs which are partially dependent on the type of II architecture (either tightly or loosely coupled) and governance (decentralized vs. centralized control): innovation; adoption; and scale. With the innovation positive feedback loop “new products and services are created as infrastructure malleability spawns recombination of resources.” (p. 918). Adoption is a positive feedback loop “by which more users adopt the infrastructure as more resources are invested to increase the usefulness of the infrastructure.” (p. 918). Scale is a positive feedback loop “by which an infrastructure expands its reach as it attracts new partners by creating incentives for collaboration” (p. 918). These three positive feedback loops can be combined to form configurations. In a review of 41 cases of II evolution, Henfridsson and Bygstad (2013) identify two configurations that correlate with the success of IIs: adoption, innovation and scaling; and adoption and scaling. The authors also find that while cases in the first configuration were characterized by loosely coupled architecture, cases in the second configuration were characterized by tightly and loosely coupled architectures.

In a study of ten healthcare IIs over the last 20 years, Hanseth and Bygstad (2014) identify two main architectural approaches: 1) the application centric/institutional interface (INA) architecture; and 2) communication system centric/service provider (SPA) architecture. An II based on INA architecture is built by extending the applications containing the actual information (application centric) through communication modules for handling information exchange. Moreover, the INA architecture mirrors the organizational structure created by the information flows between the organizations involved. In that sense, an INA architecture is characteristic of the EDI paradigm in which “there is a tight coupling between each application and the [communication] module handling the information exchange for this particular application and a looser coupling between the various modules handling the information for the various applications” (p. 18). In contrast, with SPA architecture there is “a loose coupling between the applications and the communication system and a tighter coupling between the various communication modules” (p. 18). Applications with SPA architecture are integrated according to “an asymmetric pattern where the II is established to enable some organizations to deliver their services to others in a more efficient way. And the communication system is more tightly integrated to the systems of the service providers than those of the service consumers.” (p. 18). The authors found that while the IIs following SPA architecture were all successful, the IIs under INA architecture were more problematic. The authors show that IIs based on INA architecture were characterized by complex technical solutions, complex project organization, escalating complexity, and a freezing of user practices (thus discouraging innovation).

In line with these studies, we conceive the generation of positive feedback loops that lead PHRs to bootstrap as contingent upon the architecture of the PHR. However, while these studies have mainly focused on the enabling role of architecture, we explore its constraining role. In particular, we study how architecture can pose constraints on the generation of feedback loops; and ultimately inhibit the growth of the installed user base.
3 Research approach and setting

The research approach was a single longitudinal exploratory case study (Yin 2009). We adopted this approach given that there is no established theory for studying the relationship between PHR architecture and the generation of positive feedback loops that drive PHR bootstrapping. We conducted a longitudinal case study of the design and implementation of a PHR (that we have termed RegPHR) from 2009 to 2013. RegPHR was launched in 2009 by the health and social security department of a Spanish region. Four years after the launch, the user base was still not relevant (RegPHR had not already bootstrapped). In this sense, this is a unique and revelatory case (Yin 2009) for studying our research problem.

3.1 Research site

There are several levels in the public healthcare system of this region (primary care as the gateway to the healthcare system; specialized care; hospital care; socio-sanitary care; and mental health) involving four main actors: the department of health and social security; the regional health service; health providers; and citizens.

The department of health and social security (DHSS) is in charge of establishing health policies and maintaining levels of quality in delivery by creating a health plan, determining a healthcare budget, and accrediting providers. The regional health service (RHS) performs the insurance function, and is responsible for planning, purchasing, and assessing health services according to the health needs of the population. The RHS establishes service policies in line with the health policies defined by the DHSS. The health providers are those organizations that the RHS contracts to provide care services. Those health providers form a network of institutions with public, private, or mixed ownership. When the development of RegPHR started there were 61 health providers managing 365 primary care centres and 69 hospitals.

3.2 Data collection

Qualitative data was collected over a two-year period (2011-2013). We collected data from several sources (semi-structured face-to-face interviews, statistics about adoption and use of RegPHR, workshop attendance, videos from workshops, and conferences presenting RegPHR, working documents, press articles, and professional articles) aiming at data triangulation (Yin 2009). Most of these documents were publicly available. Moreover, the first author registered for RegPHR and used it from 2011 to 2013.

We conducted 26 interviews in two periods (see Table 1). Each interview lasted between 60 and 90 minutes. Interviewees were identified mainly by snowball sampling (Miles and Huberman 1994); that is, identifying subjects for inclusion in the sample by referral from other subjects. In the first period, we conducted 17 interviews. In those interviews we asked our informants about their opinion of RegPHR and its evolution, the events they thought were most critical, and their role in those events. When the informants had knowledge about the design issues of RegPHR we asked them to relate those events with the design of RegPHR. Each in-
terview was transcribed verbatim and analysed immediately after it was conducted so that data collection and analysis took place iteratively.

We came back to the field two years later (from March to June 2013) to gather more data about the evolution of RegPHR. At that time, the adoption rate of RegPHR was still unsatisfactory for its sponsor. We conducted nine additional interviews. The informants included five people who were at the core of the implementation of RegPHR and the shared electronic health record (SEHR) for the regional health service. In those interviews we inquired about the evolution of the adoption rates of RegPHR and SEHR, the reasons for such unsatisfactory outcomes, the decisions and actions taken to spur the adoption of RegPHR and SEHR, and the motivations for those decisions and actions.

