Part I

Information Infrastructures in Healthcare

Information Infrastructures for eHealth

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2.1 Introduction

This chapter provides an introductory overview of healthcare information systems, followed by a more detailed discussion of e-prescription and governmental patient-oriented platforms. We use the umbrella term "eHealth" (also written e-health) that encompasses all health-related digital information systems including clinical, administrative, and research-oriented ones. Specifically, we adopt the eHealth definition introduced by the World Health Organization (WHO). According to this definition, eHealth is "the use of information and communication technologies (ICT) for health; examples include treating patients, conducting research, educating the health workforce, tracking diseases and monitoring public health" (World Health Organisation 2016b). Similarly, the European Commission defines eHealth as: "the use of modern information and communication technologies to meet needs of citizens, patients, healthcare professionals, healthcare providers, as well as policy makers" (European Commission 2003). eHealth is considered pivotal for improving the quality and efficiency of healthcare (Hillestad et al. 2005; Kellermann and Jones 2013), for improving the patient experience of care, and for the eventual revolutionization of healthcare (Drucker 2007).

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Strong expectations linked to eHealth are present in policy and advisory documents prepared around the globe. For instance, the introductory passage of a report by the Institute of Medicine of the National Academies (US) states: "Health and health care are going digital. As multiple intersecting platforms evolve to form a novel operational foundation for health and health care the stage is set for fundamental and unprecedented transformation." (Institute of Medicine 2011). In Europe, eHealth has been a major component of the European Commission's eEurope action plan which was endorsed at the Feira European Council in June 2000. In 2004, the Commission also set in place an eHealth map to develop targeted policy initiatives aimed at fostering widespread adoption of eHealth technologies across the EU (eHealth Action Plan). The latest eHealth Action Plan for 2012–2020 states that the promise of eHealth "remains largely unfulfilled" and the vision of a unified, interoperable eHealth Infrastructure in Europe is still not realised. Although the potential of eHealth is being discussed globally since the 1990s it remains a work in progress.

Countries around Europe have already experienced notable successes and some highly publicised costly delays and failures. These have brought attention to the complexity of dealing with a multiplicity of involved parties with diverging interests and agendas, existing fragmented systems' landscape, rapid technological advancements and regulative perplexities. In most European countries, healthcare is predominantly public and public agencies have a central role for stimulating and orchestrating eHealth efforts. In many countries, the driving force for ICT in health care has been the trend toward a better coordination of care (Winter et al. 2011). This means a change of focus for eHealth from self-contained processes within single healthcare institutions to overall care processes spreading across institutional boundaries.

The remainder of this chapter is structured as follows. In the next section we give an overview of the eHealth landscape. Then, in Sects. 2.3 and 2.4 we focus on the two types of infrastructures examined in this book: e-prescription and governmental patient-oriented platforms. Finally, Sect. 2.4 concludes the chapter with a discussion on the transformative potential of the two types of eHealth infrastructures.

2.2 The eHealth Landscape

To provide the necessary background for the reader, we initially describe information systems that support healthcare-related work within specific organizational settings (e.g. laboratories, medical imaging departments, general practitioner offices). Next, we move beyond these systems, and we present systems that have more generic character and are common enabling components for eHealth.

2.2.1 Core Information Systems in Healthcare Organizations

There is a multitude of systems that support healthcare provision ranging from more generic systems to the ones that offer specialised functionalities for specific domains. Among the specialized, for example there are Picture archiving and

communication systems (PACS) which support storage, retrieval, management, distribution and presentation of medical images, and RIS (Radiology Information Systems) which support patient administration, referrals, reports, and work lists for the medical imaging labs. Computerized physician order entry (CPOE), medication management and vital signs monitoring systems are other examples of special-purpose systems. Of more generic use are Patient Administrative Systems (PAS), also called Admission-Discharge-Transfer (ADT) systems that support registration, scheduling and logistics and Electronic Health Record systems (EHRs). EHRs play a central role in health institutions. An EHR is envisioned as a "repository of information regarding the health of a subject of care in computer processable form, stored and transmitted securely, and accessible by multiple authorised users. It has a commonly agreed logical information model which is independent of EHR systems. Its primary purpose is the support of continuing, efficient and quality integrated health care and it contains information which is retrospective, concurrent and prospective" (ISO/TR 20514 2005). EHRs organize information related to specific patients and may cover several encounters and episodes of care, possibly from birth to death. The information within an EHR may be generated during patient encounters (e.g. diagnoses, lab results, radiology scan reports, etc.) and may also come from the patients (e.g. off-the-shelf medicine, home measurements etc.). This information may be contained in multiple (discrete or interconnected) systems and repositories, each of which will hold and manage specific types of data (Winter et al. 2011). In addition to the systems that directly support healthcare provision, there is also a multitude of systems that support management functions (e.g. systems for management reporting, systems for reimbursement handling, etc.) and research activities (e.g. advanced computational tools for genetic data). There are also systems that support generic, but indispensable services such as user authentication and authorisation services.

2.2.2 Information Systems Beyond the Healthcare Organization

Beyond the spectrum of systems supporting work within the boundaries of a specific healthcare organization, there is also a class of systems and technological capabilities that are more generic, over-arching and serve as common enabling components for a wider eHealth infrastructure. Inter-organizational networks and messaging services for instance, facilitate information flow between organizations (e.g. message exchange between different healthcare providers) and across different levels within the healthcare system (e.g. reporting activities to health authorities and clinical information to health registries). These require the existence of shared infrastructural services like address registries, broadband networks and security infrastructures. In addition, information needs to be shared along a patient's trajectory if it involves diagnosis and treatment in multiple different localities and organizations. To enable easy access to relevant information about a patient, governments have sought to build

cross-cutting systems such as e-prescription systems and shared EHRs (often in the form of summary or emergency care record systems). Standards, both interoperability standards and terminology and nomenclature standards are crucial components in facilitating eHealth infrastructures that go beyond organizational boundaries.

Such inter-organizational eHealth information infrastructures are important for multiple users in different organizational settings: clinical and administrative healthcare professionals, health researchers, public health authorities, health insurance companies and various other involved actors. Furthermore, a continuously growing number of eHealth systems are covering the interaction between patients and healthcare providers, or peer-to-peer communication between patients or health professionals. In this book, we explore infrastructures for e-prescription and patient-oriented platforms. Both of them are inter-organizational and have been a strategic priority for several countries recently.

2.3 E-Prescription

E-prescription solutions support the electronic flow of information related to prescribed medications. Most European countries have taken steps for implementing e-prescription solutions while the aim of the European Union is to have a cross-border electronic system which will enable patients to retrieve electronic prescriptions anywhere in Europe (World Health Organisation 2016a). Nevertheless, there are different degrees of maturity and coverage of e-prescription solutions in the different European countries. In some countries, e-prescribing is used routinely while in other countries there are only some early-stage initiatives.

2.3.1 Prescriptions and e-Prescribing

Modern medicine relies heavily on the use of medication. The production, distribution and use of medication is regulated by longstanding institutions. Over-the-counter medication can be purchased freely and used by anybody without medical supervision. If a medication is not available over-the-counter it can only be dispensed when a prescription is provided, to ensure that its use happens within a care scheme approved by a healthcare professional. National regulations govern who can issue a prescription. In general, doctors have the broadest prescriptive authority and are the main prescribers everywhere in the world. Additionally, other healthcare professionals (for instance: dentists, midwives, pharmacists) may also have the right to prescribe medications related to their area of practice; this varies from country to country.

A prescription may be handwritten on a clean sheet of paper or on pre-printed forms, or typed and printed, or transmitted electronically to pharmacies for dispensing. The content of a prescription includes information about both the patient and

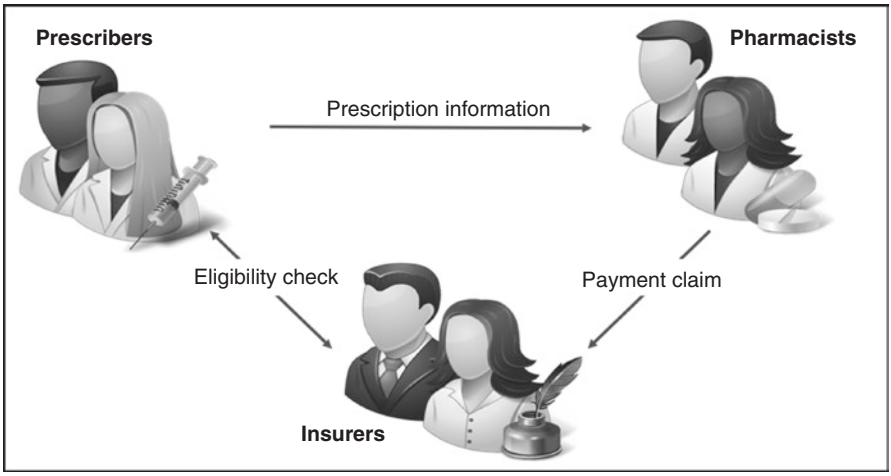

Fig. 2.1 Information flows between prescribers, pharmacists and insurers

the prescriber, the medication specifications (type, quantity) and directions for the patient to follow. Prescribed medication can be partially or fully reimbursed by healthcare insurers (public or private), hence, prescription information is also needed by insurers.

