Plug-in Healthcare

Development, ruination, and repair in health information exchange

Marcello Aspria

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Plug-in Healthcare
Development, ruination, and repair in health information exchange

De logica van de stekkerdoos
Ontwikkeling, verval en herstel bij gegevensuitwisseling in de zorg

Thesis

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All flowers
in time
bend towards
the sun

Jeff Buckley

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PREFACE

This dissertation describes many things that no longer exist. An online health portal, a personal health record, and various e-Health applications that failed to find an audience. Partnerships, companies, and government agencies that dissolved. Standards that never caught on, infrastructures that became obsolete. It is a story of promises, prototypes, and pilot projects, but also of abandonment, breakdown, and loss.

That story spans more than a decade; a period marked by many different life events – some happy, and some deeply sad. Between 2009 and 2013, I was supervised by dr. Marleen de Mul, dr. Samantha Adams, and prof.dr. Roland Bal. They continued to read my work long after my PhD contract expired. I could not have wished for better guidance, and am grateful for their relentless support and encouragement. Bringing this dissertation to completion after such a long time is a satisfying experience. At the same time, it is a painful reminder that Sam is no longer with us.

Sam was someone I looked up to. An accomplished researcher and lecturer, she was inquisitive, well read, witty, and sharp as a knife. She valued creativity in writing, had an open mind about theory, and was an unlikely, avid supporter of PSV Eindhoven. She moved campuses from Rotterdam to Tilburg in 2014, where she explored exciting new paths in digital care. We kept in touch in the three years that followed, and I visited her at home in Eindhoven to talk about my research.

Sam had a bright academic future ahead of her. She was alert to social disparities and inequalities in healthcare, and worked on fundamental questions about ethics and power/knowledge structures in the digital world. With her untimely passing, all her dreams, hopes, and ambitions were cut short. I often wonder what she would have thought about current developments in her fields, and how her work would have branched out in new directions.

Sam's voice and presence are deeply missed by everyone who knew her, and by the academic community as a whole. This dissertation is filled with traces of her work, suggestions, and insights. I hope it comes close to the high standards she always strived for in her own writings.

I dedicate this book to the memory of Sam Adams (1976-2017).

General Introduction

Gaps and absences in technoscience

In 2007, artist Katie Paterson translated the first movement of Beethoven's famous Moonlight Sonata into Morse code.[1] Using Earth-Moon-Earth radio communication, she then beamed the code to the Moon. As the code hit the lunar surface, small parts of the transmitted information were absorbed by the Moon's craters and were lost in its shadows. The altered code bounced back to Earth and was re-translated in readable format for an automated grand piano. The new score included gaps and absences that intensified as the piece progressed. The piano played them as intervals and rests; it was a 'Moon-altered piece' in which the Moon talked back to Earth.[2] Paterson describes how the automated keys, moving in the absence of a pianist, make it an almost ghostly performance – as if the Moon itself were playing the music.[3] While notes and chords gradually go missing, the new score tells us about the imperfections of the lunar surface; it is a striking symbiosis of conceptual art and technology that alerts the audience to what was lost in translation.

In technoscience, these gaps and absences occur everywhere, all the time.[4] They are the uncertainties and grey areas in project plans (Ciborra et al., 2001); the politics of difference in medical research (Epstein, 1996; 2007); ambiguities of representation in scientific practice (Coopmans et al., 2014); contingencies in technological trajectories (Law and Callon, 1992); tensions between rigid implementation models and local adaptations (Star and Ruhleder, 1996); residual categories in classification schemes (Bowker and Star, 2000); the 'digital divide' in information and communication technologies (Norris, 2001); and the 'negative spaces' that reveal themselves in broken

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[1] Moonlight Sonata is the byname of Piano Sonata No. 14 in C-sharp minor, Op. 27, No. 2: "Quasi una fantasia."

[2] See https://katiepaterson.org/artwork/earth-moon-earth (accessed 2 September 2022).

[3] See https://vimeo.com/104617947 (accessed 2 September 2022).

[4] Following Latour (1987: 174–175), I use the term technoscience to refer to science and technology as non-discernible, deeply intertwined, and open-ended activities, separated only by disciplinary boundaries. Technoscience is what we study when we follow research and development in action; it precedes the more commonplace, black-boxed versions of science and technology.

infrastructures (Jackson, 2013). These and other gaps and absences are part of technoscientific development: loose ends, troubles, and ambiguities that disturb modernist ideals of order, continuity, and progress, and that become visible when we focus on what people and things do in practice.

In project plans, policy documents, and advisory reports we rarely read about the messy, unruly practices of technoscience: they are overlooked, ironed out, black-boxed, or even rejected as inadmissible and dangerous (Star, 1995; Puig de la Bellacasa, 2016; Bowker and Star, 2000; Lampland and Star, 2009). While such documents can help us to understand how expectations and visions of technological futures are construed, or how new realities and agendas are discursively produced (Borup et al., 2006), they typically focus on promises, barriers, and challenges in technological development, or paths to progress and growth. Similarly, retrospective accounts of technological development often reflect Whiggish notions of determinism and hubris: they identify landmarks, revolutions, and turning points in technological change, and celebrate the heroic role of engineers, designers, and entrepreneurs in that process (Bowker, 1992). In doing so, these accounts ignore – or fail to acknowledge – how people tinker with instruments, negotiate constraints and procedures, create workarounds, and mediate anomalies in everyday use. Moreover, they rarely show how people are coerced into rigid structures and categories, or indeed how they try to avoid or reclaim them. In short, conventional accounts of technological development rarely question technological development itself; they tend to gloss over heterogeneities and discontinuities in relations between people and things, and pay little attention to translations and articulations of difference (Bijker and Law, 1992; Star, 1995; Bowker and Star, 2000; Lampland and Star, 2009; Puig de la Bellacasa, 2016).

We know that these deferential approaches to technology as a driving force of change have real consequences. Most notably, they sustain deterministic perspectives on technological development that draw attention to effects and outcomes in project work; perspectives that incite the use of models, road maps, and blueprints, and the summative use of monitors, dashboards, or other instruments for comparison and evaluation. Moreover, they make us forget what is lost in the translation of artefacts, standards, protocols, and regulations from one context to another, and limit what can be learned from technology in practice. These negations of heterogeneity, difference, and the actual work that people and things do in processes of technological development, impede serious investigations into alternative repertoires of action (Berg, 1998; Berg and Timmermans, 2000; Bowker and Star, 2000; Timmermans and Berg, 2003).

This study is an exploration of the mundane work implicated in technoscience, and an attempt to articulate a congruent perspective on technological development. It suggests a revaluation of *repair work*: the work that people do to 'keep things going' and maintain a sense of order in a complex, chaotic, and uncertain world (Rip, 2006; Jackson, 2013; Tronto, 2013; Tsing, 2017; Anand et al., 2018). Repair is not only about fixing what is broken, misaligned, or falling apart; it is the ongoing tinkering and negotiating in the margins of technological development; the precarious work that goes undocumented in project plans and reports; the seemingly negligible, situated interventions that help to shape and mould technologies over time; but also, a normative form of attachment to what is at risk of being lost. In this study I present it as a form of articulation work in expanding networks of people and things, where gaps and disruptions are temporarily restored and stabilized through local, ad-hoc interventions (Jackson, 2013: 223; Star and Strauss, 1999). As a heuristic device, repair sensitizes us to different ways of caring for people and things that do not fit, fall in between categories, and resist social conventions. It reminds us that technologies and their infrastructures emerge in unevenly distributed sociotechnical configurations (Latour and Woolgar, 1979; Latour, 1987, 1996), and that they produce new dependencies, orderings, categorizations, and values of care and the self – all of which we are only just beginning to discover, and all of which we barely understand.

Research scope

This study focuses on technological and infrastructural development in health information exchange in the Netherlands. In very basic terms, health information exchange refers to the use of digital information technologies, such as electronic health records and online patient portals, to enable the exchange of health-related information (Vest and Gamm, 2010; Kuperman, 2011). Since the 1970s, medical professionals in the Netherlands and elsewhere have seen the emergence of a wide range of computer-based health information technologies and systems to foster health information exchange. One of the ongoing challenges in this process is the growing variety of (health-related) information systems in use: systems that are often incompatible with each other, for example because they are based on different standards, protocols, and infrastructures, or because they adopt different medical vocabularies and nomenclatures. These differences are known, among many things, to affect the quality and safety of clinical work, to inhibit patients' access to information, and to hamper insurance reimbursements, performance measurements, and public health research (Berg et al., 2004). In recent decades, medical professionals and policy makers have sought ways to contain this growing differentiation, and to align or unify different technologies, systems, and conventions in health information exchange (Otte-Trojel, 2015; Otte-Trojel et al., 2015). This challenge marks the starting point of this study.

The very term *health information exchange* emerged in the wake of this challenge, and requires explanation.[5] In its abbreviated form, HIE can refer to the *act* of mobilizing electronic health information, or "enabling the interoperability of automated health data" across departments or organizations (Kuperman, 2011: 678); think of clinical test results being transferred from a hospital to a general practitioner's office. But HIE can also designate *technologies* for electronic health-related data exchange, or serve as a shorthand for the facilitating *organization* "that addresses the business issues of interoperability" in these contexts, particularly in the United States (Kuperman, 2011:

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[5] It is likely that the term first emerged in the United States, where it was interwoven with the creation of dedicated national and federal offices for health information technologies. Its use aligned with many of the aims and ambitions for quality as described by the Institute of Medicine in 2001, including timeliness, accuracy, reliability, efficiency, accessibility, and transparency in care provision (Vest and Gamm, 2010).

678; Shapiro et al., 2011).[6] As these definitions suggest, HIE is often used in conjunction with the concept of 'interoperability' in information systems – another term that can have different meanings in different contexts.

I refer to health information exchange more loosely as "the process of (electronically) sharing patient-level information across a network of actors, such as medical specialists, family physicians, pharmacists, and patients" (Pluut, 2017: 8; see also Vest and Gamm, 2010). This working definition is more attuned to the Dutch equivalent of 'informatie-uitwisseling in de zorg:' it accentuates the *process of sharing* health information and the discursive centrality of patients in that exchange, and places less emphasis on questions of 'interoperability.' In my use of the term, health information exchange encompasses registration and curation work in electronic records, the consultation of medical images, the use of e-Health applications and online health portals, and many other practices relating to digital information technologies.[7] With that, I stress that health information exchange is not a 'technological' challenge alone; it is part and parcel of gradual, complex transformations in healthcare – from how it is provided, managed, and governed, to how it is valued and experienced by people in everyday life.

Empirical case

I draw on a single, longitudinal case study to examine the work done by people and things in health information exchange on a regional scale. The case revolves around the development and demise of Zorgportaal Rijnmond, an online health portal for the Rotterdam Rijnmond region of the Netherlands. Built between 2009 and 2012, the portal was meant to serve as the main access point for health-related information and services in the region; in that sense, it can be described as an attempt to counter problems of fragmentation

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[6] These organisations are known as Health Information Organizations (HIOs) or Regional Health Information Organizations (RHIOs) in the United States and Regionale Samenwerkingsorganisaties (RSOs) in the Netherlands (Kuperman, 2011: 678).

[7] Examples of electronic records as mentioned in this study are electronic medical records (EMRs), electronic health records (EHRs), and personal health records (PHRs).

in regional health information exchange (Otte-Trojel, 2015; Otte-Trojel et al., 2015). It was imagined, among many things, as a gateway to online care for healthcare professionals and the general public, and as a platform for innovation and new economic activity in e-Health[8] (Aspria et al., 2016). By the summer of 2012 it gave access to several web applications, including a fully operational video education program and the prototype of an electronic health record system.

I build on ethnographic field work to show how the Zorgportaal Rijnmond project unfolded between 2009 and 2012. At that time, the portal existed on local test servers, in news reports, and in small networks of project managers, engineers, patients, healthcare professionals, and policy makers. Like Latour's (1996) *Aramis* it was tied to these people and things, but it did not speak for itself. To reconstruct later developments around the portal, I use document research and archival work spanning a period of ten years (2009-2019). I view the development of Zorgportaal Rijnmond as a reaction to increasing expansion and differentiation in health information exchange, but also as an interesting historical case: it was the first online health portal in the Netherlands that explicitly aimed at regional health information exchange, which in many ways represented an uncharted terrain in the Dutch e-Health landscape.

Research aims and questions

The first aim of this study is to understand how 'integration' in health information exchange is done in practice. I use the term 'integration' as a sensitizing concept, without a clear preconception of its meaning or implications (Charmaz, 2003). I attempt to make visible the work involved in the integration of standards, infrastructures, and users in an online health portal: how this work is imagined and talked about, and how it is translated into project work in different places and settings. I do so through my active

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[8] e-Health was defined by Eysenbach (2001: e20) as "an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies." See Boogerd et al. (2015) for an update of this definition.

participation in the development of Zorgportaal Rijnmond: I observe what becomes visible in that process, and what is overlooked, hidden, or taken for granted. Similar research on integrated health information exchange has been conducted earlier (see for example Røed, 2011), but the longer temporal scope of my study allows me to reflect on continuities and discontinuities in development processes, and to raise questions of cohesion. I am interested in what binds people and things, and how people seek to create unity and uniformity in a rapidly digitalizing world that we still struggle to understand (cf. Halpern, 2015; Marres, 2017).

The second aim is to develop concepts and insights that may help us to rethink technological development in healthcare. I bring together insights from actor-network theory (ANT), science and technology studies (STS), and figurational sociology[9] to extend current (reflexive and critical) understandings of technological development. ANT allows me to follow practices in health information exchange without looking up to 'the research field' as a preconceived or clearly delineated entity. The STS lens helps me to view technological development and knowledge production as one and the same thing – including my own interventions in the portal's design and development. Insights from figurational sociology allow me to connect small continuities and discontinuities in health information exchange with long-term historical processes and changing dependencies between people and things.

These research aims bring me to formulate three central questions, in which problems of technological development and health information exchange are addressed in different ways:

1. *What work is done in the development and demise of an online health portal?*
2. *How are relations between people and things shaped in that process?*
3. *How can insights from this study help us to understand changing sociotechnical figurations in health information exchange?*

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[9] 'Figurational sociology' is often used as a shorthand for the sociology of Norbert Elias, who described his own work as 'process sociology' (Elias, 1978).

