BUILDING NATIONAL INFRASTRUCTURES FOR PATIENT-CENTRED DIGITAL SERVICES

Complete Research

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Abstract

Patient-centred digital services are increasingly gaining impact in the healthcare sector. The premise is that patients will be better equipped for taking care of their own health through instant access to relevant information and by enhanced electronic communication with healthcare providers. One initiative to provide such services to patients is the Danish national e-health portal, sundhed.dk, which is at the forefront of governmental initiatives and which serves as a unified hub between the various participants in the healthcare sector. Studying the evolution of sundhed.dk in light of information infrastructure theory, we highlight the enabling and constraining dynamics when designing and building a national infrastructure for patient-centred digital services. Furthermore, we discuss how such infrastructures can accommodate further development of services. The findings show that the Danish national e-health portal successfully managed to establish a solid foundation by means of providing direct usefulness and by building on existing information systems, routines, and governance structures in the healthcare sector. However, during this process, a number of unintended side effects appeared that have challenged the continuous development of the portal. We conclude that sundhed.dk needs to strike a balance between generativity and control to accommodate further development of services.

Keywords: Patient-centred digital services, National e-health portal, Design principles, Information infrastructure.

1 Introduction

This paper investigates strategies for designing and building national infrastructures that provide patient-centred digital services (PCDS). It further investigates how to accommodate for continuous development of PCDS once a national infrastructure for such services is in place. PCDS are highly relevant in today's healthcare landscape in which technologies have potential to support citizens' involvement and participation in their own healthcare (Sherer, 2014, Dawson et al., 2009). Advances in information technologies are creating unprecedented opportunities for patient-centred care that is responsive to individual patient needs, preferences, and wellbeing. New technologies are leveraged to achieve 24x7 disease management, to enhance the wellbeing of patients, and to support home-based healthcare and other patient-centred service innovations. The field of patient-centred e-health is experiencing major advancements through for example mobile technology for personal health management (Klasnja and Pratt, 2012), wearables and sensors for personal and remote health monitoring (Lymberis, 2003), and improved communication by means of telemedicine solutions. PCDS can be provided as standalone services that require the user to manually provide the data (Detmer et al., 2008) or as integrated and highly interconnected service platforms that are populated with data sources from different healthcare providers, insurance companies, and government agencies. Portals provided by, for example hospitals,

insurance providers, or regional and national authorities can facilitate such services (Protti, 2007, Silvestre et al., 2009, Grisot et al., 2014).

In recent years, there has been an increasing focus on facilitating PCDS in regional and national e-health strategies (Danish Regions, 2010, The Danish Government et al., 2012, NHS, 2012, Norwegian Directorate of Health, 2014). In Denmark, the Danish national e-health portal, sundhed.dk (i.e., healthcare.dk), facilitates PCDS that provide both access to- and information about all the Danish healthcare services. Sundhed.dk serves as a unified hub for electronic communication between patients and healthcare providers. The portal is cross-sectorial, both in terms of its governing structure as well as the several national and regional solutions it encompasses. Sundhed.dk provides a presentation layer to solutions that exist independently of the portal as well as solutions developed in-house. Currently, sundhed.dk provides functionalities such as access to medical records, renewal of prescriptions, booking of appointments with GPs, quality ratings of hospitals, and an overview of the Danish healthcare services. Sundhed.dk is creating linkages between existing data sources, opening up data sets to new user groups, and facilitating communication between healthcare providers and citizens. The portal provides core services such as a secure infrastructure, search optimization, and user interfaces as well as a supporting organisation to encourage further development of new services.

Since its launch in 2003, sundhed.dk has been perceived to be at the forefront of governmental e-health portals. The portal has gained good reputation and high standing in the healthcare sector, having received considerable attention from other countries and businesses attempting to build similar solutions (Sundhed.dk, 2014b). Sundhed.dk has not only been successful in providing a number of PCDS, it has also demonstrated how to establish close collaboration and buy-in from all relevant healthcare partners across municipalities and regions in Denmark. However, the portal now seems to be at a point where there is a need to rethink and further develop its services to better accommodate the partners' needs and to cater for technological advancements. Our case illustrates that establishing national infrastructures for supporting the provision of PCDS is challenging, as it requires a mobilization of technical standards as well as change of organisational boundaries (Vikkelsø, 2010). Additionally, as infrastructures grow larger over time, they scale up – not only in the number of users and/or functionality – but also in complexity (Sahay and Walsham, 2006). There is limited research performed on how to accommodate new services within such information infrastructures. This calls for the opportunity to study how to ensure continuous development of services to establish and maintain robust national infrastructures that at the same time are responsive to future change. In this paper, we address the evolution of such infrastructures in healthcare to single out both the enabling and constraining dynamics that underline their design and continuous development. We ask the following research questions;

(1) What are the enabling and constraining dynamics when building a national infrastructure for patient-centred digital services? and *(2) How can a national infrastructure accommodate the development of new services?*