<table>
<thead>
<tr>
<th>Interviewees</th>
<th>Period 1 (March - June 2011)</th>
<th>Period 2 (March - June 2013)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Third-party providers of health applications</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Project managers of RegPHR</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Coordinator of health IT at the DHSS and sponsor of RegPHR</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Former coordinator of health IT at the DHSS and sponsor of RegPHR</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>IT security manager at the DHSS</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Consultant of RegPHR project</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>CIO of a health provider</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Responsible of the standards and interoperability office at the DHSS</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

Table 1. Summary of interviews for each period of data collection

### 3.3 Data analysis

Data analysis proceeded in three steps. Firstly, with all the data gathered we constructed an initial timeline of events for RegPHR, and created a first thick descriptive narrative of the case. We shared that narrative with three of the informants who were at the core of the team managing the RegPHR project (the two project managers, and the coordinator of health IT at the DHSS who had sponsored RegPHR) to check for validity (Yin 2009). The three informants mostly agreed with our interpretation about the evolution of RegPHR, but suggested minor changes that were incorporated within the narrative.

Secondly, we analysed the lack of bootstrapping depicted in the narrative through the analytical lens of the feedback loops. To identify feedback loops we started by identifying the list
of interventions from the managers and designers of RegPHR and SEHR (e.g., the extension of RegPHR with a new service, the start of the roll-out phase, development of an API, development of iPhone access for RegPHR, the extension of RegPHR with new users, the enrolment of a new health provider, the approval of a norm, the redefinition of a contract between a health provider and the regional health service, and the upgrade of a system). We analysed the motivations and rationale behind these types of interventions to see which positive feedback loops they were supposed to spur. This led us to identify five positive feedback loops that managers and designers of RegPHR and SEHR expected (see Table 2). We also analysed the actors that were supposed to be involved and affected by the positive feedback loops. It can be observed that there were positive feedback loops involving the same type of actors (doctors or patients in the first and third feedback loops respectively) and others involving different types of actors (second, fourth, and fifth feedback loops).

<table>
<thead>
<tr>
<th>Feedback loop (expected by managers of RegPHR and SEHR)</th>
<th>Actors</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The more health providers (doctors) publish patient health data in SEHR (the regional shared electronic health record), the more doctors will be willing to access SEHR in their daily practices</td>
<td>Health providers / doctors</td>
</tr>
<tr>
<td>2. The more the health providers (doctors) publish patient health data in SEHR, the more patients will find it valuable to use RegPHR; and in turn, the more patients that use RegPHR, the more doctors will see the value in publishing data in SEHR</td>
<td>Health providers / doctors, patients</td>
</tr>
<tr>
<td>3. The more patients use the services of RegPHR that enable them to interact with other patients or generate content, the more attractive RegPHR will become for existing users (patients) and new patients</td>
<td>Patients</td>
</tr>
<tr>
<td>4. The more patients use RegPHR, the more easily RegPHR management will be able to raise more resources to innovate new services for patients, and in turn, those new services will attract more users</td>
<td>Patients, RegPHR developers</td>
</tr>
<tr>
<td>5. The more open is RegPHR, the more third-party developers will be willing to publish their applications in RegPHR. The more healthcare applications that are available in RegPHR, the more patients will find it valuable to use RegPHR. The more patients that use RegPHR, the more third-party developers will be interested in developing healthcare applications for RegPHR.</td>
<td>Patients, third-party application developers</td>
</tr>
</tbody>
</table>

Table 2. (Expected) feedback loops and actors involved

In the third step, we analysed the relationship over time between those unrealized five feedback loops and the architecture of RegPHR and SEHR. We identified four themes that explain how the architecture constrained the activation of these positive feedback loops. We discussed with two of the core informants the expected positive feedback loops and the four architectural constraints. In that way, we established the validity of our interpretation (Yin 2009). Once we had a clear picture of the causal processes relating the architecture to the feedback loops, we wrote a
narrative of the historical implementation of RegPHR that integrates the feedback loops and architecture. The following section presents the narrative covering a five-year period (2008-2013). The narrative is organized into three phases: genesis; pilot and rollout; and opening.

4 Case narrative

4.1 Phase 1: Genesis of RegPHR

RegPHR is a web-based personal health record through which the health and social security department (DHSS) gives citizens secure and confidential access to their health data (generated in the public healthcare system). The health data that appears in RegPHR comes from SEHR, a shared electronic health record (SEHR) for the regional public healthcare system that was launched in 2008. SEHR interconnected all the electronic health record systems of the healthcare institutions providing services in the region.

The main goal of SEHR is the improvement of healthcare delivery services by means of sharing health information among doctors from different health providers. SEHR was neither conceived as the sum of the EHRs of the health providers, nor as a way to replace the EHRs of providers, but as a system to organize access to health data stored in the electronic health records of providers and in some DHSS databases. SEHR consisted of a central database working as an index or a repository of documents that gives doctors and general practitioners access (through a web browser) to the information in the EHRs of the diverse providers (see Figure 1). The information displayed in the browser is the following: socio-demographic data regarding the citizen; documents or reports (radiology, laboratory, therapeutic procedures, hospital release, and emergency room); diagnostics; prescription and immunization; and so on. Likewise, SEHR provided a set of tools for direct messaging between health professionals to facilitate their cooperation. In June 2008, 15 hospitals, 292 primary care centres, and 22 centres of special care were connected to SEHR – i.e., they were ready to publish and access information from SEHR. By September 2009, SEHR contained 12 million health reports corresponding to 6.8 million citizens and 5,689 doctors had accessed the system. In June 2013, 93% of hospitals and 87% of primary care centres were connected to SEHR.