Before I explain these questions in more detail, I need to clarify that they follow from an iterative, abductive research process (Alvesson and Sköldberg, 2018; Tavory and Timmermans, 2014). To explore my empirical case, I latched on to ethnographic studies on information systems and infrastructural work, most notably from STS, information systems (IS), and computer-supported cooperative work (CSCW). These studies include research on information exchange between doctors and patients (Henwood et al., 2002, 2003; Vassilakopoulou and Grisot, 2014; Vassilakopoulou et al., 2016); healthcare practices in digital worlds (Bal and Mastboom, 2007; Berg et al., 1998; Berg and Winthereik, 2004; Oudshoorn et al., 2004; Vikkelsø, 2005; Winthereik et al., 2007); and questions of standardization, integration, and adoption in health information technologies (Aanestad and Jensen, 2011; Berg and Timmermans, 2000; Bowker et al., 2010; Ellingsen and Monteiro, 2003, 2006, 2008; Greenhalgh et al, 2010, 2017; Hanseth, 2001; Jensen, 2008, 2010; Monteiro and Hepsø, 2002; Winthereik and Vikkelsø, 2005). Each of these studies opened new doors in my research. Following an abductive logic, I moved back and forth between theories and concepts from these literatures, and insights I gained from my empirical cases along the way. This (largely unplanned) process allowed me to reinterpret theories and empirical insights 'in the light of each other' and to 'adjust and refine' my own concepts and research questions accordingly (Alvesson and Sköldberg, 2018: 5). In what follows, I elaborate on the main theoretical premises and concepts in this study, which also help to clarify my research questions. I start with my operationalization of the concept of work, which is largely rooted in STS, and then unpack the concept of sociotechnical figurations, which combines ANT and figurational sociology.

Theoretical embedding

Infrastructural work and building network extensions

The first research question – What work is done in the development and demise of an online health portal? – has an explorative character, and zooms in on the actual (and often very mundane) work done by people and things in technological development. I start from the premise that this work is inherently infrastructural and relational: it exists “in relation to organized practices” and cannot be analysed separately (Star and Ruhleder, 1996: 113; see also Bowker and Star, 2000; Ellingsen and Røed, 2010; Jæger and Monteiro, 2005; Lampland and Star, 2009). I therefore refer to it as *infrastructural work.* This work has real consequences: in the context of health information exchange, it entails “political, ethical, and social choices” that produce new values and technological affordances, and that reflect invisible or taken for granted assumptions about ‘good care’ (Bowker et al., 2010: 99; see also Hanseth et al., 1996; Star and Ruhleder, 1996). The concept of infrastructural work also emphasizes that design, development, and maintenance are fundamentally interwoven activities, and therefore need to be studied and understood in relation to each other (Bowker et al., 2010; Karasti and Baker, 2004; Karasti et al., 2010; Monteiro, and Hepsø, 2015; Parmiggiani, 2015; Van Pijkeren et al., 2021).

The second research question – How are relations between people and things shaped in the development and demise of an online health portal? – has a more conceptual character. Here I elaborate on the concept of infrastructural work by proposing the notion of *building network extensions*, or the work required to make things actionable. I describe network extensions as modes of association between human and non-human actors: these include standards, protocols, laws, and regulations implicated in developing a health portal, but also pilot projects, organizations, archives, technological artefacts, and their users (Latour, 1987). An example of a network extension is the national authentication and authorization system DigiD, which is currently required for citizens in the Netherlands to access their medical records. This network extension is not neutral: for example, it reconfigures existing relations between doctors and patients by connecting local or regional arrangements to national infrastructures, and by strengthening links or associations between healthcare provision and government services. Aside from reconfiguring doctor-patient relations, DigiD also has real consequences for specific (groups of) people; for example, it excludes undocumented migrants from online medical record access, as they cannot apply for DigiD.[10] Like plug-ins in software programs, network extensions make new sociotechnical arrangements actionable by displacing people and things in the network; these displacements have different consequences for different people, and require different types of translation work, or negotiations and articulations of difference that change "something into another form" (Stoopendaal and Bal, 2013: 79).

The notion of building network extensions helps me to describe how infrastructural work shapes and reconfigures relations between people and things. Following Latour (1987), I contend that the character of their associations changes as they converge around specific network nodes. An example of a dense node in the development of Zorgportaal Rijnmond was the IT department of Rotterdam's teaching hospital, where different lines of action came together: from political negotiations and standardization efforts in regional health information exchange, to the national implementation of DigiD in healthcare. By tracing how extensions are built around (more or less) dense nodes in a network, we can describe *how* underlying assumptions, values, and normativities are inscribed in technologies – and by extension, how relations between people and things are shaped over time.

Sociotechnical figurations

To answer the third research question – How can insights from this study help us to understand changing sociotechnical figurations in health information exchange? – I describe how people and things are bound together, and how they are continuously ordered and (re)configured. I use the concept of *sociotechnical figurations* for this purpose. The adjective *sociotechnical* aligns with what Bijker and Law described as the 'seamless web view' of social and technical relations in ANT:

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[10] Applying for DigiD requires the citizen service number BSN ('Burgerservicenummer'), a personal identification number issued by Dutch municipalities. Undocumented migrants lack a BSN.

> [this view] resists the notion that the division between the social and the technical is either stable or matter-of-fact. To say this is not, of course, to deny that it is possible to point at, and distinguish between, machines and those who operate them. Rather it is suggested that this distinction should be seen as an accomplishment, rather than something that can be taken for granted. Accordingly, it is argued that analysis should start with a seamless web of elements and look to see how that seamless web is broken up under different kinds of circumstances to create different *kinds* of objects. (Bijker and Law, 1992: 201; italics in original)

A sociotechnical perspective on health information exchange presupposes a view of networks of people and things that are always 'in the making', and that gain new meanings and produce new values over time (Akrich, 1992: 207). In this study, for example, I alternately refer to the health portal as an idea, a technology under construction, a regional infrastructure, a failed project, and a network of weakly associated elements. In different contexts it is enacted as a gateway for health information, a commodity for doctors and patients in the region, or a platform for health information exchange. These different 'technological frames' often exist alongside each other, sometimes blend in, and sometimes compete for supremacy (Bijker, 1987 [2012], 1992). Importantly, they entail a view of technologies and their infrastructures as heterogeneous, malleable, and never finished.

A sociotechnical perspective also includes the materiality and generativity of language, discourses, and sociotechnical imaginaries that enable and constrain new lines of action in infrastructural work. I build specifically on Akrich (1992), Bijker (1987 [2012], 1992), and Orlikowski and Gash (1994) to analyse the implications of technological frames and inscriptions in the development of an e-Health application, and use the work of Oudshoorn et al. (2004) and Oudshoorn and Pinch (2005) to show how people and things are (re)configured in that process. I draw on Schön (1996) and Jasanoff and Kim (2009, 2013) to discuss the materiality and generativity of metaphors in project work, and on Schön and Rein (1994) to trace how narratives in medical science literatures reflect in policy advisory reports. This attention for language is particularly relevant in this study; we know that frequently recurring concepts in health information exchange such as ‘patient-centered,’ ‘personalized,’ and ‘integrated’ care are never unambiguous or neutral. Rather, they are imbued with different meanings, and continuously reinterpreted and renegotiated; at the same time, they also generate new (and unevenly distributed) social realities. These concepts therefore need to be handled with care.

I use the term *figurations* to point to mutual relations of dependence between people and things in health information exchange. I borrow the term from Elias (1978), who described figurations as relations of human interdependence. To illustrate the concept of figurations, we can imagine people moving around in urban traffic. On a busy day, we see complex flows of pedestrians, cyclists, and drivers using designated spaces and infrastructures (such as roads, pavements, traffic lights, and street signs) and their knowledge of formal and informal rules (including the traffic code and social norms about ‘good conduct’) in an apparently orchestrated or coordinated manner. In this figuration of urban traffic, one person’s actions have direct or indirect consequences for others; all people who make up this figuration are dependent on each other in various ways. Their individual behaviour in this figuration cannot be explained as the result of external social structures or institutional arrangements, nor as their own rational choice; rather, it is an outcome of “the interweaving of multiple lines of action, all colliding with each other in ways that cannot be predicted beforehand” (Van Krieken, 2019: 5–6).

Like actor-networks in ANT, figurations are primarily “intended as a counter to the notion that ‘social agencies,’ ‘institutions,’ and ‘society’ are entities that exist somehow separately from the people who comprise them” (Dunning and Hughes, 2013: 52).[11] In both figurational sociology and

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[11] Elias criticised the reification of ‘the individual’ and ‘society’ as antagonistic entities; he argued for a view of society that does not exist outside the individuals that constitute it (Elias, 1978: 119), that focuses on social processes, and that cannot be reduced to “unstructured congeries of freely-choosing individuals” (Dunning and Hughes, 2013: 57). He regarded the analytical separation between people and ‘the social’ as a tendency in sociology to reduce processes to fixed states – what he called ‘process-reduction’ (Elias, 1978).

ANT, the concept of power resides in relations between people, rather than in individual people, organizations, or other forms of human association. A figurational analysis implies a view of social structures as "a verb" and "a site of struggle, a relational effect that recursively generates and reproduces itself" (Law, 1992: 385–386);[12] it also "adds sensitivity to the dimension of asymmetrical power relations" in networks of people and things, which are either subdued or explicitly dismissed in ANT (Van Krieken, 2019: 16; see also Newton, 2001, 2002).

There is, however, a more fundamental difference to negotiate between the premises of figurational sociology, and the aforementioned 'seamless web view' of social and technical relations. In Elias' work – and in the writings of many sociologists he inspired – figurations are regarded as human accomplishments, where human beings are viewed as 'homines aperti' – social, open, and inherently bound to each other (Elias, 1978; see also Callon, 1999: 185; Newton, 2002: 530). By contrast, technological artefacts often feature as self-contained, passive elements in Elias' work. His reflection on the development of weapons of mass-destruction illustrates this point:

> Technological developments do indeed influence the direction in which human interweavings develop. But the technical 'thing in itself' is never the source of the compelling forces or hardship to which people are subject; these are always caused by the way people apply technology and fit it to the social framework. What we need to fear is not the destructive power of the nuclear bomb but that of human beings, or more accurately of human interweavings. The danger lies not in the progress of science and technology, but in [how] research findings and technological inventions are used by people under the pressure of their entangled interdependence, and in the associated struggles over the distribution of power chances of all kinds. (Elias, 1978: 25)

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[12] In a footnote to the quoted sentence, Law (1992: 386) points to similarities between Elias' figurational sociology, Giddens' structuration theory, and Bourdieu's notion of habitus.

The example shows how Elias essentializes the nuclear bomb as a 'thing in itself:' an unexplained technology, a mute object, or an artefact lacking human fingerprints. Elsewhere, Elias introduced the term 'technization' to describe the process whereby "people learn to exploit lifeless materials to an increasingly greater extent for the use of humankind" (Elias, 1995: 7). There too, he discussed technologies as strictly human accomplishments, and as the outcome of changing human figurations over long periods of time; in his words, they have "no will of their own" (Elias 1978: 24). Taking a departure from these ideas, I build on the premise that both people and things are implicated in technological accomplishments. Whereas Elias deliberately prioritized human relations in technological change, I take a more even-handed view on that relation by ascribing agency to people, artefacts, standards, and language in infrastructural work. In that sense, my analyses are more in line with ANT's seamless web approach to sociotechnical development.

The conflated concept of *sociotechnical figurations* helps me to emphasize the constructed character of relations between people and things: they are not a mere result of inescapable interdependencies that lead to increasing social and psychological pressures within and between individual people,[13] but they are shaped by work that changes over time, and that requires explanation. Sociotechnical figurations make visible the 'pattern of forces' that bind people and things as they travel between networks, compete for supremacy, and build on, work against, or dominate each other:

> [...] the point is not, as in sociology, to emphasize that a particular type of element, the social, is fundamental to the structure of the network; rather, it is to *discover* the pattern of forces as these are revealed in the collisions that occur between different types of elements, some social and some otherwise. (Law, 1987 [2012]: 108; italics in original)

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[13] Think of growing expectations of self-management, self-monitoring, and self-regulation that are intertwined with the rise of health information exchange.

Describing sociotechnical figurations means tracing the character of associations between people and things in continuously changing constellations: those associations weaken or strengthen in unpredictable ways, expand in some directions, and collapse in others. There is no pre-given hierarchy in the power relations between them, nor a central network node around which all people and things converge. When tracing sociotechnical figurations of health information exchange, I reconstruct how related practices, values, and expectations are shaped and change over time, and how this goes hand in hand with infrastructural growth and expansion, but also with loss and decay.

I contend that new associations are built through network extensions, and that these extensions require ongoing repair work. Strong associations between nodes are dense and durable, whereas weak associations are thin and unstable; all associations are continuously put to the test, and constantly under threat of being dissolved (Callon, 1986; Latour, 2007). The precariousness of these relations is a recurring theme in this study; I am interested in how relations are built, stabilized, and fixed in place, and how fragile orders are repaired and maintained in that process. Conceptually, repair work helps me to describe what happens in weak associations of people and things; these can reveal themselves as gaps and ruptures in technological development, but also in the margins of successful interventions, or in abandoned places and empty spaces after a project comes to an end.

The importance of studying repair work

I contend that repair is a fundamental element of what binds people and things in technological development, and that studying repair helps to better understand the changing relations between them (Rip, 2006; Jackson, 2013). Navigating between linear promises of growth and the prospect of ruination and breakdown, repair alerts us to the fluid, unstable, and unsettled character of sociotechnical relations, and to brief moments of continuity in the fragile worlds we inhabit (Jackson, 2013). In this study, repair is the subtle – and often invisible – work that is required to articulate differences, negotiate gaps, and translate interests. It provides an alternative to modernist accounts of development where deficits are fixed by ‘plugging in’ technological solutions at will; accounts in which technology is viewed as a self-contained entity, a politically neutral extension of social life, or a lifeless arrangement of things – much like the smooth surface of the Moon from a distance. Those views-from-a-distance help to sustain technology’s mythological power and its implied attachments to control, objectivity, stability, predictability, transparency, and growth; indeed, as the saying goes, “distance lends enchantment” (Collins and Pinch, 2014: 3). This study continuously moves between distance and proximity; in those movements, repair becomes a way of addressing the inherently social and political character of technologies and their infrastructures, as well as an attempt to revalue attachments to messiness, unruliness, instability, and decay.

Plug-in healthcare

My insistence on repair is a response to modernist conceptions of technology and infrastructural development, which often reflect in a mechanistic or technocratic outlook on policy making. I refer to that outlook as the logic of ‘plug-in healthcare:’ a logic of creation, alignment, and expansion that does not question the values and assumptions embedded in technological artefacts, and that largely ignores the social and organizational dimensions of healthcare. Plug-in healthcare conceals the politics of technologies and human work, and detracts the attention from increasing dependencies between healthcare organizations, governments, and markets. In doing so, it inconspicuously reproduces neoliberal orderings of the world; orderings that reinforce, among many things, ideals of transparency, bureaucratic homogeneity, and market-driven standardization. It is a logic that does not account for the heterogeneity of people and things, and that disregards the messiness of practices in real life.