To address these research questions, we draw on the literature on information infrastructure (II) evolution (e.g., Star, 1999, Star and Ruhleder, 1996, Tilson et al., 2010, Hanseth and Lyytinen, 2010). This stream of literature characterises IIs by the number and heterogeneity of included components and relations, and their dynamic and unexpected interactions. We are applying design principles for information infrastructure development (Hanseth and Lyytinen, 2010) as organizing concepts to highlight critical passages in national health infrastructure evolution. Our point of departure is that the development of integrated PCDS is a "relational" and "networked" activity (Bowker et al., 2010, Henfridsson and Bygstad, 2013) that has to take into consideration the shared responsibility of many organizational entities and technical components. This leaves the design and governance of infrastructures inherently politically charged (Rolland and Aanestad, 2003, Bekkers, 2009).

The remainder of the paper is structured as follows. The next section reviews the literature on design principles with respect to information infrastructure initiation and continuous development. We then describe the research setting and the methodology used. In analysing our case, we ask how sundhed.dk has evolved in light of the information infrastructure design principles. We discuss how the development and inclusion of new PCDS can be facilitated within such infrastructures, as they move beyond the first phases of conception.

2 Information Infrastructures in Healthcare

The concept of infrastructure entails that information systems have become increasingly interconnected and it seeks to capture the challenge that managers and designers face when attempting to deal with complex networks of systems, work processes, and hardware components. IIs can be seen as socio-technical systems that emerge and evolve through the interplay of technology, users, and policy makers (Janssen et al., 2009). IIs are defined by Hanseth and Lyytinen (2010) as a "shared, open (and unbounded), heterogeneous and evolving socio-technical system (which we call installed base) consisting of a set of IT capabilities and their user, operations and design communities" (p. 4). In a recent research commentary, Tilson et al. (2010) highlighted the urgent need to theorize the evolution of digital infrastructures in a context where we move beyond individual tools and administrative systems. They further define IIs as the basic information technologies and organizational structures along with the related services and facilities necessary for an enterprise or an industry to function (p. 748).

2.1 Building information infrastructures

The evolution of information infrastructures has been conceptualized as driven by economic network effects, where value is dependent on a rapid growth in the user base (Varian and Shapiro, 1999). According to network economists, such demand-driven mechanisms transform user adoption into self-reinforced growth (Hughes, 1987). Designing and building information infrastructures requires both technical and social coordination of heterogeneous IT capabilities and actors: "From a technical view point, designing an II involves discovery, implementation, integration, control and coordination of increasingly heterogeneous IT capabilities. Socially, it requires organizing and connecting heterogeneous actors with diverging interests in ways that allow for II growth and evolution" (Hanseth and Lyytinen, 2010, p.2). Illustrated by the case of building the Internet, design principles are presented by Hanseth and Lyytinen (2010) for kick-starting and further maintaining information infrastructures. The authors introduce bootstrapping as a design principle referring to making the solution directly useful before a large user base can be obtained. Furthermore, they suggest building upon already existing systems and structures as well as generating positive network effects by extending the user base. The principles, summarized in table 1 below, balance immediate usefulness with long-term infrastructure.

Design problem	Explanation	
Bootstrap problem	Design initially for direct usefulness	The solution must persuade the initial users by targeting their needs and solving their problems, be easy to use and implement, and be useful without a larger user base
	Build upon existing installed base	Existing infrastructures, portals or communication formats already in use should be exploited; no need for new support infrastructures
	Expand installed base by persuasive tactics to gain momentum	Positive network effects from extending the user base should be generated; the user base must be ensured to have grown to sustain the added cost of development and learning before adding new technology

Table 1.   The bootstrap design principle (adopted from Aanestad and Jensen 2011).

Aanestad and Jensen (2011) revisit these design principles to analyse two cases of standardization in the Danish healthcare sector. The authors confirm the thesis of Hanseth and Lyytinen (2010) by arguing that the realization of nation-wide IIs for healthcare requires a gradual transition of the installed base. In addition, they present a modular implementation strategy as an approach that addresses the challenges related to mobilization and organization of multiple stakeholders. In line with their observations, we build on the II theory to analyse the case of building national e-health services for patients. We also take into consideration other streams of research that disagree with the premise that IIs can be deliberately designed and purposely built. For example, Ciborra and colleagues (2000) present 'drift' as a term to explain this lack of control. They illustrate through several empirical cases how companies or institutions often get in a vicious circle of striving for management control. Consequently, they argue that technology evolves without central control or simply drift due to turbulent environments and flawed implementation tactics. Holmström and Stalder (2001) further argue that in order for a socio-technical system to stabilize, it must drift from a single-purpose network, reflecting the interest and agenda of its designers/originators, to a multi-purpose network that reflects the interests of all involved social actors. The observations made by Ciborra and colleagues (2000) as well as Holmström and Stalder (2001) are relevant to our case on sundhed.dk in that we want to investigate the enabling and constraining dynamics when designing and building a national infrastructure for PCDS. Furthermore, the concept of drift is useful for discussing how such infrastructures can accommodate further development of services.

