Part III

Governmental Patient-Oriented eHealth Infrastructures

Navigating Towards Self-Care: The Catalan Public Patient Portal

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11.1 Introduction

This chapter presents the genesis and evolution of the public patient portal called Carpeta Personal de Salut[1] (CPS) of Catalonia, Spain. Our account of the CPS covers the period 2008 to 2015. The CPS gives citizens secure and confidential access to their health data (generated in the public health system). The case narrative shows how the installed base was gradually extended with new partners and services aiming to increase the value and usefulness of the infrastructure in order to attract more users. The reminder of the chapter is structured as follows. In the next two sections, we present the Catalan healthcare model and the installed base of IT systems. This is followed by our narrative of the case. Next we discuss the implications of our findings.

11.2 The Catalan Healthcare Model

The Spanish National Health System comprises both the Central Government Administration and the autonomous regions. The former is in charge of the (1) health basic principles and general coordination; (2) foreign health affairs and international relations and agreements; and (3) legislation on pharmaceutical products. Each autonomous region is responsible of health planning, public health, and healthcare services management. The Health System of the autonomous region of Catalonia involves four main actors: the Catalan Department of Health (DoH); the CatSalut (the Catalan Health Service); health providers; and citizens. The DoH 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

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[1] Personal Health Folder.

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providers. The CatSalut is the public insurer that is responsible for planning, purchasing, and assessing health services according to the needs of the population. The CatSalut establishes service policies in line with the health policies defined by the DoH. The Catalan territory is divided into seven health regions. Each region is structured in turn in health sectors, which bring together the so-called basic health areas formed by neighbourhoods or districts in urban areas, or one or more municipalities in rural areas. The health providers are those organizations that the CatSalut contracts to provide care services. Each health provider has a multiannual contract with the CatSalut that is revised on a yearly basis and includes health objectives, activity, economic amount, rates (pricing), invoicing system, and evaluation system.

The provision of healthcare is done by multiple contracted providers having different ownership: public companies – the Catalan Health Institute (ICS) is the biggest one–, consortia, municipal foundations and private foundations (see Table 11.1). The provision of healthcare is organized into four main levels: primary care; specialized or hospital care; socio-sanitary care; and mental health. Primary care is the gatekeeper and responsible for coordinating the patients' care along the care continuum. Since the primary healthcare reform (in 1985) primary care has evolved from a predominantly curative care model (upon demand from the user population and the work of individual healthcare professionals) to a model that focuses simultaneously on preventive healthcare, curative healthcare, rehabilitative care and the promotion of community health. This transformation was structurally achieved through the creation of basic health areas and the gradual introduction of primary care teams. Nowadays, there are 369 primary care centres, around 77% of them being managed by the public provider ICS.

Specialized or hospital care acts as a consultant of primary care and is responsible for more complex care. There is a public network of hospitals distributed over the territory following the schemes of population distribution. The model of hospital has changed in recent years, progressing from a traditional model of a more closed centre that provides conventional inpatient care, emergencies and an outpatient department, to a centre with a greater outpatient focus, with significant roles for ambulatory major and minor surgery, day hospital and home hospitalization. Nowadays there are 69 hospitals (the ICS manages 8 of those hospitals). Around 79% of the specialized care is managed by non-public providers.

Table 11.1 Ownership of healthcare facilities

	Public		Non-public	
Type of center	Property (%)	Management (%)	Property (%)	Management (%)
Specialized/hospital care	25,94	21,43	74,06	78,57
Primary care	95,40	87,72	4,60	12,28
Mental care	28,87	27,38	71,13	72,62
Long-term care	68,63	62,75	31,37	37,25

Source: Catalan Department of Health

11.3 The Installed Base of IT Systems

The multi-provider nature of the Catalan healthcare model had always given providers autonomy in the management of centers and freedom in selecting, building and managing their health IT (HIT) systems. Historically there had been no guidelines regarding the HIT systems that health providers should have in place. So, the Catalan health system traditionally had a completely decentralized governance model for IT. This led to a situation with more than 60 different HIT systems for primary care and hospital care without any kind of integration, and heterogeneity among providers in terms of the level of adoption of HIT.

For instance, in the case of hospital care there are multiple HIT systems supporting different clinical protocols, messages, catalogues, etc., meaning that each provider has to build multiple interfaces for the same purpose (to interact with other providers). Major providers have HIT systems based on SAP.[2] For instance, ARGOS is a SAP-based HIT developed by IBM that runs in the 8 hospitals of the ICS and some other hospitals.

At the level of primary care, there are several HIT systems (e.g., eCAP, OMI-AP, GO-WIN, SIAP-Win); eCAP is the dominant one. eCAP was developed in 2000 by clinicians of the Catalan Health Institute (ICS). The motives for the development of eCAP were: the existence of three different HIT systems for primary care within ICS; provider lock-ins; and interoperability issues among those HIT systems. More than 80% of primary care centers run eCAP. Moreover, the Health Plan 2011–2015 (HealthPlan 2011) proposed making available eCAP to all the other providers in 2012 aiming at having a common HIT system for all primary care providers. However, by that time there were multiple versions of eCAP reflecting the diverse rollouts of eCAP in the territory. In addition, eCAP had more than 20 databases and each patient's data were stored in several databases. Further, eCAP had a strong physical architecture meaning that professionals were aware of the server they connected each time they run an application.

11.3.1 The Shared Electronic Medical Record of Catalonia

Overall, the multiplicity and heterogeneity of HIT systems, data models and standards, and working processes turned into a problem as the DoH defined efficiency, continuity of care and integrated care as priorities in the successive health plans since early 2000s. The implementation of these priorities required standardizing and sharing information within and across health providers. This motivated the DoH to build and rollout the Historia Clínica Compartida (HC3), a Shared Electronic Medical Record, in 2008. The purpose was that any healthcare professional could access data about her patients regardless which providers had generated the data. The HC3 interconnected all the electronic health record systems (EHR) of the healthcare providers operating in the Catalan public health system. The HC3 was

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[2] http://go.sap.com/solution/industry/healthcare.html

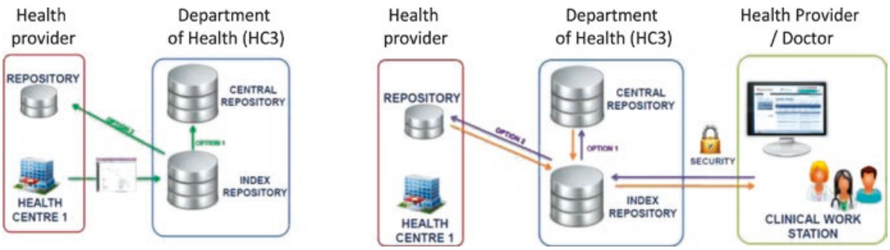

Fig. 11.1 Information management processes of the HC3

neither conceived as the sum of the EHRs of the health providers nor as a way to replace the existing EHR of providers, but as an infrastructure that would organize the access to health data stored in the EHRs of health providers and in some databases of the DoH (Marimon-Suñol et al. 2010). The HC3 consisted of a central node working either as an index or a repository of documents that would give access to all doctors (through a web browser) to the information coming from the EHRs of the diverse providers (see Fig. 11.1).

The information displayed in the doctors' browser came from (1) health providers: primary care (diagnoses, healthcare reports, immunizations, and chronic patient labels), specialized care, long-term care and mental care (discharge report, emergency reports, specialized outpatient clinic reports), and diagnosis procedures (pathology and laboratory reports, radiology image, imaging diagnosis reports, interventions); and (2) the DoH: medical activity database (diagnoses, procedures), prescribed/dispensed drugs (electronic prescription), and advanced directives. The HC3 provided a set of tools for direct messaging between health professionals to facilitate their cooperation.

The interconnection of healthcare providers' systems to the HC3 was regulated through an agreement between providers and the DoH (AgreementForHC3 2009). That agreement established the commitments of parties as well as the technical requirements. Moreover, the CatSalut promoted providers adoption of HC3 by means of economic incentives (defined in the annual contracts with providers) related with the publishing of documents. By the end of 2011, 96.5% of primary care centers and 85.5% of hospital care were connected to HC3 (CatSalutReport 2011).

The HC3 grew with new users, functional requirements (e.g. types of health data, identification codes, interconnection of the HC3 with the Spanish Shared Electronic Medical Record and with the European Patients-Smart Open Services), and technological requirements (e.g. compression of data, new security layers, HL7 messages). Moreover, the Health Plan for the period 2011–2015 (HealthPlan 2011) defined a project, within the line of action number 9 called "Sharing information, transparency, and assessment", to transform the HC3 from a repository of health data into a network of information and services that facilitated the integration of providers. All this involved extending the HC3 with new sources and formats of data, access modes and services, and standardizing the patient trajectory

Table 11.2 Evolution of HC3

	Repository of health data (2008–2011)	Network of information and services (2012–2015)
Source of data	Repository of health data from primary care	Repository of health data from primary, hospital, socio-sanitary and mental care
Format of data	Document-oriented database (stores PDF documents, or a link to the document in the provider EHR)	Structured data about diagnosis, immunizations, spirometry, patient trajectory, etc.
Access	Access through web-browser	Access through web-browser and integration with clinical work stations
Services	Static view of the patient data	Extension of HC3 with a messaging platform to include the patient trajectory and the management of the clinical protocols for the ten chronic pathologies prioritized in the (HealthPlan 2011)

and the management of clinical protocols across providers (Carrau et al. 2013) (see Table 11.2).

Overall, although HC3 respected the installed base of HIT systems, its evolution influenced some of its components. On the one hand, the HealtITPlan (2012) suggested that eCAP (the dominant HIT system at primary care) became the unique system of primary care. First, that would create efficiencies (e.g., any change is implemented once and replicated everywhere; having a unique data model for all the primary care). Second, the strategy of integrated care defined in the HealthPlan (2011) was built around primary care, thus having a unique common system for primary care was supposed to be aligned with the vision of integrated care and continuity of care. On the other hand, in specialized care there are multiple HIT systems. Yet the fact that the major health provider (ICS) runs ARGOS (developed by IBM), and that IBM is a central actor in the definition of the new messaging platform (that extends the HC3) might be catalysts for the reduction of the number of HIT systems in specialized care. Next section presents the story of the Catalan public-oriented portal which was built on the achievements of the HC3.

Method

Data was collected from three main sources: semi-structured in-depth face-to-face interviews (37 interviews), participant observation (the author registered for the CPS on 2011 and has used it intermittently during 2011, 2012, 2013 and 2015; workshop attendance; and informal conversations), and archival data (press documents, reports, meeting minutes, and videos), aiming at data triangulation (Yin 2003). Conducting the interviews was organized in three stages between 2011 and 2015: (1) from March to June 2011 (17 interviews); (2) from March to June 2013 (10 interviews); and (3) from December to October 2015 (10 interviews).

We identified interviewees by referral from other subjects. All the interviews were recorded and immediately transcribed and analyzed next two the archival data and other observations. In that sense, data collection and analysis took place iteratively.

With the data gathered, we constructed an initial timeline of events for the evolution of the CPS. We then wrote a rich chronological case story that put at the forefront the role of the installed base. We organized the case narrative into three stages covering the period 2008–2015.

11.4 Case Narrative

11.4.1 Phase 1: Genesis and Pilot (2008–2011)

The Catalan Department of Health (DoH) launched the project of the Carpeta Personal de Salut[3] (CPS) in 2008 as part of the execution of the Catalan health IT strategic plan for the period 2008–2011 (HealthITPlan 2008).[4] The leader and sponsor of the CPS was the coordination of Health IT of the DoH. With the CPS they wanted to promote responsibility and participation of citizens in matters of their own health (preventive actions and self-care); to have a secure environment for citizens to interact with health system, providers and professionals; and to improve the health care quality and coordination between different care areas, levels and professionals. Following existing regulations about the information rights and autonomy of the patient (InformationRightsAct 2000; PatientAutonomyAct 2002), the health data displayed in the CPS would come from the HC3 (Cerdà-Calafat et al. 2010). The HC3 was the main source of data of the CPS (see Fig. 11.2). The CPS would be a module of the HC3, acting as a web-browser based viewer for citizens to the data generated in the public health system.

Another line of action of the health IT strategic plan, related with the development of the CPS, was the diffusion of digital certificates among citizens in order to interact with the health system. Following the regulations about the protection of personal data (DataProtectionAct 1999; DataProtectionDecree 2007), CPS management decided that citizens would use their personal identification code[5] and a digital certificate to access the CPS. Data transfer would be (https) encrypted with 128-bit

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[3] Carpeta Personal de Salut means Personal Health Folder.

[4] The HealthITPlan (2008) was part of the Health Plan for the period 2006–2010, which for the first time defined IT as a strategic lever of the health system. The HealthITPlan (2012) defined the project of the CPS as part of the strategic line "Facilitate and orient the access of citizens to information and service for self-care".

[5] The DoH gives each citizen of Catalonia an individual health card which contains data fields such as personal identification code (which corresponds to the code of the insured citizen), the name and surname, the social security affiliation number, type of insured (level of coverage), the expiration data. All these data fields are coded in a magnetic stripe.

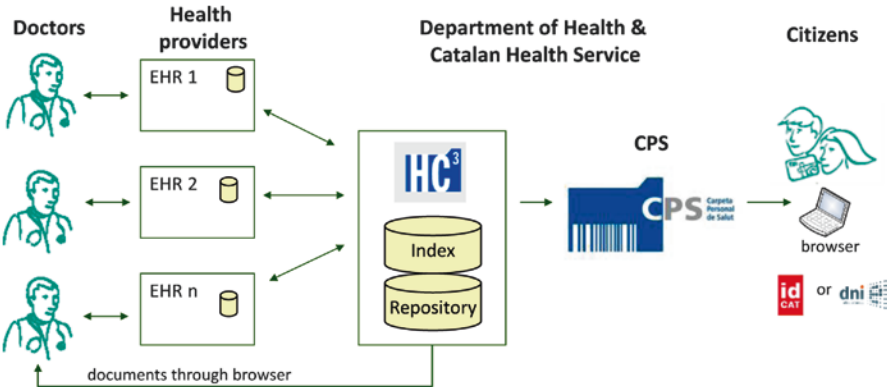

Fig. 11.2 Architecture showing the relation between HC3 and CPS

key. There would be two types of valid digital certificates: the one issued by the Catalan Certification Agency (CATCert[6]) called idCat, and the one embedded in the National Identity Number (DNI electronico). To obtain the first type of digital certificate citizens would have to first fill an online form, next they would have to physically visit a registration agency where their identity would be checked and they would be given a password. Citizens later would use that password to download the digital certificate from the website of the CATCert. In short there would be three actors involved in the registration process: the citizen, the CATCert which would act as a Certificate Authority, and the organization which would accredit the identity of the citizen. During authentication, CPS would check in the database of insured citizens (of the CatSalut) that the personal identification code corresponded with the identity number contained in the digital certificate, and that the citizen had the right to access data.

In 2009, the sponsors of the CPS run a first pilot with a group of 90 citizens working in the health sector of Calella aiming to test the usability, the adequacy of the data, and identify new requirements. The users were employees of the City Council of Calella and of the main health provider operating in the health sector.[7] Users assessed the CPS satisfactorily: 97% of users evaluated the CPS as something useful or very useful, with 73% of them evaluating the navigation through the CPS as good or very good, and 92% of the users evaluating the language used as appropriate or very appropriate (Saigí et al. 2012). After this pilot, CPS management decided to roll out the CPS on July 2010 with the 21,000 citizens of the health sector of Calella. This release of the CPS included two main types of services: health data from HC3 (e.g. diagnosis, vaccines, and reports such as ambulatory care, hospital

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[6] The CATCert is a governmental agency that was set up in 2002 in order to implement and rollout the digital signature in all the Catalan governmental institutions and provide services to those organizations ensuring that the electronic transactions fulfill the legal guarantees.

[7] The name of the provider is the Corporació de Salut del Maresme i la Selva (http://www.salutms.cat).

emergencies, and hospital admission) and access to some administrative services that the Catalan Government already offered (e.g. http://web.gencat.cat/en/tramits/index.html).

The rollout involved the cooperation and engagement of several local actors in the territory who were close to citizens: the health provider operating in that health sector; the city council that was in charge of communicating to the public; and other local organizations (one of which issued the digital certificates). The leader of CPS qualified such a rollout strategy as "low profile": "we started with this very limited concept of a personal health folder in the sense that it was a collection of documents that were already in the shared electronic medical record [HC3]". The sponsor considered that it was important to adopt a strategy that minimized conflict with professionals since the CPS entailed profound changes in the role and relationships between doctors and patients, and between doctors themselves.

Following this territorial rollout strategy, the CPS was extended to two additional health sectors where the same health provider operated. The CPS was also extended to 1,500 blood donors (from throughout Catalonia). Yet by that time the usage of CPS was still marginal; on December 2011, 88,727 citizens had access to the CPS, but only 365 had accessed it 1,282 times (CatSalutReport 2011).

11.4.2 Phase 2: Opening the CPS (2012–2013)

The health IT strategic plan for the period 2012–2015 (HealthITPlan 2012)[8] defined an strategic line "Deploy a multichannel network to communicate and interact with citizens" involving seven concrete actions on the CPS: (1) boost an strategy that promotes citizens self-care; (2) extend the CPS to all the citizens of Catalonia; (3) increase the functionalities of the CPS; (4) include the medication plan into the CPS; (5) include value-added services into the CPS; (6) promote the access to the CPS through different channels; and (7) promote the diffusion of digital certificates among citizens.

In accordance with these actions, by early 2012 the CPS was extended to other health sectors in Catalonia where other providers operated. Secondly, they built a mobile web app to access the CPS. They also extended the CPS with new reports (e.g., laboratory test results and imaging reports) and new information services from other systems of the DoH (e.g. the medication plan from the electronic prescription system) (see Fig. 11.3). In March 2012, the DoH launched the web-portal Canal Salut,[9] which provided information to citizens in order to promote healthy lifestyles, strengthen the ability of citizens to make informed decisions about their own health

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[8] While HealthITPlan (2008) putted the focus on the need to build technical/hard infrastructure, HealthITPlan (2012) changed the focus an emphasized the need for service infrastructure. This change in focus was aligned with two lines of action of the HealthPlan (2011): line of action 2 "A system that is more focused on chronic patients", and line of action 9 "Sharing information, transparency, and assessment".

[9] Canal Salut means Health Channel, http://canalsalut.gencat.cat

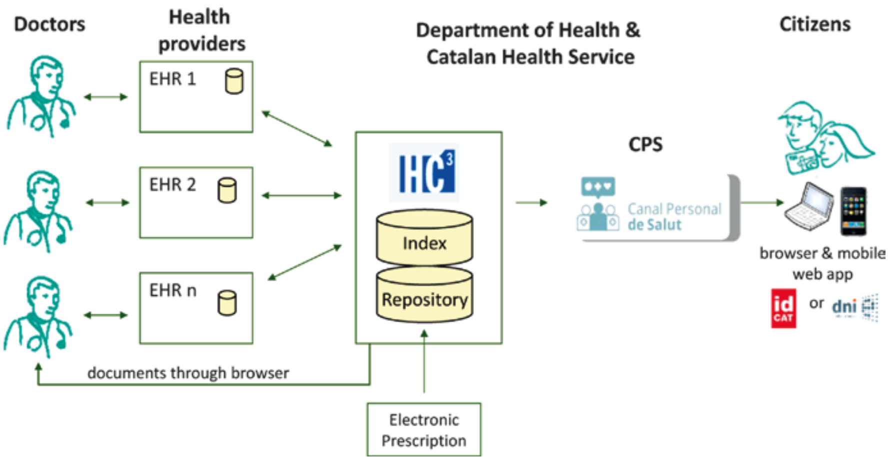

Fig. 11.3 Extension of the CPS architecture

care, and improve citizens' access to health services, among others. By the end of 2012,[10] the DoH announced the deployment of CPS to everyone in Catalonia (about seven million people), and the name of the CPS was changed from Carpeta Personal de Salut (Personal Health Folder) to Canal Personal de Salut (Personal Health Channel) to emphasize the idea of interactivity and communication between patients and professionals.

Until then the CPS had mainly worked as a viewer of the HC3. This was a constraint since the CPS mainly offered content (general reports and health records) to patients but not services. In addressing this constraint, by mid-2012 the CPS managers decided to open CPS to third-party services that were not owned by the DoH. With this opening strategy CPS management aimed to leverage on the installed base of services of third-parties (e.g. health providers, software vendors, pharmaceuticals) and on the latter's capacity to keep innovating on new services. Furthermore, this opening strategy added value to the CPS without requiring the DoH to increase the budget of the CPS. To implement this strategy, TICSalut[11] set up an interoperability framework that defined the conditions for third-party devices, systems and services to interoperate with CPS (InteropFramework 2012). Companies that wanted patients to access their services through CPS would have to fulfil certain conditions in order to obtain the interoperability recognition. Accordingly, under this interoperability framework, the ownership and control of the services of the CPS started to separate. The DoH would gave up the ownership of the new services

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[10] By that time, there was the appointment of a new coordinator of Health IT at the DoH who also became the leader of the CPS.

[11] TICSalut is an agency, constituted in 2006, within the DoH that works to promote the development and use of IT in the field of health, acts as an observatory for new trends, innovation and monitoring of emerging initiatives and provides services for the standardization and accreditation of products.

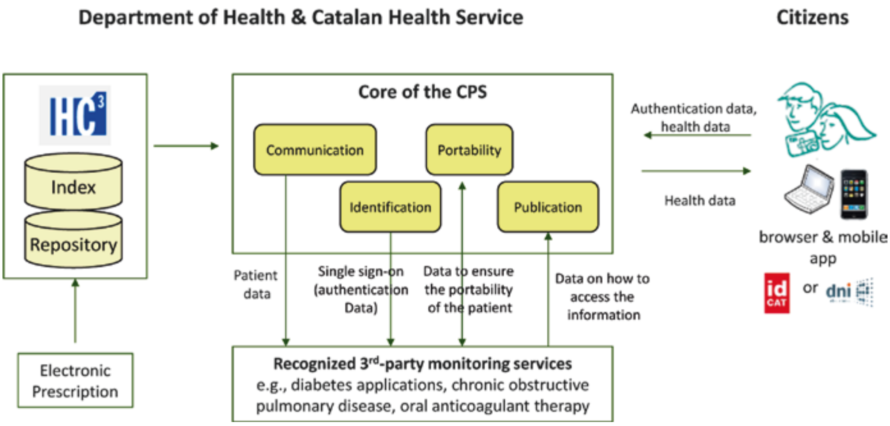

Fig. 11.4 Extension of the CPS to incorporate the interoperability framework

but not their control (e.g., the DoH had the right to decide which new services would be offered).

In the case of systems and services, the interoperability framework consisted of four profiles (see Fig. 11.4): identification (in order to guarantee a single sign-on from the citizen for the CPS and the third-party service); communication (so that third-party services can access relevant patient information stored in HC3); publication (the third-party publishes a set of services that citizens will see in CPS; patients can access those services directly by means of a service embedded in CPS or an URL); and portability (a set of conditions to ensure that personal health data stored by the third-party service can be moved, if the citizen desires, to other third-party services). Each of these profiles defined a set of messages that CPS and the third-party services should exchange. With the deployment of the interoperability framework, the DoH would not develop new services but would partner with those third-party providers who offer their services through CPS. The DoH would control the content and the application of the interoperability framework.