Health authorities around the world support the adoption of electronic prescription systems (e-prescription). E-prescription solutions capture and circulate prescription information between prescribers, pharmacies and insurers that handle related payments (Fig. 2.1) expediting flows and eliminating legibility issues (frequently faced when using handwritten prescriptions). Such solutions can support aims for cost containment, enhancement of patient safety, control over doctors' prescription patterns and process quality assurance. Overall, putting e-prescription in place entails working with multiple and diverse sociotechnical components, finding ways to link and organise them (Rodon and Silva 2015).

Beyond the traditional use of prescriptions in primary care, in hospital settings and in nursing homes, prescription information is needed by nurses that are administering medications. Furthermore, prescription information may be collected and processed by health policy institutions for planning and monitoring purposes. Overall, medication prescriptions and dispense data are monitored for various reasons, for instance, public health authorities may monitor and regulate the use of antibiotics, may monitor and exercise health control over the use of reimbursable drugs, may monitor and supervise imports and distribution. Therefore, most countries have an information infrastructure around the medical prescription. These information infrastructures can be paper-based or digital or in hybrid form and typically link multiple Health Record Systems, Pharmacy Systems, Drug Registries and Health Insurance Systems (electronic or not).

2.3.2 Key Parts of e-Prescription and Variations

It is common to distinguish between three parts of e-prescription infrastructures:

eCapture: support in producing notes for prescribed medication. This can be a simple tool for registering electronically medication information (ensuring quick transmission and elimination of illegibility issues) or more elaborate arrangements that include decision support functionalities such as automatic checking of drug interactions (based on other information from the patient record), automatic retrieval of commercially available drugs and package sizes, support for the selection of drugs with the use of protocols based on the diagnosis descriptions.

eTransfer: transfer of the prescription information. Both electronically generated prescriptions and paper prescriptions filled by hand and scanned can be transferred digitally. Various models are adopted, for instance, the prescription can go from the prescriber to a specific pharmacy, or it can be deposited to a central repository accessible by all pharmacies (allowing the patient to choose where to go at a later stage). With electronic transfers the information flows can be expedited and also, it is possible to better control the duration of prescription's validity (for instance, the message or the information content can expire after a set date). Furthermore, the electronic transfer of prescriptions can allow secondary uses of the data (e.g. facilitating the checking and payment of pharmacy claims and the accumulation of information to support quality healthcare and effective cost management).

eDispensing: support in producing records of the actual medication dispensing. This can be a simple note on the date and place of dispensing or can include complete medication packaging information allowing full traceability and control of drugs.

The coverage of e-prescription projects varies in terms of:

- Actors: the e-prescription infrastructure must cover at least pharmacies and prescribers. In many cases e-prescription is covering only key prescribers (e.g. General Practitioners in primary care). In other cases it includes also hospitals, or even, other prescribers depending on national regulations (e.g. dentists, midwives, pharmacists). Furthermore, most e-prescription systems cover also information flows to insurers.
- Functionality: basic or advanced support for eCapture (e.g. might include decision support for prescribers), eTransmission (can be fully digital or quasi-digital e.g. paper with barcodes), eDispensing (registration of extended or limited information upon dispensing). Additional functionality may include facilities for patients to trigger prescription refills, full integration with Electronic Health Record Systems (EHRs), repository management facilities.
- Access: rules for data access can vary depending on national regulations and on designers´ choices. Actors that can access personalised medication lists may

include prescribing healthcare professionals, other healthcare professionals that provide services to the patient, pharmacists, public authorities, private insurers and patients.

There are variations among countries with different health systems. Variations relate to: what constitutes prescriptions drugs, who can issue a prescription, what is the minimum required content of a prescription, who can dispense a prescription, how medications are reimbursed. There are also legal differences: is electronic transmission of prescriptions legal? Are digital signatures accepted? Does the patient need to consent? Should the patient be able to request a paper copy? Is counselling compulsory before prescriptions are written? In Europe, each country has some particularities, for example: in UK there is some authority transferred to community pharmacies, in Norway nurses can prescribe some drugs (e.g. contraceptives), in Greece and Italy there is control over the physical medication packages that have unique identification numbers. Also, there are differences on insurance schemes for medication reimbursement. For example, in some countries (e.g. Norway) public insurance is unified while in other countries (e.g. Germany and Greece), there are multiple insurance institutions or social security funds.

2.3.3 Drivers for e-Prescription Projects

Expenses for medications contribute significantly to total healthcare expenditures. The expenditure on medications as a share of overall health expenditure varies throughout Europe ranging from 6 % (Denmark, Norway) up to 29 % (Greece), furthermore, the public share of this medication expenditure can range from less than 50 % (Denmark, Finland) up to around 70 % (Germany, Greece) (OECD 2013; World Health Organisation 2014). Therefore, it is seen as critical for governmental authorities to monitor and control prescriptions not only for ensuring healthcare quality but also for reasons of cost control. The expectations for better cost control fuelled the interest for e-prescription systems in European countries during the past decade. Sixteen of the member states of the EU included e-Prescription in their national strategies or eHealth implementation plans already in 2006; in 2011 this number was raised to 22 (Stroetmann et al. 2012). Still, in 2011, only Denmark, Estonia, Iceland and Sweden had in place a full, national e-Prescription solution while at the same time, there were partial implementations in the UK and the Netherlands, regional implementations in Spain, and several initiatives including pilots in Portugal, Czech Republic, Finland, Italy, Norway, Greece and Poland (Kierkegaard 2013; Stroetmann et al. 2011).

With the introduction of e-prescription the collaboration between physicians and pharmacists is mediated by technologies. E-prescription reduces the risks associated with traditional prescription-writing, and has the potential of bringing different benefits to different stakeholders, especially if implemented at scale (Cornford et al. 2014). At the same time, the inscription of rules to the system can be a powerful

control mechanism for prescribers and dispensing pharmacists. In this respect, e-prescription has a dual role: it is not only a tool introduced to everyday work to improve healthcare delivery but also, a governance mechanism for regulating, controlling and monitoring a large array of dispersed temporally and geographically professional tasks (Vassilakopoulou et al. 2012).

In the chapters included in the e-prescription section of this book we present the experiences of different European countries that implemented e-prescription during the past decade. The different cases illustrate different strategies for linking pre-existing infrastructural arrangements (the installed base) to new technological solutions and for extending and renewing the overall prescription related infrastructures. The cases are linked to each country context, the specific characteristics of health systems, the technological maturity of the healthcare environment and the different institutional actors. The cross-examination of the cases can bring a number of insights about different implementation approaches and overall, about the dynamics of infrastructural evolution.

2.4 E-Services for Patients and Citizens

The development of patient-oriented eHealth services is recent. Traditionally, healthcare information systems were developed for clinical and administrative use of health personnel in the context of healthcare organizations. However, recently several countries have initiated projects for establishing patient- or citizen-oriented eHealth solutions and infrastructures. Overall, the aim of these initiatives is to put in place secure and reliable technologies allowing patients to access general and personalised health information and providing electronic services for communication, self-management, and administrative tasks.

2.4.1 Patient-Oriented eHealth Services

Patient-oriented eHealth services are diverse (Fig. 2.2). Some services are mainly information-oriented. For instance, many governmental eHealth websites, but also hospital websites provide citizens with updated and quality-assured information about symptoms and treatment options. These services respond to the increasing interest for using the Internet as a source for health information, and to the problem of the variable quality of information available. Other services are set up to offer access to personal health data that healthcare institutions have registered about individuals, e.g. in the patient record systems, laboratory and imaging systems etc. To support the collation and use of personal health data, various specialised solutions for Personal Health Records (PHR) have been developed. PHRs are in some cases standalone patient-controlled solutions, while in other cases as “tethered” to institutional EHRs.

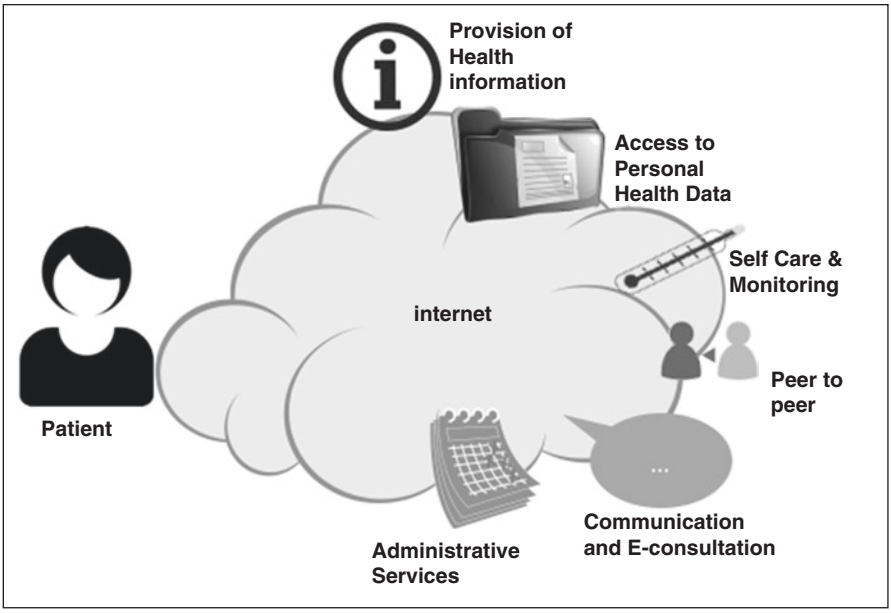

Fig. 2.2 Patient-oriented eHealth services

Additionally, a range of services for self-monitoring and self-care are made available to patients. Some of these services do not entail any involvement of healthcare practitioners while others are linked to healthcare providers that take responsibility for care plans and may assess the information collected. Furthermore, patient-oriented eHealth services may also support peer-to-peer patient networks and forums and in some cases, connections to social media platforms.