2.2   Maturing information infrastructures

Moving beyond the bootstrap challenge, Hanseth and Lyytinen (2010) address what they call the adaptability problem, which refers to the ability to move beyond what was originally intended to facilitate future needs. Related to the bootstrap problem, the authors argue that IT capabilities should be kept as simple as possible. What makes a collection of IT capabilities simple or complex is a function of its technical complexity as defined by the number of technical elements, their connections and rate of change. Further, one should promote modularization with loosely coupled sub-infrastructures.

Design problem		Explanation
Adaptability problem	Make the IT capability as simple as possible	Make the information infrastructure as simple as possible (both technically and socially); promote overlapping IT capabilities
	Modularize the information infrastructure	Separate the layers of infrastructures from each other and exploit gateways to connect different layers

Table 2.   The adaptability design principle (adopted from Aanestad and Jensen 2011).

Henfridsson and Bygstad (2013, p. 919) argue that there are three mechanisms that drive the evolution of IIs: (1) adoption by a continuously growing number of users, (2) scaling through integration with a growing number of other solutions or IIs to attract new partners by offering incentives for collaboration, and (3) innovation in terms of enabling new products and services. Based on a survey of more than 40 case studies, the authors further point out that the combination of all three mechanisms yields the best success for sustaining IIs over time, while the combination of adoption and scale is the second most fruitful combination. The three mechanisms provide additional insights to our case by highlighting that the future development of sundhed.dk requires not only new functionalities and services but also the attraction of relevant partners through incentives for collaboration.

Addressing the notion of sustaining and further developing IIs, the term generativity has been introduced to explain the ability to generate new content beyond what was originally intended. Zittrain (2006, p. 1980) argues that technology can have generative capacity by means of "its overall capacity to produce unprompted change driven by large, varied and uncoordinated audiences". In line with this, Hanseth et

al. (2012) define an II's generative capacity as the degree to which it enables continuous innovation, adoption and scaling. Nonetheless, cultivating digital infrastructures entails a process of controlling generativity (Eaton et al., 2011, p. 6). This is further described as not only a paradox between centralized and distributed control (Tilson et al., 2010) but also as situations in which control exists because of generativity (Eaton et al., 2011). Consequently, a key capacity of IIs is the degree to which they enable continuous innovation, adoption, and scaling (Hanseth et al., 2012) outside their intended scope at the point of inception (Zittrain, 2006).

We find the design principles of Hanseth and Lyytinen (2010), along with other concepts in the information infrastructure research stream, such as drift, generativity, incentives for collaboration, and control, useful for studying the evolution of an e-health information infrastructure that provides PCDS. Moreover, we can build on Aanestad and Jensen's (2011) study, which moves the design principles to a healthcare setting. While II theory advocates a bottom-up approach (Aanestad and Jensen, 2011, Coiera, 2009), by first solving small-scale problems, our case demonstrates how a broad mobilisation of stakeholders is beneficial for building (i.e., bootstrapping) the national infrastructure for PCDS. We add to these studies by showing how the development and continuous development of national IIs come with a number of side effects. Especially, the sundhed.dk case shows how an II can grow large, and become a "success" story, and then struggle with the consequences of continuously developing new services and expand.

II theory highlights the adaptability design principle as a way to facilitate further scaling and adoption beyond inception by keeping IT capabilities simple and by modularizing the information infrastructure. While this design principle is useful in the case of building and continuously innovating IIs, we further want to investigate how applicable these principles are in the particular setting of national infrastructures for PCDS.

3 Research Methodology

3.1 Research setting

Sundhed.dk is developed as part of a well-established healthcare infrastructure. Denmark has 5.6 million inhabitants and like other Scandinavian countries, it is well-known for its comprehensive welfare system. Access to primary healthcare such as GPs, home nursing, ambulance and emergency services and rehabilitation is free of charge. The provision of healthcare in Denmark is largely public with only a few privately owned hospitals. Healthcare is embedded in a decentralized administrative structure, consisting of five regions and 98 municipalities (Pedersen et al., 2012).

Although Denmark is a small country in terms of population and geographic area, it is at the forefront in the digitalization of medical information and in its electronic healthcare record management. Centralized databases store medical information of Danish citizens, including hospitalization information and prescription history. GPs, hospitals and pharmacies are electronically connected to handle patient records, e-prescriptions, and electronic referrals to hospitals and specialists. Lab results and discharge letters can also be received (Protti and Johansen, 2010). Much of the digitalization of the Danish healthcare sector is enabled by common standards for health message exchange and the secure Danish Healthcare Data Network.