The DoH started by targeting firms providing services for monitoring diabetes (in 2012), and the management of chronic obstructive pulmonary disease and oral anticoagulant therapy (in 2013). In the case of the services for monitoring diabetes, CPS management exploited the fact that the ICS was making a tender for the supply of test strips for the following years.[12] The DoH asked the ICS to include compliance with the interoperability framework as a bid condition. From that moment, the interoperability framework became an obligatory passage point for providers of devices for the treatment of diabetes who wanted to access the public health system. These services for tele-monitoring diabetes provided three main types of functionalities: patients recording and tracking of blood glucose readings and other informa-

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[12] The providers of test strips – usually pharmaceutical companies such as Sanofi, Roche – also provide the other devices for the treatment and control of the disease – e.g. glucometers, insulin pens, and the software application for patient to self-monitor their disease.

tion, health professionals monitoring the status of patients, and information exchange between patients and health professionals. Yet the fact that these services could be accessed through the CPS did not add additional value because the CPS was merely an additional channel to access those monitoring applications. Moreover, neither health professionals nor patients received any incentive to go through the CPS. So the fact that these three types of services got the interoperability recognition, did not mean that patients and health professional would immediately abandon their direct access to those services in favor of the CPS.

For providers of those services it was a way to stay close to the DoH. Moreover, CPS management realized that the providers would not easily update their services to new releases of the CPS' APIs. One of those providers argued that they had already done an effort to adapt their application to the CPS for the first time, but they could not keep the pace of updates required by the CPS because decisions about service changes were not made in the local office in Catalonia, but in the headquarters office which was abroad. In short, the CPS was not able to revert the existing practices of the health professionals, diabetes patients, and providers of diabetes monitoring services, and the relationships between health professionals and those providers.

11.4.3 Phase 3: Scaling the CPS (2014–2015)

By mid-2013 the adoption level of the CPS was still unsatisfactory – e.g., until May 2013 only 4,664 citizens had accessed the CPS since its inception; on average there were less than 1,000 accesses per month; reports and diagnoses were the top searched information services (Gallego 2013). CPS management considered that its low rate of adoption and use was due to the lack of use of digital certificates among citizens and the associated registration and authentication processes. These processes were cumbersome and complicated for citizens, particularly, taking into account that some health providers (e.g., ICS) already offered online services for patients (e.g., booking appointments) with much simpler authentication procedures (e.g., code of the citizen's health card). However, the CPS' registration and authentication processes had been implemented following the recommendations of the Catalan Data Protection Authority (APDCat[13]) in 2009. By mid-2012 CPS management asked again the APDCat about the need for a digital certificate. This time the APDCat reinterpreted the need for a digital certificate and suggested that a username and password were sufficient (ElectronicDataAccess 2012). So, removing the digital certificate would simplify the registration and authentication processes and this in turn, would make the CPS more attractive for citizens.

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[13] The APDCat was created in 2002, and its Statute regulated in 2003. It is an autonomous and independent authority whose competences in the public sector data are registration, control, inspection, sanction and resolution, and also the adoption of proposals and instructions. http://www.apd.cat/en

The changes to the registration and authentication processes were as follows. First, registration would take place at the primary care center of the citizen, where she would have to physically visit to request the access to the CPS. At the primary care center they would check the identity of the citizen through national identify number and the identification code of individual health card, and the citizen would sign an authorization form. Then the citizen would receive an SMS with a PIN code that she would use in the registration process and an email with a link to complete the registration process. In this last step of the registration process, the citizen would choose an 8-digit password. The access to the CPS would take place through the personal identification code plus the national identity number plus the 8-digit password (so there was no need for a digital certificate). Second, citizens' usernames and passwords would be managed by the CatSalut; the CATCert would not be involved in the registration and authentication process.

On October 2014, a pilot was launched in 33 primary care areas. As a result of the positive outcomes of the pilot,[14] on May 2015 they started the deployment of the new registration and authentication processes to the rest of primary care areas of Catalonia. On August 2015 more than 25,000 citizens had accessed the CPS (Solans 2015).

In parallel, the CPS was renamed again from Canal Personal de Salut (Personal Health Channel) to Cat@Salut La Meva Salut (Cat@Salut My Health). This change aimed to increase the involvement of citizens and strengthen its diffusion, use and awareness. Accordingly, the user interface of the CPS was also adapted so that the access to data was simpler and more intuitive.

Within the context of the HealthITPlan (2012) the DoH created in 2013 a working group that defined a non-face to face care model for the Catalan health system (NonF2FCareModel 2014). The model, which put the CPS at its core, included the functional requirements, the agents and the interactions among agents, the contents, and the communication channels. The goal was to transform the CPS into a dynamic and proactive environment rather than a passive one. This required integrating non-face to face care into the existing clinical working stations, and giving recognition to the non-face to face activity of health professionals as part of their duties. One of the services defined by the non-face to face care model was eConsultation (a non-face-to-face, secure consultation service between citizens and health professionals). With eConsultation, citizens can send (through the CPS) at any time a request to the health professional (doctor or nurse), receive email notifications when the professional responds the request, check the response at the CPS, and see a record of all the queries. This service is integrated with the clinical workstation of professionals. This service has been integrated into the CPS and is being piloted at nine primary care centers of Barcelona, which are operated by three health providers[15] running the eCAP workstation, from July 2015 to October 2015. Moreover, three additional services of the ICS got the interoperability recognition (e.g., online booking appointment, change of doctor, international vaccination).

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[14] Monthly accesses more than tripled (Solans 2015).

[15] The three health providers are ICS, PAMEM and CAPSE.

On February 2014, the TICSalut, commissioned by the DoH and the Department of Social Welfare and Family, collaborated with the mHealth Competence Center of the Mobile World Capital Barcelona[16] in the development of the Mobility Master Plan for Health (mHealthPlan 2015). The goal of the mHealthPlan (2015), which the DoH approved on February 2015, was to boost the mobility of health and social services as a lever to improve the health and welfare of people and contribute to the sustainability of the system. The mHealthPlan (2015) identified the lines of action and projects of the HealthPlan (HealthPlan 2011) and the non-face to face care model (NonF2FCareModel 2014) that could incorporate mobility.

As part of the implementation of the mHealthPlan (2015), the TICSalut worked on a health apps marketplace[17] that would match the demand (the public health system, patients and rest of citizens, social and health professionals) and supply (health and social care providers, IT vendors, pharmaceutical companies, insurance companies, and medical equipment vendors) of health and social services. A core component of the marketplace would be the accreditation process which aimed at generating trustworthy apps through a quality certificate. The accreditation process assesses four main aspects of apps: (1) design and usability (assessment of the user experience); (2) content and functionality (assessment of the quality and utility of content); (3) confidentiality and security of data (assessment of the management and processing of data); and (4) technological requirements (assessment of the reliability and adaptability requirements).

The accreditation process comprises six steps: (1) an app developer requests a accreditation for an app; (2) the developer does a self-assessment of the app; (3) if the app meets a minimum criteria then the developer can ask to provisionally include it in the marketplace (with the status "pending accreditation"); (4) an accreditation committee does a complete and detailed assessment of the app; (5) if the app passes this assessment it gets the quality certificate; and (6) the app is finally published in the marketplace as accredited; the marketplace acts as a portal with information about health apps accredited and redirects users to the corresponding Android and/or iOS market in order to download the app.

Initially they conceived three main types of apps to be prescribed by health and social care professionals: core apps (public-owned apps that exchange data with existing systems of the DoH); non-core apps having the exchange capacity (publicly or privately owned apps that exchange data with the CPS); and non-core apps not having the exchange capacity (privately owned apps that do not exchange data with the CPS).

From mid-2015 TICSalut started working on the design of another core architectural component of the marketplace: the Digital Health Platform (see Fig. 11.5).

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[16] The mission of the mHealth Competence Center is to promote the improvement of the welfare and health of citizens by personalizing services based on mobile technology. The director of the mHealth Competence Center is the former executive president of TICSalut.

[17] By the end of 2013 the TICSalut started conceptualizing a marketplace of health apps with different degrees of certification and validation where patients could find apps recommended by doctors (RepTICSalut 2013).

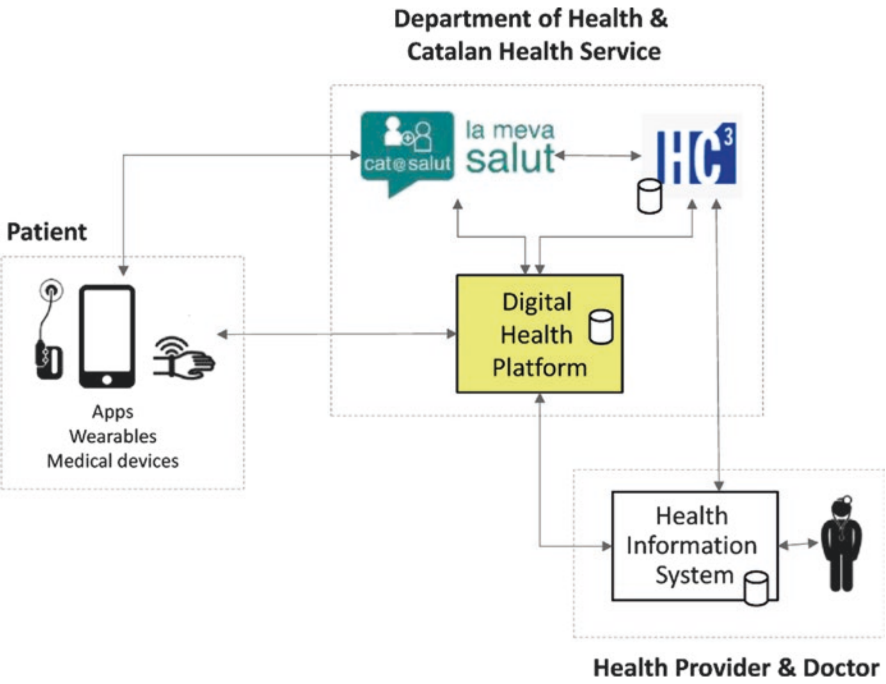

Fig. 11.5 Relationship between the Digital Health Platform and other components

Those apps (and later wearables and medical devices) that are accredited will be allowed to store and/or retrieve information from the Digital Health Platform. So the Digital Health Platform will act as a repository of patient-generated health data and in turn, it be interoperable with the CPS, HC3 and/or health information systems of health providers. Patients will access the content of the Digital Health Platform through the CPS. In other words, the Digital Health Platform will give the public health system access to health data generated by patients outside the public health system.

11.5 Analysis and Discussion

Our account has shown how the CPS was built on an installed base. It started as a web-browser viewer of a subset of citizens' health data stored in the systems of the public health system, and has gradually turned into an information infrastructure as new relations with other systems, services, actors, regulations, practices, and so on, have been established. Table 11.3 summarizes the evolution of the CPS according to several dimensions (goal, users, services, authentication mode, access mode, regulations) for each of the three phases.

Table 11.3 Evolution of the Catalan public patient portal

	Phase 1: genesis and Pilot of the CPS (2008–2011)	Phase 2: opening the CPS (2012–2013)	Phase 3: scaling the CPS (2014–2015)
Name	*Carpeta Personal de Salut* (Personal Health Folder)	*Canal Personal de Salut* (Personal Health Channel)	*Cat@Salut La Meva Salut* (Cat@Salut My Health)
Goal	View health data	Promote communication between patient and professional	Promote e-health services around the mobile
Users	Pilot in Calella (21,000 citizens) with the only health provider operating in that town. Afterwards it was extended to nearby towns (e.g. Malgrat de Mar, Lloret de Mar, Palafolls) were the same provider operated, Blood donors (1,500). There was 90,000 citizens with access	The rollout was gradually extended from 2012. It was organized into 3 phases: (1) 0.35 million citizens; (2) around 1,5million citizens; and (3) all Catalonia (7million)	All citizens insured by the CatSalut (around 7 million)
			Not only health but also social services

(Continued)

Table 11.3 (Continued)

	Phase 1: genesis and Pilot of the CPS (2008–2011)	Phase 2: opening the CPS (2012–2013)	Phase 3: scaling the CPS (2014–2015)
Services and functionalities	Health data from HC3: personal data, diagnoses, vaccines, and reports such as ambulatory care, hospital emergencies, and hospital admission	+	+
		Medication plan (a system which is not part of HC3)	Recognized services: Online booking appointment of the ICS (22/12/2014); Change of doctor of the ICS (22/12/2014); International vaccination of the ICS (1/12/2014)
		Promotion of health (push to citizens) through the web-portal Canal Salut	eConsultation (pilot July 2015)
	Access to the virtual procedures office to do some request with the health service	Anticipatory wills	Waiting list for the surgical processes (surgical process, status, center, data of inclusion, surgery forecast, average time at the waiting list, maximum time guaranteed by the CatSalut)
		New reports (Laboratory test results, imaging reports)	Integrated with other external sources (e.g. other regions’ reports, other systems of the DoH)
		Patients’ agenda/schedule at primary care	Development of the apps marketplace
		My controls (recognized tele-monitoring services and devices):	Digital health platform
		Diabetes: Emminems (Roche, 23/8/2012), MedicalGuard (Grupo Pulso, 22/6/2012), Diabetic (Sanofi, 22/6/2012)	Tracking claims and request of health certificate
		Oral anticoagulant therapy: TAOnet (Roche, 26/08/2013), G.O.T.A (Isaza Distribuciones Técnicas, 8/8/2013)	Interconnect with patients’ social media platforms
		Spirometer for chronic obstructive pulmonary disease: DATOSPIR 120 i 110 (A,B,C,D) (Síbelmed, 31/5/2013); DATOSPIR 600 (D,T,F) (Síbelmed, 31/5/2013); DATOSPIR MICRO (A,B,C) (Síbelmed, 31/5/2013); DATOSPIR Touch (Easy,Diagnostic) (Síbelmed, 31/5/2013)	

Authentication	Two digital certificates: idCAT (Windows and Linux) + eDNI	+	+
		Two digital certificates: idCAT (Windows and Linux) + eDNI	New authentication process: username and robust password;
			idCAT for Android
			Pilot: biometric signature on tables (at Hospital of Campdevànol) and mobile identity (with 25 users)
Access mode	Browser (laptop, desktop)	Browser (laptop, desktop) and mobile web app	Browser (laptop, desktop) and mobile web app; wearable; medical device
Regulations and other expressive components that consolidate the CPS	Information rights and autonomy of patients	Health Plan 2011–2015	ElectronicDataAccess (2012)
	Protection of personal data	Health IT Strategic Plan 2012–2015	NonF2FCareModel (2014)
	Health plan 2006–2010	Interoperability framework developed by TICSalut	Mobility master plan for health (mHealth.cat)
	Health IT strategic plan 2008–2011		Accreditation process developed by TICSalut
			Health plan 2016–2020
			Government Agreement (25/2/2014) to create the integrated health and social care plan (SocialHealth 2014)

The underlying vision for the building of the CPS has been the idea of self-care and preventive care – i.e., that citizens become more autonomous, responsible and participative in matters concerning their own health. The realization of this vision requires reconfiguring multiple of the existing relationships and the creation of new ones. For instance, since patients will have more information about their own health, their relation with professionals, who are used to have control over the access to the patients' data, will probably change; the relationship between patient and the government is expected to become less paternalistic; the responsibilities boundaries among professionals will most likely shift; and since the CPS will become a new channel for the provision of health services, the public administration will have to reconsider the payment criteria for those services to health professionals and providers.

Accordingly, the effects of realizing this vision are multiple and complex, and beyond the control of any single actor in the health system. For the sponsors of the CPS that meant that they had to engage with indeterminacy and uncertainty, and with multiple possible alternatives. Furthermore, since many of the services could not be specified in advance, their decisions and choices had to be exploratory and adaptable. At the beginning of the project, the sponsors of the CPS took refugee into something known and safe; they decided to tie the CPS' architecture, project organization and development team, and budget to the ones of the Public Shared Electronic Medical Record (HC3). So the CPS started simple, without a big architectural blueprint and complex anticipatory design; the CPS was launched as a web-browser viewer (a module) of the HC3. Since then the CPS has gradually grown in terms of users and services.

A catalyst for that growth has been the building of specific gateways that interconnect the existing socio-technical components with new ones. For instance, the choice of authentication and registration procedures in which CPS' sponsors interpreted existing regulations in a way that maximized the security and confidentiality and by doing so, avoided opposition of professionals who were concerned about it and stimulated adoption from citizens; the interoperability framework, the app accreditation process, and the Digital Health Platform.

Those gateways have encouraged certain effects. First, the interoperability framework and the app accreditation process, for instance, have constituted the base on top of which third-parties can develop new services which add value to existing patients as well as attract new ones to the CPS. Another effect of these two gateways is the changing role of the public administration (DoH and CatSalut) in the provision of certain services. For instance, the DoH does not own those new services but accredits them; in that respect, the public administration keeps the control over the kind of services offered through the CPS. Likewise, with the building of the Digital Health Platform, they are able to leverage the potential of patient-generated health data to grow the existing infrastructure and at the same time, that opens new opportunities for both sides: app developers as well as the public health system.

Overall, this chapter suggests that in order to cope with the conditions of indeterminacy and uncertainty characterizing the building of patient-oriented information infrastructures, designs must always be incomplete, open and connectable so as to be able to respond to new possibilities.

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The Norwegian eHealth Platform: Development Through Cultivation Strategies and Incremental Changes

12

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12.1 Introduction

This chapter presents the approach followed for the development of the Norwegian national solution for patient-oriented eHealth services (here called HealthNorway). Our research interest is twofold: first, on understanding the initial design decisions and initial evolution in relation to the installed base of existing digital capabilities, and, second, on understanding how HealthNorway was further developed after the initial launch in relation to the long term vision of offering comprehensive and readily available health services to citizens. Drawing from the case, we identify different approaches for infrastructural development in the form of proactive cultivation strategies related to extending, complementing and creating substitutes within the installed base.

The remainder of the chapter is structured as follows: we provide first a brief overview of the Norwegian health system and its digital infrastructure; we then introduce our case and present key activities, concerns and decisions for HealthNorway

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development. Afterwards, we analyse the different approaches that were followed for relating to the installed base. We conclude by discussing our findings.

12.2 Norwegian Healthcare

12.2.1 Overview of the Norwegian Healthcare Model

Norway has a predominantly public healthcare sector, where the National Insurance Act guarantees every citizen access to healthcare services paid by the state. Inpatient hospital care is free, while there are consultation fees for physician visits and outpatient treatment, and payment for prescription drugs up to a limit. The patients have free choice of hospitals, but General Practitioners (GPs) serve as gatekeepers for referrals to hospitals or specialists. The specialist healthcare including hospitals and psychiatric care is governed by the Ministry of Health, through four regional Health Authorities established in 2002 (Region West, South-East, Middle and North). These authorities govern also the ICT investments in clinical and administrative systems within their region.

Primary healthcare is offered at the municipal level; GPs, antenatal and postnatal care, immunization and care for the sick and elderly at home or in nursing homes. The municipalities' autonomy is strong, and they make their own ICT investments. In 2008, the Coordination reform, has targeted the less than optimal collaboration between specialist and primary healthcare, primarily through regulatory and financial instruments, but also by supporting standards for electronic communication between the actors. Many physicians (specialists and GPs) run private practices and purchase ICT solutions independently. The government, through the Directorate of Health (from now on referred to as the Agency), has in the last few years taken a more pro-active role in developing national e-health solutions, such as e-prescription, a national summary care record, and web-based health services for citizens. Lately, the e-health related units of the Agency were detached from the overall organization and formed the “e-Health Directorate” which was established on 1.1.2016.

12.2.2 The Digital Infrastructure for Healthcare in Norway

In Norway all GPs offices, hospitals and nursing homes have Electronic Patient Record systems (EPRs). The communication across organizations is supported by a dedicated secure network called Norwegian Health Network (NHN). NHN was established in 2004 by the Regional Health Authorities. NHN was created by harmonizing and consolidating previous existing regional broadband networks, and by pursuing national standards for electronic communication in the health sector. Initially, NHN was used to connect hospitals and gradually it was expanded to GPs, community health centres, nursing homes and recently also pharmacies. All parties sending or receiving electronic communication have their own listing in the National Register of Electronic Addresses.

Over the years, nationally coordinated initiatives sought to shift the health sectors' communication from paper and telephone to electronic communication across the NHN. The exchange of information is currently supported by using standardized messages, for example for referrals and discharge summaries, requisitions and test results, and electronic prescriptions. It should be noted that NHN is a network dedicated to the health providers, and not intended to include communication with the patients.

In November 2012 the white paper "One citizen, One record" was issued by the Government. The strategy identified three main aims: (i) healthcare professionals shall have easy and secure access to patient-and user information; (ii) citizens shall have easy and secure access to user friendly and secure health care services online; (iii) data should be registered automatically and made available for quality improvement, monitoring, governance and research. Against this vision, a number of challenges were also identified such as under-utilized technological possibilities, many independent entities, and many systems with little integration across systems.

Method

Data were collected via three main sources: interviews with informants from the Directorate of Health and technology providers; analysis of project documents, reports, strategy and policy documents; and observations of meetings and workshops in the context of the Digital Dialogue project. Fieldwork was conducted in the period August 2013–December 2014. The data gathered were organized by constructing the event timeline, and by writing the case narrative with attention to main events and decisions taken. The concept of installed base has guided our analysis of the data and directed our focus to how existing socio-technical arrangements have influenced the development of HealthNorway.

12.3 Case Narrative

12.3.1 Phase 1: Rationale for the Development of HealthNorway and Launch

The creation of HealthNorway started with a Government mandate in the Spring of 2010. The mandate pointed to the existence of many patient-oriented initiatives and webpages related to health, both private and public, but to the lack of a national-level, comprehensive initiative. Hence, HealthNorway was initiated with the aim to provide secure digital services, quality checked information on diseases and treatments, and to help citizens perceive services as available and comprehensive (Norwegian Ministry of Health and Care Services 2012). The Norwegian Government envisioned that HealthNorway will strengthen the citizen's role in healthcare by making it easier to find and choose health providers, providing access to personal health information, and by offering services self-service and self-help.

A procurement process started in the summer of 2010 and an agreement was signed in October 2010 with a technology provider. It was made explicit that the Government required a fast pace for HealthNorway. A manager from the technology provider's side recalls: "*It was very high-speed process because the Minister of Health set a politically defined date for launch and that was the 15th of June 2011*".

Work on the development of HealthNorway started in the autumn of 2010. At that point, in order to meet the deadline of June 2011, it was considered realistic to adopt the simplest of a number of alternative concepts presented and aim for an information oriented portal. The underlying idea was that patients/citizens should be able to find consistent and quality checked definitions of illnesses and treatments in the information pages. The realization of this concept required substantial work in gathering material from the different health service actors and agreeing on common definitions. Reaching consensus among hospitals and other competent centers in the health sector was especially difficult for certain illnesses and diseases. Furthermore, it was decided to use as main information sources material written in English which not only required translation to Norwegian but also adaptions to convey information on the specific treatments used in Norway. On top of these challenges, the information content had to be expressed in a way that would be understandable by everyone and this created the need to involve professional writers.