Patients and citizens are also offered administrative eHealth services. For instance, many countries offer to patients the possibility to choose among health care service providers, check waiting times, and book appointments. Additionally, solutions for e-consultation services and more generally, electronically supported patient-healthcare provider communications are also in place, often by GP offices in primary care. With these solutions patients are given secure electronic channels for online communication. E-consultation services are mostly used for asking follow up questions after a consultation, asking about medication use and passing on to healthcare providers health related data from self-monitoring practices.

Many European countries have established governmental eHealth patient portals with the aim of offering to citizens one single entry point to the various patient-oriented eHealth services offered in the public health sector.

2.4.2 Drivers for Patient-Oriented eHealth Projects

Many health strategies and policies contain visions of more patient-centric healthcare systems (Klecun 2016). Several countries initiated the development of patient-oriented eHealth solutions seeking to realize visions for patient-centeredness. The informed and empowered patient is prominent in the visions. Within medicine, the formulation of "patient-centered care", as articulated nearly a century ago (Peabody 1927) promotes a model of care that entails keeping patients informed, involving them in decisions and self-care management activities, and acknowledging their experience of illness and psychosocial context. In the seminal "Crossing the Quality Chasm" report (Institute of Medicine 2001) patient-centred care was defined as: "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions". Patients are seen as integral part of the care team and responsibilities of care-taking and monitoring are partially transferred to patients. Empowerment, transparency and individualization of treatments are emphasized. To realize these visions, new information and communication solutions need to be provided for both patients (enabling them to contribute meaningfully in decision-taking) and providers (providing them better insight on patient circumstances). Such eHealth solutions can support communications, information sharing and distributed data management. Hence, eHealth is seen as a core mechanism for reorienting healthcare towards patient-centeredness.

Another driver for patient-oriented eHealth is a more managerial vision to improve the efficiency of healthcare provision. Organizing shared care solutions around individual patients is expected to help overcome existing communication barriers between institutions and across administrative levels. For instance, a shared patient record system, may help to bridge unconnected "islands" and allow a more efficient overall utilization of resources (Ball et al. 2007; Piras and Zanutto 2010). Furthermore, providing patients with solutions that will allow them to make informed choices can put them in a quasi-customer role. This new patient role is expected to to incentivize a stronger focus on quality and efficiency within the sector. For instance, new patient-oriented services that provide comprehensive information on performance indexes for particular health providers (such as waiting times or treatment-related infection rates) aim to facilitate the patient as a 'customer' to make choices that may create a better working healthcare sector.

Another discourse related to patient-oriented eHealth is the one that emphasizes prevention and the responsibility of each individual to conduct responsible health choices. As such, the scope of attention is expanded from "patients" towards "citizens", i.e. healthy members of the society. This discourse therefore, is not only about disease and treatment, but also, about health and wellness related activities, products, and services that address lifestyle, nutrition and exercise. Currently, information from the mobile applications and devices for self-monitoring used by healthy persons are rarely transferred to the wider institutionalised health system. However, there are initiatives for the provision of eHealth services that can enable the fusion of such privately collected information with medical records. Wellness and health related technologies also enable service models that involve cross-border movement

and globalization of health service provision. Furthermore, the spread of medical surveillance of patients living at home (including telemedicine solution and welfare technologies) also produces new data streams, with new potentials for analysis and use, and new requirements for infrastructures. Awareness is arising of the need to provide platforms that are able to receive and integrate data of this kind, often coming through "third-party" or non-health related solutions.

Finally, eHealth services may also seek to support peer-to-peer patient networks or more flexibly organized health communities (Eysenbach 2008; Spagnoletti et al. 2015). Peer networks may help patients cope with handling their disease, help navigating the health system or contribute to political work such as awareness and attention to specific patient groups. Based on collecting patient data that are shared in such peer networks, new types of research are becoming now feasible, sometimes organized and coordinated by the patient collectives themselves (Kallinikos and Tempini 2014).

Conclusion

E-prescription and patient-oriented eHealth services respond to different needs of citizens and healthcare providers and have different roles within European health systems. Overall, e-prescription is more well-defined than patient-oriented services in terms of functionality and in many cases is deeply embedded within pre-existing applications and prescribing tools. Nevertheless, both e-prescription and patient-oriented services have the potential (and frequently the explicit aim) to transform healthcare delivery. E-prescription initiatives are usually seen as opportunities to improve healthcare delivery by systematic and not dramatic change (controlling the ever-increasing medication costs, improving patient safety and providing rich information for performance management). Patient-oriented eHealth services are usually seen as opportunities to pursue wider and more radical innovation, aiming to strengthen the patients' role and to facilitate a shift from provider-centred healthcare towards patient-centeredness.

eHealth infrastructures are expected to instigate the reshaping of core roles and relationships within the healthcare systems (Vikkelsø 2010). Therefore, eHealth is not just about more effective 'tools' for addressing particular problems, but needs to be seen as part of longer and more transformative processes of 'digitalization' (Tilson et al. 2010). Digitalization will transform the existing relationships and institutions in healthcare. For example, electronic tools are changing the clinical encounter between a healthcare professional and a patient (May 2007; Winthereik 2008).

Despite having such a transformative orientation, the novel eHealth infrastructures typically leverage existing services, capabilities, institutions, data sources, systems, and communication channels. These sometimes exist within the healthcare providers' organization, and sometimes they can be built upon applications that are not part of the official healthcare system. The eHealth infrastructures can be part of nationally governed initiatives, or initiatives growing out of local action, e.g. from hospitals or health plan providers.

Expectations are that eHealth infrastructures will help governments improve the quality and efficiency of healthcare and achieve better coordination of care. However, the introduction of novel technologies will not in itself bring into these changes into effect. The underlying premise for this book is the recognition that technology is not an invariant in a transformation process – rather we may expect that any solution will be contested and that it will change shape during realization, implementation and usage. Both technology and institutional transformations trigger complex change processes (Agarwal et al. 2010, Davidson and Chismar 2007) with a reciprocal interaction between technologies and organizations. The stories of building eHealth infrastructures included in this book illustrate several aspects of such complex, interactive transformation processes.

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Information Infrastructures and the Challenge of the Installed Base

3

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3.1 Introduction

In this chapter we present the core theoretical concepts underlying the research included in the book. The empirical cases concern inter-organizational information systems, specifically e-prescription and governmental patient-oriented eHealth platforms. These systems span organizational boundaries and comprise multiple local systems as well as shared system components. Such interconnected networks of systems can be conceptualized in different ways. In software engineering, notions like "system-of-systems" (Maier 1998), "ultra-large scale systems" (Feiler et al. 2006) or "coalitions of systems" (Sommerville et al. 2012) are employed to draw attention to the specific characteristics and challenges that such systems pose.

We employ a perspective that denotes these interconnected, distributed collections of systems as "information infrastructures". This perspective emerges from a different, disciplinary diverse background. It stems from Information Systems studies, Science Technology and Society studies, and Innovation studies; i.e. disciplinary domains that have a dual focus that covers both technology and human/societal aspects (Monteiro and Hanseth 1995). In the next section we present this overall perspective. We then zoom in on one of the core notions of the information

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infrastructure perspective – the installed base. This notion helps us examine the trajectories of evolution for the e-prescription solutions and patient platforms.

3.2 Information Infrastructures

Some informatics researchers seek to understand technologies from a socio-technical perspective, i.e. to include the organizational and social context of its design and use. The fields of Information Systems (IS) research, Computer-Supported Collaborative Work (CSCW) and Human Computer Interaction (HCI) have this orientation to actual use situations and real users. Here it has emerged a body of research based on ethnographic studies of how people work with technologies. The recognition of how technology is intimately intertwined with organizational structure, procedures and work practices is a fundamental insight from this stream. For instance, Winthereik and Berg (2003) describe the historical evolution of the patient record over the last century as related to the organizational development of hospitals and the professional development of the medical and other health professions. Technologies for documentation and coordination of work have co-evolved together with the organizational structure, the personnel's skills and the work routines. The resulting collection of paper-based tools (forms, records, binders, tables, shelves etc.) and organizational routines comprise a complex information infrastructure that supports medical work (Berg 1999; Berg and Goorman 1999). This is often taken for granted, and its crucial role is often only realized when disturbances occur, e.g. when a digitization project is initiated (Vikkelsø 2005). For instance, the consequences of replacing a paper form with a digital version may not be fully realized unless one sees the paper form as not just being an information carrier but also a 'signalling device' for the coordination of work. The underlying, supporting and often invisible role of this set of technological components and organizational routines is one reason to call this an "information infrastructure". An organization-wide information infrastructure that is deeply embedded into work routines across several departments will be difficult to change, however, careful analysis of all its aspects can inform change strategies (Hanseth and Lundberg 2001; Ellingsen and Monteiro 2003; Silsand and Ellingsen 2014; Petrakaki et al. 2016).