Another relevant principle for SEHR was that the citizen is the owner of his data, and has direct access to the data. According to this principle, SEHR served as a basis for the building of RegPHR. A main vision behind RegPHR is to give people responsibility for their own health, enabling them to take part in the management of the preventive actions and care, and improve the quality of care and coordination between health areas and professionals. RegPHR has no central database. It acts as a viewer of SEHR. All the information presented in RegPHR comes from SEHR. Information for citizens is presented in a web browser (that has same feel-and-look as the browser that doctors use to access SEHR).

The registration and authentication processes for RegPHR were designed as follows. To access RegPHR citizens have to enter their personal identification code and use a digital certif-
icate. There are two types of valid digital certificates: those issued by the regional certification agency; and the certificate embedded in the national identity number. To obtain the first type of digital certificate citizens have to first fill an online form, next they have to physically visit a registration agency where their identity is checked and they are given a password. Citizens later use that password to download the digital certificate from the website of the regional certification agency. During authentication, RegPHR checks in the database of insured citizens that the personal identification code corresponds with the identity number contained in the digital certificate, and that the citizen has the right to access data.

![Figure 1. Architecture showing the relation between SEHR and RegPHR](image)

### 4.2 Phase 2: Pilot and rollout of RegPHR

After a satisfactory pilot of RegPHR in 2009 with a group of ninety users, the managers of RegPHR decided to release the system in July 2010 in the same village (having about 20,000 inhabitants) where the pilot was run. The first release of RegPHR included two main types of services: health data from SEHR (e.g., diagnostics, vaccines, and reports such as ambulatory care, hospital emergencies, and hospital admission) and access to administrative services that the DHSS already offered through other portals.

The rollout involved the cooperation and engagement of several local actors: the only health provider operating in that village; the city council that was in charge of communicating RegPHR to the public; and other local organizations (one of which issues digital certificates). Managers of RegPHR considered that the rollout strategy did not require many resources from the DHSS, and it ensured the involvement and commitment of the actors in the territory who were close to citizens. Moreover, the sponsor of RegPHR qualified such a rollout strategy as “low profile”: “we started with this very restricted concept of a personal health folder in the sense that it was a collection of documents that were already in the shared electronic health record [SEHR]”. The sponsor considered that it was important to adopt a strategy that minimized frictions and
conflicts since RegPHR entailed profound changes in the role and relationships between doctors and patients, and between doctors themselves.

Following this rollout strategy, RegPHR was extended to other two villages (next to the first village) and where the same health provider was operating. However, the usage of RegPHR was still marginal. For instance, in March 2011 around 47,000 citizens had access to RegPHR, but only 190 citizens had accessed the system with a total number of 721 accesses since July 2010 (nearly nine months after the rollout had started). The managers of RegPHR then broadened the rollout strategy. Firstly, they extended RegPHR to other health districts where other health providers operated, and to other groups who were independent of any given territory (e.g., blood donors). Secondly, they built an iOS app for iPhone to access RegPHR, and extended RegPHR with new information services from other systems of the DHSS (e.g., the medication plan that was in the electronic prescription system) (see Figure 2). By mid-2012 nearly 90,000 citizens could access RegPHR – but barely 500 citizens had logged on and used RegPHR. By the end of 2012, the DHSS announced the deployment of RegPHR to everyone in the region (about 7 million people).

![Figure 2. Extension of the RegPHR architecture](image)

**4.3 Phase 3: Opening RegPHR**

At the end of 2011 the RegPHR managers decided to open the system to third-party applications that were not owned or controlled by the DHSS. The idea was that citizens could personalize RegPHR with the health applications they were already using. This opening strategy entailed transforming RegPHR into a platform for third-party applications. To achieve this, the managers of RegPHR set up an interoperability framework that defined the conditions for third-party applications to interoperate with RegPHR. Companies that wanted patients to ac-
access their applications through RegPHR would have to fulfil certain conditions and obtain recognition/approval from the DHSS. The interoperability framework consisted of four profiles (see Figure 3): identification (in order to guarantee a single sign-on from the citizen for the RegPHR and the third-party application); communication (so that third-party applications can access relevant patient information stored in RegPHR/SEHR); publication (the third-party publishes a set of services that citizens will see in RegPHR; patients can access those services directly by means of an app embedded in RegPHR or an URL); and portability (a set of conditions to ensure that personal health data stored by the third-party application can be moved, if the citizen desires, to other third-party applications). Each of these profiles defined a set of messages that RegPHR and the third-party application must exchange. With the deployment of the interoperability framework, the DHSS would not develop new applications but would partner with those third-party application providers who offer their services through RegPHR. The DHSS would control the content and the application of the interoperability framework.

Figure 3. Extension of the architecture to ensure the interoperability with third-party applications

The DHSS targeted firms providing applications for monitoring diabetes in 2012. The managers of RegPHR took advantage of the fact that the major health provider was tendering for the supply of test strips for the following years. The DHSS asked the health provider to include compliance with the interoperability framework as a bid condition. From that moment, the interoperability framework became an obligatory passage point (Callon 1986) for providers of devices for the treatment of diabetes who wanted to access the public healthcare market. The DHSS targeted firms providing applications for the management of chronic obstructive pulmonary disease in 2013. Three companies had obtained recognition from the DHSS by May
2013. Although these three providers complied with the interoperability framework, patients could still directly access the application for monitoring diabetes and did not have to go through RegPHR.