Technically, HealthNorway was built upon an off-the-self platform which made possible its swift launching in June 2011. The Agency kept both the ownership and the management of HealthNorway and soon after the initial launch a new organizational unit dedicated to HealthNorway was created within the Agency. One of the Agency managers explained how work was organised: "*our main job is to develop HealthNorway. Everybody works on the whole of it especially the ones working with user experience, they work not in silos but as a whole group, but our budgets are organized by projects, and we have resources allocated to these different projects, but we are still working on finding a good model where we make sure that we cannot focus just on this project but we need to see the whole system for the user, and the users want that*".

12.3.2 Phase 2: Strategy Beyond the Initial Launch

After the launch of HealthNorway, a process started to define a new strategy toward 2017 aiming at describing the vision and action plan for further development. A manager from the technology provider's side recalls: "*then we started to look into what kind of services we think we should develop on our own, what have other countries developed, what works or doesn't work, and we tried to get as much input from patients and services as we could, so we have a road map for the next five years*". The strategy team received input from a range of stakeholders. They organized workshops inviting participants both within and outside the Agency, from patient organizations, to health professionals from different hospitals, and professionals working with health and communication. A manager recalls: "*we tried to recruit a broad group of people, and we started out with open questions, so now we have this portal, the Minister of Health has released it, it's out there, so what should*

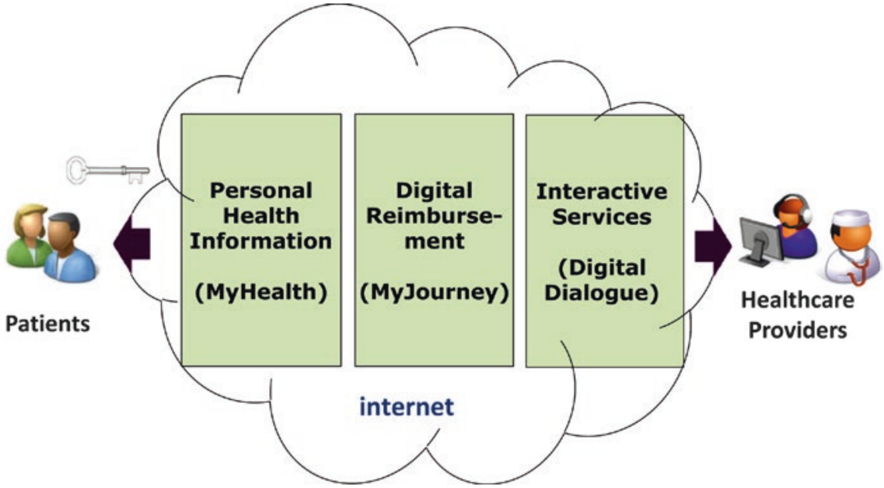

Fig. 12.1 Three priority areas for the extension of HealthNorway

we fill it with now, what do you need?". Thus, the development of the services on HealthNorway started as an open process.

During the fall of 2011, the strategy team planned the work for two main dimensions: information content and electronic services. It was agreed that the priority should be on designing new citizen-oriented services in line with the main strategic political goals to "*reinforce patient- and users- role by making the everyday experience of healthcare easier and at the same time contribute to increase quality and effectiveness of health services*" (quote from the strategy plan). The strategy was ready in February 2012, it described the services to develop and how HealthNorway will fulfil the requirements and expectations of citizens while at the same time addressing health policy objectives.

From March 2012, the strategy plan was implemented starting with a pre-study (March–June 2012) where the feasibility of three different services was assessed: My Health Information (later called My Health), My Patient Journey (for health-related reimbursable travel expenses), and secure messaging services between patients and healthcare providers (later called Digital Dialogue). The three service areas were considered as having a relatively high degree of maturity, potentially substantial benefits and acceptable implementation complexity in relation to other services outlined in the strategy plan. Figure 12.1 presents the three priority service areas, which are described in the following three subsections.

12.3.3 Access to Personal Health Information

According to the pre-study, "MyHealth Information" was a service area that would give citizens access to their personal health information. This service area was identified in the strategy for HealthNorway as well as requested by patients' and health professionals' organizations. The service aimed to offer citizens unified access to personal health information, independently of when and where information was produced (e.g. GP office visit, hospital stay, prescription). The pre-study team mapped different types of personal health information, and identified which information would be more relevant for citizens to access and would give more benefits (e.g. discharge letters, referrals, tests results). Also the team identified constrains in relation to e.g. ethical, legal, technical aspects.

The pre-study also mapped a number of ongoing local initiatives developing solutions for giving patients access to specific health information and met with key respective actors: a project at the University Hospital of North Norway (UNN) in Tromsø for online access to patient records (pilot in 2012–2013), a portal for patient – hospital communication that was already in use at Oslo University Hospital (OUH), a solution in use at Diakonhjemmet hospital in Oslo for sending electronically discharge letters to patients, a portal supporting communication between hospital, users and relatives at Sunnaas rehabilitation hospital, and a solution used by a private medical laboratory for giving on line access to laboratory test results. These were organization-based projects aimed to give patients access to specific health information. The HealthNorway team also looked at international experiences related to sharing health information with patients. A case considered interesting in the context of public healthcare was the national health portal in Denmark.

In addition to these solutions, a number of ongoing national initiatives were identified which aimed to give access to specific health information such as Summary Care Records, active prescriptions "My Prescriptions", vaccination "My Vaccines" records, and expense reports "My Expenses". These solutions had at the time of the study different levels of maturity. The Summary Care Record was planned to start piloting in September 2013, while My Prescriptions, My Vaccines, and My Expenses were already in use. These solutions provided access to information residing at national-level data repositories. In the pre-study it was decided that for the short term, MyHealth Information would include the existing services (e.g. My Prescriptions) and also the Summary Care Record for users in the pilot area. The pre-study also indicated the need to consider the prospect to incorporate local (mostly hospital-based) ongoing initiatives. Such local initiatives were the one by UNN for providing access to the patient records, and the OUH initiative that supports patient access to discharge letters.

Another key consideration of the pre-study was the fulfilment of the legal conditions for offering access to personal health information. It was decided to allow citizens themselves to "opt-in" on a voluntary basis for accessing electronically personal health information (through an individual consent). Furthermore, security level 4 would be required. This is the highest security level defined in the "Framework for Authentication and Non-Repudiation in Electronic Communication in and with the Public Sector" which is maintained by the Agency for Public Management and eGovernment (DIFI) and contains overall guidelines for public agencies when it comes to security for electronic communications.

The pre-study concluded that the services were to be developed over time and it advised to start with services most readily available, where information elements are structured and standardized.

Digital Support for Reimbursing Health Related Travel Costs

The second service area presented in the pre-study was “Patient Travel”. This service aimed to simplify the administrative process of requesting reimbursements for travelling to health services. In Norway patients have the right to reimburse all expenses related to travelling “to and from” health service providers, including both primary care and specialists, and for travels to and from rehabilitation services. There are significant volumes of reimbursement claims processed annually so the simplification of the related processes can contribute to substantial cost reductions for the government and service improvement for the citizens. The process in place was paper-based and with very high daily volumes of letters to be processed manually. Every day the central office would receive about 100 kg of post and send out a similar amount. After each travel, patients would fill a paper form, attach a certification of their visit, receipts and relevant documentation, sign and post to the national center for patient travels. After the processing of their reimbursement claim, they would receive a letter with the decision in the mail, and the sum would be transferred to their bank account. This process made reimbursements slow and complex.

The aim of “Patient Travel” was to create an online electronic form for requesting reimbursement and make the service both more efficient for the public administration and more accessible to patients. The long term goal defined was to have a mechanism in place that would trigger reimbursements automatically without the need of having patients to proactively claim the funds that they are entitled to receive. The pre-study concluded that a pre-project had to be initiated in order to identify the legal, economical, functional and technical requirements for the digitization of the current process and the development of the new electronic service.

Digital Communication Between Patients and Healthcare Providers

An overall mapping of services that could make use of secure digital communications between patients and healthcare providers was included in the pre-study. The intention was to make everyday life easier for patients, and to a certain degree also for health providers. A key requirement defined was the user-friendliness of the new services and the assurance that they will be intuitive, clear and adapted to different individual needs.

The pre-study focused on asynchronous communication between patients and their health providers in cases where a patient-provider relation was already established, for instance between patients and their General Practitioner (GP). It indicated also that secure message services should initially target primary care: “*The reason is that user-initiated communications will intervene significantly in the work processes, organization and ICT support, and that this seems more complex for hospitals than for primary care. For contracted specialists it will be* *considered to implement certain dialogue on an equal footing with primary care*" (quote from the pre-study). The services considered were the ones judged as generic and applicable to different health provider groups and different health institutions. The study clearly stated: "*processes around appointments, e-consultation and document/form exchanges are generic processes that can be transferred from one area to another*".

It was concluded that communication services will be developed first for supporting GP-patient interactions. Specifically, the pre-study specified the need to develop the following electronic services: renewal of prescriptions, appointment reservation and dialogue messages. In addition, the pre-study identified the need to create a storage solution for the messages of the dialogue service. If messages were to be stored only in the GPs' Electronic Patient Record systems (EPRs) it would be difficult to ensure uninterrupted accessibility by patients. Another aspect discussed in the pre study was how to make patients' messages available to GPs and what would be the role of the EPR vendors in setting up the services. The pre-study stated that it was not yet clear how HealthNorway would relate to private actors, such as vendors, but it recognized the importance to enter in dialogue with them for defining an integration strategy between HealthNorway and existing systems used by health personnel.

Different options were considered. One possibility was to link the HealthNorway with the existing private eHealth portals already used by several GP offices for their communication with patients. Some of these solutions had functionality for booking appointment, and renewing prescriptions and medical certificates. These solutions and their users – GPs, administrative personnel in the GP offices, and patients – could be a possible installed base for the new services. Technically, this would require to redirect users from HealthNorway to the private portals. It was decided not to opt for this solution and instead to link the healthcare providers' side with HealthNorway via the existing GPs' EPR systems.

One reason for this decision was that although all GP offices have an EPR system, not all of them offer electronic services to their patients (Vassilakopoulou and Grisot 2014). A participant of the pre-study from the Agency recalls: "*It was a large discussion about how could it actually be possible to use what was already in the market and how would actually turn out before the citizens. (…) how would the user experience be in that case, and how would the security be*". It was considered best if HealthNorway created an equal right and opportunity for all regardless of where they lived, or the kind of system their doctor had. Another reason was that the future plan for HealthNorway was to provide a comprehensive interface for patients to access organized information from multiple different sources. This comprehensive interface would gradually support the creation of a timeline as organizing principle for messages, prescriptions, certificates, appointments, diagnoses, and discharge letters in one place. Thus, it was important to not redirect to third parties in order to avoid missing pieces of the overall communication history. Furthermore, redirecting to third parties would

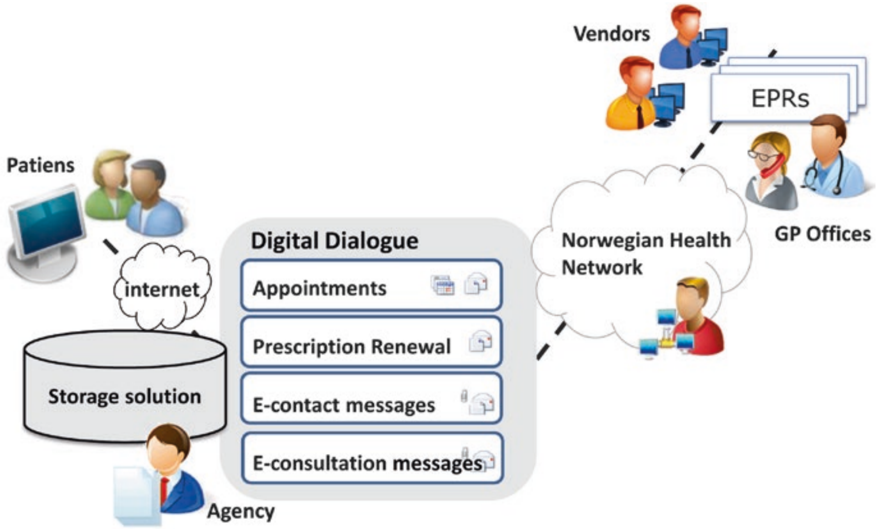

Fig. 12.2 Digital communication between patients and GP offices

harm the uniformity of the user experience and would create complications in security handling.

The decision to link the healthcare providers' side with the patients via the existing GPs' EPRs created the need to work with the EPR vendors and enroll them in the project. However, it was not certain that all EPR vendors would be willing to participate. Some were small vendors who provided EPR systems to GPs but not patient portals. One pre-study participant recalls that for them this was a "*fantastic opportunity to join, to hop on the boat*". But other vendors had their own patient portal and questioned "*how should we earn money in this market, because what's happening now is that we have our patient portal, with other services that you say that you want to develop we have them in place already, it's not big, we have them spread all over, but now you want us to just blend in with the others and that you just take over the portal side*". It was realized that having to rely on EPR vendors' collaboration was a major risk but it was decided that the expected benefits justified the risks. Figure 12.2 presents the overall arrangement decided for the digital communication between patients and GP offices.

12.3.4 Phase 3: Mature Services and Further Development Through Alliances

In August 2013, the secure service MyHealth was launched. By logging-in citizens could access the following main services: My Expenses, My GP, and My Prescriptions. Additionally, a number of other simpler services were offered such as electronic forms for ordering the European health insurance card and submitting notifications of experienced drug side effects. The highest security level for patient authentication was ensured using three alternative and already existing eID solutions: BankID (the Norwegian Banking Sector's common digital authentication and online signing solution), Buypass (jointly owned by Norway Post and Norwegian Lottery) and Commfides (a private solution). At a later point, other functionalities were added, for instance a service called "About me" where citizens could access their personal and contact information from the central National Registry and the GP Registry.

In November 2013, access to the Summary Care Record was added to MyHealth for the inhabitants of the pilot area. This service was the result of a project run by the Agency with the aim to support health personnel in emergency situations with access to patients' core medical information. The Summary Care Record contains key patient health information entered by GP/attending physician, and it retrieves prescription history, and information from national registries (e.g. the history of admissions and hospitalizations in the specialist health service is retrieved from the Norwegian Patient Registry (data from 2008)). In MyHealth, citizens can access the record, see the access log, register new information such as primary contact person, and disease history (structured selections), or they may opt out of the record entirely.

During autumn 2013 and the first semester of 2014, HealthNorway was redesigned, and in June 2014 relaunched with a new interface supporting mobile use. It was also migrated to a new version of the underlying technical platform, with a new search engine. This was important for improving usability and also, for ensuring the long-term evolvability of the platform.

In the same period, two local initiatives aiming for patient-oriented services started. Both initiatives were aligned with two priority areas of HealthNorway – providing personal health information and providing interactive services between patients and health providers – and contributed to its further development.

The first initiative was taken by UNN (University Hospital of North Norway in Tromsø) that decided to offer patients access to their hospital records. A survey revealed that most patients requesting copies of their hospital records would like to have them electronically. A project to develop a "proof of concept" solution for online access to patient records was launched in March 2012. The project was managed and financed by UNN and was implemented in close collaboration with the software company that provides the EPR for hospitals in the North Region. The EPR provider developed a solution for extracting data from medical records based on the specifications provided by UNN and also, based on the national recommendations provided by the Agency. From March 2014, the North Regional Health Authority took over the project. The online record access service was tested with 500 end-users and soon after testing it was made available to all residents of North Norway (in December 2015). The new electronic service allows patients to electronically retrieve health record documents from public hospitals in North Norway. Since 2015, the service can be accessed by patients through the secure HealthNorway interface.

The second initiative was a project initiated by the West Regional Health Authority who wanted to facilitate message exchanges between hospitals and patients. This was motivated by the need to reduce the number of appointment "no-shows" improving the utilization of available resources. In 2012 there were 82,000 missed scheduled appointments in the Western Region resulting in a significant waste of resources. In September 2013, the Agency endorsed the initiative and started a project to provide electronic support for the communication between patients and hospitals aiming for better coordination between the two parties. The project delivered a new electronic service for patients that have appointments at hospitals in the Western Region. These patients can have an overview of their appointments, confirm their attendance and send messages to the hospital (e.g. for changing the appointment time or even deciding to cancel the appointment altogether). Additionally, patients can check the status of their referrals for specialist services within the hospitals in the Region. For each referral they can check when it was received by the hospital, if it is still being processed or if a time slot has already been allocated to the. This service was offered in HealthNorway in 2015. By endorsing and including the two regional initiatives, HealthNorway is gradually becoming a universal interface to patient oriented electronic services in Norway.

In 2014 the Agency collaborated with the Norwegian National ICT (NICT) which is the interest body for information and communication technologies in the specialist healthcare sector formed by the four Regional Health Authorities. The collaboration aimed to the identification of citizens' needs for digital services in specialized care. The objective was to obtain insights for further developing HealthNorway and making it an entry point for both primary and specialized digital health services. The result was an extensive mapping and analysis of users' needs involving health personnel, citizens and management bodies of the health regions. The analysis ended up with the identification of 11 priority service areas (for example, services for supporting hospital appointment booking including preparation and follow-up after visits, services for providing an overview of visited health providers). This work informed the formulation of a strategy for digital specialist health services for citizens up to 2020, and led to the formation of a specific project on digital citizen services for the specialist sector (named the DIS) which started in January 2015. The project is expected to launch new electronic services in 2017.

In Fig. 12.3, we provide an overview of key milestones in the evolution of HealthNorway. Additionally, in Fig. 12.4, we present the time series of users per month from July 2011(right after the portal launch) till August 2016. HealthNorway managed to attract users' interest over the years and the monthly number of users is now about 1,4 million (the total population of Norway is approximately 5 million).

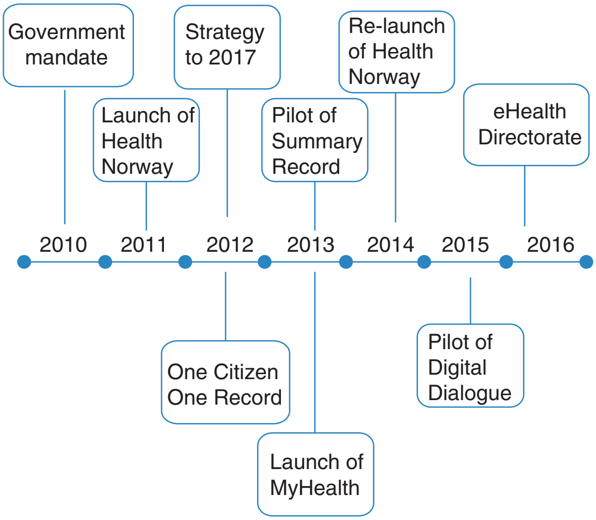

Fig. 12.3 Key milestones in the evolution of HealthNorway

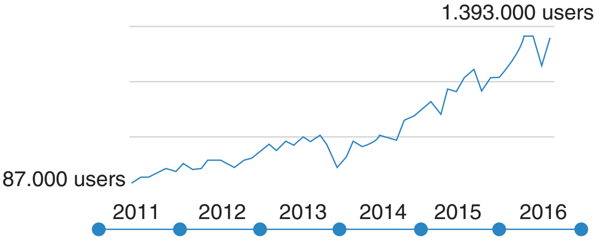

Fig. 12.4 Users per month from HealthNorway launch till Aug 2016

12.4 Analysis

In the paragraphs that follow we analyse how the installed base influenced the evolution of the portal, and how designers have engaged in "cultivation" strategies (Dahlbom and Mathiassen 1993; Ciborra 1997; Ciborra and Hanseth 1998). The installed base consists of various existing information systems, work and information practices, legal frameworks, standards and institutional conventions which relate to patient-oriented electronic health services. When faced with the installed base, the team building HealthNorway took different strategic decisions on what to "grow" in the new eHealth solution and what to redesign and substitute. This process stretches in time. The development of HealthNorway is not an "one-off" effort but entails a long lasting process of continuous launching of new services and further refinements. Thus, HealthNorway's services, contents and architecture were not fully specified and designed beforehand, but gradually grew by taking into account the overall government aims for patient oriented electronic services, the desires of the prospective users (citizens and healthcare providers) and the opportunities and limitations of the healthcare milieu. This process developed according to different reasons as for instance the qualities (e.g. scalability) and levels of maturity of existing components.

The strategy after the initial launch was to grow by adding relevant electronic services. Specifically, three service areas were identified and prioritized: (i) access to personal health information, (ii) travel reimbursements, (iii) digital dialogue with health practitioners. The Agency approached the design of these new services first by mapping existing technologies and information practices, and making sense of the existing institutional arrangements. In our analysis we interpret the ways the three service area were grown, as the enactment of strategies to deal with different aspects of the installed base.

In the case of access to personal health information, My Health, the pre-project team mapped a set of already existing projects, some of which had already implemented solutions on national level for giving access to selected personal health information, and were accessible via various health providers' websites. For instance, ePrescription was rolled out on a national scale and citizens could see their active and old prescriptions. On a different website, it was possible to log-in and change GP. The approach here was to include in HealthNorway services that were already developed in projects run previously by the Agency itself or by other public health organizations. In addition, the strategy was to create an area – My Health - where types of access to personal health information could be easily added, and which would work as central access point for citizens. Following this strategy, after the launch, My Health was gradually enriched by offering even services which were not yet nationally scaled and were only offered to citizens in specific geographical areas. Thus, the Agency developed My Health by including existing services which acted as a strong installed base to build on. This approach allowed reaping benefits in the short term. Indeed, this service area was launched relatively swiftly and made available in August 2013. The Agency followed the more long-term strategy to gradually complement the installed base of existing services by adding new services according to the long-term visions of offering access to comprehensive personal health information.

In the case of "Patient Travel" the aim was to simplify the administrative process of requesting reimbursements for travelling to health services. In this case the installed base consisted of existing work, communication and information practices and of a paper-based system (citizens sending forms to the reimbursement office). In this case, the Agency decided for a digitization of the existing arrangement, adding brand new digital capabilities to the installed base that could serve as substitutes the traditional paper-based capabilities with the aim to eventually phase them out. The core idea was that an online electronic form would be made available for citizens requesting reimbursement to facilitate the transition from purely paper-based processes to digital supported ones. Digitization processes are seldom straightforward transpositions of pre-existing non-digital arrangements. The participants in the pre-study were aware of the possible complications and they defined as a next step the analysis of the legal, economical, functional and technical requirements. Indeed, this service area is the least developed today (January 2016). The digitization necessitated changes in the corresponding regulations that were adopted by the

Norwegian Parliament in June 2015. These changes included the legal ratification of electronic claims submission for the patients that choose to do so, a new provision that stipulated that patients do not have to provide travel evidence as this would be retrieved from the registries and a new rule for covering a standard mileage allowance instead of the cost of cheapest scheduled public transport. It is envisaged that the electronic service will be made available in HealthNorway in 2016.