This underlying and invisible role caused by technology's embeddedness within a work and organizational context is not the only reason to use the label of "information infrastructure". The IT systems implemented in healthcare are usually intended to connect multiple sites, either within an organization or beyond it. An information infrastructure that is non-local and distributed will encompass multiple actors that may have different needs and interests that may not be aligned. For an information infrastructure to work, some working resolution between the multiple local interests and the over-arching or "global" interests of the network as a whole, needs to be found (Star and Ruhleder 1996).

Understanding the complexities and mechanisms involved is a core ambition of information infrastructure studies. Earlier studies on the historical evolution of large-scale technical systems, for instance the emergence of electric power grids

(Hughes 1987), have drawn attention to the contests among the actors and their strategies for promoting their own solutions or interests. From such studies comes a set of concepts that help us understand the role of network effects, which are the mechanisms at play in interconnected setting with a large number of actors with different agendas and interests (Arthur 1989, 1990; David 1985). For instance, recognising that value is generated by the network, not the parts in isolation, and that initial moves in a particular direction encourage further moves along the same path, is crucial. While in early stages in the evolution of systems the path is relatively open, at later stages it becomes more bounded or may create lock-in situations.

Earlier research has illuminated what we may call on the one hand socio-technical complexity (caused by technologies being deeply embedded into organizations, and organizations being deeply embedded into technologies, see e.g. Leonardi 2011) and on the other hand network-related complexity (caused by the unpredictable dynamics between a large number of connected actors without central control, see e.g. Williams 2016). Based on these insights, IS researchers have attempted to formulate different ways to think about and deal with large-scale, complex and interconnected information infrastructures – approaches that are sensitive to the presence of complexity. Based on a number of in-depth case studies in global organizations, Ciborra et al. (2000) challenge traditional management approaches based on a control paradigm and advocates more humble, iterative and incremental managerial strategies. "Cultivation" is a metaphor that serves to characterize this alternative approach, in contrast to the prevalent "construction" mode based on detailed preplanning and tight control. A cultivation approach would prefer monitoring and intervention activities over strict control and ongoing adjustments over rigid preplanning. The evolution of the Internet is a paradigmatic example of technology development that has not followed the traditional managerial top-down approach. Hanseth and Lyytinen (2010) uses this case to derive design principles that are sensitive to (and exploit) the network effects that are a core defining feature of information infrastructures.

To build (or grow) infrastructures is a challenging endeavour for several reasons: information infrastructures expand through integrating previously separate systems, however, integration is not only a technical concern of achieving interoperability, rather a process embedding political and institutional interests. For instance, in the context of national or regional e-health infrastructures, a large number of heterogeneous actors, including developers and users' organizations, are involved with diverging interests, which requires ongoing political negotiations (Sahay et al. 2009). In addition, large-scale infrastructural projects require adequate coordination mechanisms. Infrastructure development is characterized by uncertainty. It is basically an open process due to the many interdependencies that need to be dealt with. Furthermore, unintended side effects and the participating actors' reflexivity can add to the complexity (Hanseth and Ciborra 2007; Hanseth et al. 2006). Moreover, infrastructure development is a visionary and political process with a moving target. It deals with an extended time span, as infrastructures are designed today to address future and unknown needs of users.

With this book we aim to contribute to the emerging body of literature that apply the information infrastructure perspective to study eHealth infrastructures.[1] Specifically, this book focuses on the process of evolution of various cases of information infrastructures in the health sector. The information infrastructure perspective encourages such a temporally extended process view, and the "installed base" concept is central in such analyses.

3.3 Installed Base

One of the core messages of the information infrastructure body of research has been to draw the attention to the role of the pre-existing, built environment, which is often overlooked by other conceptualizations of large, complex systems. Studies of information infrastructures emphasize the durability and central role of existing practices, conventions, tools and systems, and this "installed base" is seen to fundamentally impact the evolution of information infrastructures. This perspective emphasizes that "infrastructure does not grow de novo: it wrestles with the "inertia of the installed base" and inherits strengths and limitations from that base." (Star and Ruhleder 1996, p. 113).

Among practitioners the challenges posed by the installed base are well known. For instance, a corporations' huge and messy portfolio of IT systems from different technical generations that have accumulated throughout the years may significantly impacts the corporation's freedom to improve and innovate, for both technical and financial reasons. The metaphors of 'greenfield' versus 'brownfield' projects, imported to systems development discourse from the building industry, signify the same practical recognition of the power of the installed base. While a greenfield site has no prior installations, in a brownfield site there may be existing installations, other buildings, pipes and cables in the ground, or contaminated soil. Changes and innovations happen in that constrained space between what is already there and what can become realized in an already populated landscape.

The notion of installed base refers in general to the number of installations or products sold. The size of the installed base and existence of complementary products may, through self-reinforcing growth mechanisms, determine success or failure in the market (see e.g. Farrell and Saloner 1986; Schilling 1999). However, in Information Infrastructure studies the notion of installed base has a broader meaning. It was initially used in the context of a discussion on standardization and communication protocols, where it was commented that "a fundamental problem with OSI is that it is "installed base hostile" (Hanseth and Monteiro 1998b). The notion was later used in an extended way to encompass "all that is there", including the existing work practices with their tools and established

[1] See e.g.: Aanestad and Jensen 2011; Jensen 2013; Schellhammer et al. 2013; Grisot and Vassilakopoulou 2013; Rodon and Chekanov 2014; Grisot et al. 2014; Johnson et al. 2014; Rodon and Silva 2015; Thorseng and Jensen 2015; Hanseth and Bygstad 2015; Vassilakopoulou et al. 2016; Williams 2016.

division of labour, the legal and professional regulations in place, and so on (see e.g. Hanseth and Monteiro 1998a). The main argument is that information infrastructures are never designed from scratch, but they develop through the evolution of an installed base. Hanseth and Lyytinen (2010) define an installed base as the existing "set of ICT capabilities and their users, operations and design communities", and it also encompasses existing institutional and organizational components (Lanzara 2014). In the health sector for example an installed base may encompass patient record systems, medical departments, various groups of professionals as users (nurses, clinicians), dispensing practices, regulations etc. Accordingly, the main argument put forward in this book is that projects for the creation of large-scale health information infrastructures are shaped by the existing installed base: the organizational, institutional, regulatory, sociotechnical arrangements that are already in place.

We should keep in mind that an installed base is not a given 'thing', it is rather a conceptual tool. This conceptual tool can help us to capture the continuities and discontinuities in infrastructure evolution. It becomes observable and visible when analyzing plans and interventions acting upon the existing infrastructural arrangements. Rather than asking "what is the installed base" we should ask "when is an installed base"? In other words, rather than pointing to specific elements, we need to ask when and how some element of an existing reality becomes significant, for whom, with what effects? In what way do the different elements become significant, are they working as triggers, as resources, as competitors, as alternatives? For instance, will a particular feature of the organizational culture serve to facilitate or hinder change? The concept of installed base is a sense-making tool to examine and reflect on the challenges faced in the development of infrastructures. It implies a process-oriented understanding where it becomes crucial to trace and analyse the historical sequence of events and decisions that shape the forming of infrastructures.

The generic change strategy of the information infrastructure perspective – "cultivation of the installed base" – denotes a strategy that starts from what already exists (the installed base). This implies a re-conceptualization of the very notion of design of information infrastructure. Rather than design in the conventional sense, dealing with the evolution of infrastructures requires strategies to intervene and influence ongoing processes. The Information Infrastructure evolution process is best captured by the notion of 'growing' (instead of e.g. 'building' or 'constructing') since it gives a "sense of an organic unfolding within an existing (and changing) environment" where there is a "recurring issue of adjustment in which infrastructures adapt to, reshape, or even internalize elements of their environment in the process of growth and entrenchment" (Edwards et al. 2007, p. 369). These processes of infrastructure evolution happen along multiple temporal scales (Edwards et al. 2009; Ribes and Finholt 2009; Karasti et al. 2010). In this perspective, we approach the cases by paying attention to the strategies enacted in order to deal with the installed base, and examine how developing infrastructures entails engagement in processes of extension, recombination, substitution of parts and arrangements that already exist. In this view, new information technologies should never be seen

as isolated and univocal, but embedded in an intricate web of technologies, practices, routines to which they relate in specific ways. The pre-existing systems may serve as a foundation for a new system, components from the previous information infrastructure may be reused in the new, and other components me be redefined or removed. The challenges associated with this is the topic of the next section.

3.4 Challenges of Installed Base Cultivation

Infrastructures are never built "de novo" – they develop amidst a stream of technical antecedents, social conventions and professional rules and have to be adaptive to the developments of work practice. As these elements are changing, the information infrastructures are continuously evolving. At the same time, they have to be stable enough to reliably support activities that make use of them: "only a stable installed base allows new connections to be created" (Tilson et al. 2010). Taking an infrastructural perspective reorients our attention to interconnections and relationships as well as to issues of durability and permanence. The challenge is then to devise strategies for effectively managing future evolution (Ribes and Finholt 2009; Karasti et al. 2010). The installed base is both enabling and constraining infrastructure evolution (Hanseth et al. 1996; Hanseth and Aanestad 2003), it can be "a resource for creative design and innovation or a trap from which it is difficult to escape" (Lanzara 2014 p. 19). To manage the further evolution of the installed base is challenging, as it entails building on the installed base and transforming it at the same time. This creates a paradox: new developments need to fit and make use of existing arrangements and at the same time transform them. Overfitting on the existing installed base may strengthen its irreversibility and hinder change, disregarding it may limit the initial utility of any initiative and impede growth (Henningsson and Hanseth 2011). The paradoxical relationship between the installed base and infrastructural development initiatives cannot be resolved with simplistic approaches e.g. the old obliteration dogma of Business Process Reengineering or naive digitization ("putting electricity on paper"). Rather our argument is that the installed base matters in each case in a specific and contingent way.