5 Analysis

5.1 Generation of feedback loops

This section depicts the feedback loops (Figure 4) that were supposed to be generated in the three phases of the case narrative. As shown in the first phase of the case ‘genesis of RegPHR’, RegPHR was initially conceived as a two-sided network built on top of SEHR: (1) health providers would publish the data into SEHR; and (2) patients would access some of that data (e.g., diagnostics, vaccines, and reports such as ambulatory care, hospital emergencies, and hospital admission) through RegPHR (RegPHR would filter and bundle that data to offer information services for patients). Feedback loops were supposed to be generated on the side of health providers (first loop of Figure 4) and across patients and health providers (second loop of Figure 4). For instance, the more health providers (doctors) published information in SEHR, the more doctors would be motivated to use SEHR (first loop). For that purpose, SEHR management: 1) created a simple browser for doctors; 2) persuaded health providers to publish data to SEHR and doctors to access SEHR; and 3) developed APIs so that health providers could easily integrate the data from SEHR into their systems. The more health records published in SEHR, the more likely that patients would perceive value in using RegPHR; and the more patients using RegPHR, the more doctors and health providers would see the value of publishing data in SEHR (second loop).

In the second phase ‘pilot and rollout of RegPHR’, the sponsors of RegPHR aimed to strengthen the generation of the second type of feedback loops (Figure 4). RegPHR management adopted several measures to spur the third feedback loop (Figure 4); that is, the more patients participating in those online communities, the more value for the existing patients, and the more other patients would be willing to adopt those services. Health providers, city councils, and other local institutions were involved to reach citizens. An iPhone app to access RegPHR was created, access to RegPHR was opened to blood donors, the medication plan and other administrative services were incorporated, and associations of patients were enrolled and asked for feedback regarding new services. Moreover, the more patients that used RegPHR, the more able RegPHR management would be to raise more resources and innovate with new services for patients (fourth loop of Figure 4).

In the third phase ‘opening RegPHR’, given that the adoption rate of RegPHR was still irrelevant by the end of 2011, RegPHR was extended into a three-sided network: health providers who publish health data; third-party application providers who publish their services; and patients who access health data and use the services. This was achieved by setting up an interoperability framework that transformed RegPHR into an open and extensible platform. This
was supposed to be a key to driving RegPHR uptake, and hence, to drive a new type of positive feedback loop: new applications offered by third parties through RegPHR would attract existing and new patients to use RegPHR, and that in turn, would stimulate more third parties to join (fifth loop of Figure 4). This would also stimulate the third and fourth feedback loops. Likewise, during this phase, the interoperability framework was included as part of the tender for the supply of test strips to spur the second feedback loop. By May 2013 a total of 4,664 citizens had accessed RegPHR since its inception and reports and diagnostics were the most searched information services. By that time, four years after RegPHR was launched in 2009, there was only limited evidence of the first positive feedback loop and managers of SEHR regarded this as insufficient; and there was very limited evidence for the second, third, fourth and fifth feedback loops (Figure 4).

![Figure 4. (Expected) positive feedback loops associated with RegPHR](image)

### 5.2 Architectural themes

This section presents four themes showing how certain aspects of the architecture of SEHR and RegPHR (e.g., location of the data, modularity, and degree of interface openness) constrained the generation of the five positive feedback loops (see Figure 4). Obviously, besides the architectural constraints there are non-architectural factors – e.g., project structure, available resources, governance, social practices, and legislation. Our analysis also takes into account the interactions of those non-architectural constraints with the architectural features. In Table 3 we relate the four architectural constraints with the affected feedback loops.
Theme 1: Poor data quality

RegPHR was designed to act as a viewer of SEHR (which was the only source of information for RegPHR). The flow of information went from SEHR to RegPHR, but not the other way around (see Figure 1). This was a constraint for the type of services that RegPHR could initially offer. Those services (e.g., diagnostics, vaccines, and reports such as ambulatory care, hospital admission, and release) relied on data stored in SEHR. The DHSS did not implement services such as doctor-patient messaging, online communities of patients, or enabled patients to upload additional health data since RegPHR did not have a database for that purpose.

The quality of data in SEHR (e.g., in terms of accuracy, completeness, and timeliness) determined the value of the RegPHR information services. Managers of the DHSS acknowledged that even though the number of health providers connected to SEHR was satisfactory, the behaviour of those health providers in terms of uploading or publishing information was unsatisfactory. Not every health record was immediately published and so the quality of health data on SEHR was not good enough. As doctors and citizens perceived poor quality, they gave up using SEHR and RegPHR respectively, thus generating a negative feedback loop – the poor quality of the data published at SEHR meant that doctors and citizens gave up using SEHR and RegPHR. In short, the dependence of RegPHR on SEHR resulted in a ‘garbage in, garbage out’ effect in which, the quality of the health data on SEHR determined the usefulness of RegPHR.

From the point of view of the DHSS, the low quality of the data on SEHR was due to the failure of health providers to upload data, not because they did not have such data. Health providers had the health data in their EHRs, but they did not properly publish it on SEHR. SEHR worked either as a repository of health data (health providers uploaded the health data of patients); or as an index (in which health providers published a link to the health data). In any case, the architecture forced health providers to upload health data or publish links (push from health provider to SEHR), which meant that the quality of SEHR, and in turn of RegPHR, depended on doctors and health providers. In reality most of the health providers used SEHR as a repository for upload health records, but did not publish links to those health records (with the exception of three providers). Some health providers who uploaded health records to SEHR did not like doing so because they claimed that created redundancy and a sense of loss of control. For instance, a CIO of a health provider running a major hospital and several primary health centres noted: “I want to keep the data on our systems. They [the DHSS] should come to search for the data in our systems.”