In the case of secure digital communications between patients and healthcare providers the task was to design and create a novel service, which would complement other existing modes of communicating such as visits and phone conversations. In this scenario, the team had different options for the development of the service. The team examined existing web-based services that some GP offices already offered, for instance for requesting appointments or renewing prescriptions. However, this base was considered weak because it was heterogeneous (many different and diverse websites), not secure enough (not all private eHealth portals in the market had implemented the security level required by law), and the user experience was evaluated as becoming too complicated and fragmented in a scenario where the national portal would redirect to the each GP's own page. Alternatively, the approach adopted was to work with the installed base of EPRs in use in the GP offices (all GP offices in Norway have an EPR system), and extend them to support the dialogue service. In this case the installed base included also the capabilities and knowledge of EPR vendors about GP office practices. However, this entailed a complex coordination effort. Indeed, the development of this service proved challenging and it necessitated the development of a sensitivity to the constraints and singularities of all the actors enrolled and the emerging interdependencies (Grisot and Vassilakopoulou 2015). As of early 2016, the new communication services are being piloted and it is expected that they will be fully launched soon.

Overall, the analysis of how the installed base has influenced the evolution of HealthNorway in the three different service area, show that the Agency engaged in different ways with the existing installed base, by complementing, creating substitutions, and expanding it. Overall, the analysis shows some key characteristics of cultivation strategy. First, in building HealthNorway, the Agency has deliberately engaged with the existing technology and institutional arrangements in place, and has built alliances for bringing together the efforts of distributed actors. Second, HealthNorway has expanded by orientating towards the satisfaction of concrete needs in order to motivate prospective users to adopt the new services. Third, overall changes have been incremental, exploratory and gradually intervening on various level (architecture design, user experience, technical platform) while keeping a coherent vision.

12.5 Discussion and Conclusion

In this chapter, we explored the different approaches employed for advancing the development of the Norwegian patient oriented healthcare portal (HealthNorway) that was initially launched with a limited functionality. The aim for HealthNorway is to eventually become a single, national point for patient oriented electronic health services. This aim created the need to engage with the installed base in a variety of ways and with different purposes.

We identified that the overall strategy employed entailed starting with concrete needs, capitalizing on what is already in place and proceeding in an incremental and exploratory way. This seems to be a prudent strategy. Prior information infrastructures' literature has indicated that the successful development of information infrastructures such as the Internet, mobile phone platforms and healthcare-specific arrangements has been achieved by following similar strategies (Hanseth and Lyytinen 2010; Aanestad and Jensen 2011; Aanestad and Hanseth 2002). Our findings are specific to processes for advancing the development of infrastructures that are already in place, nevertheless, they are congruent with recent findings by Grisot et al. (2014) that identified three different types of infrastructure innovation: in, of, on infrastructures. Innovations of infrastructures are about implementations of totally new infrastructures, innovations in infrastructures concern replacements/modifications of an infrastructure's existing components without changing the architecture and innovation on infrastructures concern additions of new components on top of what exists. Similarly, in our case, complementing the installed base entails finding ways to realize some of its latent potential by embracing capabilities already developed by others and linking to them. This is an approach that can yield benefits in the short term. Creating substitutes within the installed base entails creating new working arrangements and this involves encountering and handling sociotechnical complexity. Hence, this approach requires the dedication of efforts for a considerable length of time. Finally, extending the installed base entails complex coordination and enrolling efforts for the multiple actors that control distributed information infrastructure resources.

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Building National Healthcare Infrastructure: The Case of the Danish e-Health Portal

13

Tina Blegind Jensen and Anne Asmyr Thorseng

13.1 Introduction

Sundhed.dk facilitates patient-oriented digital services which provide access to and information about the Danish healthcare services. Since its launch in 2003, sundhed.dk provides several functionalities such as quality assured health information, access to medical records and medication, and an overview of the Danish healthcare system. Sundhed.dk creates linkages between existing data sources, opens up data sets to new user groups, and facilitates communication between healthcare providers and citizens. The portal also ensures further development not only by providing a secure infrastructure, search optimization, and user interfaces, but also by supporting the development of new services.

Sundhed.dk has earned good reputation and high standing in the healthcare sector internationally. Health authorities from other countries, that wish to build similar solutions, have approached sundhed.dk for advice and best practice (Sundhed.dk 2014a). However, the positive reputation and high level of maturity of sundhed.dk has not been established overnight. Thus the assumption by other countries of simply copying the code, the user interface, and the technical infrastructure is far too simplistic if they wish to attain what Denmark has achieved with respect to e-health services for citizens. Other infrastructural resources in place, including existing systems, regulations, communication standards, as well as organizational structures in the Danish healthcare sector, have played a vital role in establishing the national

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e-health infrastructure (Thorseng and Jensen 2015). Consequently, the design, development, and implementation of an e-health initiative such as sundhed.dk, that has become an integrated part of a national infrastructure, becomes relevant to study.

In line with the aim of the book, this case chapter provides insights into the role of the installed base – i.e., pre-existing technologies, regulatory frameworks, data resources, and organizational arrangements – in the evolution of sundhed.dk. In particular, we argue that the main reasons for the current positioning of sundhed.dk have been its ability to (1) collate and assemble existing data resources, (2) repurpose and enhance current data sources in the health sector, and (3) engage a multiplicity of stakeholders. We argue that these activities represent three ways of capitalizing on the installed base that has led to the evolution and current situation of the e-health portal. At the same time, we show how these three modes come with a number of challenges for sundhed.dk in its pursuit of further innovation.

The rest of the chapter is organized as follows. We start out by introducing the Danish healthcare sector to set the context for sundhed.dk. Further, we describe the development of sundhed.dk, its purpose, as well as its current organization. Based on this description, we analyze how the organization behind the e-health portal succeeded in establishing a national healthcare infrastructure by assembling existing data resources, repurposing current healthcare services, and mobilizing key stakeholders. We conclude the chapter by providing some thoughts on the future for sundhed.dk.

Method

The empirical material for this chapter stems from 13 semi-structured interviews conducted between March and October 2014 with staff at the central office of sundhed.dk as well as with partners from the regions, ministry, and other health authorities in Denmark. In addition, we have included documents in the form of press releases, official papers, internal documents, and online information. Three representatives from the sundhed.dk office have read the chapter and verified its content before publication.

13.2 The Danish Healthcare Sector

Denmark is like other Scandinavian countries known for its comprehensive welfare system. Denmark provides free and equal access to public healthcare services to its relatively small population of 5.6 million inhabitants. Accordingly, access to all public hospitals as well as general and specialized practitioner services is financed through general taxes. Dentists, out of hospital medicines, as well as some therapies are provided under co-payment or private models on a case basis. The public healthcare system is organized in primary healthcare and the hospital sector. Primary healthcare deals with general health problems and consists of general practitioners

(GPs), practicing specialists, dentists, physiotherapists, nursing homes, dental care for children, and preventive health schemes. The hospital sector handles medical conditions that require specialized treatment and intensive care. Patients are referred to the hospital by their GP unless it is acute illness or accident. Patients have the right to choose between all public hospitals for treatment, and since 2002, they also have the right to choose a state financed treatment at a private hospital if waiting times are exceeded.

The healthcare system in Denmark is predominantly public and government-controlled through comprehensive legislation and annual budgetary allocations. The Ministry of Health has a coordinating and supervisory role, but operational responsibilities are embedded in a decentralized administrative structure consisting of 5 regions and 98 municipalities (Pedersen et al. 2012). The regions are responsible for the everyday operation of hospitals and primary care. At a national level, the interest organization – Danish Regions[1] – coordinates the common interests of the five regions and negotiates the annual financial framework for the regions with the government, as well as with the private practicing sector. The municipalities are in charge of public health, homecare, nursing homes, school health service, rehabilitation, and social services. The ambition is to provide a healthcare system that is efficient, of high quality, and that enables free choice of provider by its citizens. In 2015, the annual government healthcare expenditures amounted to 150 billion DKK (equivalent to 20 billion euros).

The Danish healthcare sector relies heavily on information technology for the provision of healthcare. More than 95% of the Danish population have access to the internet, and broadband penetration is among the highest in Europe (Danish Regions 2010). A unique personal identifier (CPR number) is issued to all Danish citizens at birth, and citizens can obtain a secure web-ID (NemID) free of charge to access public sites with e-services. Denmark is a small country in terms of population and geographic area; yet, it is at the forefront in the digitalization of medical information and in electronic healthcare record management. Centralized databases store medical information of Danish citizens, including hospitalization information and prescription history. GPs, hospitals, and pharmacies are electronically connected to handle patient records, e-prescriptions, lab results, discharge letters, and electronic referrals to hospitals and specialists (Protti and Johansen 2010). In 2014, 97% of laboratory test results were delivered online, and 100% of prescriptions were transmitted to pharmacies electronically.

The high level of digitalization of the Danish healthcare sector can be explained partly by the early development of communication standards[2] initiated in the mid-1990s for the common communication flows between medical practices, hospitals, and pharmacies, as well as the secure Danish Healthcare Data Network. In addition, over the last decade, the Danish government has initiated and sponsored a number

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[1] Danish Regions is the interest organization for the five regions in Denmark.

[2] MedCom was established in 1994 as a public funded, non-profit cooperation. It facilitates the cooperation between authorities, organizations, and private firms linked to the Danish healthcare sector.

of initiatives to increase the digitalization of its healthcare services. National healthcare digitalization strategies have been published since 1996 to set the agenda for e-health initiatives. One such initiative is the Danish national e-health portal, sundhed.dk, which provides access to and information about patient-oriented digital services in the Danish healthcare sector. Next, we describe the purpose of sundhed.dk, its evolution, as well as its current organization. This description serves as background information for analyzing how sundhed.dk managed to capitalize on its installed base to become what it represents today.

13.3 Case Narrative: Sundhed.dk

13.3.1 Purpose of Sundhed.dk

The purpose of sundhed.dk is to consolidate relevant information from all parts of the healthcare service and establish an electronic gateway for citizens and healthcare providers to the Danish healthcare system. The ambition is to empower patients by offering insight into and transparency of healthcare services, as well as to offer healthcare professionals easy access to clinical information about their patients. Since its launch in 2003, the objective of sundhed.dk has been to obtain better coordination across healthcare services by providing a government-controlled entry to health information across a relatively decentralized healthcare system. At a strategic level, the ambition is to encourage a common strategy, investments, and solutions for the healthcare services at a national level and to integrate healthcare services on the internet (Sundhed.dk 2016).

Sundhed.dk is at the forefront of governmental e-health portals (Sundhed.dk 2014b), and it serves as a unified hub for electronic communication between patients and healthcare providers. The portal is sector-wide in terms of its governing structure as well as the several national and regional solutions it encompasses. The e-health portal is presented as a central component for patient-oriented digital services in the national healthcare digitization strategies (The Danish Government et al. 2008, 2012).

Internationally, sundhed.dk is recognized for its provision of patient-oriented digital services at a national level. Other countries turn to the central office of sundhed.dk to learn from their experience. However, the development of sundhed.dk – as we know it today – was built step-by-step over a number of years, as we describe next.

13.3.2 Timeline of Sundhed.dk

In 2001, the Association of County Councils in Denmark and the Ministry of Interior and Health initiated the work of establishing a common public e-health portal. The various stakeholders in the healthcare sector agreed on the prospect of establishing a common infrastructure and a shared system across municipalities and regions all

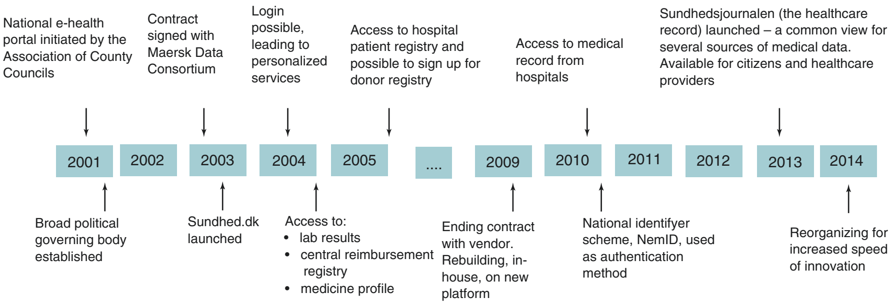

Fig. 13.1 Timeline of main events

over Denmark. Figure 13.1 shows the timeline of the main events that led to and further triggered the development of sundhed.dk.

A broad political governing body, consisting of The Association of County Councils, The Ministry of the Interior and Health, The Greater Capital's Hospital Association, as well as Copenhagen and Frederiksberg Municipalities, was established to support the start of the e-health portal. One of the first tasks for the board of directors was to prepare a tendering process. Due to the scope and complexity of establishing the common infrastructure, it was decided to carry out the tender as a contest, which was launched in spring 2002. The winner of the contest was Maersk Data Consortium consisting of LEC, ACURE, PLS/Ramboll and Bysted with whom the central office of sundhed.dk signed a contract in the beginning of 2003. An analysis of the needs and the development of the first version of the e-health portal was carried out before its launch in December 2003.

In the initial phase of sundhed.dk, the purpose was to add quality-assured medical information that would serve both citizens and healthcare providers. Information about waiting lists at certain hospitals soon became available on the portal. At the beginning of 2004, the functionality of sundhed.dk was expanded with services that require login with a digital signature. A first attempt was made with electronic access to lab results for healthcare providers by connecting to a subset of lab systems already in use in Denmark. From 2004, patients were able to view their electronic medicine profile online. The prescription solution built on an already existing solution called "Medicine Profile" provided by the Danish Health and Medicine Authorities. Later, in 2014, this solution was phased out and replaced by a new solution for prescription handling called "Common Medicine Card" provided by the Danish Public Health Institute. An electronic guidance to the healthcare service was established and it was possible to search for healthcare providers, i.e., GPs, physiotherapists, and psychologists, based on location and availability. Finding their GP on sundhed.dk, patients would be directed to the GP website to initiate booking of appointments and conducting email consultations. Since vendors of booking and email-consultation solutions already had a strong market position, the partners of sundhed.dk agreed to directing patients to the GPs' own sites, where they could access their GP's solution for booking and e-consultation.

By 2005, patients were able to access the Danish National Patient Registry in which all treatments performed in the hospital sector were listed. This registry, created in 1977, contains personal data about all patients admitted to hospital since 1977, and from 1995 also out-patients registrations (Lynge et al. 2011). Additionally, based on the Central Reimbursement Registry, information about all treatments a patient had received in the public health service were accessible to the patient. By 2006, doctors in 11 out of 19 counties could check online lab results via sundhed.dk. By the end of 2007, the portal had about 170,000 unique users every month.

In April 2009, sundhed.dk was launched on a new technical platform, which meant that the central office gained more control over the portal and reduced costs by being independent of external consultants and developers. This process was described by staff as "*taking the portal home*" (head of staff, sundhed.dk). Subsequently, a development department now did most development of services in-house, while external consultants were approached to develop standalone services. Apart from smaller developments, there were two major initiatives in this period. One initiative was to make medical records from public hospitals available so that patients would be able to see parts of their medical record such as treatments, diagnoses, and notes made by the healthcare personnel. The e-record was created to ensure information sharing across regions and hospitals; for example, if a patient from Copenhagen were admitted to another region of the country, doctors would now have access to data from previous treatments. The e-record was thus a read-only repository that supplemented the local electronic healthcare information with information from other areas. An important milestone for sundhed.dk, in 2010, was managing access to the portal via NemID. Citizens could now use the same authentication method as banks and other public Danish agencies. This meant that single sign-on was enabled and users needed to remember only one password. In 2015, approximately four million Danes had a NemID account (NemID 2014) and could thus potentially log onto sundhed.dk.

Another major initiative in this period was the healthcare record (sundhedsjournalen) launched in 2013. This initiative enabled a 'one-stop-view' for both patients and healthcare providers with access to medical data such as records stemming from the e-record described above, medicine data, and other critical health information.

13.3.3 Sundhed.dk Organization

Sundhed.dk is organized around key stakeholders in the healthcare sector. It consists of a secretariat (i.e., the central office which in 2016 counted 45 employees) and a number of partners that contribute to the development of the portal. The organization is illustrated in Fig. 13.2.

The stakeholders (see the left box) contribute to sundhed.dk through participation in governance activities, projects, and by providing content such as information

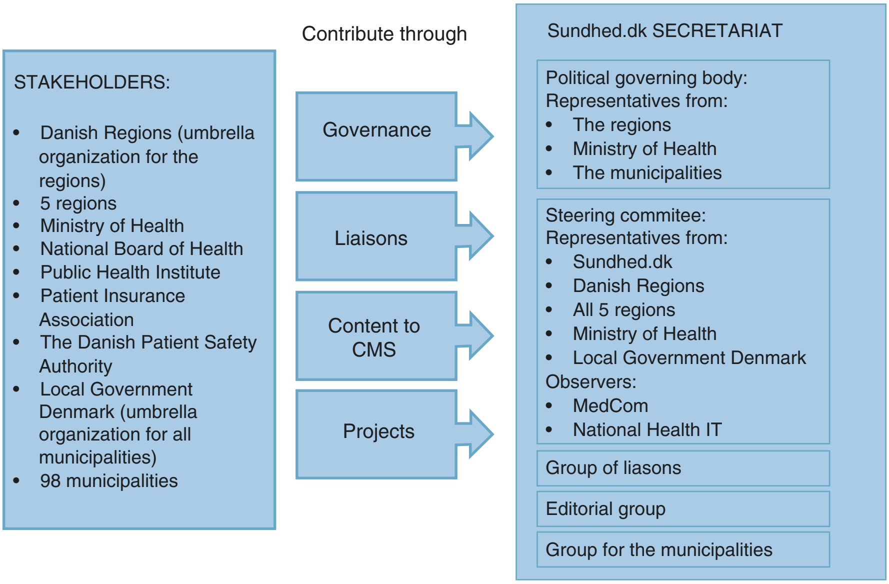

Fig. 13.2 Organization of sundhed.dk

about their activities, updated guidelines, etc. The secretariat in sundhed.dk (see the right box) is responsible for administration, marketing, maintenance, and daily running of the portal. The secretariat further comprises a team of assisting partners that take part in conceptualizing and developing new solutions. A political governing body with representatives from Danish Regions, the Ministry of Health, and the municipalities, as well as a steering committee with representatives from the main areas in healthcare are responsible for the overall strategy and prioritization of services and funds.

Health data and services provided through sundhed.dk is based on displaying already existing data from various sources. In some cases, data is being extracted from data sources such as hospital systems, GP systems, prescription databases, and lab systems to be presented through sundhed.dk's presentation layer. In other cases, services are "framed" to achieve sundhed.dk's 'look and feel' although the service is located and run somewhere else. Lastly, sundhed.dk also points or directs users to other existing services in the healthcare sphere, such as booking of appointments for GPs. Figure 13.3 illustrates the architecture of sundhed.dk.

Security is maintained with patient login by means of the national electronic identifier scheme, NemID. Health personnel can access patient data provided through sundhed.dk in their electronic medical records. Health personnel's access to patient data is restricted by ensuring there is an existing treatment relation between patient and health personnel and further that the patient approves health personnel access. Access to patient data by the health personnel is logged and the logs are available to the patient.

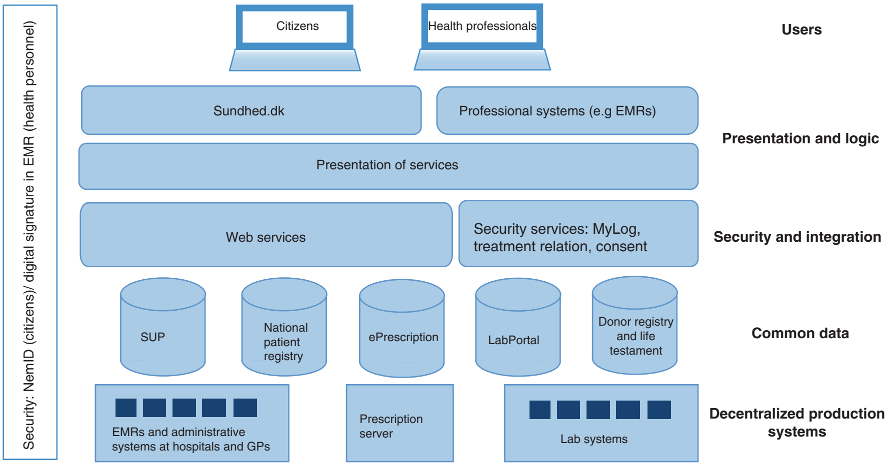

Fig. 13.3 Sundhed.dk architecture

13.4 Analysis: Three Modes of Capitalizing on the Installed Base

The introduction to sundhed.dk gives an indication of how the organization draws upon, recombines, and repurposes existing technical, legislative, and organizational resources and services. In this section, we detail how the organization of sundhed.dk has: (1) collated and assembled existing data resources, (2) repurposed and enhanced current data sources in the health sector, and (3) engaged multiple stakeholders to obtain its current position. The three modes of capitalizing on the installed base have corresponding opportunities and challenges that we present below.

13.4.1 Collate and Assemble Existing Data Resources

Sundhed.dk explicitly aims to provide access to health information, and several of their services involve a collation of pre-existing data sources: "*Our ambition is to collect data and to establish easy access to data*" (head of administration, sundhed.dk). One example of collated data is 'sundhedsjournalen,' where various data sources, such as lab results, prescriptions, and medical records from hospitals are displayed in one view for the citizen and health personnel. In 'sundhedsjournalen,' citizens can also access laboratory results, and they can register for organ donation, as well as set up their living will.

Another example of collated data is the functionality, whereby all healthcare providers are listed with details about opening hours, core services, email consultations, renewal of e-prescriptions, etc. Patients can get information about and overview of healthcare providers, and they can gain direct access to their websites through the portal.

A third example is the collection of quality-assured health information. The assembling of data sources enhances the value and usefulness of singular data sources in terms of providing easy access to as well as a contextualizing of information. For example, in the case of 'sundhedsjournalen,' data from one source is shown in relation to another. This means that a patient or health professional can see where a patient has been admitted, and at the same time, they can gain access to prescribed medications and discharge notes.

Displaying information to patients relies on laborious work conducted over several years to achieve extraction of data from multiple sources. A representative from one of the regions argued: "*Some of these services already existed such as the Landspatientregisteret [The National Patient Registry], so basically, in Denmark, we had an existing infrastructure that was useful when establishing sundhed.dk*". In addition, Denmark has a well-established IT infrastructure such as the common standard for health message exchange and the secure Danish healthcare network. This infrastructure has been a prerequisite for the success of sundhed.dk: "*In Denmark, we have a strong tradition of digitalization and many solutions were already established locally – let the thousand flowers bloom*" (representative, SSI[3]). In other words, the informant argued that, opposed to centrally directed development of digital services in the healthcare sector, local initiatives have been the source of many current information systems. For example, the e-record builds on a mature infrastructure that was the outcome of the project, initiated in 2000, called 'Standardized pull of patient data' (SUP). This database was built to make registered patient data in EPR systems, the Patient Administrative Systems (PAS), and other systems on currently and previously admitted patients available in other hospitals across the country. Initially, SUP provided a majority of hospitals and GPs across Denmark with the possibility of accessing electronic health records across counties. Extracts of patient data are transferred via a nationwide MedCom XML standard to a SUP database/Internet server, where an Internet browser provides access for healthcare professionals to view selected patient information and record data by searching on the patient's civil registry number (Aanestad and Jensen 2011; Jensen 2013). The head of administration at sundhed.dk explained: "*We have 'buttoned on' services and applications over time […]. We had no ambition of developing something new… rather, we wanted to enable access and gather what already existed […]. So, basically what we do is to develop a user interface that covers all existing solutions and then make data available from there*" (head of administration, sundhed.dk).