This book aims to bring empirically based and theoretically informed insights into how the installed base matters. The book's empirical analyses investigate the various strategies in which infrastructure "builders" engage with (or disregard) the installed base. The stories describe how initiatives are shaped and paced by decisions on how to relate with the installed base, or alternatively, how they are shaped by the insensitivity to what is already in place. The two categories of cases, e-prescription infrastructures and governmental patient-oriented eHealth platforms are differently positioned with respect to the installed base. E-prescription initiatives are typically oriented to digitize an already present paper-based and analogue information infrastructure. The governmental patient-oriented web platforms are typically expected to allow more radical innovation, including new interaction patterns, roles and responsibilities for both patients and healthcare personnel. Overall, e-prescription initiatives are usually aiming to improve healthcare delivery by

systematic change, building in an orderly way upon the existing arrangements, while initiatives for patient-oriented eHealth platforms are usually seen as opportunities to pursue wider and more radical innovation (dramatic change) (Huy and Mintzberg 2003). Nevertheless, in any of the two types, pre-existing arrangements need to be taken into account, after all, these pre-existing arrangements are providing the contextual meaning of change. Hence, change has to be managed with a profound appreciation of the installed base.

The book chapters go beyond the initial design and development of each case and include experiences of reworking and reconfiguration during and after deployment as this has proved to be pivotal for systems' evolution. The narratives of each case bring forwards the paradoxical relationship between new eHealth initiatives that need to fit and make use of existing arrangements and at the same time transform them. The accounts of actual trajectories may not necessarily be neat "roll-outs"; detours and plan changes are part of the stories. Nevertheless, all cases are about large-scale planned and professionally managed initiatives with specific goals. The book is about this type of initiatives and aims to provide insights on how strategies can be specific to each context. Going beyond universal best practices that can be deadening and unresponsive to the actual challenges requires developing an awareness of the installed base. This awareness means being able to discern what is relevant and needs to be foregrounded and acted upon from what can be handled as mere background. In other words, the aim with the book is to help create an "installed base sensitivity" in decision-making both at the policy/strategic level and at the concrete e-health design level.

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Strategies for Building eHealth Infrastructures

4

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4.1 Introduction

This chapter presents a cross-case analysis of the different strategies for dealing with the installed base in the 11 empirical chapters of this book. The empirical chapters are organised in two sections. One focused on cases of design and development of e-prescription and one focused on patient-oriented eHealth platforms. Both e-prescription and patient-oriented eHealth initiatives have a transformative role, but they are differently positioned within the eHealth landscape. Overall, e-prescription is more well-defined in terms of functionality than patient-oriented services. Furthermore, there are clear interdependencies between e-prescription and specific existing healthcare applications (e.g. Electronic Health Record systems and Pharmacy systems) and also with well-established work practices (for prescribing, drug dispensing and reimbursements) and tools (the installed base). Compared with e-prescription initiatives, the initiatives to build patient-oriented eHealth platforms are more open in scope, the functionalities to be included are frequently decided after an exploratory process, and the needs for linkages to existing systems and practices are concretised only after the specifics of functionalities are defined. Overall, e-prescription initiatives are usually seen as opportunities to improve

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healthcare delivery by systematic and not dramatic change while patient-oriented eHealth services are usually seen as opportunities to pursue wider and more radical innovation.

In the sections that follow, we unpack these aspects drawing from the six prescription cases and the five patient-oriented eHealth cases included in this book. Specifically, we present the actual scope of the different initiatives (i.e. the actual services included), their starting points and their motivations. We then, compare the different cases in terms of the observed strategies towards the installed base. We conclude the chapter with some reflections on the importance of a conscious and well-informed strategy towards the installed base for addressing the challenges of putting in place eHealth infrastructures.

4.2 E-Prescription

4.2.1 Overview of the Case Studies on E-Prescription: Services Offered, Starting Points, Motivation

The six case studies on e-prescription show similarities and differences with respect to the *functionality domains* covered, their *starting points* and their *motivations*. These are described in the following subsections.

Functionality Domains Covered and Starting Points

The projects cover a variety of processes related to prescribing and medication management. The projects in Norway, Catalonia, England, and Greece started with a broad aim and national scope (in the Catalan case the scope covered the semi-autonomous Catalonia region), and with a focus on the *transmission of prescription information* from the prescribing doctor to the pharmacies. Most of these projects did not only support prescribing of drugs by General Practitioners (GPs), but also the prescribing at hospital's outpatient clinics and hospital prescribing for patients that are about to be discharged from the hospital.

The case from Germany and the case on UK hospital prescribing are significantly different from the other cases. The project reported in the case from Germany is not a national e-prescription project, but a project which started with the specific aim to improve medication compliance for polypharmacy patients by providing patient-specific medication packs that could function as dose administration aids. In order to implement this, the electronic transmission of prescriptions was required. The project's starting point was related to the needs of a specific category of patients and to the possibilities offered by a specific way of drug delivery (medication packs). In addition, this project was one of many other initiatives promoting the dispensing of packaged medications in Germany. The case on e-prescription in the UK hospitals is about the implementation of various different Hospital Electronic Prescribing and Medicine Administration (HEPMA) systems in NHS England. The systems' functionality and implementation efforts described in this case are specific to hospital contexts and do not cover any primary care activities.

Motivations

Regarding motivations behind the initiatives and expected benefits and outcomes, the cases have a lot in common. Firstly, they all aimed for *cost containment*, partly through automating parts of the overall process, but also through enhanced monitoring of drugs' expenditures and physicians' prescribing practices; also, they aimed for *improving patient safety* and for *improving the overall quality* of the service delivered to patients. There was, however, also some variety across the projects regarding motivation.

In two cases the interests of *pharmaceutical actors* played a major role. In Germany, the project on the medication packs was initiated and managed by a representative of the pharmaceutical industry with business interests to expand its market presence and promote a specific type of solution (blistering). Also in the Catalan case, although the project was initiated by the health authorities, the pharmacies and their association played a central role in defining its aims. The project got a strong focus on improving the practices in the pharmacies, and the pharmacy association managed to get a key role in the process. This key role was secured by establishing an overall architecture that allowed the pharmacy side infrastructure to be as autonomous as possible from the rest of the e-prescription infrastructure.

In Greece, the e-prescription initiative was motivated by some of the common arguments found in other cases: to enhance control over pharmaceutical expenditure, to improve doctor-pharmacy collaboration and patient safety and to capture data required for evidence-based policy development. However, the economic situation of the country played a role in pushing the project forward. The project was run during a difficult period for the Greek economy, and this accelerated the introduction of new electronic tools to reform the healthcare sector. In Norway, the project was initially triggered by the Office of the Auditor General's critique of inadequate monitoring and control of costs related to drug use. However, in order to ensure physicians' buy-in, the focus of the project changed early on from monitoring, control, and cost containment, towards improving patient safety.

Finally, in the case for establishing e-prescription in UK hospitals, the interests of *the vendors* played a significant role. Vendors of HEPMA applications were investing in expanding their market base internationally and in England, and for this purpose they adopted diverse strategies. Overall, this case brings forward the interests that shape the market within the domain of systems for hospital electronic prescribing and medicine administration.

4.2.2 Strategies Towards the Installed Base

In this section we will compare and contrast the six e-prescription cases regarding their strategies for how to relate to the existing installed base, and how to further develop it.

In section "Strategies for Dealing with Existing Practices and Technologies" we will look more carefully at how the different projects related to their respective installed bases. We will consider the installed base in terms of both existing user

practices and technological systems. The different projects under study have followed approaches that were: *installed base-friendly*, *installed base-ignorant* and *installed base-hostile*. The installed base-friendly approach seems to be the one with higher chances to establish a new infrastructure and reach a stage where the adoption and use of the infrastructure get momentum. This approach implies that the new infrastructure first of all supports and aligns with existing work practices, second, that the new technological solution is as simple as possible, third, that it is built upon existing technologies when possible, and, finally, that it requires as few changes to the technological installed base as possible. However, once the infrastructure is established, it remains to see if it will lead to a lock-in process where existing practices are embedded into more complex and hard to change technological structures, or if it may enable future changes and improvement of the actual practices.

Thus, in section "Strategies for Further Development" we will turn our attention to projects' *strategies for enabling future changes* by modifying and extending the infrastructure after it is established, i.e. strategies for how to *"cultivate" the new installed base* built. Across all cases studied, once the initial arrangements for e-prescription were put in place and adopted in practice, a series of modifications and additions followed. These further developments to the e-prescription infrastructures were driven by stakeholders´ interests and were the outcome of case-specific strategies for forward-looking development.