An option to address the data quality problem resulting from the misbehaviour of health providers was to implement a pull architecture in which SEHR would request data from health provider systems – and not the other way around. However, one of the arguments of the designers of SEHR against the pull architecture was that it required 24/7 availability by health providers. That could not be guaranteed due the differences of technological readiness of health providers and the amount of health providers. So the pull architecture was discarded. The option to address the data quality problem, which the DHSS and RHS finally chose in 2012, was to include clauses in the contracts with health providers\(^5\) obliging them to upload data under certain conditions of quality, detail, and time.
Theme 2: Coordination across heterogeneity

In the regional public healthcare system there is a great heterogeneity of health providers in terms of ownership, the type of services they deliver, and the territory where they deliver those services. It is normal that a patient visits a general practitioner in a primary care centre of one health provider, then the general practitioner refers the patient to a specialist of another health provider, and the patient then returns to the general practitioner for monitoring. Health providers need to coordinate their operations in order to provide integrated services. To address those coordination needs, health providers have long implemented mechanisms and practices to share health data. Obviously, those mechanisms and practices are local and support the coordination agreements that health providers have in place. For instance, a given primary care centre of a health provider has a given hospital of another health provider as a reference for specialized care, and accordingly, both centres set up a mechanism for sharing data which is only valid between them. These coordination mechanisms and practices mirror the territoriality of the provision of health services.

However, SEHR was designed as a general standard solution that would solve coordination needs among health providers for the whole territory. SEHR was supposed to be respectful of the EHRs of health providers as it acted as an index that kept the healthcare data distributed in the EHRs of health providers. However, SEHR neglected the mechanisms and practices that health providers had implemented on top of their EHR in order to solve those coordination needs. SEHR threatened those inter-health provider coordination mechanisms. For instance, we identified three types of scenarios that illustrate the tensions between SEHR and the mechanisms that were already in place.

In the first scenario, we found that health providers coordinated the provision of care services with other providers (for instance, because one delivers primary care services and the other offers specialized care in the same health sector) by defining mechanisms and practices to exchange and share health data (e.g., giving direct access to each other’s EHR). In this scenario, SEHR involved abandoning the cost-effective mechanisms to which health professionals had become accustomed. In the second scenario, we found cases in which diverse health providers had gone beyond the sharing of health data by giving direct access to each other’s EHRs, and have jointly created integrated EHRs to coordinate the provision of services in a given health sector. In this scenario, the health providers usually argued that SEHR added nothing to the integrated EHR they had in place. In the last scenario, the largest health provider, which operates in most health districts providing primary care and specialized care services, had already implemented an integrated EHR. This large health provider saw little value in using SEHR because its own EHR already fulfilled the coordination needs among their centres and between the different levels of care.

Moreover, two of the health providers that were interviewed noted that while the design of SEHR was oriented towards the document, their EHR and coordination mechanisms were usually oriented towards the clinical protocol and associated workflows. For the purpose of coordinating professionals at different healthcare levels or at the same level, an EHR oriented towards the protocol is supposed to be more effective that one oriented towards documents. As a response to this, in the regional health plan for the period 2011-2015, the DHSS defined as
a key project the extension of SEHR to include the clinical course of patients and the management of the clinical protocols for the eight chronic pathologies prioritized by the DHSS.

In short, territoriality of the provision of health services in the region was already supported by various heterogeneous mechanisms and practices that health providers had already implemented. Although SEHR might, from a technical perspective, be more effective and efficient in some cases because all the data would be centralized, it did not mirror the territoriality in the provision of integrated healthcare services. This discouraged health providers from uploading data to SEHR as they did not see much value in doing so – thus hindered the generation of the first positive feedback loop in Figure 4. This in turn, undermined the usefulness and value of RegPHR for patients as they did not always find all their health data on RegPHR—and this hampered the second feedback loop in Figure 4.

**Theme 3: Privacy and control**

All the informants of this research argued that the processes of registration and authentication were a major factor in the low uptake of RegPHR. They considered that these processes were cumbersome, particularly, taking into account that some health providers already offered online services for patients with much simpler authentication procedures. For instance, some health providers had long offered their patients a web-based system for booking appointments where patients identified themselves simply with the number on their individual medical card. However, the RegPHR registration and authentication processes were implemented following the recommendations of the regional data protection authority in 2009. Thus the regulatory framework constrained the design of RegPHR.

In 2012 RegPHR managers started to consider an alternative authentication mode for RegPHR, and they asked (again) the regional data protection authority about the need for a digital certificate—and this time they were told that a username and password was sufficient. As the former coordinator of health IT at the DHSS noted: “the last thing I did before I left [at the end of 2012] was to ask the regional data protection authority whether a digital certificate was still needed. Big surprise! It was no longer needed”. This would facilitate the registration and authentication processes and make RegPHR more attractive for citizens. However, this simpler process would generate additional tensions. Firstly, given the confidential nature of health data not all the sponsors of RegPHR were in agreement. Even some of the early citizen adopters of RegPHR, who were legitimized actors, opposed a lower level of security. The DHSS was considering using both two processes and letting citizens choose the desired level of security. Secondly, this simple authentication process would mean that the RHS (as the only insurer in the public healthcare system) rather than the regional certification agency would ensure the confidentiality of transactions by generating, storing, and maintaining usernames and passwords. This meant that the RHS would have to play an additional role, but that also meant more costs, which given the economic crisis and health budget cuts in Spain, increased the difficulty of changing the authentication process.
Theme 4: Re-configurability

A core objective of SEHR was to improve coordination among health professionals. A core objective of RegPHR was to help patients take more responsibility and control over their health (i.e., the self-management of health and disease). While the architecture of SEHR was designed to support the coordination of health providers (although with some shortcomings as shown in the first and second themes), the architecture of RegPHR constrained the realization of its vision because it did not meet patient needs. From the outset, RegPHR was conceived as a generic portal to access the health data of citizens. Such a conception can be explained by the circumstances of the genesis of RegPHR (i.e., to act as a viewer of SEHR), which forced sponsors of RegPHR to start with information services for citizens that could be provided by SEHR. Yet the realization of the vision of RegPHR required taking into account the heterogeneity of patients and their diseases, and health self-management practices that could take place outside the control of the DHSS. For instance, citizens could have health records with health providers that were not part of the public healthcare system, and these health providers would have to be willing to integrate all their health data in a single place. However, since RegPHR neither had its own database nor could store data at SEHR, patients had no means to upload and store their health data on RegPHR. RegPHR provided little support for their healthcare practices.