Collating and assembling already existing data sources provides easy access to a number of health services for citizens and healthcare professionals; however, it also comes with some challenges. For example, collecting and publishing quality-assured health information and information about the healthcare services requires comprehensive quality control: "*More and more quality requirements are being posed from our side [sundhed.dk]. At some point, the amount of editorial content on sundhed.dk was simply overwhelming and then we started talking about quality*" (head of administration, sundhed.dk).

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[3] SSI stands for 'Statens Serum Institut', National Institute for Health Data and Disease Control.

Similarly, the organization of sundhed.dk needs to adhere to national regulations and procedures, including pre-existing legal frameworks concerning data ownership on how data is treated and how it can be displayed and accessed. The organization needs to take into account these regulations and therefore it engages in close collaboration with authorities when displaying these data. For example, displaying a collection of medical information to the patient is based on existing legislation on the right to view own health information, in which a person over the age of 15 has the right to see what is being written about him/her. Requesting a physical copy of one's record directly from the hospital requires that the medical staff perform an evaluation of what is disclosed to the patient to avoid distributing sensitive material. However, when making the records available to citizens through the e-health portal, this professional "filter" is no longer present. Through discussions with the health authorities, and interpretation of the existing law on information access, a 14-day delay has been implemented on availability of records to the patient (this delay has been further reduced to 3 days in 2015). This way, health staff can communicate and explain results to the patient before he or she accesses them online. Health personnel on the other hand can access the patient's data immediately.

13.4.2 Repurpose and Enhance Current Data Sources in the Health Sector

Part of the ambition of sundhed.dk is to create access to current healthcare data sources, not to "*reinvent the wheel*" (head of administration, sundhed.dk). Some of the first services on the portal provided access to existing registries. Several of the data sources, which are displayed through sundhed.dk, were originally intended for other purposes than citizen access.

For example, the central reimbursement registry mainly ensures that health providers are reimbursed for the services they provide to patients. The registry serves administrative and research purposes. Another registry is the National Patient Registry whereby a range of data is recorded about patients when they receive care as part of the specialist healthcare service. The data is used for several purposes; for health research, surveillance of diseases, activity monitoring at the hospital, and to estimate and review the total use of hospital services across counties and regions (representative, SSI). Through building on already existing data sources by giving a new user group access, new use of the data is enabled. Through sundhed.dk, patients can use the same data to get an overview of their treatments and movements around the health service.

Second, a gradual expansion of linking to new registers and systems has taken place, and in some instances, sundhed.dk has not only displayed the data, but also enhanced the underlying systems. One example is the donor register; in 1990, legislation was passed defining the legal criteria for being brain dead, which meant that donating organs, besides kidneys, could be performed. Consequently, a donor registry was established to keep track of potential donors. By 2005, an electronic sign-up option for the donor registry was created. This means that patients can now register whether they allow all or no organs to be donated, whether they want only some organs to be donated, or whether the decision is to be made of next of kin. Another example of enhancing an already existing system is the program for colon cancer screening, which all Danes between 50 and 74 years are offered. Through sundhed.dk, it is possible to opt out of this screening.

Third, sundhed.dk also utilizes and repurposes already familiar infrastructures for their users. For example, authentication that citizens are familiar with from banking and other public electronic service was introduced in 2009 (i.e., NemID). By exploiting an authentication method, which is available to and widely used by the Danish population, sundhed.dk is readily available to the Danes.

Although existing data sources, systems, and registries are repurposed through the e-health portal, the organization behind sundhed.dk avoids "data management" responsibilities. Rather, the solutions and data repositories which sundhed.dk links to or integrates with are themselves responsible for data management. For example, if the user has questions regarding data presented via sundhed.dk, the entities in the health service, which provided the health service and subsequently health data, are the point of contact. The role sundhed.dk has had in terms of being a public, authoritative site on health without having any form of responsibilities for the data displayed was "*new turf*" (head of administration, sundhed.dk). The fact that Danish health authorities have a long tradition of registering data and providing local health services challenges the repurposing and enhancing of existing data on the portal. For example, the partners have started to discuss and agree upon who owns what and how (representative, SSI).

Furthermore, the repurposing and enhancing of existing healthcare services has gradually changed the way in which partners perceive the organization behind the e-health portal. They have started to question the role of the portal and they voice their critique of sundhed.dk for not having ensured that its strategy is aligned with that of the partners. They question the overall direction of the portal: "*It seems that it is the jukebox principle that defines what services are developed. To us it is not clear what are the criteria for prioritizing services… the strategy is not clear and sometimes I wonder if the strategy is technically driven in the sense of 'we have this new thing' and then they build it without any overarching strategy*" (representative, the regions). For sundhed.dk, establishing a clear strategy is further challenged by the fact that there is not one common strategy for healthcare in Denmark: "*It gets really complicated when you have so many strategies in play – the Digitization Strategy and the Healthcare Digitization Strategy at a national level, the Healthcare IT Strategy at a regional level, and then the municipalities have their own strategy*" (head of administration, sundhed.dk). Whereas there is a common understanding of the overall vision of sundhed.dk, the existing ideas and strategies among the partners seem to be difficult to reconcile. In addition, partners question whether a regional strategy is more important compared to a national initiative. These concerns reflect the third mode of capitalizing on the installed base, which has to do with the engagement of multiple stakeholders, as we discuss next.

13.4.3 Engage Multiple Stakeholders

The governing bodies and financing partners of sundhed.dk consist of members from Denmark's five regions, the Danish Regions, the Municipal Organization, and the Ministry of Health. This broad representation of key actors gave legitimacy to the portal at an early stage: "*The purpose was to establish a common public healthcare portal […] that vision was crucial, and then of course it was important that they managed to engage the most influential partners, such as Danish Regions, that primarily runs sundhed.dk, together with the municipalities and the Ministry of Health as partners*" (representative, The Ministry of Health). In addition, informants describe it as a clear advantage that the organization of the governing bodies resembles the way in which the remaining healthcare system is organized. For example, the relationship between the regions, the government, and GPs has been maintained through general agreements: "*The collaboration model we find in the Danish healthcare system is reflected in the organization of sundhed.dk. I believe that if we wouldn't have had this organization in place, it would have been very difficult to establish sundhed.dk*" (representative, the regions).

The initial phase of sundhed.dk can be characterized as a political showcase for regional collaboration with solid political unity and common ambition. The involved parties have largely gathered around the common ambition of having one access point to the healthcare services: "*At the outset, there was a clear vision, which was politically anchored in the Association of County Councils – one entrance point to healthcare services and cross-sectorial collaboration – it was a vision we all could agree upon*" (head of administration, sundhed.dk). In addition: "*We were told that if we could find a project that could strategically mark the 14 counties across, and not as silos, we would receive funding*" (representative, the regions). In the initial phase, there was little disagreement concerning what should be offered to citizens and healthcare providers. The political unity and broad collaboration of stakeholders was described as key reasons for the success of the portal.

While there was a clear political mandate and a broadly agreed-upon vision, the partners had different starting points in terms of already existing digital services. One of the initial challenges was to get everyone at the same level: "*It was a great opportunity to establish cross-sectorial collaboration, but this was also one of the biggest challenges […] For example, not all regions had very advanced webpages*" (head of administration, sundhed.dk). In addition, it was a challenge to get everyone onboard: "*In the beginning, a lot of partners were happy about sundhed.dk and many believed in the overall vision. But if a region was working on a local project, it was difficult to get its buy-in. We spent much time in the beginning to go out locally and defend our existence. There was no choice for opting out. We basically told them that they themselves had decided that we should exist*" (head of administration, sundhed.dk). The engagement of multiple stakeholders did not come automatically but had to be enabled actively by the staff at sundhed.dk. It was important to engage actors, since sundhed.dk did not have any authoritative responsibility or obligations. The overall purpose was to make services available and to establish editorial access to more than 900 partners over time. The role of sundhed.dk was to engage and, at the same time, control the partners. This was considered a "…*difficult balancing act for sundhed.dk*" to get the regions and municipalities to engage and own the process while at the same time manage and coordinate the efforts (representative, the regions).

Building on the installed base of a core set of actors was in this case a double-edged sword, as one of the informants also stated; "*What is their [sundhed.dk] strength is also their weakness*" (representative, SSI). The informant here is referring to the broad alliance of partners, which gave the organization and e-health portal legitimacy, but also made it heavy and inflexible in the sense that many considerations were required for every decision. For example, the prioritization of tasks was described as a politicized decision-making process: "*It is very difficult to be sundhed.dk in terms of serving so many masters*" (representative, Ministry of Health). The head of administration in sundhed.dk further elaborated on the challenges in decision-making and prioritization processes: "*We cannot prioritize projects ourselves [internally in sundhed.dk]. We need to do that in collaboration with our partners. They have their own interests and local benchmarks and we don't have resources to financially support all their wishes*". This situation put sundhed.dk in a certain bind. In addition, priorities seemed to shift after certain tasks had been initiated, thus making the daily development of new services cumbersome: "*You can risk that when the economical agreements are made, a politician will suddenly say 'Now we need more people to donate their organs, so in 2013 this should be registered on sundhed.dk'. This was not how it was earlier – we knew very well what we needed to do. Now our partners often want to lift their IT-strategies and projects via the portal*" (head of administration, sundhed.dk). Although it complicates development when having to accommodate all partners' needs and IT strategies, it is encouraged and part of sundhed.dk's overall mission.

Overall, there has been broad support from relevant players in the Danish healthcare arena, but at the same time, it has been challenging for the sundhed.dk organization to serve so many masters. As time passed, the majority of actors started to question what was in it for them. The regions, who financed 80% of sundhed.dk, wanted to see their requests being realized: "*When we pay for a service, we also assume that it will appear on the portal*" (representative, the regions). In particular in 2009, when sundhed.dk decided to do most development of services in-house as opposed to development by external consultants, it was a challenge for them to keep up with the pace of demands since "*the pipeline was getting too tight*" (head of administration, sundhed.dk). A representative from one of the regions, who argued that the production line was too limited with the consequence of delayed projects, confirmed this observation: "*… there has been a shift from being a client to being a vendor, and this has been a challenge for sundhed.dk. Mostly because the production line has become very narrow […] and there has been too many things that have been important for the regions, but we don't want to constantly discuss prioritizing those services that are included on sundhed.dk*" (representative, the regions). The request for the future was that the organization behind sundhed.dk would be able to develop projects in parallel.

In the next section, we conclude the chapter by discussing the findings and reflecting upon the future of sundhed.dk.

13.5 Discussion: Moving Forward

What makes the sundhed.dk case unique is the mobilization of a large number of stakeholders. Sundhed.dk has managed to cultivate a large network of alliances, which makes it successful and at the same time difficult for other countries to replicate. As we demonstrated in the analysis, the engagement of multiple stakeholders did not come automatically. Although the initiation of the portal came with a political mandate, sundhed.dk still had to engage actively the different stakeholders. It is fascinating to see how the collaboration among different stakeholders made it possible to integrate divergent priorities and strategies into one shared portal. This conclusion is in line with previous research (e.g., Aanestad and Jensen 2011), which shows that the realization of nation-wide information infrastructures for healthcare not only requires a gradual transition of the installed base; the development also needs to ensure the mobilization and organization of multiple stakeholders.

However, it was not only the active engagement of stakeholders, which made sundhed.dk a success. The installed base in the form of pre-existing technologies, regulatory frameworks, data resources, and organizational arrangements played a key role in the gradual evolution of sundhed.dk. The main reason for the current positioning of sundhed.dk was its ability to collate and assemble existing data resources, and also to repurpose and enhance current data sources in the health sector.

Taken together, these activities were important for sundhed.dk in order to capitalize on the installed base. At the same time, however, the organization now faces a number of challenges in staying relevant for its partners in the time ahead. While the portal was very visionary at the beginning, it could easily get behind regarding current trends in a fast moving sector of digital health services. Large leaps are being made in fields such as mobility and "quantified self," whereby patients provide data about themselves either manually or through sensors and this leads to high demands from society, and the younger generations specifically, on how services are offered digitally. Additionally, as new digital systems are being introduced in the health service in the regions in Denmark, sundhed.dk needs to be aligned with these changes. For example, at the time of writing, the regions in and around the capital are introducing EPIC as an all-encompassing suite for the tertiary health service (Jensen 2016), and sundhed.dk needs to link up with these new data sources and providers.

To stay relevant over time, sundhed.dk also needs to broaden its capacity to develop services at a pace that is needed for the involved partners. This could mean easing the possibility for external developers to create services and having a flexible governance structure and an agile development methodology. These measures should, at the same time, be balanced with measures to ensure that quality and professionalism are not compromised. These are issues that sundhed.dk are working on at the time of writing. A program, targeting the above-mentioned challenges, has led to a reorganization of sundhed.dk to ensure increased delivery capacity and stronger portfolio management. In the future, focus is on being proactive and assist the partners in developing and maturing new service concepts. According to sources at sundhed.dk, this work yields positive results.

Lastly, without any formal mandate, sundhed.dk has to keep a balance between being a receiving part, acting on their partners' wishes, while at the same time contributing to a clear direction within the Danish healthcare sector. This is the main premise of the organization behind sundhed.dk, which has led to the evolution of the e-health portal, but now needs to show the future direction of the portal.

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The Swedish Patient Portal and Its Relation to the National Reference Architecture and the Overall eHealth Infrastructure

14

Nina Sellberg and Johan Eltes

14.1 Introduction

This chapter presents the evolution of the Swedish patient portal and how it has co-evolved with the eHealth architecture and the overall national eHealth infrastructure. It focuses on the period from 2000 to 2015. The patient portal with related e-services give citizens access to for instance e-scheduling, e-pharmacy, e-referrals, telemedicine, access to personal health information, digital self-services around the clock, Internet-Psychiatry, Electronic Health Record (EHR) logs, e-services that visualize planned care procedures including upcoming encounters, pre-visit form submission, e-communication with their physician or nurse, and secure disclosure of their health data (generated in the public health care system) to third party vendor's apps and systems.

The case narratives illustrate the role a broadly and timely agreed upon national reference architecture has played during 8 years of distributed, yet harmonized development of a national eHealth infrastructure and the eHealth innovation made possible by that infrastructure. During these 8 years the installed base was organically expanded with new regulations, users, infrastructure components, portals and e-services, proving the importance of the infrastructure as a basis for innovation carried out and utilized by a broad range of stakeholders.

The remainder of the chapter is structured as follows: in the next section the Swedish healthcare model is presented, thereafter an overview of the core components building the Swedish eHealth architecture is illustrated. This section is followed by our narrative of the Swedish case. Next we analyze and discuss the core activities and actors that have evolved the installed base supporting innovation and

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entrepreneurship. Our findings support the argument that infrastructure evolvement comes out of the complex interplay between many different actors intertwined in step-by-step cultivation. In Sweden the infrastructure evolvement is done through the governance of a reference architecture endorsed by all entities contributing to the installed base. The installed base has evolved through the strategy of extending existing components, through complementing the installed base with new components and through the substitution of existing components with new ones. We also see a reference architecture as a vision-carrying foundation for many years of bottom-up, middle-out, top-down and yet harmonized, infrastructure evolution. More specifically, a shared, well understood and purposeful reference architecture may even be a contributing factor in reducing the probability and implication of "political" games.

Method

Data were collected as an action research study conducted from 2009 to 2015. Nina Sellberg was the R&D manager at the department of eHealth, Stockholm County Council (largest eHealth department in Sweden) between 2010 and 2014 and CTO at 1177 Vårdguiden between 2014 and 2015, with the responsibility of the national citizen platform. She was also appointed project manager of the My Care Pathways project, between 2011 and 2015 and appointed project leader of the development of the New Patient Overview Service implemented in all county councils and municipalities in Sweden from December 2015. Johan Eltes was consulting as head of architecture of My Care Pathways between 2011 and 2013. He was consulting architect at Inera AB between 2006 and 2013 for the development and management of the national reference architecture. He is deputy CTO at Inera AB since 2014, with the responsibility of the national interoperability profiles and the national reference architecture. Data collection included information gathering (a) from central stakeholders at Inera AB, My Healthcare Contacts, and project developers and vendors and, (b) from documents on national eHealth strategies, project management documents, the system specifications and IT architecture documents.

14.2 Swedish Healthcare

14.2.1 Overview of the Swedish Healthcare Model

The responsibility for health and medical care in Sweden is shared by the central government, county councils and municipalities. The Health and Medical Service Act regulates the responsibilities of county councils and municipalities, and gives local governments more freedom in this area. The role of the central government is to establish principles and guidelines, and to set the political agenda for health and medical care. It does this through laws and ordinances or by reaching agreements with the Swedish Association of Local Authorities and Regions (SALAR), which represents the county councils and municipalities. Sweden is divided into 290 municipalities and 20 county councils. There is no hierarchical relation (chain of command) across state, county councils and municipalities. The patients have free choice of hospitals, but General Practitioners (GPs) serve as gatekeepers for referrals to hospitals or specialists. The councils' and municipalities' autonomy is strong, and they make their own ICT investments. Costs for healthcare of Sweden's gross domestic product (GDP) is fairly stable and on par with most other European countries. They represent in 2016 about 9.5 % of GDP (OECD 2014, WHO). The bulk of health and medical costs in Sweden are paid for by county council and municipal taxes. Contributions from the national government are another source of funding, while patient fees cover only a small percentage of costs.

14.2.2 Rationale for Developing the Swedish eHealth Architecture

The rationale for the development of the Swedish eHealth architecture was firstly the National IT Strategy that was taken forward in 2005. This was a work initiated by the Swedish Government with the intention to support (1) Citizens', patients' and families' access to readily available and comprehensive information on health in general and on their own health, (2) Professionals' access to information across organizational boundaries using effective and interoperable IT integration platforms that ensure patient safety and facilitate health professionals' daily work, and (3) Healthcare decision makers' access to relevant information enabling them to monitor and follow up patient safety, quality of care and healthcare performance.

The second rationale for developing the Swedish eHealth architecture was the National EHealth Strategy for Accessible and Secure Information in Health care, 2010. This work was also initiated by the Swedish Government with the intention to support: (1) Citizens, patients, clients and family members with access to quality-assured information on health also including access to clinical documentation from their previous efforts and treatments. Citizens should be offered innovative e-services for the exercise of participation and self-determination on their own terms, (2) Professionals with innovative and integrated decision support systems facilitating their daily work. Access to information across organizational boundaries should build the basis for the decision support systems, and (3) Healthcare decision makers with innovative tools and authority systems to continuously monitor the quality and performance of activities in order to optimize resource allocation. The focus was chosen to secure individual's integrity in the follow-up and management of work.

The third rationale for evolving the Swedish eHealth architecture was the National Action Plan for eHealth, 2009–2012 and further evolved along the subsequent national action plan for eHealth, 2013–2018. The national action plans were agreed upon by the Swedish public care buyers – the 21 county councils. The county councils organize the national coordination of the action plans through the company Inera AB, which is owned by the county councils[1]. The action plans were set up to

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[1] Inera AB was formerly known as Center for eHealth.

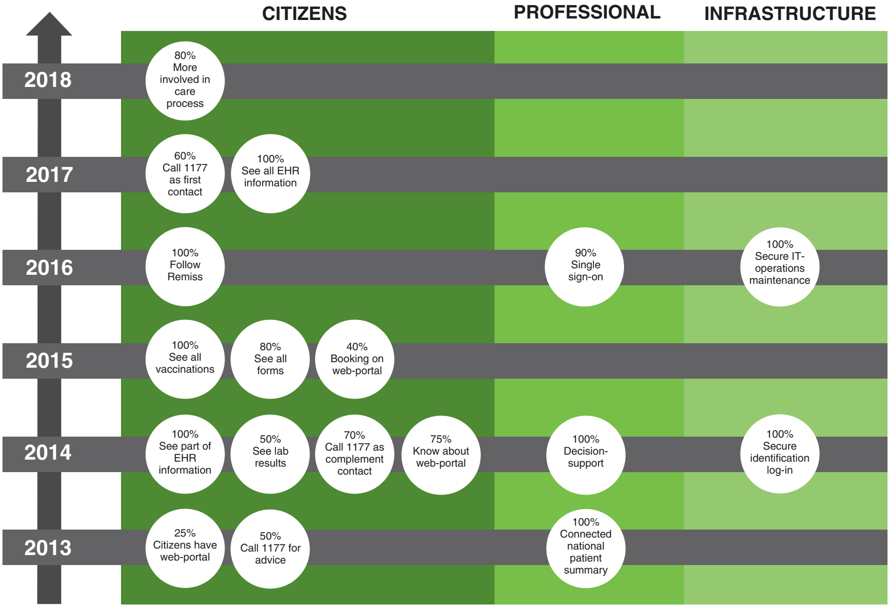


Fig. 14.1 Visualization of the National Action Plan for eHealth, 2013–2018

reach a set of goals: (1) that citizens shall both be able to access all clinical information about themselves and actively participate in their care. This shall result in increased patient empowerment, active participation with smarter eHealth services and collaboration across organizational boundaries – Care Anywhere, (2) professionals with smarter eHealth services and access to all relevant medical information about a patient across organizational boundaries, and (3) infrastructure in place with secured operational maintenance and identification log-in.

The first and second strategies intended to change people's mindset, promoting a vision of eHealth use. The third strategy is different from the first and second ones as it is not promoting an abstract vision but rather a very clear action plan demanding all county councils to get on board the eHealth train, with a clear structure of what should be done when. This led to a process where a number of national services and solutions were planned and implemented on a larger national scale. The third strategy is followed up in a different way compared to the first two strategies. It is followed up by statistical documentation of eHealth goal fulfilment (see Fig. 14.1), whilst the first two strategies were followed by early adopter success stories.