Strategies for Dealing with Existing Practices and Technologies

As described in the introductory chapter on "Information Infrastructures for eHealth", e-prescription is relatively well-defined in terms of functionality and is built upon pre-existing applications and prescribing tools. Accordingly, the Catalan, Norwegian, English and Greek projects started out with *a focus on paper prescriptions* and aimed at first to digitalize the paper-based prescribing processes. They started out with the (implicit) strategy of replicating existing paper-based practices and then, to a varying degree, enriching these with additional functions for detection of medication errors and decision support that would improve patient safety. Such projects can, then, be said to be "*installed base friendly*". As explained in the analysis of the case on e-prescription in England, new developments show some *fidelity* to established structures, practices and professional roles within the healthcare system. For instance, in the e-prescription project in England, elements of the old paper prescription form were retained and used also for the electronic solution ensuring a better 'fit' of the new prescription service to the wider healthcare context, both conceptually and practically. However, these four projects while trying to stay close to the existing practices, had to find appropriate strategies for actually building e-prescription upon the installed base and faced different challenges.

The Norwegian and Greek projects employed almost opposite strategies for dealing with the existing technological installed base. In the Norwegian case, the strategy chosen was to *integrate tightly* the e-prescription modules implementing the new functionality with existing systems, in particular Electronic Patient Record and Pharmacy Management systems. Due to the comprehensive functionality specified, this implied that the project required extensive work from the vendors' side. The

vendors had to develop new and quite complex software components, modify their existing solutions, and integrate them. This resulted in a situation where the overall Norwegian project became heavily dependent not only to the activities of the vendors directly involved in the e-prescription project, but also to the overall situation within the vendor organizations. For instance, the project was slowed down by one vendor's delayed development of a new product.

Differently from the Norwegian project, the Greek one developed first a simple solution based on easily available and straightforward web technologies *without pursuing integration* with the Electronic Patient Record and Pharmacy Management systems that were already in place. These integrations were made possible at a later stage, after the initial launch of the simple solution. Due to economic and political commitments, the initial solution was developed within a very tight timeline and was launched within less than a year from the moment that development started. This is in huge contrast to the Norwegian solution in terms of both complexity and time. The "rollout" of the solution in Norway started 7–8 years after the project was established.

In the English case, the e-prescription solutions for doctors and pharmacists were developed by software vendors according to a set of output-based specifications describing how to manage and process electronic prescriptions. These solutions were built upon the technological installed base which included agreed national informatics standards and common supporting components such as a data centre and communications backbone (the Spine) which enables the transfer of data between computer systems in the NHS. In the Catalan case, the technological installed base included Pharmacy Management Systems, but lacked a national secure health network. This secure network had to be built before the project proceeded.

Differently from the other four cases, the UK hospital case and the German case started from *available technological capabilities*, rather than the existing work practices. E-prescription in hospitals in England was based on Commercial Off-The-Shelf (COTS) 'packaged' software systems that were used for various purposes different from medication management, rather than existing work practices. The vendors of the systems tried to adapt them to support and improve the activities related to medication management. However, in many cases the COTS systems had non-clinical origins and were 'foreign', lacking alignment with UK hospitals' internal processes and needs, and the diversity of practices across hospitals, department, and specialties. In this case, the approach followed in the project could be said to be "*installed base ignorant*" as the existing practices were not taken into consideration in the process of infrastructure development. This resulted in requests to adapt the systems to local practices and preferences, which forced vendors to perform multiple cycles of modification to their products. However, the process turned out to be complex and slow, resulting in the current uneven growth and variable success of HEPMA systems in England.

Similarly, the German project started with a technological vantage point and the ambition to change existing practices. The project promoted the dispensing of packaged medications in blisters, with a specific process flow around it, and a controlled

medication lists. However, the innovative blistering practice and the infrastructure supporting it, were seen as a controversial by key actors. Blistering practices would require the *transformation and extension of various existing practices* such as: medication management and related information sharing practices, practices of distributing medication and practices of invoicing and reimbursing medication. In this case new technologies designed for Multi-Dose (or Automatic Dose) Dispensing were not adapted to what was already in place. In addition, core infrastructural components were questioned and opposed. For instance, the assortment of 400 medicines for blistering was perceived as controlling medication practices. Overall, the relation to the installed base in the German case can be seen as 'hostile' for various reasons. From the perspective of the project, the innovative blistering project met an '*installed base of opposition*' as many key actors critiqued and strongly opposed the project. This eventually ended the project. From the perspective of the existing practices and technologies, the project's approach can be said to be "*installed base hostile*" considering the mismatch between the novelty of the blistering project, and the existing arrangements in the surrounding environment.

Overall, all the six cases had to deal with what we have described as the '*paradox*' of the installed base in the chapter on "Information Infrastructures and the challenge of the Installed Base". This paradox is about aiming for developments that need to fit and make use of existing arrangements *and* at the same time transform them. This specific need to be both fitted and transformative can explain why cases that initially adopted *installed base-friendly* approaches may at a later point become more *installed base-hostile*. For instance, in the Norwegian case, the project aimed initially to establish stronger control of public expenses related to drugs, which implied closer monitoring and control of physicians' work practices. The project owners realised that physicians might be unwilling to adopt a technological solution aimed just at such monitoring. Accordingly, it was decided to add functionality to the solution specification to make the solution more aligned with physicians´ work practices. This move however, made the technological solution more complex and more "*installed base hostile*" regarding technology.

Strategies for Further Development

In this section we turn our attention to the different cases' *strategies for enabling forward looking changes* by modifying and extending the infrastructure after it was established. Of the six cases examined, three have enough similarities for being cross-analysed. Specifically, the Catalan, Greek, and Norwegian cases covered similar functionalities, started all with installed base-friendly approaches and were pursued to a great extent through centrally decided and implemented development plans. Those information infrastructures evolved more or less continuously after they were put in place according to different strategies. These three projects illustrate three different ways in which the continuous modification and enhancement of an already established and adopted infrastructure can be facilitated, i.e. how an installed base can be "cultivated."

In Catalonia, the infrastructure was continuously changed and a range of new services have been introduced. Key elements in this process were the architectural changes which turned the SIFARE server into *a platform that could be accessed*

through an API and web services. Over the years the API and the web services have been extended and modified to provide a vast range of services. These services offered Pharmacy Management System vendors (14 in total) possibilities for developing new services supporting and improving the work practices of their customers. Over the years the vendors have been innovative and added many new services to their products based on the SIFARE platform. Partly the vendors have innovated and developed new services individually, partly this has happened through coordinated initiatives like the "Paperless Pharmacy" project.

The Greek solution was first extended by developing and providing APIs that the vendors of Pharmacy Management and Electronic Patient Record systems could use to integrate their solutions with the infrastructure. Then, various new functions were added such as the electronic implementation of therapeutic prescribing protocols, and diagnostic tests' ordering. These changes were implemented in short time and at low cost. This was possible because the new infrastructure was based on *an expandable component-based architecture*. In addition, the initiative was run and maintained by a small centralized organization that had flexibility in modifying the solution. Overall, multiple changes have taken place as a sequence of small steps.

The Norwegian infrastructure is significantly more complex than the Greek one. Furthermore, the Norwegian case was the only one of the three that expanded beyond the traditional prescription areas. Specifically, the Norwegian case expanded into medication management of chronically ill patients at home and in nursing homes through the development of new functionalities for supporting Multi-Dose Dispensing. The hospitals in Norway have also expressed interest in integrating the e-prescription solution with their Chart and Medication Systems. For all major changes in this complex infrastructure *the application independent GPM module played an important role*. The central project organization used this module to develop the new functionalities in an experimental fashion being able to test prototypes and the launch pilots without involving application vendors. After having successfully established a number of pilots, the specifications for the extended functionality could be frozen and then implemented as extension to vendor applications if the vendors wanted to.

Due to these improvements and modifications of the e-prescription infrastructures the installed bases of technologies and user practices also changed. Actually, in all cases work practices evolved as the infrastructures were modified and extended.

4.3 Patient-Oriented eHealth Platforms

4.3.1 Overview of the Case Studies on Patient-Oriented eHealth: Services Offered, Starting Points, Motivations

The five case studies on patient-oriented eHealth platforms tell different stories about strategies towards the installed base. This is not unexpected as each case has a different starting point and is related to different sociotechnical settings. Furthermore, the locus of each initiative is different: the case from Italy describes an initiative that started from one *municipality* growing to the region level, the case

from Sweden is about multiple parallel *county-level* initiatives under national coordination, the other two cases from Scandinavia are about initiatives taken at the *national level* (Denmark, Norway) while the case from Spain is about an initiative taken centrally at the level of the *semiautonomous region* of Catalonia. The cases offer a good variety of scenarios in which patient oriented services have been successfully developed.

Services Offered and Starting Points

The types of services offered through the platforms cover the whole spectrum described in the second chapter of this book (on Information Infrastructures for eHealth). The three Scandinavian platforms (Denmark, Norway, Sweden) and the Catalan one include an impressive *range of offerings*: quality checked information on health and disease, information on the performance of different health institutions, access to personal health data stored in medical records across the health sector, administrative services (e.g. GP change, tracking of referrals, claims or requests), booking services, patient-provider message exchange and e-consultation. Some of these platforms also include tools for disease-specific self-monitoring and self-care and links to patients' social media platforms or facilities for peer-to-peer networking. There are plans for expanding towards these directions for the platforms that do not yet include such functionalities. The case from Italy is different from the other four as it has a specific focus on booking services, which emerged as an initial service in what later grew to a larger citizens' platform. The Italian case is very interesting as it offers an account of the evolution of (probably) the first e-booking system in Europe.