Managers started depicting RegPHR in public presentations in 2010 as a tool for self-care management and prevention by emphasizing the idea that RegPHR was evolving towards a customizable model. Patients were supposed to be able to personalize in the near future the type of services in RegPHR according to their profile and healthcare needs. However, with the exception of a few new services (such as access through iPhone and access to medication plans) the type of information services that citizens could use remained the same. One of the members of the core of the team managing the RegPHR and SEHR projects noted: “we realized that RegPHR could not simply be a viewer; rather it should feed information back and forth to patients, and hence citizens should be able to interact with RegPHR. But in March 2010 we were not ready to add this type of functionality. We could only offer a viewer for SEHR”. This quote shows that the mismatch between the vision and the architecture was not so much a design flaw but the result of aspects related with organization, governance structure, and project budgeting. For instance, in terms of project organization most of the members involved in RegPHR were also involved in SEHR. The person in charge of the functional aspects of RegPHR had 10% of her time assigned to RegPHR and 90% to the SEHR project. Moreover, the RegPHR project did not have a specific budget. It depended on the budget of SEHR. As the former coordinator of health IT at the DHSS and sponsor of RegPHR noted: “all the money has gone to SEHR; moreover, the total amount of money decreased, and this means that we could not transfer money to the development and extension of RegPHR”. Likewise, the initial rollout strategy of RegPHR mirrored SEHR in the sense that it was driven by health providers and not by patient needs. The information services provided by RegPHR were based on the information obtained from health providers rather than the needs of patients.

Given these architectural and non-architectural constraints, the DHSS tried to address what they considered were the needs of patients by opening RegPHR. The DHSS expected that the opening of RegPHR would spur the production of new services (by third-party application providers) that met patient needs, and hence would feed a positive feedback loop between patients
and third-party applications (fifth loop in Figure 4). To manage and govern that transformation from a two-sided to a three-sided network, RegPHR management set up an interoperability framework. The interoperability framework entailed a radical change in the strategy and role of the DHSS—and RegPHR became a gateway to other IIs (not only SEHR). Under the interoperability framework, the ownership and control of RegPHR started to separate. The DHSS gave up the ownership of new services that RegPHR offered but not the control. The DHSS kept control over RegPHR in terms of what can be offered, and more importantly, to whom it can be offered. For instance, third-party providers that obtain recognition from the DHSS cannot target new patients directly through RegPHR. Rather, they can publish their applications in RegPHR, and when a patient selects a third-party application for the first time, RegPHR checks online whether the patient has the right to use that service. However, when this study was conducted it remained to be seen whether events would unfold as expected.

<table>
<thead>
<tr>
<th>Architectural themes</th>
<th>Feedback loops negatively affected by the architecture</th>
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<tbody>
<tr>
<td><strong>Theme 1: Poor data quality</strong></td>
<td>In response to poor quality data published in SEHR, doctors (first feedback loop) and patients (second feedback loop) gave up using SEHR and RegPHR. As fewer patients used RegPHR, managers of RegPHR had less capacity to raise resources to innovate new services for patients (fourth feedback loop).</td>
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<td><strong>Theme 2: Coordination across heterogeneity</strong></td>
<td>Since SEHR did not fully support the coordination of the provision of care services between health providers, doctors did not perceive much value in using SEHR (first feedback loop). This behavior was detrimental for the quality of health data uploaded to SEHR and hence to the value of using RegPHR for patients (second feedback loop), and the capacity of RegPHR management to innovate new services for patients (fourth feedback loop).</td>
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<td><strong>Theme 3: Privacy and control</strong></td>
<td>The registration and authentication processes and mechanisms discouraged citizens from accessing RegPHR (second and third feedback loops), and in turn, diminished the capacity of RegPHR management to raise additional resources to innovate new services for patients (fourth feedback loop).</td>
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<tr>
<td><strong>Theme 4: Re-configurability</strong></td>
<td>The fact that RegPHR was initially conceived as a viewer of SEHR, which patients could not personalize to their needs, discouraged the latter from using it (second and third feedback loops), and this in turn, hindered the capacity of RegPHR management to innovate new services for patients (fourth feedback loop). Likewise, since patients could not personalize RegPHR, third-party healthcare application providers had little incentive for interconnecting (and offering) their services to RegPHR (fifth feedback loop).</td>
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Table 3. Architectural constraints on the feedback loops
5.3 Architectural constraints and design principles

The section analyses the four architectural constraints on the generation of positive feedback loops presented in the previous section against the four design principles for II bootstrapping proposed by Hanseth and Lyttinen (2010) and Aanestad and Jensen (2011).