14.2.3 Core Components in the Swedish eHealth Architecture

This section presents the core components of the Swedish eHealth architecture (see also Fig. 14.2). Our account of the architecture is a snapshot from 2015. The presentation of these components aims to help the readers to follow the case narratives

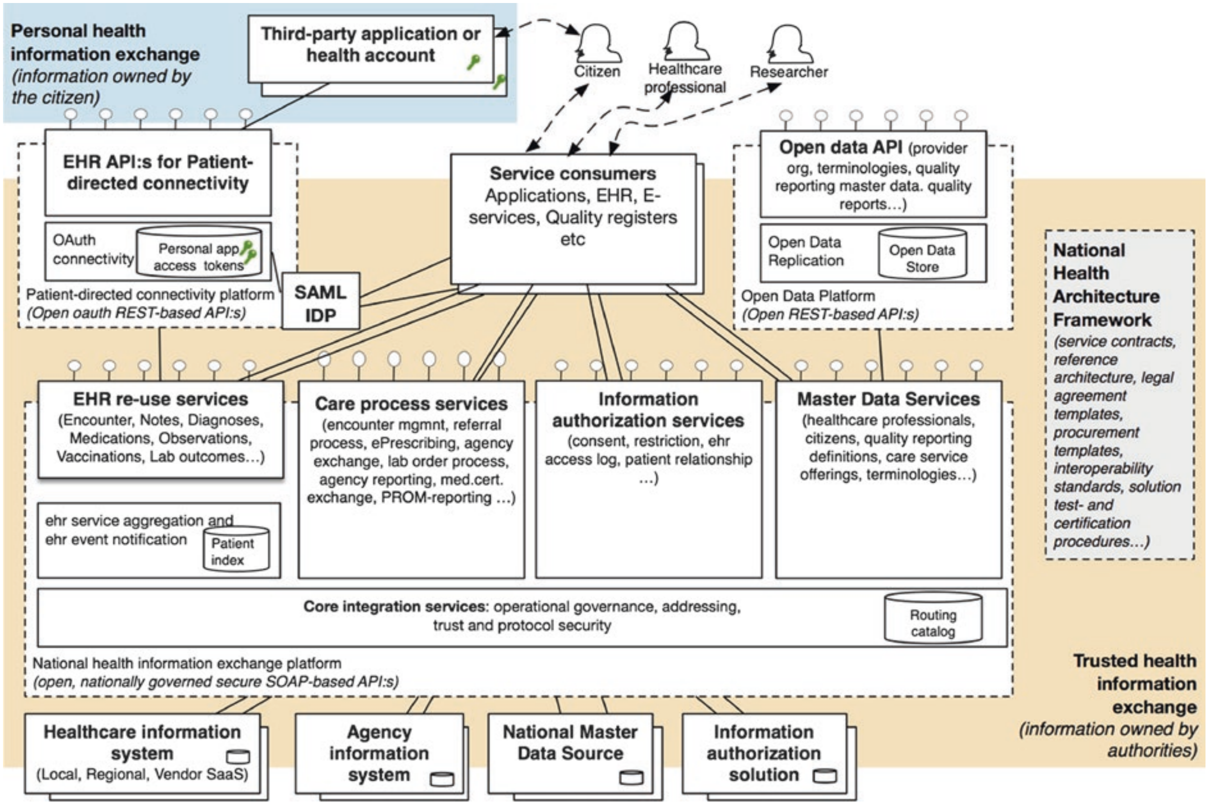


Fig. 14.2 Simplified illustration of the Swedish eHealth Architecture. Examples of missing parts are: Health innovation framework, citizen, care and academic portal

presented. The narrative outlines events of importance to the trajectory of the case study, but is confined to the events that are significant to the e-services of the case study. As a consequence, it doesn’t list events related to national eHealth development in areas such as cross-provider referral processes, medical certificate exchange, e-prescription processes, quality indicators, analysis of healthcare-associated infections and birth certificates.

The National Reference Architecture Framework was the first component of the Swedish eHealth architecture to be nationally applied by Inera AB and its owners (the 21 county councils). It has been in operation since 2007. The reference architecture defines a set of architecture principles, architecture patterns and guiding examples that govern nationally as well as regionally funded projects that contribute to the evolution of the Swedish ecosystem of connected eHealth. The reference architecture states six architecture principles: (1) A set of architecture principles govern eHealth projects. (2) The principle of information security, (3) The principle of national functional scope, (4) The principle of loose coupling, (5) The principle of organic/local evolution/contribution to the national ecosystem (6) The principle of federation. It is referred to the installed base as an ecosystem. The fifth architecture principle encourages local and regional organizations to initiate development of missing core components to the Swedish eHealth infrastructure. Thus, many core components have been developed and implemented by regional projects that were neither steered nor funded nationally. Over time they were linked or canonized to the national eHealth architecture, either as a new, an updated or a replaced component. New components are able to be linked when the shared reference architecture framework has been applied during the development work regardless if it has been conducted on a local, regional or national level.

Local, regional and national parties have cooperated, in a case by case way, in evolving the installed base in a successful way through the shared use of the national reference architectural framework. Of course a county council like Stockholm has contributed more than others due to its size and financial capability. When national prioritizations have not been aligned with local and regional needs, a group of county councils, municipalities and solution vendors have been able to join forces to develop solutions on their own for more local and regional use. The principles of national functional scope, secures that the solution can be applied on a national scale in the future. As time passes by, county councils, municipalities and solution vendors continuously negotiate to bring their local or regional solution to a national level, sharing the solution with all publicly funded care in Sweden. Therefore, the core components in the Swedish eHealth infrastructure are owned by various parties although shared through the Swedish eHealth Architecture and coordinated by Inera AB. Examples of such components are clinical APIs (Application Programming Interfaces for access to medical record information), care process services, core integration services, application frameworks and a patient-directed connectivity platform. Whether local and regional component will develop into national components or not depends on how they align with the national action plans for eHealth and the national reference architecture. In practice, there is ongoing collaboration and knowledge exchange between local, regional and national projects over time. Inera AB has implemented a national program office in order to formalize a process for supporting local and regional initiatives with a national ambition. There is currently a dispute between Inera AB and some regions whether ownership (IPR etc.) has to be transferred to Inera in order to get national funding as part of national canonization of a regional solution. This fact may affect the power balance between national, regional and local projects. The Swedish healthcare system evolves through a combination of centralized and decentralized models for ICT innovation (bottom-up, middle-out and top-down). The reference architecture framework is a centralized joint effort of all county councils and municipalities while the ICT development work occurs locally, regionally and nationally.

The second component developed was the national health information exchange (HIE) platform. The concept of a national health information exchange platform is defined by the national reference architecture. It defines a set of strategic service-oriented integration patterns along with a set of platform capabilities required for systematic and manageable instantiation of these patterns. The patterns aim at supporting technical and semantic connectivity requirements while still supporting regional and local evolution of the installed base (primarily the regional ongoing consolidation of health information systems). The patterns are information aggregation, service virtualization and protocol adaption. The protocol adaption pattern is however only applied at the national level when protocol adaption is not possible at the local or regional level. The overarching idea is to represent all local and regional EHR solutions as a single virtual, national EHR system in terms of an API and management via Inera AB. The API is utilized by national, regional and local API clients. The HIE platform makes it possible for an API client to access information and invoke transactions on all EHR systems in Sweden through a single connection point (the HIE platform) and a single API.

The Swedish reference architecture does not rely upon central storage of EHRs. The architecture is service oriented. All transactions and information requests are processed by the source system of the care provider in real-time. Technical and semantic interoperability depends on agreed integration profiles. These are labeled “service contracts” in compliance with OASIS Reference Model. The national HIE platform depends on a couple of utility services: a patient index to support information aggregation and a service routing registry to support a virtual service contract endpoint to resolve the logical address (e.g. an id of a healthcare provider) into the web service end-point address of the regional or local EHR system supporting that logical address (i.e. a healthcare provider). The national HIE platform was first released into production in 2010 by Inera AB. Inera AB has maintained the national health information exchange platform since its release. In October 2015, the monthly service invocation rate was 280,000,000, scattered across 180 national service contracts (integration profiles) supported by 4,500 endpoints (local and regional health information system installations). Roughly 2,000 of the clinical endpoints were connected during 2015, as part of the migration from the legacy EHR viewer (built on a closed/dedicated connectivity architecture) to a new version built to utilize the national HIE platform.

The third category of components developed was national service contracts. A service contract defines the requirements of a service-oriented communication end-point in terms of technical protocol, message formats (request and response messages) and functional and nonfunctional requirements of the interacting parties. The EHRs of the Swedish health care providers implement service-oriented communication end-points in line with these service contracts. The service contracts are based on OASIS WS-I Basic Profile 1.1 for technical interoperability. The messages of the clinical service contracts are designed according to the HL7 green CDA methodology. Security of message transfer between connected nodes is achieved at the transport level, by standardizing on https and mutual authentication (TLS). Message-based security is not used in the national technical interoperability profiles. The portfolio of national service contracts is governed by Inera AB. The service contract portfolio contains about 200 released service contracts (interoperability profiles). They have been developed, verified and applied in production scenarios since 2009. About 25 % of the released service contracts have been developed by Stockholm county council and thereafter handed over to Inera for governance and maintenance. The financing of this development has either been made directly by Stockholm county council or by external funding that Stockholm has applied for. Sometimes the external funding has been channeled through Inera due to administrative reasons although the application has been made by Stockholm county council.

The exchange of healthcare provider information across the HIE platform is regulated through commercial and data control agreements between county councils and Inera AB. The HIE platform and its management has become a hub for both information exchange and data control agreements.

Service contracts comprise API requirements for security, functionality and message structure. This means that beside APIs with code, service contracts contain for instance SLA requirements, e.g. response time, uptime, load, speed and recovery time. Over the period 2009–2011 service contracts were developed to support interoperability domains of scheduling, listing, security and drugs. Hereafter the focus has been on facilitating reuse of clinical data stored in local and regional health information systems. By the end of 2010, 95 % of hospital care and primary care centers were connected in line with the preferred care provider service contracts. Appointment scheduling expanded in a slower process. By the end of 2015, about 50 EHR end point systems support the service contracts for appointment scheduling. In Stockholm county council there are more than 1,500 Electronic Health Record (EHR) systems installed. However, one of the EHR systems holds about 80 % of the clinical data in Stockholm county council.

The ministry of Social Affairs promoted the interconnections of healthcare provider's systems to clinical service contracts by means of economic incentives and support. At the end of 2015 100 % of the county council's healthcare providers will be connected to the subset of clinical service contracts (facilitating reuse of clinical data) of most interest to the patient and the healthcare professionals. These are the service contracts covering medication history (ordination, prescription and administration of medications), clinical notes, care contacts, diagnosis and laboratory order outcome. In all there are 21 clinical service contracts covering reuse of all patient related clinical data in an EHR system.

The service contracts cover several areas of information exchange: (1) Re-use of medical records from the complete health care system: Clinical notes, medication history, structured observations, referral outcomes, imaging outcomes, laboratory order outcomes, referral status, immunization history, alert information, ECG outcomes, maternity medical records, care encounters and care plans (2) Care provider/Governmental agency information exchange: e-prescriptions, medical certificates; (3) National Master data Catalogues (unique citizen social security numbers, unique medical professional and healthcare provider identities; and (4) National agencies (Social Insurance (illness certificates) and Ministry of Social Affairs (code systems)).

All healthcare providers work with their preferred EHR systems and work processes in a heterogeneous environment where they can exchange information across organizational boundaries with partners that are supported by completely different EHR systems and work processes. Everyone has access to the information in its own installed technology base and in its own existing work processes. In this way the multiplicity and heterogeneity can remain whilst access to information across organizational boundaries is secured.

14.2.4 Core Components Developed by Stockholm County Council

In addition to the three components described above, four other core components were developed in parallel by Stockholm county council. They are offered on a national level by Stockholm county council. This means that maintenance is not yet funded by all county councils through Inera and is not yet governed by Inera. It is instead funded and governed by Stockholm county council through a parallel business model with connected county councils, however, negotiations are ongoing regarding ownership and funding in order to have a single coordinated funding and governance structure. The handover of components between local, regional and national levels are conveyed according a complicated organizational arrangement. It had reached a point where it was unclear if de facto-national infrastructure components developed by Stockholm County Council would be canonized into national governance at Inera AB. Meanwhile Stockholm county council has – for future development of nationally applicable solutions – decided to initiate development through the Inera program office. However, since Inera has limited resources to govern initiatives, the board of the 21 county councils has to prioritize which regional projects to govern. In that respect the ecosystem evolution seems threatened by new elements of centralization in conflict with the architecture principle of organic/local evolution/contribution to the national ecosystem.

The fourth component is the Application Framework. This is a generic name for application frameworks supporting development targeted at healthcare, researchers and citizens. The application frameworks consist of downloadable open source code framework and API documentation for simplified development of solutions that depend on web browser and mobile app client access to the HIE platform. Applications require login via strong authentication. Through the application framework, various systems and e-services can reuse for example single-sign-on and context-managing functions. Simplified access to the endpoints of the HIE platform are managed by the Application framework, e.g. ADL, Imaging Outcome, Diagnosis, Care Documentation, ECG, Functional Status, Prescribed Medication, Laboratory Outcome, Care Contacts, Maternity Medical History, Care Plan, Alerts, Medication History, Vaccinations, Care services, Other Examinations, Medication, Form service.

The fifth component is the Application Innovation Portal (HIP – Health Innovation Platform). It is a web-based one-stop-shop for developers of eHealth solutions that want to utilize national and regional infrastructures. The aim of the Health Innovation Platform is to provide information and access to service development kits (SDK) of various infrastructure components, including the application frameworks. The information includes methods, guidelines and complete code samples for service development – in both traditional environment and for mobile solutions for developers and designers. Through the Innovation Platform, developers both within and outside health care get up-to-date and streamlined one-stop-shop access to resources they need to create solutions that access data from medical record systems and other sources in a simple and secure manner according to national rules for access to patient data. The Innovation Platform holds development Kits targeted for the innovation of citizen, healthcare and research services. In short, the Innovation Platform is the software developer's user interface to innovation resources that boost application development.

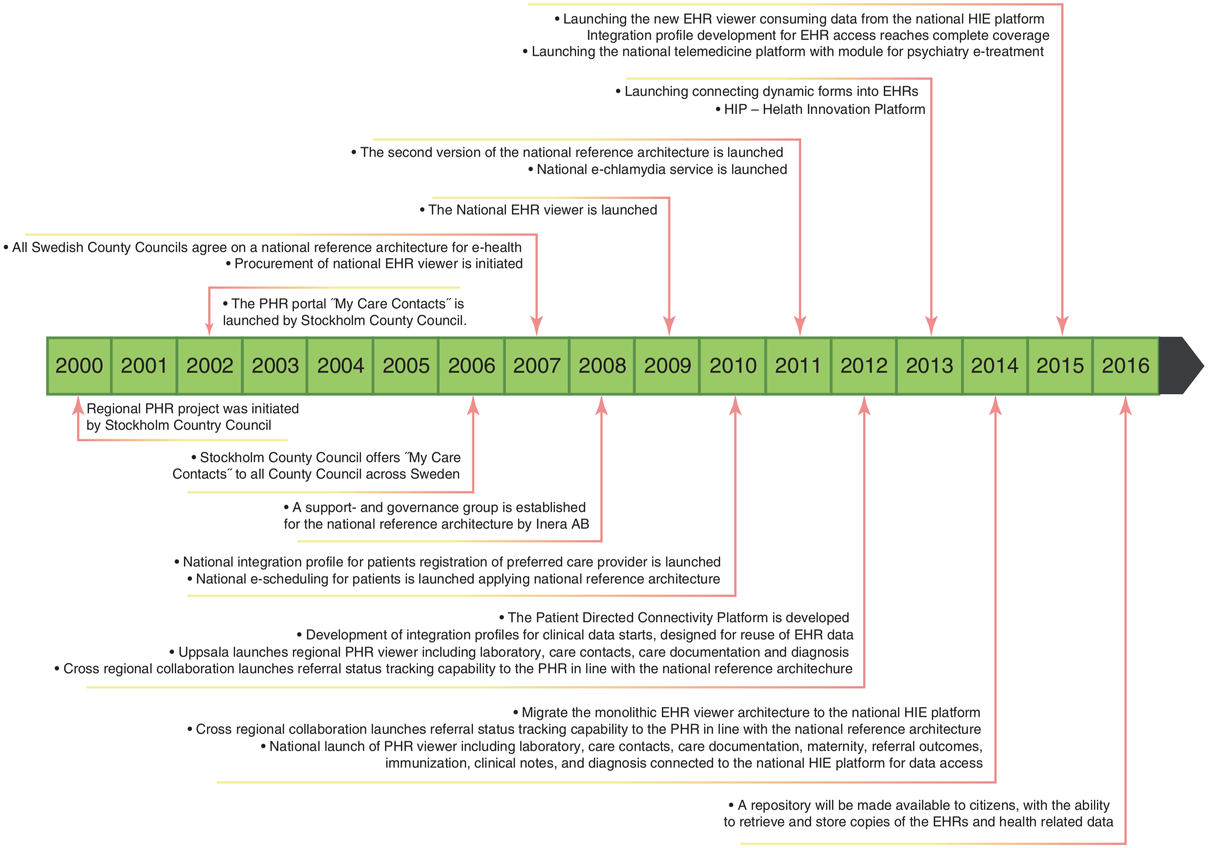
The sixth component is the Open Data Platform, a storage- and API platform for open access to data that is made available in line with the European Public Sector Information directive. Open data is made available to support innovation but it is also the means to provide APIs to non-personal healthcare master data required by e-services. This includes care provider master data, such as organizational structure, contact information, opening hours and care offering. Other examples include terminology and quality indicator master data. This offloads the national HIE platform from handling data that is publically accessible. Open data do not contain personal information and thus places no demands on secure access. The Open Data Platform is implemented in a highly scalable cloud infrastructure. Data kept in the Open Data Platform is synchronized (double stored) from the sources and made available via APIs that follow today's best practice ("RESTFul"). APIs are described on the Application innovation portal.

The seventh component is the Patient-directed Connectivity Platform. This is a platform that offers patients the ability to share EHR information services and applications, and has been part of the national infrastructure since 2014. Social media has evolved far beyond e-services supplied by healthcare information owners. We can see how social services like Twitter, Google, LinkedIn, Runkeeper and Facebook have moved beyond e-services by offering its users the ability to control how information from the user's account is shared with other services and applications. Information and functions are made available through APIs. Facebook and many other social media services offer its users a dual interface: applications (e.g. the Facebook web application and the Facebook iOS application) and a user-controlled API. The Swedish county councils have a strategy to mirror this duality: The National Patient Portal offer a citizen/patient-controlled API in addition to patient e-services (detailed in the next section). The citizen/patient-controlled API is secured by the OAuth protocol. The use of the OAuth protocol makes sure that the patient is in control of which data is accessible by which app that connects to the Patient-directed Connectivity Platform. Only the patient/citizen can grant a third-party application access to EHR data through the Patient-directed Connectivity Platform. Technically, the platform obtains EHR data "on demand" from the source EHR, via the national HIE platform services. In other words, the patient-controlled API is an infrastructure layered on top of the HIE platform. This is a property it shares with patient e-services. The e-services however – do not depend on user/patient authorization to be able to access the information. They are part of the trusted network and information access of these e-services are – unlike the third party apps – under the responsibility and data control of the county councils.

From a legal perspective, the information is owned by the patient as soon as it leaves this infrastructure component and enters a patient-directed (and authorized) endpoint (third-party application). An organization that offers such an application to its users, must obtain the user's consent to be able to store or process personal data on behalf of the user. This applies even if the organization is a care provider, since the data – although sourced from an EHR – has become a possession of the user during its journey from the EHR to the app.

14.3 The Development and Evolution of the Swedish Patient Directed Infrastructure

In the beginning of 2000 Stockholm County Council started a patient portal and a personal health record project. The aim was to enable patients to communicate with their physician or nurse and to refill medications. The long term objective was to achieve patient centered safe and high quality care and prevention. In parallel the Association of County Councils in Sweden took the initiative to establish a public eHealth portal. This was extended in 2006 by the Association of County Councils to also include a patient portal project to offer patient-initiated refill of medications. How these different regional and national projects aligned into one gateway for Swedish citizen's national patient portal and personal health record will be described in this section (see also Fig. 14.3. for the overall timeline). This is the first phase of the evolution into a Patient Directed infrastructure.



Regional PHR project was initiated by Stockholm Country Council

- The PHR portal ´My Care Contacts´ is launched by Stockholm County Council.

- Stockholm County Council offers ´My Care Contacts´ to all County Council across Sweden

- All Swedish County Councils agree on a national reference architecture for e-health
- Procurement of national EHR viewer is initiated

- A support- and governance group is established for the national reference architecture by Inera AB

- The National EHR viewer is launched

- National integration profile for patients registration of preferred care provider is launched
- National e-scheduling for patients is launched applying national reference architecture

- The second version of the national reference architecture is launched
- National e-chlamydia service is launched

- The Patient Directed Connectivity Platform is developed
- Development of integration profiles for clinical data starts, designed for reuse of EHR data
- Uppsala launches regional PHR viewer including laboratory, care contacts, care documentation and diagnosis
- Cross regional collaboration launches referral status tracking capability to the PHR in line with the national reference architechure

- Launching connecting dynamic forms into EHRs
- HIP – Helath Innovation Platform

- Migrate the monolithic EHR viewer architecture to the national HIE platform
- Cross regional collaboration launches referral status tracking capability to the PHR in line with the national reference architecture
- National launch of PHR viewer including laboratory, care contacts, care documentation, maternity, referral outcomes, immunization, clinical notes, and diagnosis connected to the national HIE platform for data access

- Launching the new EHR viewer consuming data from the national HIE platform Integration profile development for EHR access reaches complete coverage
- Launching the national telemedicine platform with module for psychiatry e-treatment

- A repository will be made available to citizens, with the ability to retrieve and store copies of the EHRs and health related data

Fig. 14.3. Timeline of Swedish eHealth Architecture development

14.3.1 Phase 1: Development of My Healthcare Contacts and Public Web

In the spring of 2000 the Stockholm County Council Executive Board decided to start the project Healthcare Guide. The stated aim for Healthcare Guide was to provide a "secure message feature" between patients and healthcare providers, and this was compared to the increasing use of Internet banks. The secure messaging could be used to share information, send inquiries, communicate and inform patients. It created a digital channel for individual care by offering a network of information and services that promoted the responsibility and participation of citizens in matters of their own health (preventive actions management and self-care); allowed digital interaction between citizens and the health system, providers and professionals; provided information on health care quality in different care areas in particular related to common diseases. Technically the creation of the public web portal started with the requirement on the platform to support x.509 certificates which was the standard for Swedish eID. The digital channel for individual care got the name My Healthcare Contacts after an internal Stockholm County Council name contest. The new platform was managed and owned by Stockholm County Council. In the spring of 2002, the development of My Healthcare Contacts began together with six healthcare centers (four Stockholm county council owned and two privately owned). During the fall 2002, the first pilots were launched with a limited number of forms such as Schedule Appointment, Renew Prescription and Cancel/Reschedule Appointment. There was a high demand for prescription services since it was often difficult to reach healthcare centers by phone. Consultation and prescription over the phone is a medical practice in Sweden. The rollout involved the cooperation and engagement of several local health providers and professionals who worked close to citizens and patients; information and communication campaigns to the public. There was never a conflict with professionals regarding My Healthcare Contacts. A reason for this may be that the e-services offered did not entail profound changes in the role and relationships between doctors and patients, and between doctors themselves. Instead early on results showed increased work processes effectiveness and less need for accessing healthcare centers by phone for renewal of prescriptions or bookings. As the awareness and use of My Healthcare Contacts increased in Stockholm county council the interest in the solution was also increasing from various other county councils. A negotiation process started which resulted in agreements between Stockholm county council and other councils e.g. Västmanland, Skåne and Halland. Through the agreements signed in 2011 all remaining councils join the cooperative development of My Healthcare Contacts led by Stockholm county council.

At that time Inera (which was then named "Sjukvårdsrådgivningen AB"), was offering public national medical related advice to patients – as searchable text on the web and through a phone service operated by healthcare professionals. My Healthcare Contacts (also including a public web site) and Sjukvårdsrådgivningen had become equally large sites by 2010. However, My Healthcare Contacts offered more services than the national site, e.g. Find Care Unit and Compare Queue Time.