In this study I describe how the logic of plug-in healthcare coerces people and things into formal classifications, and how it structures messy practices into well-delineated ‘raked paths.’ It is a logic that forgets to learn from the unstructured chaos of care, the noise it produces, and the ruins left in its wake. Making health information exchange work – adding an entry in a patient record, retrieving a discharge letter, transferring lab results, preparing the medical billing, or countless related activities within and between healthcare organizations – means moving along with ongoing displacements in figurations of healthcare professionals, patients, health IT vendors, and insurers; but also with revisions and modifications in local information systems, commercial operating systems, and government-approved identification systems. I contend that we need to pay more attention to these displacements in sociotechnical figurations, and to the repair work involved in the process of negotiating, reframing, and reconfiguring them.

Repair is not the answer to everything. We know that gaps and discontinuities in organizations and infrastructures are not necessarily a bad thing: they can allow for leeway, wiggle room, and playfulness – most notably, where 'rigid' structural elements such as laws, protocols, and procedures clash with the messiness and unruliness of life (cf. Bowker and Star, 2000; Clegg et al., 2005). I therefore call for participatory modes of development in e-Health that include engagements with failure, breakdown, and loss; we need to learn from those engagements to rethink futures of health information exchange. A renewed focus on repair can help to call into question the logic of plug-in healthcare, and the continuous expansion of hyperspecialized, market-driven, and monopolizing networks and infrastructures in healthcare.

Methodological approach

This study builds on ethnographic research, complemented by archival work and a discursive analysis of medical science literatures and policy advisory reports. The ethnographic chapters (Chapters 3-6) span a period of ten years: from the first plenary meeting in the Zorgportaal Rijnmond project in 2009 until the portal's demise in 2019. Most data were collected between 2009 and 2012, when I actively contributed to the design, development, and implementation of the portal and three of its main applications. In this study, I alternatively describe my methodological approach as a form of action-oriented, engaged scholarship, and as an interventionist, participatory form of research in which I follow people and things as they move between different situations and settings (Bal and Mastboom, 2007; Mathiassen and Nielsen, 2008; Zuiderent-Jerak, 2015). My contributions were part of a 'formative' evaluation of the portal project (cf. Buse et al., 2012); the aim was to assess and improve the portal's development along the way, and to generate some degree of 'first-order reflexivity' by enabling project members to reflect on what was happening (Beck, 1992).

Between 2009 and 2012, I conducted observations, semi-structured interviews, and document research in various locations in the city of Rotterdam. The places I visited most frequently were the office of the Regional Health Information Organization (RHIO), where members of the portal project, the steering group, and the board convened; the IT department of the Erasmus MC teaching hospital, where the personal health record (PHR) project group was based; and Erasmus MC–Sophia Children's Hospital (SCH), where I assisted in the development of a webcast application. After 2012, when the portal project had formally come to an end, I continued collecting documents about new initiatives in health information exchange in the Netherlands. Between 2017 and 2019 I completed my research by exploring the demise of Zorgportaal Rijnmond through an experimental form of archival work. Details about these different methods are presented separately in the ethnographic chapters. In what follows, I describe how I researched different types of work done in the development and demise of Zorgportaal Rijnmond, and how I traced the relations between people and things that were shaped in that process.

Researching infrastructural work and network extensions

A central element in my ethnographic research consisted of observing practices in project work. At the start of the Zorgportaal Rijnmond project in October 2009, I began to explore how various stakeholders described the main challenges in regional health information exchange, and how they envisioned the main goals and purposes of the forthcoming health portal. I looked at how different views were mobilized, how they circulated in networks, and how they were translated in meeting minutes, progress reports, and other documents. I conducted most of my observations at the RHIO's office, where I was a regular visitor for a period of 36 months. There, I saw how people addressed and negotiated the uncertainties and complexities of infrastructural work, and how their choices and decisions materialized in project structures and reflected in the portal's architecture. I actively participated in three-weekly project group meetings (n= 26), bimonthly steering group meetings (n= 17), biannual board meetings (n= 6, plus three extra board meetings in 2012), and various sounding board groups. I shared insights from my perspective as a researcher, and made unstructured field notes and audio recordings (with permission). My participation in these meetings helped me to gain a basic understanding of the politics of regional health information exchange – including how it was problematized and reframed by different stakeholders, and how specific social groups were overlooked in that process (cf. Schön and Rein, 1994; Star and Strauss, 1999).

I gained valuable insights in the workings of knowledge exchange in emerging infrastructures by participating in various activities and events, including research platform meetings (n= 3), regional and national expert meetings, and meetings with independent consultants and potential project partners. These activities and events brought together people with very different backgrounds, and broadened my understanding of knowledge work in infrastructures for health information exchange (cf. Star and Griesemer, 1989; Puig de la Bellacasa, 2016). I also benefited from informal types of knowledge sharing, such as lunchtime discussions and shared car rides with project members, where ordinary conversations sometimes mixed with gossip and indiscretions about political relations in the region. Taken together, my ethnographic observations in and around the Zorgportaal Rijnmond project amounted to approximately 200 hours, excluding many 'water cooler moments' at the margins of project work (Waring and Bishop, 2010). Analytical insights from my observations can be found in Chapters 3-6.

Another important part of my research pertained to imaginaries and expectations about the future of health information exchange, and of online health portals in particular (cf. Borup et al., 2006; Jasanoff and Kim, 2009; 2013). I found examples in policy advisory reports by the Council for Health and Society (RVS), the Netherlands Institute for Social Research (SCP), the

Dutch Scientific Council for Government Policy (WRR), and the Centre for Ethics and Healthcare (CEG), which I discuss in Chapter 2. Aside from analysing publicly accessible documents, I conducted 72 semi-structured interviews with 61 different people – including project members, relevant stakeholders, and prospective and actual users of Zorgportaal Rijnmond – in which we frequently addressed hopes, dreams, and anticipations of regional health information exchange. These interviews ranged from introductory meetings to topical interviews, user experiences, and reflexive discussions; they took place in different forms and contexts over a period of three years, and revealed different facets of infrastructural work – including the generative role of language in sociotechnical imaginaries, as discussed in Chapter 4 (Jasanoff and Kim, 2009; 2013; Schön, 1996).[14]

Many interviews helped me to position myself as a formative researcher in the project, especially in the early stages of the portal's development. Some of my later interviews had a more reflexive character, as I started sharing my insights, findings, doubts, and feelings of disconcertment about the project with key respondents. Most notably, this occurred when I assessed the progress of the project's development with the RHIO director (n= 5) and the program manager (n= 2); in these interviews we practiced a form of 'critical reflexivity' in which I upheld a mirror to my respondents, and they did the same for me (Bjørn and Boulus, 2011). A round of interviews on the governance and future of Zorgportaal Rijnmond with board members of the project (n= 7) and regional stakeholders (n= 9) allowed me to reflect on the political sensitivities and conflicts that often arise in emerging infrastructures (see Chapter 6).

I zoomed in on more mundane practices in infrastructural work at Erasmus MC–Sophia Children's Hospital (SCH) and the teaching hospital's IT department (cf. Bowker and Star, 2000; Lampland and Star, 2009). There, I engaged in informal conversations with developers, project managers, and other staff on a regular basis. At SCH I assisted in the production of webcasts

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[14] All interviews in this study were audio-recorded with permission and saved on an external hard drive. Interviews for evaluation studies and project reports were transcribed verbatim and coded inductively; other interviews were either partially transcribed or archived for later reference.

for cystic fibrosis (CF) patients at the hospital's TV studio for a period of approximately six months between 2010 and 2011; I also attended an educational meeting for parents of young patients, and a camera training session for webcast presenters. With permission of the teaching hospital's Medical Ethics Committee, I conducted interviews with pilot participants (n= 13) on their user experience in the video education program. These observations and interviews helped me to describe what is often invisible in accounts of technological development – most notably, the role of non-users in this context (see Chapter 3). After completing my evaluation work at SCH, I shifted my focus to daily practices at the teaching hospital's IT department, where my task was to evaluate and assist in the 'scaling' of the PHR application. A six-month hospitality agreement gave me access to the IT department, where I spent approximately four hours per week in one of the software test rooms. I watched project group members working on databases and test environments, actively participated in weekly PHR project group meetings, and conducted face-to-face interviews (n= 8) with staff members on the usability and scalability of the PHR. It was there that I observed the development of plug-ins from up close, which led me to conceptualize the idea of 'building network extensions' in Chapter 5.

Aside from these activities, I was involved in project meetings and events that were left unreported in the ethnographic chapters of this study, but that further helped me to think of infrastructural work in terms of building network extensions. These meetings and events included visits to the Municipality of Rotterdam, where I attended sounding board meetings for the development of a web application for social care (n= 7); semi-structured observations of clients at three offices for social care in Rotterdam (n= 19); a user panel at the office of a patient group in Rotterdam, where I tested the social care application (n= 6); working group meetings on securing the future of the portal (n= 4); two meetings on the future 'look and feel' of the portal; observations at the Rotterdam MediaLab, where students presented their design proposals for the portal; observations in two nursing homes, where an application for elderly citizens was introduced; and a visit (in May 2012) to Patients Know Best, a British social enterprise that developed a patient portal for citizens. I gradually came to view these projects and events as networks of their own; each extending the portal's network in a different direction, and placing a different light on 'integration' in regional health information exchange.

Researching sociotechnical figurations and repair

In this study I draw on a wide range of archival materials. Some were collected along the way; others were gathered retrospectively – each time with a different purpose. To understand how choices and problem definitions in the portal project were articulated, reframed, stabilized, and discarded during the first three years of the portal's development, I collected and analysed email exchanges, meeting minutes, internal memoranda, project plans, and progress reports at the RHIO's office and the teaching hospitals' IT department. I used them in different ways to reconstruct the portal project in Chapters 4-6. By 2019, I had gathered large quantities of unstructured electronic files, paper printouts, booklets, press clippings, and mementos related to the portal project. After that, I gathered literatures on a broader history of health information exchange in the Netherlands, which I present and discuss in Chapter 1. These materials became an invaluable resource to reconstruct where the portal came from, how it was developed, and how it was subsequently abandoned, repurposed, and erased. In that process, the Zorgportaal Rijnmond network became part of different sociotechnical figurations; old screen captures of the portal (originally made for illustration purposes) served to describe the gradual weakening of the portal's network in some areas, while new figurations of health information exchange started to emerge elsewhere (see Chapter 6).

Taken together, these materials formed the basis for an experimental research method that I describe in Chapter 6 as 'tracing phantom networks:' a form of infrastructural inversion that helps to piece together what is falling apart, and that exposes the politics of technologies and infrastructures in decay (Bowker and Star, 2000: 34; see also Hanseth and Monteiro, 1996; Star, 1999; Star and Ruhleder, 1996). Tracing phantom networks was an unplanned intervention that helped me to see how layers of old infrastructure can resurface in unexpected places, and how the remains of an indefinite past can sometimes haunt the present. It helped me to view the World Wide Web itself as a digital archive, and as both a productive and challenging site of research on digital infrastructures. In the Discussion and Conclusion chapter of this study, I describe how tracing phantom networks became both a political and an affective intervention: one that transformed the archive into an object of resistance against erasure, while also drawing attention to the generativity of abandonment. At the same time, tracing phantom networks provided a basis to reflect on network displacements and changing sociotechnical figurations in terms of repair: to think about ruins as an opportunity to learn about more accessible, inclusive, and equally distributed infrastructures for health information exchange.

Outline of this study

Chapter 1 situates the emergence of online health portals in the Netherlands in broader challenges and developments in health information exchange since the late 1960s. It shows how early digitalization projects in hospital information exchange were primarily driven by economic and administrative motives. In subsequent decades, a growing number of people and things became more closely involved in health information exchange, including doctors, digital and networked technologies, government agencies, commercial enterprises, and patient organizations. As new standards, systems, infrastructures, and entire scientific disciplines arose, electronic information exchange gradually became an integral part of primary and secondary care – from medical and clinical practices to managerial and administrative work. I describe how challenges in health information exchange were (re)articulated and (re)enacted, and how this shaped the political and economic climate in which health portals and related technologies emerged. In that process, the Dutch Minister of Health alternately loosened and strengthened its regulatory control on health information exchange, while delegating the development of concrete initiatives to ‘the field’. The origins and development of my empirical case must be understood in this context of regulated competition and market forces, and in a politics increasingly focused on patient empowerment and shared decision-making: a process in which (national) preoccupations with innovation and administrative motives of efficiency were increasingly intertwined with changing figurations of health professionals and patients.

Chapter 2 is the first of five empirical chapters in this study that were co-written by Dr. Marleen de Mul, Dr. Samantha Adams, and Prof. dr. Roland Bal (second, third, and fourth author respectively). In Chapter 2 we introduce health portals in relation to policies for health information exchange and ask: how are health portals framed in medical science literatures and policy advisory reports? Our aim is to show how portals have been envisioned as solutions to various problems of information provision and medical recording in recent decades; we foreground the ontological heterogeneity of health portals, and address the implications of different ontologies for policy makers. We explore narratives relating to online health portals and electronic health records in internationally oriented medical science literatures between 1995 and 2015, and show how they reflect in Dutch policy advisory reports from the same period. We thus unravel specific discourses in health information exchange: how did people talk about health portals when these technologies first emerged? Who were these people, and how did they problematize digital futures in healthcare? We draw on the concept of technological frames to explore the complex entanglements of scientific knowledge production and policy advice in different narratives (Bijker, 1987 [2012], 1992; Orlikowski and Gash, 1994), and discern three ways of framing health portals in medical science literatures that reflect specific perspectives on infrastructural work for health information exchange. We reflect on what was said and what remained unspoken in related narratives: this includes the construction of technological futures in healthcare, but also the negation of the politics of health portals, and the lacking problematization of public-private partnerships in health information exchange. We contend that these absences and silences helped to avert potential controversies in e-Health policies, and to expand the role of commercial enterprises in health information exchange.