The principle ‘design initially for direct usefulness’ relates to the identification and targeting of a small group with an IT capability that is useful, simple to use, and easy to implement. RegPHR (as shown in the re-configurability theme) was conceived as a generic solution for the health needs of all the citizens in the region. Such a conception can be explained by the underlying vision of the genesis of RegPHR (i.e., as a viewer of SEHR), which forced sponsors of RegPHR to start with some basic information services provided by SEHR for all potential users. The sponsors of RegPHR later narrowed the base of users and started thinking about specific groups (e.g., blood donors and diabetics). Yet this new approach to the user base was still limited because RegPHR and SEHR were highly interdependent in terms of architecture, project organization, and budget. Secondly, the theme privacy and control shows that despite RegPHR developed new services (e.g., medication plan) and access channels (e.g., mobile phones), the processes of registration and authentication were cumbersome and unfamiliar. The sponsors of RegPHR were aware of this fact and justified these processes as legal requirements. However, even after some regulatory changes that simplified these processes, there were discrepancies among the RegPHR management team about the level of security that was needed. Finally, as shown in the ‘poor data quality’ theme, the services offered until the end of this study by RegPHR were of the one-to-many type (e.g., reports, diagnostices, vaccines, and medication plans). This approach followed the suggestion of designing one-to-many capabilities in contrast to all-to-all capabilities (Hanseth and Lyttinen 2010). This approach is supposed to be effective as one-to-many services do not need to reach a critical mass to become quickly adopted; that is, the fact that a patient uses any of these services does not directly generate more value for other patients. However, when we look at the tight coupling between SEHR and RegPHR we can regard the services offered by RegPHR not as one-to-many type but as of a many-to-many type. The value of RegPHR depended on doctors using SEHR. Hence, since not all health providers uploaded all their patient health data (or did so with a delay), doctors saw little value in using SEHR, and that ultimately diminished the usefulness of RegPHR for patients.

The design principle ‘build upon the installed base’, advises building connections with the installed base during the design time by for instance, building gateways to existing infrastructure. The theme ‘coordination across heterogeneity’ shows that the SEHR design ignored the installed base of systems and mechanisms that health providers had in-place to coordinate their cross-organizational activity. SEHR architecture displaced this installed base. On the other hand, as shown in theme ‘re-configurability’ RegPHR could be seen as a gateway to SEHR. Yet as RegPHR was not a gateway to other systems used by patients, it did not meet the patients’ individual needs. The opening strategy adopted in 2012 for RegPHR tried to link RegPHR with other installed bases of patients. Yet it remains to be seen whether this strategy will bring results. The design principle of ‘expand the installed base by using persuasive tactics to gain momentum’ suggests that the user base should grow before adding new functionality. RegPHR management partially followed this design principle by targeting some communities (e.g., blood donors and diabetics) but the governance model did not foster enough feedback and learning. For instance,
the initial strategy for the roll-out involved relevant actors in the territory (e.g., city council and health providers) and was expected to persuade patients (citizens) to use RegPHR. However, this rollout strategy was unsatisfactory and very slow given the number of health providers in all the health districts. For this reason, RegPHR management abandoned this strategy and opted for extending RegPHR to all regional citizens (about seven million).

Finally, the design principle ‘modularize the II’ assumes that complex capabilities limit the capacity of IIs to grow adaptively and re-organize constantly. Accordingly, this principle aims to allow independent incremental change by modularizing – i.e., decomposing the functionalities into loosely coupled components and defining interface specifications for how others should interact with those components. Despite the fact that the architecture of RegPHR and SEHR were both modular, RegPHR did not bootstrap. We provide an explanation for that outcome by considering the upward and downward flexibility of the PHR (Tilson et al. 2010). In our case, RegPHR possessed upward flexibility as it was open to the provision of new services by third parties (by means of the interoperability framework and set of web services). On the other hand, although SEHR provided a set of web services for RegPHR, SEHR was the only data provider for RegPHR. Hence, we can say that RegPHR did not possess downward flexibility. In short, even though RegPHR architecture was modular, the fact that it did not possess much downstream flexibility eroded the possible benefits of modularity.

6 Implications and conclusions

In this paper we empirically investigated from an architectural perspective the genesis, design, implementation, and evolution of an integrated PHR (Tang et al. 2006) that had not bootstrapped after four years (2009-2013). Our results contribute to the literature on PHR in several ways. Firstly, to our knowledge, this paper is the first to study the failure of a PHR to bootstrap by focusing on how the PHR architecture hindered the generation of positive feedback loops. Secondly, existing PHR studies have identified lists of factors (e.g., flawed design and conceptualization of the PHR, excessive integration between the PHR and the EHR, access to information, lack of security, and privacy standards) that enable and inhibit PHR adoption from the perspective of healthcare professionals (Nazi 2013), patients (Lafkin and Horan 2011; Noblin et al. 2012), or both (Archer et al. 2011; Greenhalgh et al. 2010). Our four architectural themes concur with some of the factors captured in the literature. For instance, in line with the results of Greenhalgh et al. (2010), we show that the PHR architecture did not align well with the patient healthcare management needs (‘re-configurability’ theme), and with the access mechanisms (‘privacy and control’ theme). However, in line with the II perspective, our narrative removes the actors from the centre stage and focuses instead on wider dynamics that extend beyond what is observable from the point of view of a single actor. Our results refer to features of the PHR architecture that inhibited the uptake of the PHR by hindering the generation of positive feedback loops. By tracking the changes on the architecture our results account for the diverse interests and viewpoints of actors that are part of the PHR: health provider organisations, doctors, nurses, patients, and health authority.
Thirdly, existing literature has advocated integration between EHR and PHR. In particular, after reviewing the literature on PHRs, Archer et al. (2011) find that “because primary care doctors play a key role in patient health, PHRs are likely to be linked to physician electronic medical record systems, so PHR adoption is dependent on growth in electronic medical record adoption,” (p. 515). Our empirical results are in line with this finding. Since RegPHR was a viewer for SEHR, the quality of the data in RegPHR depended on the quality of the data in SEHR. We also show how certain architectural features of the EHR (e.g., push architecture, not mirroring the structure of the field) conditioned the behaviour of some of the health providers as the quality of the health data (in terms of completeness and timeliness) that they published was not adequate. That resulted in a garbage-in, garbage-out effect that negatively impacted on the quality of the interactions between patients and doctors (Epstein et al. 2010) thus diminishing the value of the EHR and the PHR for other doctors and patients.