Interestingly, the initial offerings for the four platforms that are now broad and all-inclusive, were different. In Catalonia, the platform started as an *access point for personal health data* from the Shared Electronic Medical Record of Catalonia that was newly established when the initiative started (started in 2008, first pilot in 2009). In Sweden, it started from a Stockholm County Council initiative to provide a "*secure message feature*" between patients and healthcare providers (initiated in 2000, first pilots in 2002 with a limited number of patient-provider interactions such as requests for appointment scheduling and prescription renewal). In both Denmark and Norway, the starting point was to provide *quality assured but non-personalised information*. In Norway, the platform started by offering consistent and quality-assured definitions of illnesses and treatments in information pages (started in 2010, launched in 2011); personalised services (that required patient authentication) were added in 2013. In Denmark, the national platform started by offering quality-assured medical information for both citizens and healthcare providers and soon after that, information about waiting lists (the initiative started in 2001, launched in 2003); services that required authentication were added in 2004. The differences in the initial offerings relate both to the different initial motivations for putting in place the patient platforms and also, to the different possibilities offered by the installed base in each country during the early development phases.

In the Italian case, the focus is on one specific type of electronic service (booking of appointments) but as the case narrative starts in 1990, it is interesting to observe

the *evolution of channels* used throughout the years for providing access to patients. The new electronic service was initially (in 1990) offered through 25 e-booking centres (including hospitals, health centres and department stores). In 1996, e-booking was also offered through pharmacies. In 2000, a call centre was added as an additional channel. In 2003, a website for changes, cancellations and bookings for limited types of appointments was made available. In 2013, a comprehensive regional e-booking website was launched. The different access options provided are directly linked to the characteristics of the installed base throughout the years. In the era before widespread home computer use and network access, it was important to link to the available installed base of patient-provider interfaces (e.g. by including service counters in health facilities and enrolling pharmacies) and by leveraging telephony (through the call centre).

Motivations

The five initiatives are also different in terms of the motivations that ignited them. In the Danish case, a key motivation was to support *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 was to encourage a common strategy, and to align investments and solutions. In Sweden, the main motivation was to promote the *responsibility and participation of citizens* in matters of their own health. This was very similar to the motivation for the Norwegian initiative which was centred around the need to promote a more active patient role and to *facilitate the engagement* of citizens by offering a national-level, comprehensive platform and *facilitating access to the fragmented eHealth landscape* of many patient-oriented initiatives and webpages related to health. In Catalonia, there was a multifaceted motivation that included *both a new vision for the role of the citizens in healthcare and an aim to improve efficiency*. The patient oriented eHealth initiative was taken to to promote responsibility and participation of citizens in matters of their own health and to improve the health care quality and coordination between different care areas, levels and professionals. Finally, in Italy, the motivation was to facilitate a *transition from a hospital-centred model* towards a new healthcare model that would be better aligned to the demand from citizens and regions. Improving citizens' access to healthcare was an element of this reform and the new electronic booking service aimed to provide remedies for long waiting lists, fragmented offerings and a lack of transparency.

In the section that follows we turn to the specific strategies towards the installed base.

4.3.2 Strategies Towards the Installed Base

Patient-oriented eHealth initiatives require good *coordination* across multiple different actors that are already present in the domain as parts of the installed base (central and local government, healthcare providers in primary care and in the specialist sector including hospitals, software vendors, patient associations).

Furthermore, patient-oriented eHealth initiatives need to be built upon a technical installed base characterised by great *heterogeneity*: multiple different technologies are already part of the healthcare technical landscape and need to be taken into account (health record systems, healthcare organisations' administrative systems, data repositories, citizen registries, healthcare personnel registries, messaging standards, data structuring standards, networks). This heterogeneity is a key challenge for all initiatives of this type.

Additionally, as the patient-oriented eHealth platforms have an open scope and are not confined to a specific type of functionalities and settings of use, all initiatives of this type have to address the challenge of *uncertainty* i.e. the challenge of being able to evolve in many different directions. This requirement is shaping the relationship with the installed base as it creates the need for organising responsiveness to evolving needs.

Finally, as all the cases are about governmental platforms, there is a need to entrench all new developments into the wider health system arrangements and ensure that they will trigger wider changes in the sector. In other words, there is the challenge of being *transformative* i.e. the challenge of becoming embedded into the installed base while reshaping it. The new platforms need to find ways of being patient-oriented in a traditionally provider-centric system.

In the following subsections we identify the different strategies employed for addressing these four key challenges for the relationship with the installed base.

Strategies for Coordination

Different strategies have been employed in the different cases to address the challenge of coordinating the work of development and implementation across multiple different actors. In some cases, there was one core leading entity that had both control and ownership of the core services (Norway, Italy), in other cases, the leading entity was exercising control without owning all services (Catalonia, Denmark) while in one of the cases (Sweden), both the control and the ownership were distributed and coordinated through a common framework. In the next paragraphs we go through these in detail.

In Denmark, *a political governing body* which included the municipalities, the regions, and the Ministry of Health was put in place. This arrangement allowed *wide representation* of interested actors in decision making processes. Since the organisational entity that ran the platform did not have any specific strategic mandate or responsibility, the role of this governing body was significant and promoted up to today a collective and consensual work mode. The challenge now is to maintain this model while keeping pace with the increasing needs of different actors and aligning with changes that happen elsewhere within healthcare.

In Sweden, patient-oriented e-health services evolved in a complex landscape of *multiple authorities with overlapping jurisdictions* that operate under an *overarching set of rules*, the National Architecture Framework for e-Health services, which has been implemented since 2007. This allowed different actors to pursue their own developments in parallel. The different actors include the 21 county councils, Inera (an organisation funded by the counties to coordinate and support their shared

e-health services) and Vinnova (the innovation agency in Sweden). The Framework includes service contracts, legal agreement templates, procurement templates, interoperability standards, procedures for tests and certification and a reference architecture which applies to nationally as well as regionally funded e-health projects. The Swedish experience shows that there are potentially positive consequences of heterogeneity within the installed base (both technical and institutional) if an effective mechanism for coordination is in place. For example, the county councils of Uppsala and Stockholm developed competing viewers of health records for patients – both with national ambitions. At the end of 2015 the Uppsala solution had significantly larger number of users, so Stockholm county council decided to decommission their viewer in favour of the Uppsala one. Nevertheless, the backend of the Stockholm solution was retained and used as a national level component. Hence, the solution eventually used is a combination of Uppsala frontend and Stockholm backend. Furthermore, since 2013, the overall Swedish e-health architecture includes a component which facilitates the engagement of external actors with the installed base. This new component is the Health Innovation Platform (HIP) and includes a software development kit, several APIs and methods, guidelines and program code to support the development of e-health services by freelance developers, designers and software companies, both within and outside the healthcare industry.

In Norway and in Catalonia, the governmental patient-oriented eHealth platforms were developed under the leadership of *strong, centrally positioned actors*. In the case of Norway, the central actor was the Health Directorate and in the case of Catalonia, the Department of Health. In both cases the central agencies orchestrated activities that included multiple actors. In the case of Norway, the Health Directorate *managed the evolution of the platform by setting priorities and keeping the ownership of the services*. The Directorate ensured the reuse of public information resources and the enrolment of private software vendors for the development of links to the information systems in use within the health sector. Furthermore, the Directorate established close collaboration 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.

In Catalonia, the Department of Health started the initiative similarly to Norway but soon, opened up to include third-party services aiming to leverage existing services offered by health providers, software vendors and pharmaceutical companies. An *interoperability framework* defined the conditions for including third-party devices, systems and services. With the introduction of this framework, the *ownership and control of the services started to separate*. The Department gave up the ownership of the new services but not their control (kept the right to decide which new services would be offered). Since 2015, an *accreditation process* for mobile phone apps was also put in place, aimed at generating trustworthy apps through a quality certificate. Furthermore, apps (and later wearables and medical devices) that are accredited will be allowed to store and/or retrieve information from a governmental repository for patient-generated health data which allows interoperability

with both the patient-oriented eHealth services and the health information systems of health providers.

In Italy, the development of e-booking services was owned and managed by a specialised unit created within the Health Department of the municipality of Bologna, the Single Booking Centre (CUP: Centro Unificato di Prenotazione). CUP was an inter-institutional office that included personnel from the three local health units and was *led by the city councillor* in charge of the department. After the launching of the service an improvement process was also launched involving all the main actors, the Health Department, the three health units, ITALSIEL (the state-owned software company that developed the solution which was at that time the largest software company in Italy) and SYNWARE (which employed the workers that staffed the 25 e-booking centres). The Health Department and specifically the CUP directorate led the process. With the advent of the e-booking project, control moved to the CUP directorate, not only for the technical infrastructure, but also for the non-technical parts of the service offering. This involved lengthy negotiations with hospitals to increase the extent of services to be offered on the centralized booking system. In the Italian case, the Health Department, represented by the city councillor, was the main protagonist and played a leadership role in both the design and realization of the project. The leadership orientation was strongly influenced by the political positioning of the city councillor and also by the specific academic background of the councillor (sociology of healthcare). The support of a well-known academic figure in the field helped to legitimize the city councillor's position in health management. Although the booking project was strongly contested by many of the participants (most notably the health units' boards of medical directors and head physicians) it was successfully carried out due to the strong political support.