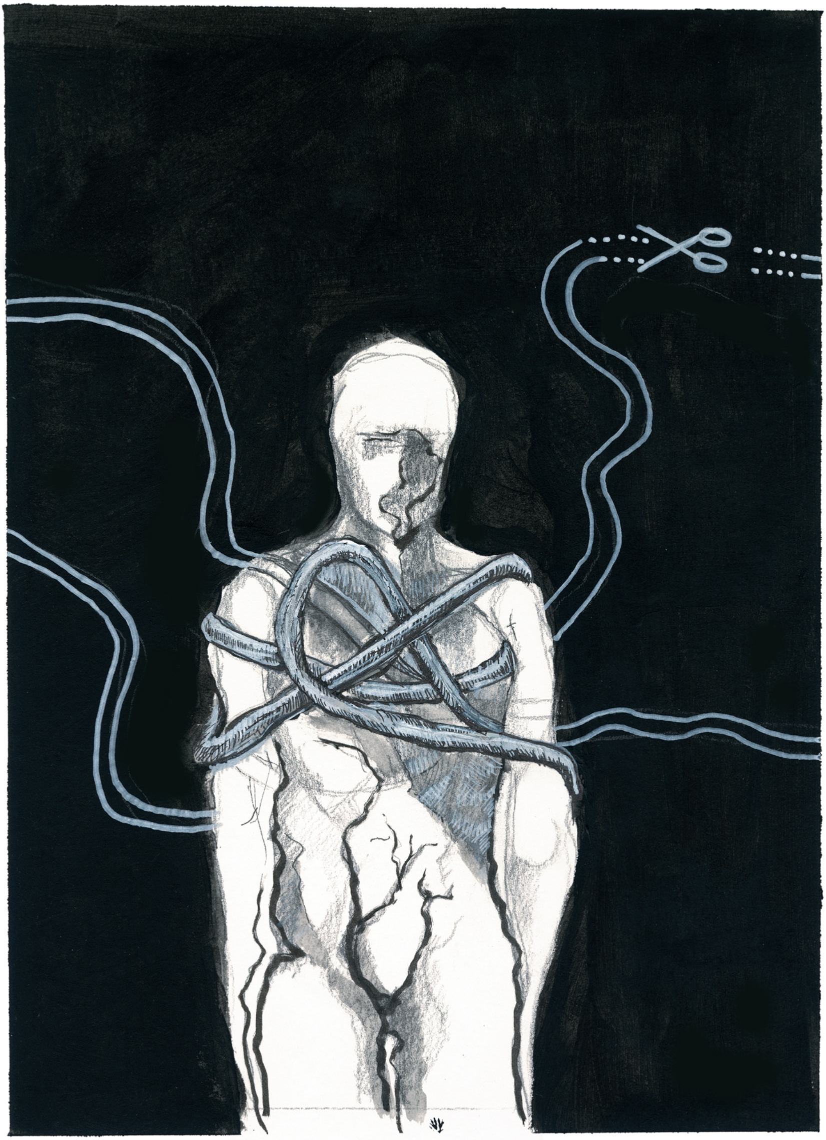
In *Chapter 3* we shift our focus from discursive practices to techniques of governing people on a micro scale: we explore how technologies are invoked to steer the conduct of patients, and how those patients are more or less successfully ‘integrated’ in project work. This chapter zooms in on the development of an online video education program at Erasmus MC–Sophia Children’s Hospital (SCH). We ask: how are doctors and patients enrolled in the development of an e-Health application? We see heterogeneous role attributions in this process (Callon, 1986): we discern users and non-users of the video education program (Wyatt, 2003), as well as a relevant group of people that was overlooked in the project’s design. We use the concept of ‘configuring the user’ (Akrich, 1995) to describe the video education program’s reframing in relation to its *actual* users, and to show how a single technology can be implicated in different, coexisting practices of care. In doing so, we unpack some of the challenges of technologies in search of an audience: like many e-Health applications, the video education program was built for an envisioned public that could not (or would not) relate to its premises and aims. We thus make a first attempt in this study to address questions of success and failure in technological development, and reflect on how formative evaluation methods can help to configure users in the design and development of applications.

Chapter 4 marks a return to the use of language in health information exchange. This chapter is based on the early development of Zorgportaal Rijnmond as a regional infrastructure, and focuses on the politics of metaphors in infrastructural work. We ask: what is the politics of language in infrastructural work? We were fascinated by the widespread use of metaphors among project members in this phase, but struggled to make sense of them analytically. In this chapter we try to understand the pervasiveness of metaphors in the context of information infrastructures: how do they shape present- and future-oriented work and imaginaries in health information exchange? And how are they enacted in practice? We view metaphors as mobilization devices that allow ideas to circulate (faster) and that influence the ways in which people argue and convince each other (Latour, 1990: 31; Czarniawska-Joerges and Joerges, 1992, 1996). Through their circulation in networks, metaphors have the potential to (re)configure people, ideas, resources, and technologies; this is reminiscent of the notion of ‘configuring the user’ in Chapter 3, where material objects were enacted in different ways in continuously changing settings. We discuss metaphors as real attributes of infrastructural work, and view them as operationalisations of sociotechnical imaginaries that leave room for ambiguities and interpretative flexibility (Jasanoff and Kim, 2009, 2013; Pinch and Bijker, 1987 [2012]). We contend that two recurring metaphors in the project concealed the politics of infrastructural work in our empirical case; we conclude that the act of 'spelling out' their meaning can open up a space for new imaginaries and alternative strategies in health portal development. In the Discussion and Conclusion of this study we further reflect on the playfulness of metaphors, which helps them to circulate in some networks, while preventing them from travelling to others.

Chapter 5 contributes to existing conceptualizations in STS on how standards travel in actor-networks. We ask: how is a standard for medical recording integrated in a regional infrastructure for health information exchange? Using a combination of participatory ethnography (2009-2012) and desk research (1999-2021), we show how the Continuity of Care Record standard (CCR) was enacted in different ways as it moved between different network nodes, and how it reconfigured people and things while being itself transformed. We build on actor-network theory (ANT) to contend that standards act as network extensions: they bring worlds together in non-linear, parallel movements; they make network nodes actionable; and they strengthen the associations between them. We complement this approach with insights from figurational sociology to show how standards lengthen relations of dependency between people and things through different 'frames of relevance' (Couldry and Hepp, 2017; Hepp et al., 2018). Empirically, we describe how CCR was accompanied by other standards in order to travel; how it temporarily reconfigured relations between people and things by extending their networks; how it acquired new meanings as it navigated between different nodes; and how it lost its relevance as concerns about health information exchange shifted in new directions. We end this chapter by reflecting on the implications of our analytical perspective on standardization in healthcare. In the Discussion and Conclusion, I further elaborate on the notion of building network extensions.

Chapter 6 rounds up the empirical part of this study, and reflects on the afterlife of Zorgportaal Rijnmond as a technology in ruins. We ask: what happens when technologies are abandoned? We describe the portal as it presented itself between June 2017 and June 2019, nested in a grey space between activity and neglect. We were fascinated by its on-going presence on the Web, and felt compelled to explore what it was doing – or not doing – there. However, we struggled to understand what exactly we were looking at: was it still the same portal we described elsewhere in this study, or had it always been different things to different people? Did it ever stop being a portal, and when or how did that happen? Was the project a success or a failure? And to what extent are these dualities of success and failure, presence and absence helpful in research on infrastructure? Starting from the premise that associations of people and things are continuously built *and* falling apart, we view technological abandonment as a displacement of people and things in sociotechnical networks, and as a weakening of network nodes. This displacement entails the creation of new alliances between people and things elsewhere. We reflect on how various forms of repair work, including the method of 'tracing phantom networks,' can be used as a way of intervening in ruins. Tracing phantom networks draws attention to organized practices in the margins of networks, and helps to piece together infrastructures that are at risk of being erased. As a fundamentally normative and political intervention, it helps to reconsider abandoned, premature, or foolish plans, and to reimagine future infrastructures accordingly.

Finally, the main themes are drawn together in the Discussion and Conclusion, where I provide answers to my central questions, elaborate on my critique of the logic of plug-in healthcare, and reflect on the revaluation of repair work. I have no pretention of being exhaustive in these matters – quite the contrary; I hope to provide useful reflections on current challenges in health information exchange, but am aware of the limitations and consequences of my theoretical premises and methodological approach. In the end, my study is a renouncement of modernist promises in technological development; in line with that renouncement, I try to avoid sweeping theoretical statements and airtight academic arguments. Like the broken score of the Moonlight Sonata, this study is an open invitation to engage with concepts, ideas, and reflections, and to fill in the gaps along the way.



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A history of health information exchange in the Netherlands

Introduction

Health information exchange has gained a prominent place in Dutch healthcare policy in recent years. More than ever before, doctors, government agencies, standards organizations, commercial enterprises, and patient groups are involved in facilitating, enabling, and promoting “the process of (electronically) sharing patient-level information” among and between healthcare providers and patients (Pluut, 2017: 8). This process can be traced in an intertwinement of seemingly different, but fundamentally interrelated developments: from technological and infrastructural transformation in healthcare to organizational and political reforms, changing socioeconomic relations, and changing values and perceptions of ‘good’ care. In these different lines of action, different (and sometimes conflicting) problem definitions accumulate, intersect, and persist to different degrees.

A distinct phenomenon in health information exchange is the rise of online health portals: an umbrella term that includes hospital portals, patient portals, and related innovations such as personal health environments (known as *persoonlijke gezondheidsomgeving* or PGO in the Netherlands). Health portals have been researched from a wide range of perspectives. There are countless studies on the use of health portals in relation to health outcomes, clinical encounters, and patient engagement (for systematic reviews, see: Lubick Goldzweig et al., 2013; Otte-Trojel et al., 2014; Han et al., 2019). However, historical reconstructions on the rise of health portals are less common; and if we narrow down the scope to the Netherlands, their emergence has mainly been documented around single case studies or comparisons over short time spans (De Mul et al., 2013; Otte-Trojel, 2015; Vennik, 2016; Van Well, 2021). Individually, these studies provide insufficient insight in health portals as a new phenomenon in Dutch healthcare: it is unclear how and why they originated, and under what circumstances. Similarly, developments in health information exchange – in the Netherlands and elsewhere – are often explained in terms of *current* clinical, organisational, administrative, and economic motives (Dixon et al., 2010; Shapiro et al., 2011), or as the outcome of new institutional arrangements and laws in healthcare (Vest and

Gamm, 2010). Consequently, they tend to lack a processual, *longue durée* understanding of changes and transformations in healthcare (cf. Pollock and Williams, 2010).

In this chapter I focus on infrastructural transformation in health information exchange, and on the rise of health portals in the Netherlands in particular. The first aim of this chapter is to identify prominent technological, scientific, and political challenges in emerging infrastructures for health information exchange in recent decades. The second aim is to outline the origins of Zorgportaal Rijnmond: touted as the first online regional health portal in the Netherlands at its launch in 2011, it serves as the central empirical case in the present study. In this chapter, I describe various transformations in healthcare that preceded its emergence, and that complement my research on its development and demise (see Chapters 3-6). Based on an analysis of policy documents, project reports, research papers, conference proceedings, and other archival materials, my reconstruction answers three questions: where and how did infrastructures for health information exchange originate? What kinds of actors and relations did they produce? And how does the emergence of Zorgportaal Rijnmond fit in these developments?

I loosely build on Asdal's (2012) historicizing approach to science and technology studies (STS) to explore how health information exchange was construed over time, and how that process entailed changing actors, problem definitions, infrastructures, and agendas. Asdal proposes the use of actor-network theory (ANT) as a way to bring back historical modes of inquiry in STS (Asdal, 2012: 380). In this chapter, I trace relations between a wide range of human and non-human actors in health information exchange over the past six decades: from hospital architectures, doctors, patient reimbursement programs, and programming languages, to archivists, a 'machine-independent' operating system, the Royal Netherlands Academy of Arts and Sciences, and the World Wide Web. In line with ANT, I try to avoid explaining the relations between them in terms of inescapable social, political, or historical 'contexts.' Instead of completely embedding health information exchange in 'external' factors and institutions, or reducing it to its 'essential' properties, I tease out various relations and interests at play, and describe their material enactments since the late 1960s. Mirroring Asdal's approach, I emphasize the *becoming* of health information exchange instead of the "*reasons for* and the *background to* its becoming [emphasis added]" (Asdal, 2012: 384). I do so by describing how heterogeneous networks of people and things reconfigured and expanded over time, and enacted different forms of health information exchange *avant la lettre*.

I refer to these long-term processes as changing sociotechnical figurations. The adjective *sociotechnical* aligns with the 'seamless web view' of social and technical relations in ANT (Bijker and Law, 1992: 201), while *figurations* points to mutual relations of dependence between people and things. I borrow the latter concept from Elias (1978), who viewed figurations as relations of human interdependence. Figurations of people and things are not the result of external social structures or institutional arrangements, but rather an outcome of "the interweaving of multiple lines of action, all colliding with each other in ways that cannot be predicted beforehand" (Van Krieken, 2019: 5–6). A distinct feature of sociotechnical figurations is that they entail a historicizing approach to relations of interdependence. While I do not aspire to a comprehensive historical account of health information exchange, nor to a rigorous application of ANT or figurational sociology, I aim to show how people and things were implicated in different lines of action, and how they became increasingly dependent on each other in changing figurations over time.

Looking at processes of automatization and digitalization in healthcare in broad brushes, I describe a gradual shift in problem definitions – from issues of administrative work and healthcare provision to questions of patient empowerment and self-management. I contend that motives of economic development and innovation played prominent roles in early initiatives for automatization and digitalization in the Netherlands, and that they continue to play an important role in current government policies for health information exchange. I argue that in the late 1960s, policy measures for automatization and digitalization in the Netherlands and the United States were based on different concerns, none of which were focused on care practices or clinical work. In the Netherlands, these measures materialized in an experiment with a hospital information system, which came to serve as an 'installed base' for health information technologies, and helped to mobilize new markets and enrol new actors in health information exchange (cf. Hanseth and Ciborra, 2007). Doctors, patients, technologies, government agencies, and markets were reconfigured in expanding networks of people and things; they (re) articulated and (re)enacted problems and challenges in health information exchange, and helped to shape the political and economic climate in which Zorgportaal Rijnmond emerged.[15]

Echoing the view of Berg et al. (1998), my reconstruction shows that doctors, hospital managers, and administrators co-construed problems of health information exchange in the early years. Under growing demands of 'integrated' information systems in healthcare, new infrastructures, standards, technologies, and entire scientific disciplines emerged alongside (and often intertwined with) existing ones. I characterize the role of the Dutch government in that process as one of detached involvement, where the Minister of Health alternately loosened and strengthened its regulatory control in health information exchange by delegating the development of concrete initiatives to 'the field', and by taking on a more directive role in health information exchange in recent years. I situate the emergence of Zorgportaal Rijnmond in entangled processes of infrastructural change – including technological developments, the rise of a new health IT market, the advent of regulated competition in healthcare, and a politics increasingly focused on consumerism, shared decision-making, and patient empowerment. I contend that the Zorgportaal Rijnmond case served as an intermediary between a long period of experimentation and uncertainty, and the recent emergence of a health information exchange market. I show how different lines of action temporarily converged around the portal project and then took off in different directions.