In 2001, the Association of County Councils in Denmark initiated the establishment of a common public e-health portal. The idea was to create an electronic gateway for citizens, patients and healthcare providers to the Danish healthcare system. The goal was to obtain better coordination in healthcare services by providing a government controlled entrance to health information across a relatively decentralized healthcare system. The portal project was well-received by the various parties in the healthcare field. A political governing body with broad representation from various areas of the health

sector was established. The first phase of the development was concluded in December 2003 with the introduction of sundhed.dk. After its launch, new functionality and services were added on a continuous basis.

At the launch of sundhed.dk in 2003, the main focus was on adding quality-assured medical information to both citizens and healthcare providers. Services such as information about waiting lists at certain hospitals and renewal of prescriptions soon became available. At the beginning of 2004, the functionality of sundhed.dk was expanded with services that require log-in with a digital signature. A first attempt was made with electronic access to lab results for healthcare providers. Access to the central reimbursement registry showed all treatments a patient had received in the public health service. Sundhed.dk was at this point integrated with about 28 different systems (Sundhed.dk, 2005). During 2004, patients could view their electronic medicine profile online. An electronic guidance to the healthcare service was established and it was possible to search for healthcare providers, i.e., GPs, physiotherapists, and psychologists, based on location and availability. Finding their GP on sundhed.dk, patients would be directed to the GP website to initiate booking of appointments and conducting email consultations.

By 2005, patients were able to access the hospital patient registry in which all treatments performed in the hospital sector were listed. They could also sign up for the donor registry. By 2006, doctors in 11 out of 19 counties could check online lab results on the portal. By the end of 2007, the portal had about 170,000 unique users every month. In 2010, access to the portal was managed through a national electronic identifier scheme, called NemID. Today, approximately four million Danes have a NemID account (NemID, 2014) and can thus potentially log onto sundhed.dk. The portal is highlighted as a central component for PCDS in common public health IT strategies (The Danish Government et al., 2012, The Danish Government et al., 2008).

In April 2009, sundhed.dk was launched on a new technical platform to gain more control over the portal and to reduce costs by being independent of external consultants and developers. This process was described by actors in sundhed.dk as "taking the portal home" (head of staff, sundhed.dk). Consequently, a development department now did most development of services in-house. Apart from smaller developments, there were two major initiatives in this period; in 2010 medical records from public hospitals were made available. In 2012 "sundhedsjournalen" (i.e., the healthcare record) was launched. This provided a 'one-stop' for both patients and healthcare providers with access to medical data such as records, medicine profile, and other critical health information. The citizen can at all times access logs of who has viewed their health data.

3.2   Sources of empirical material and analysis

To analyse the evolution of sundhed.dk, we collected data between March and October 2014. The main source of research material was interviews and a set of documents. Five interviews were conducted with the head of administration, the tester, and the concept developer from the central office of sundhed.dk. The remaining interviews were conducted with associated partners that were directly or indirectly involved in the development and maintenance of the portal. The partners involved in the sundhed.dk collaboration initiative were all members of the same coordinating committee responsible for prioritization of ongoing tasks and development of new services. In total, we conducted 13 semi-structured interviews, each lasting between 1-2 hours. The interviews were recorded and subsequently transcribed to form the basis for our coding.

Besides interviews with key partners, we reviewed documents describing the organization of sundhed.dk and its history as well as press releases and news bulletins directed at citizens. Table 3 provides an overview of the empirical material.

Method	Data source
Interviews	Staff at the central office of sundhed.dk: - Head of administration (3 interviews) - Concept developer - Tester Partners of sundhed.dk, representatives from: - The Capital Region of Denmark, Region Zealand, Central Denmark Region, North Denmark Region, National Institute for Health Data and Disease Control, Ministry of Health, MedCom, Danish Medical Association
Documents	Documents from Sundhed.dk: - Press releases from 2003-2014 - Newsletters from 2011-2014 - Request for consultancy support to develop a new IT strategy in sundhed.dk - Presentation by CEO of sundhed.dk: "Sundhed.dk, the Danish e-health portal" Documents from the partners; Danish Regions, The Danish Government, Local Government of Denmark, MedCom: - "The Danish Regions' common strategy for digitalization of the health services" - "Digitalizing with effect – national strategy for digitalizing the health service 2013-2017" - "IT brings the Danish healthcare sector together"

Table 3.   Overview of empirical data.

The analysis of the data was guided by our research objective of investigating the enabling and constraining dynamics when building a national infrastructure for patient-centred digital services. We revisited the data material in consecutive stages, where both the literature and the existing data material fed into the analysis. The interview transcripts were coded using the analysis software Nvivo. First, we identified and categorized the material into emerging themes (e.g., governance, maintenance, services, security, or law). We then categorized the empirical material by means of constructs from the II design principles and other II concepts presented earlier (e.g., direct usefulness, installed base, IT capabilities, modularization, control, generativity). Preliminary results were presented to sundhed.dk, after which we conducted an additional interview with their head of administration to verify the findings.