A new national project called Healthcare Online started in 2006, where Sjukvårdsrådgivningen wanted to create a national patient service where both the public web and the personal part would be built into a single portal platform. The public procurement that Sjukvårdsrådgivningen had conducted wasn't able to deliver, and the agreement with the vendor was terminated in the end of 2008.

At the same time, in 2008, Stockholm county council had continued its work to modernize their public site by switching to a supplier who already worked with agile practices and high delivery capability. Meanwhile, the national use of "My Healthcare Contacts" grew as an independent and relatively modular service, by means that its governance was not funded by national finances. Interestingly, by that time Stockholm county council was outperformed by another county council in terms of the number of care units connected to My Healthcare Contacts. Gradually it became obvious that the technical platform would need to be replaced as it got obsolete, but the question was how. Some felt that the entire application should be rewritten. But in the end it was decided not to shift platform. Instead, the strategy was to keep the technical platform for message handling and complement and link it to other more modern and open technology platforms for new functionality and new services. Said and done, My Healthcare Contacts got a new interface with responsive design for adaptation to mobile devices in 2012.

When Sjukvårdsrådgivningen had terminated their agreement with their preferred partner in 2008, the manager at Stockholm county council got a request to collaborate with the national Healthcare Online project. The result from the negotiations was that Stockholm provided a copy of the public web sites code to Sjukvårdsrådgivningen. The site got a new name 1177.se, and was now maintained by Sjukvårdsrådgivningen and not Stockholm. At this time Sjukvårdsrådgivningen was transformed into Inera. Inera was assigned to work with infrastructure including national HIE platforms.

In 2007, CareLink – a national eHealth standardization body owned by the county councils – released the first version of a national reference architecture for eHealth. In 2007 a new national eHealth program office was formed in which counties interacted and cooperated in an organized manner. This national program office function was called CeHis – Center for eHealth. A subsection of CeHis established an architecture governance unit to secure reference architecture conformance across the national eHealth projects coordinated by CeHis. The responsibility of the reference architecture development was transferred from CareLink to this unit. A new version of the reference architecture was released in 2011. The major highlights of the new version of the reference architecture were related to patient empowerment. The result of this work was for example six architecture principles and a set of supporting architectural patterns. It also contributed guiding examples for a list of prioritized eHealth scenarios. Stockholm county council and to some extent Inera initiated projects to establish the the national infrastructure capabilities outlined by the national reference architecture. Stockholm county council funded the majority of these capabilities. After capabilities had been developed and piloted by Stockholm county council they were handed over to Inera for maintenance. Inera receives collective financing from the county councils for this maintenance work. The uptake of the reference architecture among county councils, national projects and vendors on the market increased gradually with the increased awareness of its value to the eHealth ecosystem. In 2013 CeHis was incorporated into Inera AB. The architecture unit of former CeHis was reborn as the department of architecture of Inera AB.

In 2012 Stockholm got the national responsibility for citizen services including both the public web site and the secure digital channel My Healthcare Contacts. In 2014 My Healthcare Contacts was extended with a patient EHR viewer. This work has been funded by both regional and national program offices for development and maintenance. The purpose was to give citizens and patients digital access to the health records of the complete installed base of EHR systems. This was a prioritized goal of the national eHealth action plan for 2013–2018. The primary information data sets to be shared with patients were care contacts, care documentation, vaccinations, referral and lab results, maternity care and diagnosis. Since all parts of the national eHealth architecture are de facto developed there is a mixture of national and non-national budgets supporting its operation and maintenance. The positive outcomes of this mixture point to the key role of organic evolution for the Swedish eHealth ecosystem. The pre-requisites of an organically grown national eHealth ecosystem are captured in one of the architecture principles of the national reference architecture. This principle (i.e. allowing organic development by county councils without relying to central directions by Inera) has been fundamental for the controlled – yet organic – evolution of the national infrastructure. If this development was not opened for many stakeholders the national installed infrastructure would have taken much longer time to develop. In this way many different actor networks in parallel developed the national infrastructure. Sometimes, the principle of organic development contributed to unexpected parallel development of competing solutions. Uppsala County Council and Stockholm County Council developed competing patient EHR viewer applications- both with national ambitions. At the end of 2015 the Uppsala solution had reached a significantly larger user base. Stockholm county council then decided to decommission the “My Care Pathways” viewer eService in favor of the Uppsala patient EHR viewer. This meant that the frontend of My Care Pathways solution was decommissioned but the backend, which had become a central part of the national HIE platform for EHR access, was utilized. One frontend eService that uses this backend is Uppsala Count Council’s patient EHR system. For Swedish county councils to switch from one frontend (viewer eService) to another based on the same backend only requires administration of access rights.

14.3.2 Phase 2: Establishing and Developing the Patient Directed Connectivity Platform

This section describes how the development and modernization of My Care Contacts was conducted. It started with a presentation of an idea of a Patient Directed Connectivity Platform in late 2011. Work behind the idea was funded by Vinnova, the innovation agency in Sweden. One of the goals of the modernization project was to open up the portal architecture of My Healthcare Contacts to allow e-services to be developed and deployed outside of the portal platform itself. This should be accomplished in a way that independently deployed e-services would bring the same user experience as that of an e-service developed and deployed using the tools and infrastructure of the core portal product of My Healthcare Contacts. This would allow for regional development of national e-services using the development and deployment infrastructure of choice. The concept was labeled “The virtual portal architecture”. The virtual portal architecture is aligned with the 4th national reference architectural principle “Integrations shall be loosely mapped and re-usable for many purposes” and is thus part of the national eHealth architecture.

The modernization project had a substantial budget. It was critical to expand the pace in development of patient e-services beyond what was possible with the portal infrastructure which was available at the time and its vendor lock-in. However, the platform modernization didn’t really happen – at least not in the intended sense. Instead, focus shifted from strategic goals of vendor neutrality and increase of e-service delivery capabilities into the following main priorities:

- A new look-and-feel with support for mobile devices through responsive design
- Development of new e-services
- Governance and policy framework for hosting e-services from multiple sources

The idea of providing patient-controlled APIs along with e-services was scoped out due to resource constraints. The modernization project started in late 2010 and finished in midst of 2012. My Care Pathways was set up in 2011 with a high ambition to create several of the national service contracts, an open architecture for e-service as well as third party connectivity. In this aspect, the new project picked up where the prior modernization project was stopped: among other deliveries it delivered a virtual portal architecture proof-of-concept and a Patient Directed Connectivity Platform. All infrastructure deliveries were aligned with the national reference architecture, catering for future national uptake. This was achieved by tight collaboration with architects of the national program office at Inera. This project delivered both several back-end infrastructure components e.g. the open data API platform, Patient-Directed Connectivity Platform, Application Innovation Portal, Application Framework, Care Process Services and Questionnaire engine and front-end web services and APPs, e.g. national Form service, Survey tool, Notices, Referral status and My Care Pathways.

The Patient Directed Connectivity Platform was developed during 3 months starting in December 2011 with its first live demo on the national eHealth fair in April 2012. The demo third party application was a utility application that re-published appointments as live, subscribable webcal links. The vendor of the utility application offered the patient a live view of appointments directly in the private native calendar application of any mobile device:

Because several appointment/encounter modules of local and regional health information systems were connected to the HIE platform, the Patient Directed Connectivity Platform just had to connect to the appointment scheduling API of the

HIE platform as client in order to access patient's appointments within all connected health information systems. The Patient Directed Connectivity Platform then re-publishes the SOAP APIs as OAuth-secured REST APIs. The third party demo application acts as a client to the OAuth-protected API of the Patient Directed Connectivity Platform. The developers of the third party application used the Application Innovation Portal to learn about and explore the appointment API of the Patient Directed Connectivity Platform. They also utilized the open data platform ÀPI to get access to health care organization master data so that they could display opening hours and contact information of the appointed facility. More e-services and apps are being developed. More importantly there has been a cultural shift where apps are requested by both caregivers, patients and researchers, whereas it before was not considered as safe. Now the focus is what app is needed and how fast and easy can it be designed through the use of the Application Innovation Portal.

Although every relevant piece of the installed base were connected using the national HIE platform and applicable service contracts, information wouldn't be accessible by the third party application unless (a) each care provider authorizes the Patient Directed Connectivity Platform access to appointment records and (b) the patient uses the patient portal to grant the utility application access to a personal copy of appointment information serviced by the Patient Directed Connectivity Platform.

Both of these requirements have proven to be challenging. The public care providers generally don't seem to prioritize patient-controlled information access to the same extent as private care providers.

Regarding "b" the national organization holding the policy for connecting applications needs to find a balance between a thriving marketplace and trusting information owners. Several options are discussed for boosting the care provider's willingness to support the concept of patient-directed connectivity:

- Third-party/care provider match-making forums
- Providing the patient means to digitally request information sharing capabilities from her care provider (as a feature of the patient portal)
- Public quality indicators that allows public ranking of healthcare facilities based on the amount of data that is available for sharing with third-party applications

If the trust problem is solved a number of new possibilities to create value on patients copy of EHR data are foreseen.

A number of workshops and conference presentations have been performed over 4 years of time to inform about the new possibilities. But the main efforts were targeted at the developer community. Public care providers still show very little awareness of the concept and thus do not actively grant the patient directed connectivity platform access to the EHR data through their existing national HIE platform connections.

There is however an agreement between the Ministry of EHealth and the 21 county councils to support the infrastructure as soon as the nationally procured Personal Health Account is launched. The purpose of the agreement is that the PHR will connect to the patient directed connectivity platform. The patients will then be able to direct EHR connectivity to their account of the PHR service. In order for information to actually be available for transfer to the PHR, each care provider need to authorize the patient directed connectivity platform EHR access. Once this has happened, the same EHR information will be available for other third party applications as will (in addition to the national PHR).

Examples on information sets accessible by users of My Care Pathways include: clinical notes, healthcare contacts/appointment, prenatal care records, vaccinations, referral statuses, laboratory results, advice and support related to specific diagnoses, information about health care guarantee (referrals), child health information, living habits. Similar information sets were provided by the service delivered by the Uppsala project.

In 2013 Inera contacted Stockholm county council to negotiate a takeover of the e-service My Care Pathways. Inera wanted to combine this service with the solution provided by the Uppsala county council project. Due to contractual agreement with the financier of My Care Pathways this was not possible as there was commitment on commercialization outside of Sweden. However, Uppsala came to an agreement with Inera.

During the same time My Healthcare Contacts put forward the idea of developing a new national EHR viewer for all care givers in county councils and municipalities in Sweden. It was forwarded through Inera. The idea was granted and the development initiated. My Healthcare Contacts could give this offer due to the work conducted with My Care Pathways. Said and done, the new national EHR viewer for healthcare professionals, accessing information across organizational borders, was designed and internally tested over a period of 6 months. It was thereafter externally tested and verified for 1 year. In the end the e-service My Care Pathways for patients and citizens and the national EHR viewer for caregivers shared to 80 % the same program code. The 15th of December 2015 the new National EHR viewer for healthcare professional was implemented in all county councils and municipalities. The implementation was a cooperation between My Healthcare Contacts at Stockholm County Council and Inera. It was a success project where all parties shared the same vision, aims, working structure and process, no second agendas were applied. During the rollout of the new national EHR viewer for healthcare professional, a new national test process was applied. From the implementation of the new national EHR viewer , the 15th of December, there has in average been 80,000 request for information daily. Its development was smooth, quick and successful and was an example of the installed infrastructures' flexibility, scaling and reusability. Over this period only one web application error has been reported. Never has it been so quiet around the implementation of a new national e-service with 5,000 connected EHR systems. When the trains run on time this does not generate any headlines in the media. This illustrates the meaning of aligned interests, appropriate test procedures, coming to agreements and following it up with a full commitment. At the same period Stockholm county council through negotiations with Inera decided to decommission and stop the My Care Pathways solution in favor of the Uppsala one. In return the assignment of developing a new platform for My Healthcare Contacts is being negotiated. The results of the negotiations are not finished.

14.4 Discussion: Cultivation of the Patient Portal and the Overall Installed eHealth Ecosystem

Analyzing the trajectory of the co-evolution of the Swedish patient portal, the eHealth Architecture and the overall eHealth infrastructure we can state that much work has been done within personal health informatics and clinical informatics as well as on integrating these two. In Sweden it is understood that in order to achieve patient centered safe and high quality care these two need to be integrated in an overall SOA architecture. Many different e-services have been developed e.g. e-services that give citizens access to for instance e-scheduling, e-pharmacy, access to personal health information, e-communication with their physician or nurse, and secure disclosure to their health data (generated in the public healthcare system). These services have evolved by the replacement of old components, by complementing existing components and by building new ones. There are today many developments with further extensions of the existing eHealth Architecture. These projects are not restricted to one particular functionality but rather to manifold e.g. focusing on national interoperability issues between clinical information, patient care connectivity services whereas patient's own measurement are integrated with clinical information through apps and services linked to the EHR.

As has been described in this case, important parts of developing the national information infrastructure were security, safety and confidentiality issues, which are important since the question of trust is a key factor in the establishment of new digital tools. Security, safety and confidentiality is not only involving patients but also all Swedish County Councils and their care providers in an intertwined two-way information infrastructure that is evolving in a step-by-step process extending the installed base over time according to user, also including safety, needs. An important issue to elaborate on, when Sweden has come so far, is the security of the information infrastructure that can handle high volumes of national clinical data visualized through personalized health services.

New components can be linked as the shared reference architecture framework has been applied during the development work regardless of whether they has been developed on a local, regional or national level. Evolving the installed base local, regional and national parties have cooperated in a successful way through the shared use of the national reference architectural framework.

Various strategies and projects and activities have played different roles depending upon their character and timing. Many projects have cultivated the way individuals think about the design, interoperability and innovation of eHealth. Although some e-services did not reach a national implementation they still made an impact on the development of other e-services and infrastructure components. The importance of choosing the relevant marketing and implementation channel is crucial for the spread and usage of e-services. These examples illustrate that factors of quality, costs and functionality are of minor importance. The examples also illustrates that if a strategy has reached a maturity among its stakeholders and if implementation channels are chosen by influence and power anything can work.

In Sweden the eHealth projects have undergone a transformation from being cultural to structural and process oriented when they share the same backend. Overall, the foundation of Swedish eHealth development work is based on complicated organizational arrangements. The national reference architecture has shown itself to be an important stability actor in this work, i.e. something that actors can fall back on and agree on in their discussions. The National reference architecture constitute here a direction of what is correct, even though it is open to interpretation.

To allow different actors to individually or jointly contribute to the applied SOA architecture has led to a distributed development work. The challenges have primarily been related to power factors, i.e. negotiations between different parties at different levels. The county directors' role and responsibility to steer and control Inera's work have been more or less exerted over the years. This has of course led to a direct impact on Inera's prioritization work. In all, steering has become weaker over time.

One conclusion to draw is that if there is a national reference architecture in place, it is something that increases the likelihood of the parties to agree in negotiations. If they have a commitment to fulfill agreements is another issue. Much needs to be matched for the parties shall agree, cooperate, get involved and together successfully reach a goal.

Our findings support the argument that infrastructure evolvement come out of the complex interplay between many different actors intertwined in step-by-step cultivation. In Sweden the infrastructure evolvement is done through the governance of a reference architecture endorsed by all entities contributing to the installed base.

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The Origins of a Healthcare e-Booking System in the Municipality of Bologna

15

Andrea Resca and Mauro Moruzzi

15.1 Introduction

In Italy, the introduction of the National Health Service (*Servizio Sanitario Nazionale* – SSN) in 1978, based on law 833/1978, provided municipalities with the opportunity to make substantial innovations in healthcare. Hospital-centred care was considered outdated. The aim was to dispense with a model based on hospital hubs on the one side and general practitioners (GPs) spread throughout the area on the other. The latter operated as gatekeepers to hospital services, and still do. The introduction of the SSN challenged a healthcare system that had developed largely independently from the characteristics of the socio-economic context. Hospitals, in alliance with the medical profession and the academic environment, determined services, or supply, that corresponded only partially to the demand from citizens and regions. The law outlined a framework for rebalancing this situation. Improving citizens' access to healthcare was an element of National Health Service reform, especially in the city of Bologna where long waiting lists, fragmented offerings and a lack of transparency characterized access to secondary care. The municipality of Bologna addressed these issues by creating booking centres supported by information technology enabling citizens to book services for secondary care. In Italy, and very probably Europe, this was the first instance of an information system connecting distributed booking offices at the city level. Since 1990, citizens have been able to use this e-booking service to access specialist ambulatory services, including visits and diagnostic activities.

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In this chapter, we analyze the origin of the e-booking service. The interpretative framework for investigating the advent of an e-booking service is provided by the concept of information infrastructure, focusing specifically on the role of the installed base (Hanseth and Lyytinen 2010; Hanseth et al. 1996). The concept of installed base includes both standing elements and systems already in place and existing institutional and organizational components (Bongsug and Lanzara 2006; Ciborra and Hanseth 2000). We study how the installed base was involved in the realization of this innovative service.

The literature suggests that the installed base can have both hindering and enabling effects on technical and institutional innovation (Lanzara 2009). The case in question represents an instance in which the existing installed base challenged the institutional and organizational innovation process. The healthcare system revealed itself as a trap from which it was difficult to escape (Lanzara 2009). In fact, a service like e-booking implied abandoning routines and practices that characterized paper-based booking. Alternative organizational arrangements had to be devised as the hospital and GP-centred model did not provide a supportive environment for this innovative form of access. Emphasis was put on the mobilization of installed base components related to political, organizational and technological resources originated outside healthcare. Our objective is to shed light on what led to innovative institutional arrangements and organizational routines and what capabilities were needed to challenge the established normative order and enable the creation of e-booking.

We begin with a brief overview of Italian healthcare. In the sections that follow we present the overall trajectory of the centralized booking system over the period 1990–2015 and subsequently present an investigation of the origins of the e-booking system. We focus on a period that starts in 1987 with the issue of the Health Plan by the municipality of Bologna and ends in 1993 when the innovative booking system went full speed. We end by presenting our analysis and discuss the mobilization of installed base resources for putting e-booking in place.

Method

This chapter is based on a longitudinal study on the evolution of an e-booking system. Following Yin (2009), this can be considered both a critical and a revelatory case study as it is, probably, the first example of a solution that supports citizens' access to healthcare in Europe and because of its capacity to develop both in scale and scope.

One of the authors had a leading role in the project and was a direct witness of its main phases, participating in meetings and boards at both the political and organizational level, with access to the related documentation. Data collection was integrated with semi-structured, in-depth interviews with the key players in the project. Twelve interviews were carried out between 2013 and 2015. Archival data were used as well as Italian publications related to this experience.

15.2 Italian Healthcare Overview

The National Health Service (*Servizio Sanitario Nazionale* – SSN) was introduced in Italy in 1978 (law 833/1978) and replaced the previous system of state insurance that had been founded after the Second World War. The aim was to create an efficient and uniform health system covering the entire population, irrespective of income or contributions, employment or pre-existing health conditions. The SSN provides free or low-cost healthcare to all residents (including those from other EU countries) and emergency care to visitors, irrespective of their nationality.

The proposed healthcare model outlined an alternative to the previous hospital-centred model, by creating a network of health facilities addressing the needs of the different socio-economic contexts. The aim was to create a network of health facilities able to respond to the characteristics of the different regions, which meant local government, specifically the municipalities, acquired a leading role. Healthcare based on the medical profession, academic medical science and technological development revolving around hospitals was challenged by a vision that put citizens and their living and working conditions at the centre – or, more accurately, proposed the *decentralization* of service provision, initiated by the establishment of local health facilities. However, results were questionable and the dwindling role of hospitals was not fully covered by the provision of appropriate continuity-of-care services as well as prevention, treatment and rehabilitation programmes. Families with members suffering from mental illnesses, chronic diseases and the non-self-sufficient elderly bore the burden of this situation (Moruzzi 2009).

Local health units (*Unità Sanitaria Locale* – USL) were in charge of the transformation of the healthcare model. These were local authorities and Bologna, a city with about 400,000 inhabitants, had three USLs. The national level allocated resources to regions that, in turn, supported USLs financially. Regions were also in charge of healthcare planning. However, USL management was in the hands of the municipalities. As the government level closest to citizens, they appointed USL management committees that represented local communities and spoke for them. The intention was to monitor closely healthcare provision to citizens.

At the beginning of the 1990s, this governance system went into crisis due to four main factors: the financial instability of the municipalities; the involvement of management committee members in political corruption scandals; the rise of neoliberal policies at European level during the 1980s; and the expensive and fragmented organization of healthcare services (Moruzzi 2014).

Laws 502/1992 and 517/1993 reorganized healthcare and were dubbed the "counter-reform" of law 833/1978. USLs were transformed into local state-run companies (*Azienda Sanitaria Locale* – ASL) and big hospitals acquired a new status, University Hospital Company (*Azienda Ospedaliero Universitaria* – AOU). These organizations centralized control with three leadership positions (managing director, health director, administrative director). Management committees nominated by the municipalities were ousted and the region became the appointing authority. Social health districts, led by the municipalities, were introduced to represent local requirements and to promote integration with social services but their influence on healthcare has been limited.

A consequence of this reform was that traditional hospital-centred healthcare, governed by the medical profession and typical of the pre-National Health Service era, did not re-emerge. However, regional and corporate bureaucracy was imposed once the USL management committees were abolished. The most significant implication of this was that it proved impossible to integrate healthcare and social assistance in accordance with the 1978 legal schedule. Finally, healthcare in Italy is still governed by regulatory structures at both regional and unit level that emphasize political and bureaucratic control rather than the development of medical activities.

15.3 The Evolution of a Centralized Booking System: 1990–2015

Since 22 January 1990, every citizen of the municipality of Bologna in need of a specialist appointment or a medical examination has been able to access a dedicated centre and book an appointment through an e-booking system that pools the services available at city hospitals and health centres. A number of booking centres spread across the city was one of the main objectives of the 1987 Municipal Health Plan to deal with long waiting lists and the difficulties citizens encountered in accessing health services. At the end of the first year of operation, 264,048 users contacted e-booking centres for a total of 610,498 transactions.

In the years since, the centralized booking service has developed in both scale and scope. Table 15.1 outlines the phases that have characterized this evolution.

Pharmacies became involved shortly after the inauguration of the service, due to their network presence and the possibility of offering widespread access points to healthcare. As private businesses, they were not used to collaborate with public institutions, like the municipality of Bologna, for improving healthcare. Significant resistance had to be overcome, as e-booking was not considered an appropriate service to be provided to pharmacies and related competences were not available. However, it was clear that pharmacies did have a role to play in healthcare and after an initial experimental period, the large majority joined the project, representing a solution to offering a wider range of services. However, at first (1996) booking activity was limited to restricted services and it was only after several years that the same range was made available to both pharmacies and booking centres.