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[15] I focus on hospital information systems and their infrastructures; I deliberately ignore other electronic information systems in health information exchange, such as physician systems, clinical and nursing systems, and systems for outpatient care, which are less directly connected to the rise of health portals.

1.1 Mind the gap: early developments in the Netherlands and the United States

The origins of electronic health information exchange are diffuse and complex.[16] In the Netherlands, they can be situated by some approximation in hospital care in the early 1970s, when the work of healthcare professionals was in many ways protocolized and standardized, but still predominantly paper-based. Large quantities of information were transcribed and processed by dedicated clerks on mechanical or electric typewriters; depending on the built environment, patient records were archived in designated in-house storage facilities or in remote locations. It was in that period, and more specifically in Dutch teaching hospitals, that the first computer-based hospital information systems emerged. Early versions were based on American examples, the first of which was developed in Texas in 1959 (Collen and Ball, 2015: 347). Compared to their counterparts in the Netherlands, American hospitals benefited from advanced domestic infrastructures for research and development in computing. In addition, they were compelled to develop electronic information systems in light of the 1965 Medicare act, which required the aggregation of large quantities of data for the new patient reimbursement program (Berg et al., 1998; Berg and Winthereik, 2004; Collen and Ball, 2015). Doctors, nurses, managers, administrators, and pharmacists primarily used these new systems for billing purposes; from a clinical perspective, they "were still only incomplete prototypes that satisfied few physicians" (Collen and Ball, 2015: 375).

In the Netherlands, the rise of electronic hospital information systems had a more experimental character (Berg et al., 1998). In the late 1960s, the Dutch government expressed concerns over the 'increasing gap' with informatics and computer science developments in the United States, and feared the economic consequences of a 'brain drain' in the Netherlands (Bakker et al., 1978; Gibbels, 2013). It sought to reduce this gap by stimulating the applica-

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[16] To my knowledge, these origins are not comprehensively documented. They merit a study of their own; a comparison of different countries could provide insights in differences between national policy approaches.

tion of automation and information technologies in various sectors, including transport, agriculture, and healthcare. The Minister of Education and Sciences established committees and working groups to coordinate research and development initiatives in these areas. The focus in healthcare was on teaching hospitals, whose proximity to university departments allowed for direct access to scientists and technological support. The main aim was to boost the nations' knowledge economy; the emphasis was on stimulating innovation, knowledge production, and economic growth through public-private initiatives (cf. Janssen and Moors, 2013). Both the concern over a development 'gap' and its envisaged solution can be described as quintessentially modernist phenomena: they reflected the Dutch government's desire to bring the nation 'up to speed' or to 'close the gap' with other countries through science, technology, and industrialism (Geertz, 1995: 137).

Physically and technically, hospital information systems comprised of large, expensive mainframes running on high level programming languages and processing large volumes of data around the clock (Berg and Winthereik, 2004: 25). The mainframes worked in conjunction with smaller devices, such as computer terminals, external memory disks, magneto tapes, card readers, multiplexers, and line printers (Bakker et al., 1978). These systems were monitored and controlled by system administrators in dedicated computer centres: large rooms that were not foreseen in traditional hospital architectures, and that often competed for space with paper-based archives.[17] Early examples in the United States showed how layers of past and present infrastructures were interwoven; that new practices of ordering, storing, and archiving information emerged; and that work rhythms in healthcare were slowly changing. Doctors were gradually disciplined into new procedures for information recording that left scarce room for ambiguity or personalization; these problems were hardly recognized or researched – and indeed not defined in those terms – before the rise of human-computer interaction studies in the 1980s.[18]

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[17] For a discussion on the relation between hospital architectures and organizational efficiency, see Berg et al. (1998: 29–30).

[18] For an early example of human-computer interaction studies, see Card et al. (1983).

In the 1960s and '70s, little was known about the integration of hospital information systems in existing habits and routines; the main focus was on their design, architecture, and development. Hardware maintenance and technical support were provided by in-house personnel and external suppliers or vendors. In the Netherlands, these included multinational corporations such as International Business Machines (IBM), Digital Equipment Corporation (DEC), and Philips (Bakker et al., 1978; Gibbels, 2013). Code was written and tested by teams of software developers, who were typically recruited in informatics and mathematics departments, and who regularly consulted skilled professionals in other domains – including archivists, library scientists, and thesaurus experts. These systems-under-construction acted as boundary objects of sorts, in that they accommodated different types of knowledge and expertise and brought together different social worlds (Star and Griesemer, 1989). The latter not only included the worlds of the envisioned end-users of these systems (i.e., doctors, managers, and administrators), but also mathematicians, engineers, linguists, and maintenance workers. In addition, they laid bare the complex political challenges of information infrastructures; for example, they showed how competing machine programming languages such as FORTRAN and BASIC intersected with nomenclature standards for medical and clinical recording, notably the International Classification of Disease (ICD) and the Systematized Nomenclature of Medicine (SNOMED). These languages and standards were periodically revised, but also required on-going (and often literal) translations to be made actionable in local contexts (Latour, 1987; Bowker and Star, 2000).

As is slowly becoming clear, the beginnings of hospital information systems in the Netherlands comprised of a highly heterogeneous ecology of human and non-human actors, bound together in complex sociotechnical figurations with their own characteristics, histories, and dynamic (cf. Star and Ruhleder, 1996). In that sense, the programming languages and classification standards mentioned here merely represent the tip of the iceberg. In the following sections, I will tease out specific challenges and interests in the development of hospital information systems that further clarify the emergence of health information exchange. I will show that Dutch experiments aimed at ‘integrating’ information systems were primarily focused on organizational and logistic efficiency, and not as tightly coupled to administration and billing as their American counterparts. While academic infrastructures and government grants served as central nodes in knowledge networks in the early years, those networks were thoroughly reconfigured as commercial enterprises grew increasingly dominant in subsequent decades. To illustrate this process, I start by tracing the story of NOBIN-ZIS, the first hospital information system in the Netherlands.

1.2 Moving towards a ‘Total Hospital Information System’

In the late 1960s, the Royal Netherlands Academy of Arts and Sciences (Koninklijke Nederlandse Akademie van Wetenschappen) established a working group for the Diffusion of Scientific and Technical Information (Werkgroep Verspreiding Wetenschappelijke en Technische Informatie). The working group advised the Dutch Minister of Education and Sciences on the application of information sciences in various professional domains. One of its subgroups was the Medical Informatics working group (Werkgroep Medische Informatie), which in a 1969 advisory report articulated the contours of a “Total Hospital Information System with real-time and network characteristics” (Bakker et al., 1978: 6). Their proposal reflected wider concerns in public policy on questions of service management and operations in complex organizations; concerns that marked a departure from more established problems of documentation and archiving in information science. In 1971, these new concerns materialized in the establishment of NOBIN, the Dutch Foundation for the Advancement of Information Services (Nederlands Orgaan ter Bevordering van de Informatieverzorging).[19]

Under the auspices of NOBIN, a project group in the city of Leiden set out to create a hospital information system as envisioned by the Medical Informatics working group. NOBIN-ZIS was built in Leiden’s teaching hospital

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[19] NOBIN replaced the Institute for Information, Documentation, and Registers (Nederlands lnstituut voor lnformatie, Documentatie en Registratuur).

from 1972 to 1976 with the aim to "develop a real-scale experiment of an integrated application of the computer in a Dutch hospital" (Bakker et al., 1978: 10).[20] Funded by the Minister of Economic Affairs and the Minister of Education and Sciences, the project was supervised by Albert Bakker, who was appointed as professor of medical informatics to add leverage to his position in the hospital (Zwetsloot-Schonk, 2003).

NOBIN-ZIS comprised of a central database coupled to four sections: one for patient registration, one for communication in clinical work, one for administrative work, and one for advanced medical decision-making. Although similar subsystems had been developed earlier in the United States, this was still uncharted territory in the Netherlands (cf. Collen and Ball, 2015). The section for clinical communication included a medical record, a module for laboratory and radiology diagnostics, and one for pharmacy recipes; administrative work included patient appointments, visitor registration, and supply management and logistics; medical decision-making included progress notes, case histories, and 'critical care data' for acute interventions (Bakker et al., 1978: 44–45). The latter section required accurate and timely registration by doctors and nurses, and proved to be the most difficult to implement; it was eventually cancelled. All other sections were allegedly implemented according to plan.[21] Bakker and colleagues concluded that the integration of different systems and infrastructures in a hospital posed organizational, political, and economic challenges, and that persuading doctors to embrace new ways of registering data was particularly difficult (Bakker et al., 1978).

Undeterred by their inability to change doctors' recording habits, the Leiden project group foresaw new applications of NOBIN-ZIS. These included improved communication between primary and secondary care providers, and regional information exchange between hospitals. In their evaluation report, Bakker and colleagues speculated that:

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[20] ZIS is the Dutch acronym for Hospital Information System (Ziekenhuis Informatiesysteem).

[21] NOBIN-ZIS was later described as a 'partially integrated' hospital system (Gibbels, 2013: 20).

> […] an expansion is possible in a horizontal sense, with the initial focus being on the application of a group of hospitals in a region. Such hospitals have a large overlap in their patient base; moreover, some groups of specialists (e.g., radiology, bacteriology) exchange data with each other. From a technical point of view, it must be possible to adapt the system with limited effort so that a number of organizational units (hospitals) – with a degree of integration to be later determined – use a common physical database that allows exchanging specific types of data between some units. (Bakker et al., 1978: 185; own translation)

The quote exemplifies how questions of scalability were addressed in the project group: the goal of this horizontal expansion was to preserve the character of existing technological and organizations arrangements as much as possible (cf. Tsing, 2012). The thought that 'limited effort' would suffice to reconfigure different systems around a central database may suggest a certain degree of technological optimism by the authors, but may also have served to enrol new participants in this campaign. Overall, the report provides insights in how electronic health information exchange took shape in the Netherlands in the late 1970s. It did not start with a visionary anticipation of a future technology, but rather with the articulation of a technological possibility, or an imaginary of efficient information exchange that needed to be pencilled in. Elsewhere in the report, the authors clarified that a horizontal expansion would entail complex organizational, behavioural, and political challenges within and between hospitals (Bakker et al., 1978). In what follows, I describe how these ideas conflated with elements of the NOBIN-ZIS infrastructure to produce an 'installed base' for experiments in regional and national information exchange: an ecology of layered and interdependent infrastructures and software components that generated new standards, systems, and practices for storing and transferring electronic data (Hanseth, 2001: 59; Hanseth and Ciborra, 2007).

1.3 Emergence of an installed base

Under Bakker's guidance, NOBIN-ZIS became the starting point of what was termed a 'machine-independent' operating system for hospitals in the Netherlands. For this new initiative, teaching hospitals in Rotterdam and Utrecht joined the aforementioned group in Leiden in the non-profit foundation COZIS, a Development and Support Group for Hospital Information Systems (Centrale Ontwikkelings- en Ondersteuningsgroep Ziekenhuis Informatie Systeem) established in 1976 (Bakker and Kouwenberg, 1983). The aim of the project was to enable local data exchange between standalone minicomputer terminals and data repositories.[22] This was a complex sociotechnical challenge, in that it required the coordination, negotiation, and alignment of different languages, protocols, and hardware, as well as the cooperation of staff members in different hospitals. The use of programming languages is a case in point: the COZIS operating system originally ran on FORTRAN, which was the dominant language at that time, but switched to Pascal around 1978, as the latter was deemed more flexible and easier to use by young developers. This strategic choice for a different programming language points to the close intertwinement of standards, development work, and education in medical informatics, and illustrates how knowledge, expertise, and human resources in hospital information systems were reconfigured. Indeed, Pascal became the prevailing standard in IT education in the Netherlands in the early 1980s (Mol and Kouwenberg, 1984: 215).

COZIS was renamed BAZIS to pay homage to the work of Albert Bakker, and the dormant NOBIN foundation was dismantled in 1979.[23] In the early 1980s, the BAZIS operating system had little competition in the Netherlands. It gave hospital managers and healthcare professionals access to administrative data for logistics and billing, and to limited sets of clinical data. By the mid-1980s, approximately one million patients were registered in BAZIS, primarily through teaching hospitals (Zwetsloot-Schonk, 2003: 4). Backed by

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[22] Minicomputers were smaller and less expensive than mainframe computers running on general purpose, high-level programming languages such as FORTRAN and BASIC.

[23] See http://www.stichtingbazis.nl/historie.html (accessed 2 September 2022).

government funding, it now served as an installed base for hospital information system in the Netherlands (cf. Hanseth, 2001). In 1986, BAZIS started a partnership with Philips Medical Systems and the University Hospital of Utrecht to develop a Picture Archiving and Communication System (PACS) to store, view, and exchange radiological images. PACS added new complexities to the challenges at hand, as medical images were not automatically integrated in existing hospital information systems (Lodder et al., 1988; Kouwenberg et al., 1990). With that, the contours of a professional-oriented form of health information exchange became increasingly visible.

While medical image exchange expanded the scope of health information exchange, the proliferation of personal computers in the 1980s led to profound changes in the organization of healthcare administration. Hospital departments and general practitioners started building their own information systems for logistics and billing around desktop machines that gradually threatened the dominance of BAZIS (Berg et al., 1998; Ceruzzi, 1999). Meanwhile, there was an increasing choice of more affordable operating systems, programming languages, software applications, and hardware. These developments led to an escalation of complexity in information systems and infrastructures for primary and secondary care, and an intricate layering of domestic and foreign standards for computing and informatics (Røed et al., 2011).

Around the mid 1980s, new commercial enterprises developed ready-to-use software packages for primary and secondary care to capitalize on a growing demand for uniformity in information systems for logistics and billing (Berg et al., 1998). As new dependencies between hospitals and markets were taking shape, questions of choice and competition became increasingly important. One of the first companies to serve the American market was Epic Systems Corporation. In the Netherlands, the Dutch company ChipSoft introduced its first billing program for medical specialists in 1986.[24] Both enterprises gradually solidified their position in this emerging market, which included a growing range of clinical applications alongside medical records. Software

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[24] See https://www.chipsoft.nl/organisatie/4/Geschiedenis (accessed 2 September 2022).

packages by Epic and Chipsoft were generally touted as valuable and versatile propositions for both healthcare professionals and administrators.