4   Analysis

In the analysis, we start out by presenting the enabling and constraining dynamics when building the national infrastructure for PCDS. We then discuss how such an infrastructure can accommodate further development of its services. The analysis builds mainly on the design principles for bootstrapping and adaptability (Hanseth and Lyytinen, 2010) but we also include other aspects related to information infrastructures as described in the theoretical outline.

4.1   Building information infrastructures for patient-centred digital services

Several of the Danish regions did not have websites concerning health information when joining the sundhed.dk initiative in 2003. Consequently, "…the success criteria were largely to establish a portal and get content on it" (head of administration, sundhed.dk). This included content such as quality-assured medical information and practical information about the healthcare provision services across all regions and counties. Sundhed.dk thus focused on providing **'direct usefulness'** for its partners from the start. To ensure broad collaboration and to include all the involved partners, a decentralized editorial model in which more than 900 editors could alter the content on sundhed.dk was established. Referring to the various partners involved, one of the employees at sundhed.dk highlighted how everyone in this partnership was focused on his/her own day-to-day operations; "when I started [4 years back] […] the information was very dispersed, but during that year we managed to make agreements and have them

signed so that we had some kind of standard" (concept developer, sundhed.dk). Sundhed.dk thus soon abandoned this distributed editorial model to establish editorial groups across sectors, ensuring that all partners were represented. The partners committed to adhering to the content agreements of making content spanning across fields and geographical boundaries. For example, instead of writing about colon cancer on each region's website, it was agreed to collaborate on one single explanation with the possibility to include specific regional and local perspectives: "If you work in Frederiksberg County and you need to get vaccinated, this is the information you need to get that done" (concept developer, sundhed.dk).

Along the way, new services and functionalities were added one after the other, ranging from gaining access to consultations to seeing a person's medications and vaccines. However, ensuring direct usefulness was a challenge throughout the process of building sundhed.dk; first, healthcare providers' usage of the services on sundhed.dk was relatively low due to cumbersome login procedures and the added complexity of dealing with "one more system". Second, due to limited development capacity at sundhed.dk, functionality could not always be provided when the partners wanted it.

The second design principle, **'building on the installed base'**, refers to exploiting existing infrastructures, including communication formats already in use and work practices. In sundhed.dk, the first set of services and the governance structure was based on what was already available and in use. As described by the head of administration at sundhed.dk; "Part of the ambition of sundhed.dk was to create access to already existing services and not to reinvent the wheel" (head of administration, sundhed.dk). Some of the first services on the portal provided access to existing registries, such as the national reimbursement registry (showing where and when patients were treated) and electronic prescriptions (what medications the patient was prescribed). The governing bodies and financing partners of sundhed.dk consisted of members from Denmark's five regions, the Regional Association, the Municipal Organization, and the Ministry of Health. This broad representation of actors gave legitimacy to the project. In addition, informants described it as a clear advantage that the organization of the governing bodies resembled the way in which the remaining healthcare system was organized. For example, the relationship between the regions, the government, and GPs was maintained through general agreements: "The collaboration model we find in the Danish healthcare system is reflected in the organization of sundhed.dk. I believe that if we wouldn't have had this organization in place, it would have been very difficult to establish sundhed.dk" (representative, Region Zealand).

The initial phase of sundhed.dk can be characterized as a political showcase for regional collaboration with solid political unity and common ambition. The involved parties were largely gathered around the common ambition of having one access point to the healthcare services: "We were told that if we could find a project that could strategically mark the 14 counties across, and not as silos, we would receive funding" (representative, Region Zealand). In the initial phase, there was little disagreement concerning what should be offered to citizens and healthcare providers. The political unity and broad collaboration of stakeholders were described as key reasons for the success of the portal: "…the tight connections [between partners] and having a sponsor as strong as Danish Regions [were] among the key reasons for success" (representative, Capital Region).

However, building on the installed base has in this case been a double-edged sword, as one of the informants also stated; "What is their [sundhed.dk] strength is also their weakness" (representative, National Institute for Health Data and Disease Control). The informant here was referring to the broad alliance of partners, which gave the organization and portal legitimacy, but also made it heavy and inflexible in the sense that many considerations were required for every decision. The prioritization of tasks was described as a politicized decision-making process and priorities could shift after certain tasks had been initiated. For example, politicians could demand, after the economical agreements were finalized, that "now we need more people to donate their organs, so in 2013 this should be registered on sundhed.dk […] our partners want to boost their IT strategies and projects via the portal" (head of

administration, sundhed.dk). Coordinating this broad alliance of partners seemed challenging, as expressed by the representative from the Ministry of Health; "It is very difficult to be sundhed.dk in terms of serving so many masters". One of the regional representatives added: "… there has been a shift from being a client to being a vendor, and this has been a challenge for sundhed.dk. Mostly because the production line has become very narrow […] and there has been too many things that have been important for the regions, but we don't want to constantly discuss prioritizing those services that are included on sundhed.dk" (representative, Region Zealand). One regional representative, who was responsible for providing primary healthcare, highlighted the divide between partners with a political perspective and partners with a more operational perspective in the sundhed.dk collaboration. For example, he emphasized the importance of stability and usability for his region's GPs; "the counties and the regions are the ones with the operational focus. It is our services, it is our users. We are concerned about the user perspective and the citizen perspective. Platform maintenance and search optimation are examples of what we consider as very important" (representative, North Denmark Region). This operational perspective was not always in line with a more political perspective from, for example, the Ministry of Health. Lastly, building on existing services, in particular with respect to quality assured health information and information about the healthcare services, posed a challenge. As the amount of information provided through sundhed.dk increased, the quality of content became an issue; "More and more quality requirements are being posed from our side (sundhed.dk). At some point, the amount of information on sundhed.dk was simply overwhelming" (head of administration, sundhed.dk).