In 1990, citizens living outside the boundaries of the municipality of Bologna accessed secondary healthcare using paper-based procedures supplied in each health facility. Things changed in 1999 when the centralized e-booking service was enlarged to cover the entire area. At that point, further 600,000 people, making a total of about 1 million, were able to take advantage of e-booking centres. By the second half of the 1990s, the booking system, which had been designed in a pre-internet era, was considered outdated and inadequate for extending scale and scope. In 1999 a tender for its substitution was issued and the new e-booking system went

Table 15.1 Key milestones in the evolution of the centralized booking system for health services in Bologna

Year	Central e-booking system: scale	Central e-booking system: scope
1990	Every citizen has access to 25 e-booking centres (inc. hospitals, health centres and department store) throughout Bologna to book specialist appointments or medical examinations provided at municipal level	
1996	E-booking possible at pharmacies but only some medical examinations available. Number of centres reduced to 19	
1999	E-booking centres spread throughout the metropolitan area (Bologna and 50 municipalities in the province)	Able to book services provided by "*intramoenia*", accredited health facilities and private healthcare
2000	The software system is substituted following a competitive tender	Call centre introduced as an additional channel for booking. The range of services available is limited and will be extended in subsequent years
2003	Pharmacies provide the same services as e-booking centres	A website for changes and cancellations to bookings launched; only some services available for e-booking
2006		Electronic waiting lists introduced
2010	Ferrara is included in the e-booking system	
2012		Citizens able to book services from their own electronic personal health record (only services not subject to GP referral)
2013	Launch of the regional e-booking website	
2014	Modena and Reggio Emilia included in the e-booking system	Both the e-booking website and the electronic personal health record offer the possibility to book services subject to GP referral

into operation the following year. At first, the services provided were limited to the public healthcare. Later, the aim was to make available the full range of health services, including those supplied by the *intramoenia* (intramurale) regime (private practice confined to public facilities), accredited health facilities and private healthcare.

A call centre was established in 2000. This was an additional channel for managing appointments and medical examinations. In 2003 the booking website was launched. After this point, citizens did not need to turn to a booking centre, a pharmacy or a call centre to access healthcare. However, only changes to bookings, cancellations and a restricted number of services were made available online.

In 2006, electronic waiting lists were introduced. When a service provided by public healthcare did not meet citizens' needs, their position in these lists could be changed. This meant they were continuously monitored and were offered alternative opportunities that emerged in the meantime. The figures (2006) illustrate the extent of e-booking: 3,100,000 users per year; 13,000,000 operations per year; a catalogue of 1920 services available; 6600 specialists. All of this was facilitated by 136 counters in hospitals and health centres; 236 counters in pharmacies; a call centre with 28 dedicated telephone lines; and a website.

In recent years, other provinces in the Emilia Romagna region – Ferrara (2010), Modena (2014) and Reggio Emilia (2014) – have all decided to adopt the e-booking system used in Bologna. The e-booking service was a good fit with two other projects promoted by the region and central government: electronic personal health records and e-prescriptions. Since 2012, all citizens in Emilia Romagna had been able to access an electronic folder containing documents related to their care, provided by healthcare facilities and the patients themselves. The functions of the electronic personal health record included e-booking, which was limited to services not subject to GP referral, such as gynecology, ophthalmology and prevention. In 2014 e-prescriptions were also included in this category of services. In 2013 the regional booking website was launched. Due to the integration of several booking services, it was possible to have access to the entire range of services available at regional level.

15.4 Early Stages: From Design to Deployment of an e-Booking System

15.4.1 Antecedents of an e-Booking System

In the transition period that followed the introduction of the National Health Service, the new role of primary care and abandoning hospital-centred healthcare created problems in secondary care. Specifically, in the city of Bologna they resulted in long waiting lists and difficulty in accessing the range of services offered by a large number of providers. In 1987, the municipality of Bologna, in charge of the supervision of USLs, decided to formulate a Health Plan to addressing the emerging situation in consequence of unsatisfactory results related to the implementation of healthcare reform. The Health Plan had three main objectives: (1) to increase investment in diagnostic and therapeutic technologies; (2) to promote a campaign supporting health self-protection; (3) to improve citizens' access to healthcare.

The second half of the 1980s also saw the advent of informatics in the public sector. A large proportion of public administrations launched computerization plans to introduce automated procedures. Innovations, like e-booking systems, became objects of interest. In one of the city hospitals an automated registry of cancer cases was introduced, thanks to support from the University of Bologna. The collaboration between these two parties had produced a pilot of an e-booking system; it was presented to the city but without success. It was evident the project needed to scale-up to build a city-level system. So the collaboration was extended to the National Research Council and the state-owned ITALSIEL, at that time the largest software company in Italy.

15.4.2 Getting Ready for the Service Launch

Unlike today, neither central nor local governments were subject to financial pressures and the Ministry of Health decided to support the e-booking project proposed by the municipality of Bologna. Project design started at the beginning of 1989 and the system was expected to be ready by the end of the year. Within a few weeks, the architecture of the database was available and software development followed. At the same time, the service catalogue was compiled. Standardizing the terminology used to describe services was a fundamental concern: hospitals and health centres had different ways of identifying a radiology examination or an abdominal ultrasound on the basis of the practices they adopted. The catalogue also standardized guidelines for patients preparing for medical examinations. A software solution, supporting the use of synonyms, facilitated agreement about service descriptions and promoted the building of the service catalogue.

In 1989 the Single Booking Centre (*Centro Unificato di Prenotazione* – CUP) directorate was created within the Health Department of the municipality of Bologna. This was an inter-institutional office composed of personnel from the three USLs and led by the city councillor in charge of the department. This entity governed the entire project.

The decision not to assign the management of e-booking centres to USLs meant an alternative organizational unit, external to the healthcare sector, had to be created to take charge of them. SYNWARE was established in the spring of 1989 and staff selection (about 100 employees) began a few months later. In the autumn of that year, training courses introduced the basic elements of the healthcare system and the use of the software solution, even though it was not yet ready. At the beginning of the new year, staff were assigned to the 25 centres in hospitals, health centres and one department store.

15.4.3 Fine-Tuning the e-Booking Service

The service was launched at the end of January 1990. From the first days of operation, activity was surprisingly regular, considering that the system was finalized just days before the launch and both patients and clerks were unfamiliar with the service. An improvement process was launched simultaneously involving all the main protagonists: the Health Department, the three USLs, ITALSIEL and SYNWARE. The Health Department, specifically the CUP directorate, led this process and a number of actions were taken.

As far as ITALSIEL was concerned, a new phase for the evolution of the system was inaugurated. At first, only a limited range of specialist visits and diagnostic activities was available. More complicated diagnostic activities began to be offered in the 2 years following the launch of the service. Booking time was another issue that had to be faced during this period. It was possible to reduce booking time from an average of 18–20 to 8–10 min thanks to the optimization of user interfaces (command line interfaces) and the introduction of software tools that facilitated the retrieval of services.

SYNWARE was subject to continuous innovation of its organizational arrangements. At first, the position of primary contact was created in the most critical centres in the city. The primary contact was a point of reference for clerks and hospital/health centre supervisors in case of problems raised during service provision. The introduction of this role was considered effective but insufficient and a further organizational solution was adopted. The area covered by the municipality was subdivided into five macro areas, each headed by a coordinator who played a pivotal role as the addressee of questions raised by all the centres and other actors involved in the service (Health Department, USLs, ITALSIEL). The five coordinators constituted a unit responsible for dealing with dysfunctionalities, staff assessments and technological and organizational resources to guarantee regularity of service provision. However, this solution was also considered inadequate and a primary contact was established in each centre. This supervisory role established a contact point for coordinators. A help desk was set up in each centre to deal with inaccurate prescriptions and provide information about the range of services provided.

Besides coordinating ITALSIEL and SYNWARE activities, the most delicate responsibility of the CUP directorate was negotiating with hospitals to obtain services that could be included in the e-booking system. Before the introduction of e- booking, each hospital managed the type and number of services provided to outpatients autonomously. With the advent of the e-booking project, control moved to the CUP directorate. This change involved lengthy negotiation with hospitals to increase the extent of services to be offered on the centralized booking system.

The CUP directorate also managed the updating of the service catalogue necessitated by the introduction of new services or modification of existing ones.

The launch of the service entailed another activity that was closely monitored by the CUP directorate: updating service schedules. There was a plurality of service providers (e.g. several radiology units for each health facility), so it was necessary to know the full extent of services available. Unexpected events also had to be managed. A union strike, participation in a conference or sick leave could interrupt service provision. In these cases, schedules needed to be updated, patients informed and new appointments offered.

15.5 Analysis: The Mobilization of Installed Base Resources for the Construction of an e-Booking Service

In this section we analyse the realization of an e-booking system in the municipality of Bologna from the installed base perspective (Hanseth and Monteiro 1997; Ciborra and Hanseth 2000). This entails looking at how an intricate web of technological and institutional resources (Bowker and Star 1999; Lanzara 2009; Star and Ruhleder 1996) was reconfigured to build this service. We focus on how political, organizational and technological resources were mobilized to move from paper-based booking in individual health facilities to a centralized e-booking system that could pool the health services available at city level.

15.5.1 The Mobilization of Political Resources

Political resources had to be mobilized for coordinating, negotiating and building consensus about the e-booking project. The Health Department, represented by a city councillor, was the main protagonist and played a leadership role in both the design and realization of the project. Like a large proportion of Bologna's city council, including the mayor, the city councillor was member of the local branch of the Italian Communist Party (PCI). However, the organization of healthcare was influenced not only by a state-centric perspective, typical of communist ideology, but also by the Europe-wide 1968 social movement. The experience of barefoot doctors in China, emphasizing the importance of local medicine, occupational health and de-hospitalization, also constituted an important point of reference. Unsurprisingly, some party members distrusted the role of technology in healthcare. The e-booking project was questioned closely and the subject of articulate debate within the party. To some degree, the Health Plan issued in 1987 mirrored this debate although in due course there was a rebalancing of policies towards a more important role for technology.

Healthcare policy was debated not only among political parties and social movements but also between stakeholders, including the medical profession, medical science and research activity in general. The activity of the city councillor in the Health Department was influenced not only by his membership of the political party governing the municipality but also by his involvement in local healthcare. In fact, he was supported by two leading medical figures, both "outsiders" due to lengthy periods spent in the US, where one studied oncology and the other innovative techniques in surgery. Both were advocates of the role technology could play in healthcare and so provided support for the city councillor. The councillor himself had been a student of a leading professor at the University of Bologna who had founded a new discipline, the sociology of healthcare, establishing a school that regrouped a significant number of researchers and students. Several members of the CUP directorate had studied under him. This professor has been a central figure in Bologna's political and cultural life, a councillor for more than a decade and one of the authors of the White Paper that outlined a profound transformation of the city administration. His support helped to legitimize the city councillor's position in health management.

The strength of this support drove a new vision of healthcare for the city. The aim was citizens' empowerment through provision of a means by which they could voice their needs and be taken into account. Pursuing this aim meant establishing new citizen/healthcare relationships, involving hospitals and health centres. The mediating role of the CUP directorate exemplified this new relationship. It shook up the prevailing normative order as the roles of the medical profession and healthcare institutions were reformulated.

Technology, specifically information technology, constituted the tool for establishing this new relationship. The number of services available, their type and timing became transparent for all providers. Healthcare access was standardized and no longer subject to the idiosyncrasies of providers. Equality in service access was guaranteed, preventing discriminatory practices. Finally, a simplified and time-saving e-booking process was made available to citizens.

Then a conflict erupted. Head physicians at the university and Bologna's largest hospital, with the support of medical organizations, opposed the intervention of a third party in mediating access to healthcare and threatened not to adopt the new booking system just weeks before the launch of the service. They maintained that it was too expensive and that services offered would be poor quality. It was an impasse. Only the intervention of the mayor, who convened all the parties and emphasized how the project would be beneficial for the city, succeeded in overcoming it. However, opposition did not disappear completely. Five years after the inauguration of the service there was a further attempt to stop it and 25 years later there are still disagreements between medical directors and the Emilia Romagna regional authority, which is now in charge of healthcare management.

To sum up, the e-booking project saw the light of day because several streams of support flowed into the local branch of the PCI and the mayor was committed to backing it. This powerful advocacy was able to resist opposition from USL boards of medical directors and head physicians. Financial resources were at stake and subject to the approval of municipal representative bodies. With such a complex project, only a small reduction in the budget would have put its development and implementation at risk. Again, the political context prevented this eventuality.

Looking at the role played by the installed base – specifically, political resources – for the realization of the e-booking project, it is clear that significant mobilization took place. Local government administrative and representative bodies, the majority party and USL top management were actively involved in both supporting and opposing the project. This is illustrated by the unusual protest from head physicians who threatened to stop the adoption of the booking system and the unorthodox meeting convened by the mayor to avert it. The traditional political arena for negotiation was abandoned or considered ineffective and new ways of building consensus were put in place involving the academic sector, which was usually external to the healthcare arena.

15.5.2 The Mobilization of Organizational Resources

The installed base was also involved in the mobilization of organizational resources. Several organizational arrangements were at stake in providing the operational context for e-booking. Traditional bureaucracies favoured it. Both the Health Department of the municipality of Bologna and USL, the bodies in charge of healthcare, were public bureaucracies. Each USL ran hospitals and health centres in a specific area, coordinating and monitoring the activities of GPs and paediatricians who were self-employed professionals. These public bodies were a type of in-house provider. Their mandate was to supply the medical needs of the people in their jurisdiction and as they were governed by executive committees nominated by municipalities they reflected each municipality's political bias. This is why the

Health Department of the municipality of Bologna was in charge of the e-booking project even though it did not have the professional competences and the organizational capabilities to manage booking centres. The department's institutional mission was healthcare policy implementation on the one hand, and policy monitoring and supervision on the other. A similar lack of competences and organizational capabilities also characterized USLs. Nevertheless, USLs were used to managing paper-based booking systems and so were the natural candidates for running booking centres. Nevertheless, a different decision was made. USLs, as public bodies, were subject to restrictions in workforce management typical of the public sector of that time. The relocation of personnel from one booking office to another, or the extensive use of part-time staff to deal with peak times and long office hours (7.30–18.30), were not possible in the public sector, only in the private sector. Staff training was also necessary. The public sector was heavily unionized and lengthy negotiations would be required to reach an agreement on training and changes to tasks. There were time constraints for the project and this option was not considered feasible. Finally, the three USLs were largely independent units and the service would involve personnel coming from three distinct organizations, creating coordination problems.

At this point, the decision to establish a new company was made. Bologna could be considered the capital of the cooperative movement and a large number of cooperatives were present in sectors like catering, mass distribution, logistics, building and construction. According to the International Alliance of Cooperatives, "a co-operative is an autonomous association of persons united voluntarily to meet their common economic, social, and cultural needs and aspirations through a jointly-owned and democratically-controlled enterprise. Co-operatives are based on the values of self-help, self-responsibility, democracy, equality, equity and solidarity (ICA 1995, p. 3–4)." The new company was part of a group of cooperatives in the software sector provided with technological and organizational capabilities developed in the cooperative environment, which shared the political orientation of the municipality of Bologna at that time. Turning to the cooperative movement meant establishing a link with a large business entity in the local context and promoting specific values in order to compete, in some sense, with traditional public bureaucratic organizations such as hospitals and health centres.

Against this background, SYNWARE was formed. Its activities were supported by weekly training sessions involving top management, five coordinators and on occasion the entire staff. The training content supported, among other things, the adoption of new software, the introduction of new laboratory examinations and the management of critical issues encountered in everyday practice. The weekly sessions were the context in which organizational solutions were conceived. From the detailed analysis of practices and the direct engagement of operators, it was possible to figure out how to improve service provision. The continuous solicitation of operators created an environment favourable to open debate of continuously emerging issues. This was considered the only way to deal with the innovative nature of the service and the lack of experience of those involved in its operation. From the launch of the service to its full implementation, the organizational structure of SYNWARE has not changed significantly, apart from the coordination figures. It has maintained its relatively simple structure, as it was felt that introducing further organizational units would have obstructed the integration of the different components, which was the principal aim of the organization.

A couple of SYNWARE and ITALSIEL managers collaborated actively with the CUP directorate established at the Health Department and led by the city councillor responsible for healthcare. The directorate was regarded as the driver and control tower of the entire e-booking project and requests for services from SYNWARE, USLs or ITALSIEL were relayed to it. Any decision made at the directorate level was passed on to the party or parties involved, which activated their organizational structures accordingly.

A number of actions were in the direct remit of the CUP directorate. One of these was the building of the service catalogue. Even though this involved the establishment of work groups, led by an expert in a medical specialism and an expert in administrative procedures, both physicians, these groups were supervised by the directorate. Activities related to the catalogue building were mainly conducted in the first phase of the project. However, the process was reintroduced when new services were added or existing services changed. Schedule management and the monitoring and management of information about the services available required close collaboration between the directorate and hospitals and health centres. Each facility was responsible for communicating updated information about the services it offered. Building the service catalogue was a long and arduous process.

The CUP directorate was considered an alien presence in an environment that had always been controlled by medical science and its elite. The directorate struggled with leading physicians for control of health services. Taking only partial control of service provision constituted a significant change to established practice and was met with a hostile response from the medical profession. Power distance was a factor in this context. The profession dragged its feet when it was necessary to establish a dialogue with the directorate as it was not sufficiently legitimized in the healthcare environment.

With the advent of the new service, booking management changed considerably. Traditional public bureaucracies now had the room to innovate organizational arrangements, indicating that the installed base, insofar as it was related to organizational resources, was mobilized radically. When hindering effects prevailed, resources available outside the healthcare domain were mobilized in preference to resources present in hospitals and health centres. The existence of these external resources was fundamental to the project, as demonstrated by the involvement of the cooperative movement in running booking centres and the active role played by ITALSIEL and SYNWARE within the directorate. Now areas that had traditionally been run by the public sector saw the participation of private players. The establishment of the directorate itself was a clear example of this. The close partnership with USLs was supported by forms of coordination and control that differed significantly from those of typical bureaucracies.

15.5.3 The Mobilization of Technological Resources

During the 1980s, a computerization scheme was launched throughout the Italian public administration system and subsequently in healthcare. However, it was not able to support the e-booking system and developers had recourse to resources external to the healthcare domain – ultimately the largest Italian software company of the time became involved. Only companies of that size and experience had to capability to build systems on this scale. ITALSIEL, with branches throughout the country, had been the software provider for the whole public sector and the Italian banking system, which was largely controlled by the state at that time. Informatica Friuli Venezia Giulia (IFVG), one of these branches, developed software solutions for healthcare and was involved in designing the architecture of the centralized booking system. Two solutions were proposed by the IFVG top management, one based on the ORACLE database and the other on the dBase database. The possibility of using a product like ORACLE Forms to create screens to interact with the ORACLE database sealed the decision to select the former, which was perceived as more stable and performative. The Ministry of Health approved the solution other than the Health Department coordinated by the National Research Council and the University of Bologna. The system was expected to extend throughout the country once adopted by an important city like Bologna. Being a so-called prime mover in this business would create the conditions to achieve a competitive advantage over other software providers.

Given the size and the innovative functions of the project, the architecture proposed by IFVG was evaluated at ITALSIEL headquarters in Rome. The adoption of the ORACLE database was confirmed but not the software designed to interact with it and the COBOL programming language was selected instead. Back in the 1980s, all large projects turned to this language as it provided the most robust solutions in high complex cases. While IFVG did not fully agree with this decision, on the grounds that other and more innovative solutions could have been found, the decision was considered rational for a number of reasons. First, there were time constraints. The centralized booking system had to be deployable within 6 months and there were not sufficient competences related to specific programming languages for ORACLE databases at IFVG or ITALSIEL headquarters. Second, a large number of COBOL software components that could interact with an ORACLE database were available. The challenge was to group them together to provide interfaces connecting the database and related functions. Finally, the system performance achieved was judged satisfactory, due to the experience acquired in the COBOL environment.

Going live with the e-booking service heralded a new phase in the evolution of the system, as it was necessary to accommodate the needs of nationwide health facilities that required new services or existing services to be reformulated. The aim was to offer the most complicated diagnostic activities – those involving multiple operators and sequential steps – in the 2 years following the launch of the service. The role of staff at booking centres was fundamental to a well functioning system. At the time, automated booking processes were limited and skilled staff with expertise in using the system played a decisive role in providing an appropriate service. Another issue was GPs' handwriting: a statistical analysis of those whose prescriptions were most often rejected by operators due to their illegibility was introduced.

The identification of citizens at booking centres was enabled by a magnetic card containing personal details. Delivering a novel tool to more than 400,000 inhabitants of Bologna carried a high risk of its misuse. However, at that time polling cards were delivered to households by traffic police officers (municipal employees) and in 1990 local elections were held. The e-booking cards were delivered along with polling cards by the police, who emphasized their importance and how they were to be used. The card soon became a symbol of an innovative solution for accessing healthcare through digital technology.

The partnership with ITALSIEL confirmed the importance of the installed base in terms of technological resources. Adoption of the COBOL programming language was contingent on the presence of existing software components that were mobilized to interact with the ORACLE database. Finally, the mobilization of technological resources was necessary for the introduction of the magnetic identification card and the role of the police determined its correct use.

15.6 Discussion

The origins of the e-booking system raises questions about the role of the installed base and its constraining and enabling effects. A healthcare model characterized by a polarization between hospitals on the one hand, and GPs on the other did not provide a supportive environment for creating innovative solutions to accessing healthcare. Hospitals and health centres conceived as professional bureaucracies (Mintzberg 1979; Lam 2000) operate according to standardized and bureaucratic methods of coordination and control in a context where individual expertise and professional bodies both held relevant roles. Even though routines and practices are governed by protocol, personal judgement and peer consultation were important in these organizations. Within professional bureaucracies, such as universities, schools, hospitals and courts, supervision and control are assigned not only to hierarchical superiors but also to external professional associations. These establish regulations and guidelines and are the custodians of the profession, determining appropriate and non-appropriate behaviours. It is understandable that the introduction of an innovative, IT-based system of access to healthcare would meet opposition within a healthcare model governed by professional bureaucracies and medical associations.

It was necessary to mobilize political, organizational and technological resources that could counter this situation. Political activity led the way in coordination, negotiation and building consensus. The municipality of Bologna and the Health Department were conscious of citizens' dissatisfaction with the long waiting lists, lack of transparency and inconvenience of accessing healthcare and formulated a response.

How was the mobilization of political, organizational and technological resources demonstrated? The role played by IT was decisive here. Information technology was conceived as the driver for delineating new ways of accessing healthcare. An innovative scenario for improving healthcare services was established and contrasted sharply with existing ones. Turning to IT inevitably implied an openness towards innovation and continuous updating of implemented solutions.

The constitution of a third party able to mediate between citizens and healthcare providers represented a further aspect of the mobilization process. The CUP directorate supported by SYNWARE provided the e-booking service, eliminating professional bureaucracies such as hospitals and health centres. The service provided by these bureaucracies was substituted by organizational arrangements within the socio-economic context of the Bologna area and exemplified by the cooperative movement.

The leading role of the Health Department and the CUP directorate contributed to the legitimization of service provision outside the healthcare sphere. It was demonstrated that alternative forms of service organization could replace established ones. Traditional healthcare responsibilities, such as service bookings, shifted to an entity supervised by the Health Department and subsequently by representatives of social and political movements. Citizen empowerment was an additional aim.

Finally, the opposition of vested interests, represented by medical associations and head physicians practicing in hospitals, was overcome due to the supporting role played by the local section of the Italian Communist Party and civil society in general. The figure of the mayor was emblematic here. His authority and the consensus he acquired in the city enabled the introduction of e-booking in healthcare.

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