By the 1990s, growing demands for accountability and transparency added new complexities to the development of hospital information systems. A decade of neo-liberal politics, expressed by the rise of new public management, gradually materialized in new expectations on healthcare provision in the Netherlands, including new demands on the registration of quality measurements, performance indicators, and benchmarking. These demands placed new strains on information systems in use; it was in this period that the number of commercial enterprises in health information exchange rapidly increased (Berg et al., 1998). In 1995, the non-profit organization BAZIS was privatized and sought international expansion,[25] while large automation companies such as Getronics and Roccade added patient care information systems and electronic health records to their catalogues (Gibbels, 2013). A new health IT market was in the making, in which hospitals outsourced highly specialized work to external consultants and vendors.

In the following section I describe a new form of fragmentation that ensued from these developments. This included the phenomenon of 'vendor lock-in', where hospitals were committed to contracts with specific suppliers concerning the use and maintenance of information systems. These new contracts were increasingly difficult to reverse, and point to increasing dependencies between healthcare organizations and IT markets.

1.4 Promises of distributed information networks

As in many other countries, the development of local information systems in the Netherlands led to an unruly landscape of incompatible media, applications, standards, and languages, or a 'patchwork' of heterogeneous technolo-

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[25] BAZIS was privatized as Hiscom in 1995, and sold to Dutch investment company Baan in 1998. Around that period, it also lost its leading position in the Dutch market. It was acquired by British automatization company Torex in 2001; Torex-Hiscom merged with the British iSoft Group in 2004, which was acquired by the IBA Health Group in 2007, and by the American IT company CSC in 2011.

gies and systems (Ellingsen and Monteiro, 2003). In medical journals and related publications, information systems in secondary care (including systems for interprofessional communication, administration, image archiving, and laboratory work) were often described as ‘siloed’ to designate their inability to operate with each other (cf. Kuperman, 2011: 678). In practice, healthcare professionals, pharmacists, and laboratory technicians were increasingly confronted with incompatible information systems in their daily work. As a result, they often continued using fax machines, telephones, diskettes, CD-ROMs, printouts, and other media to exchange medical and administrative information. These and other incompatibilities in information systems echoed the so-called ‘fragmented’ character of healthcare provision itself, and exposed a complex intertwinement of technical, organizational, financial, and cultural challenges at the same time (Otte-Trojel, 2015).

Throughout the 1990s, doctors and healthcare managers in the Netherlands expressed increasing concerns over poor and cumbersome access to information, a lack of interoperability between different systems, and inefficient, costly, and potentially harmful duplications and workarounds. They also called for ‘integrated’ forms of health information exchange in light of the on-going specialization of healthcare provision, the rise of co-morbidity treatments, and the advent of new ways of organizing care – such as clinical pathways, patient-centered care, and personalized medicine. At the same time, there were systemic shortages of healthcare providers and hospital beds in the Netherlands, as well as long waiting lists and increasing costs of care. In the light of these problems, doctors and policy makers turned their hopes to the promises of networked information technologies and the internet (Zwetsloot-Schonk, 2003: 6–7).

The emerging World Wide Web in the 1990s created new alternatives for archiving, retrieving, consulting, copying, distributing, and sharing information. Based on the TCP/IP protocol, this ‘network of networks’ entails a standard set of rules connecting different computer networks in a distributed arrangement. This meant that networks no longer existed side by side, as was the case in conventional information systems, but that each node in a network (be it a computer or a server) was connected to several other nodes (Stikker, 2019: 28–30). In the United States, policy makers recognized the infrastructural potential of these distributed arrangements, and started referring to the Web as an 'information superhighway' (Cogburn, 2016; Wyatt, 2004). They imagined unbridled opportunities in healthcare, including more inclusive and democratic forms of health information provision.

In the Netherlands, the number of access points to the Web steadily increased in the mid-1990s, most notably around university infrastructures that served research laboratories, banks, publishing houses, and media companies (see Appendix A, Figure 1); in healthcare, such access points were still largely unavailable at that time. The Dutch government made large investments in internet infrastructures in the decade that followed, ranging from the promotion and facilitation of large data centers and fiber-optic cables for broadband internet access, to internet courses in secondary education. More than ever before, information became a valuable commodity for healthcare organizations, governments, and markets. With that, figurations of health information exchange also became more patient-oriented, and new challenges arose in the governance of emerging online infrastructures.

1.5 Governing health information exchange

Amidst promises of increased efficiency, connectivity, democratization, and personal empowerment, in 1996 the Dutch government made a proposal for a national electronic health record (EHR).[26] Plans for the national EHR immediately raised new problems and concerns, including questions of privacy, ethics, and governance in the use of medical information. The Minister of Health intended to take up a 'facilitating' and 'enabling' role in this process, and to delegate the actual development to 'the field' of healthcare organizations and the market (Tweede Kamer der Staten-Generaal, 1996/1997). This delegation of tasks and responsibilities was questioned in a 1998 report published by technology assessment agency Rathenau Instituut:

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[26] I provide more details about this process in Chapter 2.

> The government […] has always been a central actor in the network. The government's current intention to leave the initiative and governance to 'the field' fits in the standard model of technology development (in which the government can only 'facilitate' or 'obstruct'), but does not align with the factual, historical situation. Since political questions such as the shaping of future health practices are in part also shaped by the development of chips, cables, and EHR software, […] we need to raise the question whether the government should take on a more active role in these matters. (Berg et al., 1998: 23; own translation)

The report referred to risks of vendor lock-in[27] and path dependencies that would limit design choices in the long term. Despite these warnings, in the following years the government consistently pursued a politics of detached involvement in health information exchange. Echoing Anglo-American examples of neo-liberalism and new public management, it facilitated innovation programs in this area, but delegated practical responsibilities to dedicated, external organizational bodies. Examples are the development of a 'basic infrastructure' (Aorta) for doctors and pharmacists in 2002, and the establishment of the national centre of expertise for e-Health (Nictiz) in 2003. The latter was effectively made responsible for the implementation of the prospective national EHR.[28]

Nictiz came to serve as an important knowledge hub for e-Health development and implementation in the Netherlands; it was one of several network nodes around which healthcare providers, standardization organizations, and policy- and lawmakers converged. In addition, new promises of digital healthcare and a national EHR were addressed in health-related policy advisory reports. Social concerns focussed on growing disparities between the 'haves'

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[27] Vendor lock-in denotes a situation in which a customer depends on a specific vendor for a product because the costs for switching to another vendor are too high.

[28] An equivalent of Nictiz in the United States is the Health Information Technology and Standards Panel (HITSP), established by Office of the National Coordinator for Health Information Technology in 2005 (Kuperman, 2011).

and 'have nots' in the digital world, and on the possible emergence of a new divide in health literacy. From an organizational point of view, it was unclear how the use of standardized and uniform software architectures, registration protocols, and nomenclature lists would be enforced; how doctors would be coerced to change their registration practices; and how a national EHR would work in different settings – including care provision, hospital planning, quality control, and public health research (Zwetsloot-Schonk, 2003: 6–7). Increasingly, policy reports from that period also suggested that markets were failing to tame problems of fragmentation in health information exchange.

In the light of this perceived market failure, the government gradually took on a more prominent role in health information exchange in the mid-2000s by releasing Nictiz of its EHR responsibilities, and repositioning it as an agency for digital standards and architectures in healthcare. It launched new legislation to authenticate healthcare providers and authorize access to health records, which included the introduction of an identification system for healthcare professionals (Unieke Zorgverlener Identificatienummer, UZI) in 2006, and the implementation of the citizen service number (Burgerservicenummer, BSN) in 2007. The latter replaced the old social security number; it was already in use in a wide range of social services, and became a compulsory identifier in patient administration and medical data exchange. At the same time, the mid-2000s were a period of transition in Dutch healthcare, as market-oriented healthcare reforms and a politics of 'regulated competition' between hospitals reconfigured the playing field of health information exchange, giving more agency to insurance companies and health IT vendors (cf. Helderman et al., 2005; Schut and Varkevisser, 2017; Zuiderent-Jerak, 2009).[29]

By the end of the 2000s, the national EHR was raising debates in Parliament over questions of data security and privacy, and its future looked uncertain (Pluut, 2010). Meanwhile, public discussions on the importance of patient autonomy and self-reliance intensified, and local cooperations between

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[29] This 'regulated competition' effectively started with the introduction of the Competition Law (Mededingingswet) in 1997, which legally transformed Dutch healthcare providers in entrepreneurs.

healthcare organizations and health IT vendors flourished. From this period onwards, countless e-Health initiatives were developed – often with the help of government grants – to enable online programs for shared-decision making and self-monitoring. The Dutch Council for Health and Society welcomed these developments, and described so-called 'care-captaining' programs as a new step in the direction of patient empowerment:

> With the development of new media, a new landscape in healthcare has emerged. Some exceptions aside, the patient is able to take control of his [*sic*] care: he becomes captain. He needs his care provider, the co-pilot, to help him in making the right choices. Currently there are still some bottlenecks for care providers and patients, which means that both are not yet able to take on their new role. (Gerads, 2010: 29; own translation)

In primary and secondary care these narratives became widespread, often echoing the suggestion that citizens *expect* or *demand* more control over their own care. Amidst an explosion of e-Health initiatives, which further increased the unruliness of the digital landscape in healthcare, vendors and government agencies started exploring the potential of health portals in the Netherlands. These portals initially served as gateways to hospitals, most notably for providing information and scheduling appointments; in that form, they quickly expanded to the social care domain. Portals were not only viewed as a solution to problems of access or fragmentation in information provision, but also became a way for organizations (and hospitals in particular) to distinguish themselves from their competitors in terms of patient-friendliness and patient-centeredness.

In a parallel line of action, by the late 2000s, the Dutch government was working on the development of LSP (Landelijk Schakelpunt), a 'national switching point' for health information. LSP is a decentralized indexation system that enables healthcare providers to view data stored elsewhere without having to access local databases. The anticipation of LSP in that period was important, as the Dutch government consistently advised against centralized forms of data storage in health information exchange. It emphasizes how processes of unification in health information exchange entailed political choices regarding architectures for information systems, which played out differently in different countries (McCarthy et al., 2014; Pluut, 2010; Vest, 2015). In the Netherlands, these choices were closely guarded by government agencies.

1.6 Portals for health information exchange

The development of the first online health portals in the Netherlands featuring an integrated EHR started around 2009. They were primarily hospital portals, developed in-house with the help of commercial IT vendors (De Mul et al., 2013). Typically, these portals allowed for restricted Web access to limited subsets of patient records within a specific hospital. By 2010, 25 portals in the Netherlands allegedly provided access to patient records; these included portals for hospitals, GPs, pharmacists, mental health organizations, the Dutch diabetes foundation, and Zorgportaal Rijnmond (Heldoorn et al., 2011). Most of these were stand-alone portals; they did not enable health information exchange with other organizations. One of the distinctive features of Zorgportaal Rijnmond was its regional scope: it was presented, among many things, as a frontrunner or 'use case' for a national standard for health information exchange the Netherlands (Weggelaar and De Mul, 2011).

Zorgportaal Rijnmond was meant to facilitate information exchange for health and social care in the Rotterdam Rijnmond region, and to provide information and services on well-being and prevention. The origins of this initiative can be traced to a small group of doctors, who had been advocating for a single online environment for health information exchange since the 1990s. They were dissatisfied with their inability to exchange basic information about patients, such as medical record data, test results, and discharge letters; they argued that it compromised patient safety in acute care, induced to errors in clinical handover, and caused unnecessary repetitions of diagnostic tests. Over time, they grew increasingly critical of the costly duplication of data-rich images on different hospital servers, the overall lacking interoperability of information systems, and the use of different standards and languages in medical registration; these things made their work increasingly inefficient, cumbersome, and expensive. With promising examples emerging in other countries in the 2000s, the doctors viewed an online regional health portal as a possible solution.

The ideas behind Zorgportaal Rijnmond were ambitious. The portal was expected to enable medical and health-related data and information exchange, and provide secure access to medical information by logging in via a government-approved, single-sign on authentication procedure. It was to feature generic and personalized health information for citizens, as well as e-Health applications for specific patient groups. Not in the last place, it had to support the work of doctors and other healthcare providers and organizations. The overall estimation was that Zorgportaal Rijnmond would make healthcare services more accessible, and that it would alleviate increasing demands on care provision in the Rotterdam Rijnmond region.[30]

Touted as a "development, implementation, and research project," Zorgportaal Rijnmond had four main objectives: to address information needs of citizens and increasing their self-reliance and autonomy; to create regional unity and uniformity in health information exchange; to facilitate and promote communication between other relevant actors in the region; and to stimulate new e-Health initiatives and related economic activities (ZPR, 2009: 4). The emphasis on self-reliance and autonomy was linked to the 2007 Social Support Act in the Netherlands, which transferred responsibilities for social welfare arrangements from the national government to municipalities. The attention for more unity and uniformity in health information exchange ran parallel to other standardization movements in Dutch healthcare, most notably the development of patient registries (see for example Vander Velde et al., 2005; Van Engelen et al., 2007). The focus on entrepreneurship reflected an advisory report by the Municipalities' Economic Development Board (EDBR) and the Rotterdam Development Corporation (Ontwikkelbedrijf

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[30] At the start of the project, in October 2009, the region comprised of eleven hospitals and a population of approximately 1.2 million citizens. On average, the 600,000 citizens of Rotterdam were less healthy and lower educated, and had a lower life expectancy than other citizens in the Netherlands (ZPR, 2009; GGD Rotterdam-Rijnmond, 2010).

Rotterdam, OBR) that championed healthcare innovation as a new 'economic opportunity' (EDBR, 2008). In line with that report, the final project plan described the portal as a 'platform' for cooperation and knowledge-sharing between healthcare entrepreneurs (ZPR, 2009).

The project was supported by a 600,000 euro grant from a special program of the Dutch Minister of Economic Affairs, which funded area-based initiatives that "contribute to sustainable economic growth in the Netherlands" (Van der Hoeven 2007: 7; own translation). The grant stipulated the application of new scientific knowledge to improve the quality, efficiency, and accessibility of healthcare, and the condition that a university would participate in the network (ZPR, 2009: 9). The fee was doubled by the Municipality of Rotterdam, who sought to position itself in national and international health innovation, and welcomed the portal project in light of the Social Support Act. The RijnmondNet Foundation, a Regional Health Information Organization (RHIO) that facilitates medical data transfer in the Rotterdam Rijnmond region,[31] acted as the project's secretary and served as its physical home base, where a consortium of healthcare providers, entrepreneurs, and researchers convened. In its original configuration, the consortium consisted of the RHIO, a teaching hospital (Erasmus MC), a regional hospital, a diagnostics lab, an internet hosting company, a communications agency, three consultancy agencies, and the Erasmus University Rotterdam (see Appendix B, Figure 1).