Hanseth and Lyytinen's (2010) third design principle, **'relying on persuasive tactics'** refers to utilizing positive network effects with an extended user base. One informant highlighted the tendency towards increasing the integration between partners in the healthcare sector in Denmark; "There is a closer and closer integration of solutions in the Danish healthcare sector. When we look at the overall picture, we see that the counties are becoming more ambitious with providing digital services, especially because healthcare is part of so many different areas, for example social services" (representative, public health institute). As a reaction to this tendency, sundhed.dk indicated that a portal for a wide range of services in the healthcare sector was difficult to achieve as a standalone system. The portal provided a common infrastructure that could be used by several actors; it enabled provision of personalized services and sharing of data across administrative and geographical areas. As one of the regional representatives highlighted: "sundhed.dk can surely perform some very important things that we cannot do ourselves: secure services, personal data, input of data and connecting data across sectors, regions and councils. This is something that we in no way can do ourselves. They are the ones that can do these horizontal data collations" (representative, North Denmark Region). Several informants have highlighted how the healthcare sector in particular has certain information needs, which sundhed.dk by large addresses. One such example is that data needs to be correct, quality assured, and timely. Another example is to ensure that citizens can find all public healthcare related data in one place. Lastly it is vital that the portal performs reliably at all times for the healthcare personnel who access the portal in their daily work. Another representative also highlights the positive aspects of the portal; "It is a fantastic engine, it really is. Whenever I get a little frustrated, I just see a great potential. In that respect, we all just want more" (representative, Ministry of Health). The user base of sundhed.dk grew from approximately 130,000 unique users per month in 2005 (Sundhed.dk, 2014a) to 1.2 million unique users per month in March 2014 (Grollov, 2014) which illustrates a considerably growth in the user base.

Table 4 summarizes the start-up mechanisms and associated side effects.

Design challenge	Solved in sundhed.dk	Side effects
Bootstrap challenge (direct usefulness; building on the installed base; relying on persuasive tactics)	Ensuring relevance for a majority of partners; providing updated websites for quality health information; establishing one access point for information; building on existing information systems and governance structures	Chaotic infrastructure; need for quality assurance; serving many different stakeholders; politicized prioritization processes; challenges in providing functionality when requested

Table 4.   Design challenges of sundhed.dk.

4.2   Further development of the information infrastructure for patient-centred digital services

While the previous section has highlighted a number of aspects that enabled and facilitated the current position of sundhed.dk, we now turn to issues that contribute to, or challenge, future adaptability and development.

The fourth design principle, **'ensuring simple IT capabilities'**, refers to keeping every element of the II as simple as possible. The interconnectedness of IT capabilities becomes visible when the informants describe the challenge of involving third party developers. Sundhed.dk is an organization of approximately 45 persons divided into teams for administration, infrastructure, innovation, development, and communication. Most development and integration with external applications are done in-house. A governing body prioritizes the production queue of new functionality to be developed, but the development capacity is not large enough to accommodate for all change requests: "There are several regions with money, and a lot of councils with a lot of good ideas, but they can't get their suggestions through […]. So, now we are creating a parallel track, where we can help the regions or others to get their services on sundhed.dk (…) or get someone external to create the services for them" (tester, sundhed.dk). Put differently: "The pipeline is not particularly wide, but we have for many years only looked at the development process […] That's 'peanuts' compared to the strategic clarification work that needs to be done ahead of developing" (head of administration, sundhed.dk).

Opening up for external developers does not seem like a quick and easy process, as it requires knowledge about not only the technical aspects of the portal, but also the process of concept development: "It takes time for external developers to get familiar with the architecture and how the different things are made and how the different components are connected. So, this is why it is difficult to involve more people, because it is not only the development, but rather the whole process from a request is made until seeing it being delivered. It is a process which is rather complex" (tester, sundhed.dk). Issues such as speed of the solution, integration with the national security solution (NemID), and search functions become important issues that require constant attention, support, and maintenance. "…and this is where we see our role. We're trying to manage this beast, both in terms of quality and living up to lots of security demands" (head of administration, sundhed.dk).