Wang et al. (2012) go further to suggest that: “For EHRs and PHRs to become effective tools for clinicians and patients, they must merge into an all-in-one record, in which each party has control over updating a separate part” (p. 570). In our study, although the SEHR and RegPHR had a unique database (thus following the recommendation of all-in-one record), only health professionals had control over that information. Patients could not upload health data from other health sources, nor personalize the kind of services they could use from RegPHR. This also connects with our fourth architectural theme of re-configurability. Specifically, we have shown that the differences between the vision of the EHR and the PHR (the first oriented towards coordination, and the second oriented towards enhancing patient responsibility and control to foster patient self-management) have important consequences for the architectural approach. Both visions require different functionalities, services, and architectural features, which cannot be easily reconciled when the PHR is conceived as a viewer of the shared EHR. Such a conception limits the capacity of the PHR to cater to heterogeneous and evolving patient health needs. We argue that preserving the transformative capacity of PHRs (Grisot and Vasilakopoulou 2013) requires keeping some degree of autonomy of PHRs versus shared EHRs.

From our assessment of the four architectural themes against the four principles for II design proposed by Hanseth and Lyytinen (2010) and Aanestad and Jensen (2011), we draw two lessons. Firstly, our analysis shows that those design principles were partially followed; some decisions and interventions from the designers complied with those principles – while others deviated from them. However, the degree of compliance with those design principles varied over time. This leads us to argue that the application of the design principles must consider not only the context as Jensen (2013) suggests, but also the dynamic nature of designers’ decisions and interventions that may often change during evolution of the II. Secondly, while Aanestad and Jensen (2011) provided empirical evidence for the relation between the modularity of IIs and their bootstrapping, our empirical results complement that evidence by suggesting that in the assessment of the modularity of IIs, one must also consider the upstream and downstream flexibility of II architecture. The idea of upstream and downstream flexibility highlights the degree of coupling of IIs and the associated tensions that might be generated (Tilson et al. 2010). As we saw in our case, although the architecture of RegPHR and SEHR was modular, RegPHR did not possess much downstream flexibility because it was highly dependent on data from SEHR. Such a lack of downstream flexibility ultimately hindered the generation of feedback loops. Based on our empirical results, we conjecture that in the context of integrated PHRs, the lack of
downstream flexibility is likely to erode the possible benefits of modularity claimed by Aanestad and Jensen (2011).

Similarly, our study connects and extends previous work on II architecture by Hanseth and Bygstad (2014). Through a study of ten healthcare IIs in Norway over the last 20 years, Hanseth and Bygstad (2014) characterize two types of architectural approaches based on the degree of coupling between the applications and the communication modules, and the communication modules themselves. The authors describe the first type of architecture as INA (application centric/institutional interface) and state that the corresponding IIs are unsuccessful; the second type of architecture is described as SPA (system centric/service provider) and the corresponding IIs are more successful. We consider that despite the architecture of RegPHR resembles more SPA architecture than INA architecture our results have shown that RegPHR had limited success (it did not bootstrap) during the period 2009-2013. We consider our results complement these two architectural approaches by highlighting two other architectural features that inhibited the bootstrapping of RegPHR: 1) the location and control of data which created overdependence between the architecture of the PHR and the architecture of the shared EHR; and 2) the lack of separation between ownership and control of new services that limited the capacity of the PHR to adapt to the user community. The PHR was not independent enough from the shared EHR to deliver immediate value to users, and this lack of independence hindered the generation of positive feedback loops.

Our research has some limitations that must be acknowledged. Firstly, our architectural approach has allowed us to bring the voice of a great variety of actors (doctors, nurses, managers of health providers, third-party developers, users, designers, and managers of the PHR at the regional health service) into this research. Yet given our goal of studying the relationship between the lack of bootstrapping and the architecture, the strongest voice has been that of the core team in charge of the design, implementation, and operation of the PHR and EHR. In that sense, there are other non-architectural factors (e.g., interests and incentives of health professionals and patients) that may also explain the lack of bootstrapping. Another limitation of our study concerns the context in which it was conducted, which may limit the generalization of the findings to other settings with a different public healthcare system (e.g., having less variety of health providers).

We consider this article provides a step forward towards a better understanding of the relationship between architecture and the generation of positive feedback loops that drive PHR bootstrapping. At the practical level, we believe that the four architectural constraints on the generation of positive feedback loops, as well as the architectural alternatives presented in the paper, are relevant as they can help designers and policymakers devise more effective interventions during the implementation of large-scale systems in healthcare.

Notes

1. SEHR interconnected the diverse electronic medical records of health providers.
2. The DHSS gives each citizen in the region an individual medical card that contains data fields for a personal identification code (which corresponds to the code of the insured citi-
zen), name and surname, social security number, type of coverage, and expiration data. All of these data fields are coded in a magnetic stripe.
3. The regional certification agency is a governmental agency set up in 2002 to implement and rollout the digital signature in all regional governmental institutions and provide services to those organisations by ensuring that electronic transactions are safe.
4. The providers of test strips – usually pharmaceutical companies such as Sanofi or Roche – also provide other devices for the treatment and control of the disease (e.g., glucometers, insulin pens, and a self-monitor software application for patients).
5. The RHS makes multi-annual contracts with health providers that are revised annually. Several contractual clauses required health providers to use SEHR.

References