Strategies for Addressing Heterogeneity in Technical Components

The strategies for addressing the challenge of technical heterogeneity were also diverse. In the case of Sweden, technological heterogeneity was embraced, but a uniform user experience was ensured. Similarly, in Denmark, a uniform user experience was pursued for accessing data from different underlying sources. Still, in the Danish case, the portal included links to external services for information exchange with GP offices that did not have a uniform user interface. In Norway, this was avoided by developing new links to existing GP office health systems. The case from Italy is dissimilar to the other four cases because it started during an earlier technological era. Being a first-mover meant that there were no similar solutions already in the field. In the following paragraphs we go through the different strategies for addressing technical heterogeneity in detail.

In Denmark, the portal solution became part of an eHealth landscape where it was already possible for different technological solutions to "work together" as communication standards for information flows between medical practices, hospitals, and pharmacies were in place. The Danish solution embraced heterogeneity to a great extent. For example, the portal *directs patients to the GP websites* (provided by various vendors) to initiate booking of appointments and

conducting email consultations. Overall, health data and services provided through the portal are based on *displaying already existing data* from various heterogeneous sources. In some cases, data are extracted from their sources (such as hospital systems, GP systems, prescription databases) and then presented through the portal's presentation layer. In other cases, services are "framed" to achieve a consistent 'look and feel' although the service is located and run somewhere else.

In Norway, the existing heterogeneous technical components were addressed by a series of decisions. One important decision was to not link the platform with the existing private eHealth portals used by several GP offices for communicating with patients. So, differently to the approach followed in Denmark, the platform that was put in place *does not redirect users to private portals.* Instead, new links with the existing GP office EPR systems were developed in collaboration with the EPR vendors. The main reasons for this decision, were to ensure a uniform user experience and to control the level of security offered. Although the private portals were not linked to the platform, *several components of the public eHealth infrastructures were linked*. These components include the pre-existing national services for changing GPs and for accessing vaccination history. Furthermore, the platform provided access to prescriptions (leveraging the national e-prescription project) and to summary care records (leveraging the national Summary Care Record project). The platform did not only embrace national-level eHealth initiatives, but also regional ones that were aligned with the platform's strategy and had the potential to be scaled to a national level. One such initiative provides access to medical records and another one supports message exchange between hospitals and patients. Overall, the aim was to homogenise the quality levels and user experience for services offered nationally.

In Sweden, heterogeneity is embraced as long as a uniform user experience is ensured. For example, it is possible to allow e-services to be developed and deployed outside of the portal platform itself but 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. This allows the development of national e-services using the development and deployment infrastructure of choice. This is aligned with one of the national reference architectural principles which stipulates that integrations shall be loosely coupled and reusable for many purposes.

In Catalonia, the strategy was to embrace multiple different solutions including services offered by health providers, software vendors and pharmaceutical companies. Furthermore, an accreditation process for mobile phone apps was also put in place. Practically, the Catalonian portal *provides an additional channel to access selected applications,* but does not replace the direct access links provided by the service owners. Although this strategy does not ensure a uniform user-experience, it does ensure uniform high levels of quality. As several of the external solutions linked to the portal were developed abroad, keeping pace with the new releases of the APIs proved to be challenging. The experiences from this case study bring forward the complexity of embracing such a wide variety of solutions.

The Italian initiative started during an earlier technological era (the service was launched at the end of January 1990), when many of the currently available technological possibilities for loosely connecting heterogeneous components were not available. Furthermore, the e-booking services were innovative for that era. Being a first mover meant that initiative *did not encounter a landscape filled with alternative solutions*. The main technological concern was to develop a stable and satisfactorily performing solution given the time constraints (the centralized booking system had to be deployable within 6 months).

Strategies of Addressing Uncertainty by Organising Responsiveness to Evolving Needs

Uncertainty was another major challenge for all cases. It was important for all initiatives to put in place organisational and technological strategies that would allow responsiveness to new needs. There were two main types of strategies followed in the cases studied. In Denmark, Norway and Italy, the initiatives were organised towards *fully pre-planned change*. In all three cases, an organised process for collecting needs, prioritising them and planning new development was put in place. The cases of Catalonia and Sweden were different to the other three cases in the sense that allowed more organic change to happen with the contribution of multiple distributed actors. In the paragraphs that follow we go through the different strategies towards uncertainty.

In Denmark, development projects were *prioritised in collaboration with multiple partners* as the organisational entity that ran the platform did not have any specific strategic mandate or responsibility. This was a lengthy process and in some cases the priorities of the partners would shift after certain tasks had been initiated (for example, a new urgent need for adding functionality to register citizens' wishes for organ donation popped up and had to be accommodated). After the decision to handle most development of services in-house (as opposed to development by external consultants), it *became a challenge to keep up with the pace of demands*. Furthermore, the partners started being inpatient with the need to constantly discuss prioritizing services. 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 where there always new needs for linking up with new data sources and providers. To ensure responsiveness to needs, a re-organisation took place recently to increase delivery capacity and strengthen portfolio management. The future focus is on being proactive and assist the partners in developing and maturing new service concepts.

In Norway, a similar process of *collecting needs and prioritising development was put in place*. During the early stages of development, a number of studies were prepared with the contribution of multiple stakeholders to plan the services to be developed over time. In 2014, the Health Directorate that has ownership and control over the platform, 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 identify citizens' needs for digital services in specialized care to obtain

insights for further developing the platform. 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 priority service areas, informed the formulation of a strategy for digital specialist health services, and led to the formation of a specific project on digital citizen services for the specialist sector.

In Italy, an *improvement process* was put in place right after launching the e-booking service. The process *involved all the main protagonists*, the Health Department, the three health units, ITALSIEL and SYNWARE. The Health Department, specifically *the CUP directorate, led this process*. Overall, also in this case, organisational processes for planning and controlling changes were implemented.

In Sweden the principle of *local contribution* to the national ecosystem was formalised and became one of the six architecture principles of the national reference architecture. In the cases of local and regional needs that are not aligned with national prioritizations, 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 secure that the solution can grow to 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.

In Catalonia, the new patient-oriented eHealth services had to face uncertainty and multiple possible alternatives. Since many of the services could not be specified in advance, decisions and choices had to be *exploratory and adaptable*. At the beginning of the project, the sponsors of the portal tied the development to the Public Shared Electronic Medical Record. So, the portal started simple, without a big architectural blueprint and complex anticipatory design. A catalyst for further growth has been the decision to put in place the means for connecting to existing applications and *stimulating the development of new ones by third parties*. The interoperability framework and the app accreditation process were critical for this.

Strategies Towards Transformation

In all cases, the new platforms were developed with the aim of achieving a patient-orientation within an overall traditionally provider-centric system. In other words, they had to face the challenge of becoming embedded to the installed base while transforming it. In the cases from Denmark, Norway, Sweden and Catalonia the strategies followed were overall "*installed base friendly*" in the sense, that, all developments were based on wide consensus and transformations were attempted in small steps. The case from Italy stands out as a clearly *disruptive* strategy was followed. In the next paragraphs we elaborate on each case.

In Denmark, there has been *broad support* from relevant players in the Danish healthcare arena. Especially the initial phase can be characterized as a political showcase for regional collaboration with solid political unity and common ambition. During this phase, there was little disagreement concerning what should be

offered to citizens and healthcare providers. The political unity and broad collaboration of stakeholders were described as key reasons for the success of the portal.

Similarly, in Norway, the views and needs of the health sector and also of the technology providers were taken into account and multiple processes for "*anchoring*" the initiative within the sector were taken. These anchoring processes allowed stakeholders to voice their concerns and shape the initiative, while at the same time the designers of the new services were able to expose their plans and explain their rationales. The Norwegian platform was expanded by orientating towards the satisfaction of concrete needs expressed by potential users while the overall evolution has been incremental and gradual.

In Sweden, the e-services offered were not perceived as controversial since they *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 centres by phone for renewal of prescriptions or bookings.

In Catalonia, the underlying vision for the new eHealth services 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 relationship*s and the creation of new ones. For instance, since patients 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 responsibility boundaries among professionals will most likely shift; and since the portal is becoming 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. Nevertheless, as the *changes are paced* there has been no major opposition from the wider sector.

Finally, the Italian case is the one where disruptive changes were pursued (and actually implemented). Improving citizens' access to healthcare was an element of the National Health Service reform, especially relevant in 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 leveraging new technological capabilities that allowed bookings to be performed without being controlled by the healthcare institutions. This created tensions and strong opposition by key actors from the medical establishment. The institutional components of the installed base revealed themselves as obstacles for achieving innovation and only the large mobilization of political, organizational, and technological resources made it possible.

4.4 Working with the Installed Base for Building eHealth Infrastructures

The cross-case analysis presented in the previous sections should be read together with the rich descriptions and analysis provided in the chapters that relate to each case. The cross-case analysis offers an entry point to the cases and a possible