The fifth design principle, **'modularize'**, refers to building key functions of the infrastructure separately to cater for future unidentified needs. Sundhed.dk builds on existing service and transport infrastructures by means of building on solutions that are based on set standards for message exchange in a secure e-health network. However, at sundhed.dk, new code is released four times a year. Being able to deploy code more rapidly is certainly desired by the technical staff. However, interdependencies and the need for thorough regression testing pose challenges for continuous release of new functionality: "We dream of a situation where we just make new functionality and 'boom' out it goes, but sundhed.dk is not built like that because we have to test everything every time we make something new. Even though it is a small new piece of functionality it can influence the rest of the portal" (tester, sundhed.dk). This issue points to a certain degree of interdependency between components, an interdependency that makes it

necessary for the staff to maintain a degree of control of the portal and to check how the development of services are accomplished. The head of administration highlighted that many service developments are of a small and uncomplicated nature; however, "if you initiate a project that is to be integrated with the security setup, such as authentication, authorization and logging procedures of the portal, then one cannot help but to assign it to our people, because they know how to do this". Among some of the associated partners, this is also how the complexity of the solution is perceived; "sundhed.dk means that their main problem is that the solution is so complicated that no one else can develop functionality on it" (representative, Ministry of Health). While this issue is overly simplified in the statement made by the informant, it illustrates the interdependency in the solution. #

Technicians at sundhed.dk highlight that they strive for low coupling/high coercion between components, but due to performance and security concerns this is challenging to fully achieve. Below is a summary of the challenges related to further adaptability and development, as well as associated challenges.

Design challenge	Current status in sundhed.dk	Further challenges
Adaptability challenge (ensuring simple IT capabilities; modularize)	Not following the design principles rigidly; complex IT capabilities due to interconnectedness between components; modularizing only to a certain extent	Complete modularization is challenging in practice and requires resources; a challenge to deal with support, security, authentication and authorization, search function, logging

Table 5.   Adaptability challenges of sundhed.dk.

5   Discussion

The analysis of the evolution of sundhed.dk as a national infrastructure for PCDS showed that the parties involved rather successfully solved the bootstrap challenge. The central office of sundhed.dk managed to get "off the ground" by means of providing direct usefulness to its partners and by building on existing information systems, routines, and governance structures in the healthcare sector (see table 4). But at the same time, a number of unintended side effects occurred. Building on already existing information systems and data sets led to overlapping data and an increased need for quality control. Resembling/mirroring already established governance structures and involving partners from the existing healthcare sector were important to get started, but building on this installed base later led to tensions about what to prioritize and what direction sundhed.dk should take.

Similarly, the findings show that dealing with complex IT capabilities in the case of national e-health infrastructures is necessary but difficult. While modularizing and keeping the technical elements of the infrastructure as simple as possible is highly important, a national infrastructure with a broad range of stakeholders requires continuous maintenance of general purpose technologies and functionality. Handling search functions, authentication, authorization, logging and performance poses a separate challenge to infrastructure development, which seems crucial for the development of national e-health infrastructures for PCDS. We will elaborate on these aspects below.

5.1   Enabling dynamics and unintended side effects

In the analysis, we examined the evolution of sundhed.dk, a national infrastructure for facilitating patient-centred digital services. We started with the premise that PCDS gain value when moving beyond simple, stand-alone services to becoming integrated into the existing infrastructure. The challenge entails developing IT solutions that are cross-sectorial and spanning diverse user groups. Our first research question was: *What are the enabling and constraining dynamics when building a national infrastructure for patient-centred digital services?* By applying the II design principles in the analysis

of the initial phase of sundhed.dk, the case served to illustrate some key enabling dynamics. Building on the existing systems, data sources, and governance structures in the Danish healthcare sector contributed to the initial success of sundhed.dk. A governing structure that resembled the existing healthcare field, consisting of a broad representative group of actors, was crucial for the initial and stabilizing phase of sundhed.dk. Consensus, alignment of interests, and information domains were important aspects. These aspects are in line with Bekkers (2009) as well as Aanestad and Rolland's (2003) conclusions that information infrastructures are inherently politically charged. Providing direct usefulness through provision of a place to publish healthcare information for the various partners ensured involvement by the partners. The direct usefulness and the added services attracted the relevant partners through strong incentives for collaboration, as also pointed out by Henfridsson and Bygstad (2013).

In the analysis of the case, we realize that what made sundhed.dk 'kick-start' also came with some unintended side effects, such as the need for increased quality control, serving a broad range of stakeholders simultaneously, and agreeing on a common direction/mission. In other words, the design principles for information infrastructures were followed in the case of sundhed.dk, and they were a prerequisite for sundhed.dk's current position. At the same time, catering for PCDS at a national level also implied a degree of chaos and political tension, even though the central office of sundhed.dk implicitly followed the guidelines for bootstrapping. This adds to Hanseth and Lyytinen's (2010) principles by highlighting how successfully building on the installed base, both in terms of relying on existing information systems as well as governance mechanisms, can lead to added complexity and politicized decision-making. For sundhed.dk, this may imply that they establish clear criteria for quality control to ensure the reputation and brand of being *the* public/official channel for health information, while at the same time allow for a degree of experimentation with new services.