The portal was to include three applications to be developed in-house: an information system for care provision services, a video education system, and a Personal Health Record (PHR). Consortium members often described the PHR as the 'heart' of the project; it meant to serve all citizens in the region, and was becoming an increasingly compelling proposition in light of the political uncertainty around the national EHR's development. Consortium members saw that uncertainty as an opportunity to position their PHR as

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[31] The RHIO-concept was first promoted in the American Office of the National Coordinator for Health Information Technology to "address the governance, privacy, business, legal, technical and other organizational issues necessary to implement health-information exchange" (Kuperman, 2011: 678). In this study I use the RHIO acronym as equivalent of the concept of Regionale Samenwerkingsorganisatie (RSO) in the Netherlands.

a more feasible regional alternative. In doing so, they stressed the patient-oriented character of the Rotterdam Rijnmond initiative:

> The national EHR's functionality is currently limited to medication records and GP records, but the ambitions and possibilities in the Rijnmond region are greater. The electronic health record [for the Rijnmond region] needs to be made accessible through a health portal on the internet; a single access point to care provision and personal medical data for all inhabitants of the Rijnmond region, citizens or patients. (ZPR, 2009: 11; own translation)

In conjunction with this ambition of patient centeredness, the consortium framed 'the problem' of healthcare from an innovation deficit approach (cf. Pfotenhauer et al., 2019). Echoing the project's grant conditions, it signalled a lack of novel initiatives and ideas in healthcare to counter efficiency and capacity problems, and stressed that stimulating innovation would help to alleviate socioeconomic problems in the region. Using terms such as 'economic spin-off' and 'valorisation,' project documents linked socioeconomic motives to an urgency for innovation, and configured competition as a driver of innovation and development (ZPR, 2009). These terms placed particular emphasis on business and markets, and reflect the aforementioned Dutch approach to public-private initiatives for innovation, knowledge, and growth (cf. Janssen and Moors, 2013).

The portal was festively inaugurated in September 2011; this was five months after the Senate definitively rejected the legislative proposal for a national EHR. In 2012, at the end of the three-year grant period, Zorgportaal Rijnmond's formal objectives had been met: the portal's architecture included a single sign-on system for secure access to medical data, a video education system, an online support system for information on care provision services, and a PHR providing access to 200 patients of the teaching hospital.[32] In that

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[32] Patients included 100 head and neck oncology, cystic fibrosis, and haemophilia patients, and 100 staff members of the teaching hospital who also had a medical record at Erasmus MC.

same year, the aforementioned national switching point LSP was officially launched. However, Zorgportaal Rijnmond had failed to live up to its intended purpose as a regional infrastructure for health information exchange, and lacked a sustainable financial plan for its continuation and expansion. The consortium dissolved in August 2012, and the portal was quietly appropriated by the RHIO in 2013.

Two other health portal projects in the public-private domain started around the same time as Zorgportaal Rijnmond. MijnZorgnet was developed by Radboudumc, a teaching hospital in the city of Nijmegen. It featured a personal health record and patient communities, and enabled direct communication between patients and healthcare providers at Radboudumc (Vennik et al., 2014, 2015; Vennik, 2016). While it served as a successful platform for pilot initiatives in e-Health in the early years, it failed to keep up with changing market requirements, and could not compete with the rapid expansion of the 'personal health environment' MedMij; MijnZorgnet was discontinued in 2019 (Bukman, 2019). PAZIO was (partially) funded by the same government program as Zorgportaal Rijnmond, but had a different ambition; its aim was to become a national e-Health portal for patients (De Mul et al., 2013; Van Well, 2021). It was developed by a consortium including the teaching hospital UMC Utrecht, a regional health center group, and various government agencies and commercial enterprises. Although PAZIO was less focused on health information exchange, it was arguably more successful in carving out its own niche in the e-Health landscape. The focus in its development gradually shifted from regional to national care provision. Currently, PAZIO serves as an e-Health innovation platform for care and well-being.[33]

Although Zorgortaal Rijnmond, MijnZorgnet, and PAZIO differed in many ways – including their scope, target audience, and implementation strategy – all three aimed to serve as platforms for health-related information and services (i.e., to enable and support new developments in e-Health).[34] In their common ambition to provide a single access point for patient data,

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[33] See: https://www.pazio.nl (accessed 2 September 2022).

[34] Chapter 2 describes how health portals were construed as gateways, commodities, and platforms in medical science literatures and Dutch policy reports between 1995 and 2015.

they faced increasing competition from hospital portals with untethered (or standalone) PHR systems (cf. Otte-Trojel et al., 2015). From approximately 2015 onwards, many hospitals in the Netherlands developed (or had started to develop) their own portals in association with commercial enterprises; implementation consultants now frequently appeared on hospital floors.[35] Increasingly, portals became a commodity for individual hospitals and other healthcare organizations. Having their own portal made hospitals less dependent on third party platforms such as Zorgortaal Rijnmond, MijnZorgnet, and PAZIO, but more dependent on commercial platforms.

1.7 New developments, ongoing challenges

Despite a wide range of infrastructural initiatives developed around the national switching point LSP, problems of interoperability between commercial PHR development platforms persist. News reports continue to resurface about doctors struggling with incompatible standards for medical recording, non-interoperable information systems, and the government's inability to offer adequate solutions (cf. Heilbron and Koopman, 2018). A poll by the Dutch Federation of Medical Specialists, held in September 2019, showed that 55% of its members said to be confronted with poor data exchange between EHRs every day; 69% said to resort to fax in such cases; and 68% used email and telephone.[36] Some reported sending paper printouts and CD-ROMs via postal and courier services, or giving paper records to patients moving to a different hospital (Federatie Medisch Specialisten, 2019). In 2018, the Minister of Health promised to introduce new laws and standards for health information exchange and to accelerate its development (Bruins, 2018). Three years later, the Minister launched a legislative proposal for health information exchange (Wetsvoorstel elektronische gegevensuitwisseling in de zorg,

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[35] In 2021, 51 hospital information systems/electronic health records were provided by ChipSoft (HiX), 11 by Epic Systems Corporation (Epic), 7 by Nexus, and 5 by Cerner/SAP (IS-H) (ACM, 2021: 4).

[36] Members of the Federation of Medical Specialists include doctors in general hospitals, teaching hospitals, mental healthcare, and independent clinics.

Wegiz). Described as “a visible step in increasing government control over the digitalization of information flows in healthcare,” the proposal includes a legal framework for the use of open standards in health information exchange (De Jonge, 2021: 1; own translation).

Meanwhile, healthcare organizations continued voicing concerns about their increasing dependence on health IT vendors. In 2020, the Netherlands Authority for Consumers and Markets (Autoriteit Consument & Markt, ACM) commissioned an investigation into problems of vendor lock-in for health information systems (HIS) and electronic health records (EHR). In an interim report, ACM described these problems as follows:

> The practical implementation of the system often involves customization. The HIS/EHR system is adapted to the individual wishes of the hospital, and in doing so deviates from certain standard modules. In practice, differences in supply and different choices and needs of individual hospitals create a heterogeneous landscape of HIS/EHR systems. In addition, market offers are not always transparent and insightful in terms of interoperability and data sharing due to the (partial) lack of functionalities based on open standards, and the lack of unity in the programming languages and technologies in use. (ACM, 2021: 5; own translation)

In its first analysis, ACM confirmed that hospitals are highly dependent on their HIS/EHR suppliers, and that switching to a different system or vendor is complicated and expensive. They pointed out that hospital boards favored risk-averse strategies in relation to health IT in recent years, and that they currently make pleas for more regulation in health information exchange (ACM, 2021: 4). In line with the Minister of Health, ACM stressed the importance of cooperation between hospitals on the use of open standards for data structure, communication protocols, and access to HIS/EHR systems (ACM, 2021: 16).

Taken together, these developments illustrate how market regulators (ACM) and government legislation (Wegiz) became important new actors in health information exchange in recent years. The case of Zorgportaal

Rijnmond thus fits in a long history of attempts by different actors not only to integrate hospital information systems, electronic health records, and other information systems for medical and social care, but also to negotiate processes of fragmentation, centralization, and monopolization in a rapidly changing landscape. The story of Zorgportaal Rijnmond provides a close insight in how problems in regional health information exchange were framed, how solutions were sought, and what measures were taken in that process. Perhaps more importantly, the case is exemplary for how infrastructures and technologies come into being as part of messy, iterative, and largely unpredictable processes, which sometimes move in parallel lines, and sometimes drift apart in opposing directions (cf. Ciborra et al., 2001).

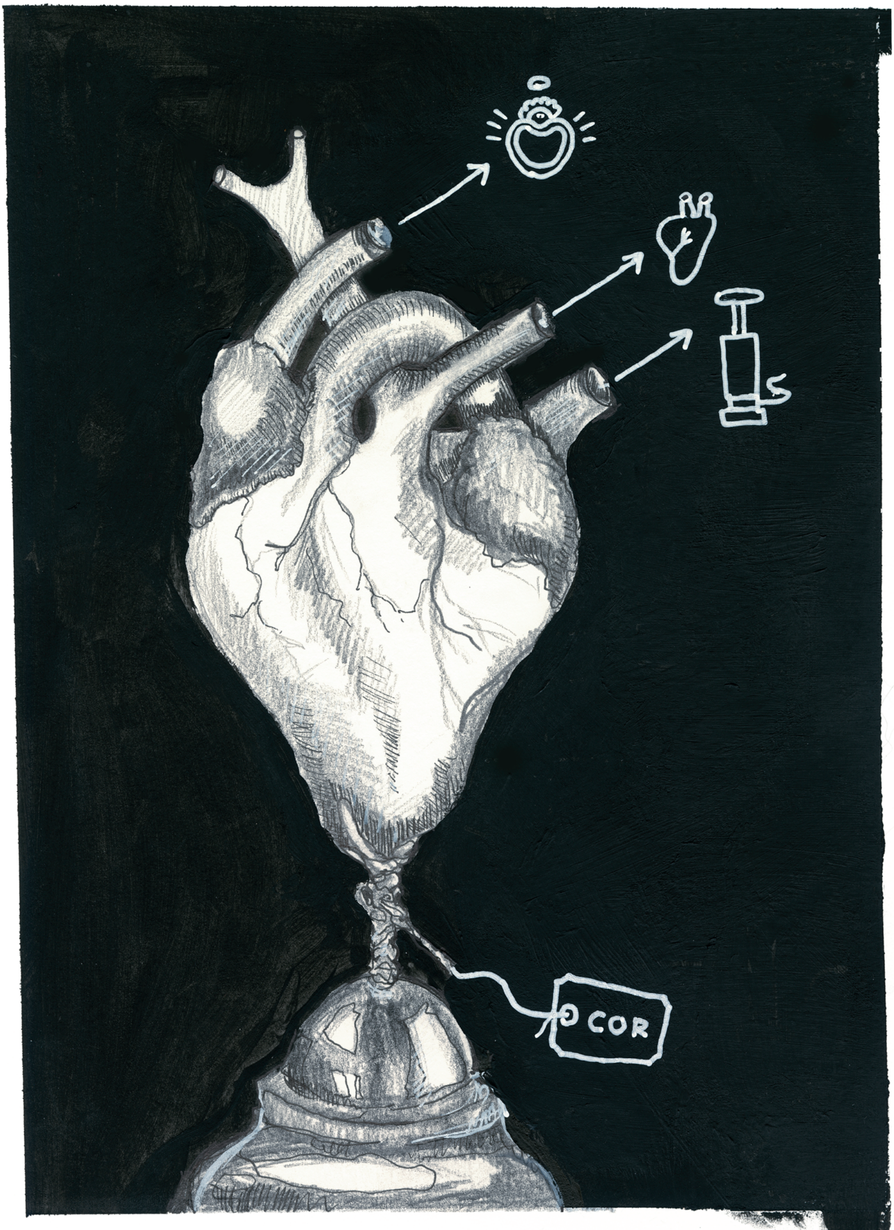
1.8 Concluding remarks

To answer the first question in this chapter – where and how did infrastructures for health information exchange originate? – I started my reconstruction in the United States and the Netherlands in late 1960s. I described how in the Netherlands, doctors took the lead in the development of electronic hospital information systems, but that their clinical use was initially outweighed by administrative motives. Teaching hospitals, government grants, innovation policies, hardware suppliers, and a wide range of experts from different (mostly academic) fields converged around early automatization and digitalization initiatives. In the wake of that process, specialized commercial enterprises were established, generic software packages were developed, personal computers made their way into healthcare, and the early contours of health information exchange became visible. Subsequently, a more organized market for health IT emerged. This went hand in hand with standardization processes, new practices, values, and expectations in healthcare provision, the rise of new professions, and countless other reconfigurations of people and things. At the same time, it led to new forms of fragmentation – most notably, problems of interoperability between commercial development platforms for EHRs and PHRs from the 2010s onwards. The Dutch government continued to subsidize and facilitate digitalization projects, but took on a more directive role in health information exchange in recent years. Old and new lines of action were thus intertwined in complex sociotechnical figurations that persisted to different degrees over time.

Looking at the actors and relations that were produced in this transformation, I described how health portals and the national switching point LSP sharpened the contours of health information exchange in the Netherlands. While the first four decades of my reconstruction were characterized by uncertainty, experimentation, and highly mobile, heterogeneous networks, recent developments suggest the emergence of relatively stable, but also densely woven networks of healthcare organizations, government agencies, and commercial enterprises. All actors and nodes in these networks were reconfigured: while insurers, patient organizations, health IT consultants, policy makers, and regulators gained more prominence, doctors lost their position as spiders in the web of health information exchange. With two commercial enterprises dominating the current EHR and PHR market in the Netherlands, policy makers, regulators, and lawmakers are increasingly mobilized to counter monopolization processes in the Dutch health IT market.

The development of Zorgportaal Rijnmond can thus be viewed as an intermediary between two related, but also distinct sociotechnical figurations in health information exchange: a long period of dynamic, fluid, and uncertain relations (in which the very notion of health information exchange was still in the making), and a short period of tightly knit relations in a crowded or saturated health information exchange market. My *longue durée* reconstruction dispels the view of health portals as a purely 'technological' innovation, and emphasizes how their development is entangled in broader continuities and discontinuities in healthcare, rather than simply being embedded in social or economic externalities (cf. Ciborra et al., 2001; Pollock and Williams, 2010). Insights in how these continuities and discontinuities are continuously (re)negotiated – both at an institutional level and in everyday practices – are crucial in addressing political and ethical questions on data ownership, infrastructural control, social inclusion, and the governance of health information exchange. As the following chapters will illustrate from up close, health portal projects (like Zorgportaal Rijnmond, MijnZorgnet and PAZIO in the

Netherlands) created spaces for experimentation and learning. They raised fundamental questions of governance and control, and paved the way for new standards and initiatives. Despite sociotechnical figurations of health information exchange becoming denser and more durable in this process, a seamless integration of different information systems containing patient data has been far from accomplished. Whether that ambition is at all attainable – or indeed desirable – merits more public debate and serious ethical scrutiny.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What's in a frame?