5.2   Maintaining and developing the core of infrastructures

Our second research question relates to *how a national infrastructure can accommodate the development of new services?* Once central solutions were built and the base of sundhed.dk was established, the politics of what needed to come next became more apparent. The partners requested new PCDS on sundhed.dk, but the portal was not equipped with sufficient capacity to accommodate the development of all change requests. Hanseth and Lyytinen's (2010) principles for adaptability and room for further development highlight simple IT capabilities and modularity as key factors for success. The authors used the example of building the Internet to illustrate these principles for unbounded growth. While sundhed.dk in part was following the principles for simple IT capabilities and modularity, the wish to ensure simplicity and decoupled architectures was not easily achieved due to the very nature of this national infrastructure for PCDS. Performance, security, and quality control were mentioned as reasons for why this was challenging. Additional complexity to the portal in terms of technical dependencies, continuous maintenance- and optimization work made accommodating change requests and third party development more challenging. This aligns with the conclusion by Sahay and Walsham (2006), who argue that scaling of health information infrastructures involves more than users and functionality, namely increased complexity. Similarly, the findings align with Ciborra et al.'s (2000) argument that pure top-down management of such infrastructures is futile.

To accommodate further innovation of services, sundhed.dk needs to strike a balance between generativity and control. On the one hand, sundhed.dk needs to provide open interfaces and support of third party developers by developing their concepts and code, while, on the other hand, ensuring control over the core. Without their partners, the portal does not have legitimacy so the development organization lives a "dual" life-balancing consensus and broad involvement versus the need to open up for third party development. As the inter-organizational work becomes more politicized, the accommodation for heterogeneity through an agile organization and governance model seems crucial

for moving forward. Based on the case, we argue that accommodating for further innovation of PCDS on a national infrastructure is a twofold challenge. Ensuring sufficient resources for maintenance and development of the 'core' of the national infrastructure for PCDS seems important to facilitate the development of new services. This includes coordinating and taking responsibility for issues such as support, redundancy, security, authentication and authorization, search function, logging, and compliance.

Theoretically, one can argue that Hanseth and Lyytinen's (2010) principles for adaptability do not take into account the role of a coordinating body when developing national infrastructures. Someone needs to be responsible for the core of the infrastructure (i.e., the portal) through which the services are provided. This is in line with Riebes' (2014) study on how large research infrastructures require core functionalities and services to be able to function. We argue that along with the scaling of users, services and integration to external systems, a growth in centralized services such as authorization, authentication, logging and search need to be handled. While applicable in many sectors and industries, this is especially important in infrastructures for PCDS as they require content to be correct and quality assured as well as restricted and logged access procedures. However, the control needed to manage a national initiative with a very broad panel of stakeholders might slow down innovation speed, and thus reduce the portal's generative capacity (Bygstad, 2010, Henfridsson and Bygstad, 2013). Portal control seems highly important for sundhed.dk and its partners as they have a responsibility for the stability, authenticity, correctness, and security of the portal. On the other hand, the parties involved in the inter-organizational collaboration have their own individual goals for development, such as ensuring usefulness for the healthcare providers and fulfilling local IT strategies. Maintaining a balance between the two is relevant to ensure further innovation of PCDS on a national infrastructure. For sundhed.dk, this may imply ensuring sufficient funding to maintain core functions of the portal and to have routines for assisting external developers so that there is increased capacity for adding functionality.

6 Concluding Remarks

In this paper, we have addressed the opportunities and challenges of creating and maintaining infrastructures for the development of PCDS. Through presenting a case of building a national infrastructure for such services in Denmark we have highlighted various difficulties and opportunities they faced in the process of starting up. Secondly we have emphasized the challenges they faced in terms of accommodating further development of new services. Applying the information infrastructure design principles of Hanseth and Lyytinen (2010) to analyse the case of sundhed.dk, we argue that building upon existing information systems and governance models were favourable for getting started. However, the very success factors such as broad collaboration and a synthesis of large amounts of pre-existing data about the health service came with unintended side effects that brought on constraining effects such as a politicised decision process and the need for rigid quality control.

Ensuring further development of PCDS on the national infrastructure requires a balance between control and generativity in a way that ensures its position as a secure and authentic portal, while at the same time cater for change in a tempo that ensures that the national portal stays relevant to their partners. We argue that managing and maintaining the core of the national infrastructure is one such form of control. We contribute to the principles for II design by highlighting these unintended side effects and the importance of maintaining the core of the II. We also contribute to the literature on PCDS by highlighting their interconnected nature when moving beyond simple smart phone apps and stand-alone applications with manual data entry. Our study has been conducted within the Danish healthcare sector, but we argue that the findings from this case have validity outside this particular case. We believe that it is relevant also for other information infrastructure development projects that involve several organizations and stakeholders and that are of national character.

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