Introduction

Information exchange between doctors and patients is an integral part of healthcare. Scholars in organization studies – and information systems (IS) researchers in particular – describe a world of rapidly changing technologies and infrastructures in healthcare, and of shifting promises, expectations, and challenges for doctors, patients, nurses, managers, executives, and others (Boonstra et al., 2008; Davidson and Chiasson, 2005; Hanseth and Bygstad, 2015; Henwood et al., 2002; McLoughlin et al., 2016; Modol and Chekanov, 2014; Vassilakopoulou et al., 2016; Vikkelsø, 2005). Two important transformations in this context are the transition from paper-based to electronic medical records since the 1970s, and the provision of health information on the World Wide Web, which has its origins in the early 1990s (Berg and Winthereik, 2004; Cotten and Gupta, 2004; Hardey, 1999). Both developments entailed new ways of archiving, retrieving, consulting, copying, distributing, and sharing information, and new practices of data classification, measurement, registration, and interpretation. These practices echoed new modes of organizing, governing, and managing healthcare, as well as changing values of 'good care.'

Online health portals are among the countless innovations to have sprung from these developments. At the start of the 21st century, health portals came to serve as new technologies for disseminating health-related information and services. Increasingly, they also became technologies for health information exchange (HIE), or "the process of (electronically) sharing patient-level information across a network of actors, such as medical specialists, family physicians, pharmacists, and patients" (Pluut, 2017: 8; see also Vest and Gamm, 2010). Portals in the latter category provide access to electronic health records (EHRs) or personal health records (PHRs), and are often referred to as 'patient portals:' they allow patients to "maintain and manage their health information (and that of others for whom they are authorized) in a private, secure, and confidential environment" (Healthit.gov, n.d.; see also Davidson and Chiasson, 2015: 192). Health- or patient portals can also serve other purposes, such as facilitating patient education, self-management, and shared-decision making between doctors and patients (Otte-Trojel et al., 2014).

In IS literatures, portals have been researched in such diverse contexts as clinical encounters, patient engagement, business models, and public policy (Baird and Raghu, 2015; Cobb Payton and Kiwanuka-Tondo, 2009; Klecun, 2017; Klein, 2007; LeRouge et al., 2007). As the latter area is relatively underrepresented, the aim of this chapter is to explore how health portals have been discussed by various actors in and around healthcare in recent decades, and how this reflected in policy advice. Our empirical focus is on the Netherlands. Based on a critical discourse analysis of health portal related literatures published between 1995 and 2015 (Fairclough, 2012; Paul, 2009), we examine how dominant ways of framing health portals in internationally oriented medical science literatures reflected in policy reports by Dutch advisory boards. We raise three questions: how are health portals framed in medical science literatures? To what extent are those frames reflected in Dutch policy advisory reports? And what are the implications of those frames for the public governance of HIE in the Netherlands?

Analytically, we draw on the concepts of technological frames (Bijker, 1987 [2012], 1992; Orlikowski and Gash, 1994) and frame reflections (Schön and Rein, 1994) to explore the complex entanglements of scientific knowledge production and policy advice. The concept of technological frames has been widely applied in organization studies to understand "the underlying assumptions, expectations, and knowledge that people have about technology" (Orlikowski and Gash, 1994). Typically, such frames are researched in ethnographic studies on how different actors in an organization interpret (or give meaning to) new or emerging technologies. If we narrow down the scope to IS literatures, the main focus is on organizational practices relating to information systems, technological artefacts, infrastructures, and their users. Our approach differs from that body of work in at least three ways: we research technological frames in texts instead of (social or sociotechnical) interactions; we take a comparatively wide temporal scope; and we focus on policy rather than organizational concerns.

Our main premise is that different technological frames entail different problem definitions and solutions: they reveal differences in perspective between (more or less discernible) groups of people, and are consequential for processes of agenda-setting (Bijker, 1987 [2012], 1992; Orlikowski and Gash, 1994; Schön and Rein, 1994). With that, we view technological frames as inherently political: they bear real consequences for people and things; they play active roles in the transformation of healthcare; and they gain or lose their relevance across different settings (Bijker and Law, 1992; Bijker, 1987 [2012]; MacKenzie and Wajcman, 1999).

In this chapter we show how health portals have been construed as relatively uncontroversial technologies for HIE in the Netherlands, and how this went hand in hand with an increased market presence of IT vendors and suppliers, and a lack of centrally regulated or enforced standards for HIE. We argue that since the mid-1990s, the national government assumed a position of detached involvement in the development of large-scale HIE initiatives, and that both normalizing and radicalizing frames in medical science literatures and policy advice contributed to depoliticize health portals in the Dutch policy context. We discuss some of the underexposed questions, problems, and challenges pertaining to the public governance of HIE in the Netherlands, and briefly reflect on the relevance of technological frames and frame reflections in policy-oriented research in IS.

We structured this chapter as follows. First, we elaborate on our theoretical framework and methodological approach. Next, we sketch the role of the Dutch government in the emergence of HIE in recent decades. We then present our findings sequentially: each subparagraph describes a specific frame in medical science literatures and its reflection in policy advisory reports. We discuss our findings and conclude with brief observations on the broader implications of our study.

2.1 Theoretical framework

The sociological notion of framing is commonly attributed to Goffman (1974), and has been applied in many strands of research on technological development. A variation on framing is the concept of technological frames, which has been operationalized in different ways by different authors (Bijker, 1987 [2012], 1992; Orlikowski and Gash, 1994; Davidson and Pai, 2004). We build on Bijker's use of this concept, where it "refers to the ways in which relevant social groups attribute various meanings to an artifact" (Bijker et al., 1987 [2012]: 102). More precisely, a technological frame encompasses a set of assumptions, expectations, and knowledge about a technological artefact that "structures the interactions among the actors of a relevant social group" (Bijker, 1987 [2012]: 169). Deviating from a strictly sociological approach to framing, Bijker conceptualizes technological frames as relational and emergent properties between people and things: "Thus it is not an individual's characteristic, nor a characteristic of systems or institutions; technological frames are located between actors, not in actors or above actors" (Bijker, 1987 [2012]: 168).

We start from the premise that different social groups have different ways of attributing meaning to health portals. The technological frames they co-produce have a structuring effect on practices, institutions, and values in healthcare, but are mutually shaped by them at the same time. Each frame emphasizes a specific solution or problem to be solved, to the extent that a health portal can present itself "as essentially different artefacts" to different social groups (Bijker, 1992: 76; see also Bijker, 1987 [2012]). Taking these differences rather than similarities as our vantage point, we avoid essentializing health portals or reducing their meanings to a single definition.

Framing plays a constitutive role in how problems are defined, and has the potential to enable certain strategic choices while limiting others. In the context of policy-making, Schön and Rein (1994) describe framing as the work of different institutional actors who formulate problems differently, and thus mobilize different ways of 'doing.' The authors emphasize that frames reflect "culturally shared systems of belief," or more specific expressions of those belief systems, and that they are used by individuals and organizations in situations of public controversy (Schön and Rein, 1994: 33). In line with Bijker (1987 [2012], 1992), Schön and Rein stress that frames do not predetermine agency, and that "the same frame can lead to different courses of action" (1994: 35). We apply their notion of frame reflections to analyse discursive (dis)continuities, tensions, and gaps in Dutch policy advice.

Critical discourse analysis allows us to discern political, normative, and ethical assumptions underlying health portal narratives. We apply this method to show how wider discourses in healthcare are operationalized or 'put into practice' in text over time (Fairclough, 2012: 12). We do so by focussing on the wider political and strategic implications of different narratives, and by describing how they are (re)produced and (re)enacted by different institutional actors and relevant social groups as health portal technologies emerge (Bijker, 1987 [2012], 1992). Importantly, we recognize that texts always build on many frames at the same time, and that our analysis is an act of framing in itself (Goffman, 1974). Indeed, we subscribe to the idea that "those who construct frames […] do not do so from positions of unassailable frame-neutrality" (Schön and Rein, 1994: 36), and that a myriad of other discourses can be discerned in the texts we study.

In our analysis we make a distinction between normalizing and radicalizing frames. The former echo professional norms in medical practice that build on the 'traditional scientific doctrines' of evidence-based medicine, while the latter challenge those norms by promoting emergent societal or activist goals such as patient empowerment or the democratization of healthcare (Essén and Värlander, 2019: 464). We mainly use this distinction to highlight, categorize, and compare different political orientations in the narratives we studied, although we also describe some examples in which a 'blending' of normalizing and radicalizing frames occurs (Essén and Värlander, 2019: 459).

2.2 Methodological approach

We conducted a critical discourse analysis of health portal-related narratives in medical science literatures and Dutch policy advisory reports issued between 1995 and 2015. We organized our data collection in two rounds. The first round (conducted in 2015) entailed purposive samples in the PubMed/

MEDLINE database.[37] We collected abstracts in which health (or patient) portals were explicitly mentioned. Our searches were based on the following keywords: health portals, patient (web) portals, internet portals, web portals, and e-portals. We discarded search results in languages other than English, and instances in which the term 'portal' had a physiological connotation ("a communicating part or area of an organism" or "the point at which something enters the body"). This resulted in 873 abstracts of academic papers, trade magazine articles, and conference proceedings from various disciplines in the medical and social sciences, including biomedicine, medical informatics, communication sciences, and organization studies.

Using a focused coding approach (Charmaz, 2006) we read the abstracts and made handwritten notes to identify common terms and unifying themes. Our notes focused on the technical, cultural, political, and economic dimensions of health portals, which we view as congruent with the main topics in IS literatures. We categorized recurring terms and themes which led to four thematic groups: 'access', 'information exchange', 'monitoring' and 'integration'. Next, we scanned through 73 full papers in which one or more of these themes were addressed. We wrote down relevant sentences and frequently recurring terms (such as 'gateway') that helped us to identify three dominant frames: access to information and services, commodification, and personalization. We followed an iterative procedure to fine-tune and improve our analytical framework in this process (Paul, 2009: 247; see also Law, 2004).

In our second round of data collection (also in 2015) we looked for relevant policy advisory reports issued between 1995 and 2015 in publicly accessible digital databases of four Dutch governmental advisory boards: the Council for Health and Society (RVS),[38] the Netherlands Institute for Social Research (SCP),[39] the Dutch Scientific Council for Government Policy (WRR), and

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[37] See: https://pubmed.ncbi.nlm.nih.gov (accessed 2 September 2022).

[38] See: https://www.raadrvs.nl/about-the-rvs (accessed 2 September 2022).

[39] See: https://english.scp.nl (accessed 2 September 2022).

the Centre for Ethics and Healthcare (CEG)[40]. We excluded the National Technology Assessment Organization (Rathenau Instituut)[41] from our study, as their reports were not retrievable from their website at that time. We used the same keywords as in our PubMed/MEDLINE search, and extended our search to include electronic health records (EHRs), personal health records (PHRs), information and communication technologies, internet technologies, and the World Wide Web. We found texts referring to health portals and HIE in 34 publications by the Council for Health and Society (1996-2015) and in 16 publications by the Institute for Social Research (1997-2013); these include advisory reports, background studies, debate reports, discussion papers, explorative studies, reviews, and yearbooks.[42] The term 'portal' occurred twice in one report by the Scientific Council for Government Policy from 2010, and we found no explicit references to portals in publications by the Centre for Ethics and Healthcare (1995-2015).

We highlighted relevant excerpts from the Council for Health and Society and Institute for Social Research reports, and recorded them verbatim in separate Excel tables. We attributed an identification code to each entry, specified its source and authors, and added brief contextual information. We then analysed the content of these tables in light of the three dominant frames discerned from our PubMed/MEDLINE analysis. The bracketed 'PM' codes in our results section refer to sources from the PubMed/MEDLINE database (listed in Appendix C); the 'SCP' and 'RVS' codes refer to policy advisory reports (listed in Appendix D). Before we present those findings, we briefly sketch the role of the Dutch government in the emergence of HIE.

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[40] The Centre for Ethics and Health (Centrum voor Ethiek en Gezondheid) is a joint venture of the Dutch Health Council (Gezondheidsraad) and the Council for Health and Society (RVS).

[41] Rathenau Instituut is a 'knowledge institute' that advises the government on "socially relevant aspects of science and technology". See https://www.rathenau.nl/en/about-us/who-we-are (accessed 2 September 2022).

[42] See: https://www.raadrvs.nl/documenten (RVS); http://www.scp.nl/publicaties (SCP) (accessed 2 September 2022). Editions six and seven of SCP's yearbook on 'ICT and society' are not included in our study, as they were not freely available.

2.3 Health information exchange and the Dutch political context

Since the 1990s, governments across the world have pursued different strategies to explore national arrangements for what we describe here as health information exchange (HIE). Some chose to develop HIE around central data repositories (examples include the United Kingdom and Canada), while others (including the Netherlands and Denmark) opted for a more 'decentralized' or 'distributed' approach to data storage (McCarthy et al., 2014; Pluut, 2010; Vest, 2015). They also engaged differently with the practical challenges at hand: whereas the Danish government was actively involved in the creation of a national health portal (www.sundhed.dk), we characterise the Dutch engagement in HIE as a position of *detached involvement*. In what follows, we explain that position through a chronological reconstruction.

In 1996, the Dutch Minister of Health declared that the government would play a facilitating role in the rapidly expanding digitalization of information exchange between healthcare providers, and that it would focus its efforts on standardization measures. It was up to 'the field' (i.e., healthcare providers, insurers, and patient federations) to shape concrete initiatives (Tweede Kamer der Staten-Generaal, 1996/1997). Following advice from the Dutch Council for Health and Society (RVS), a year later the Minister promised to explore infrastructural requirements for a national EHR (Tweede Kamer der Staten-Generaal, 1997/1998). Subsequent advisory reports sketched the organizational and legal contours of these arrangements.

In 2000, the Minister invited representatives of umbrella organizations and interest groups to draft an action plan for the development of a national EHR, which ran parallel with the government's ambition to optimize the billing stream in healthcare (Tweede Kamer der Staten-Generaal, 2000/2001). Various versions of the EHR plan were criticized by general practitioners and patient federations, who expressed concerns over privacy, reliability, and safety (Heilbron and Olsthoorn, 2018; Pluut, 2010: 26). In 2002, the national centre of expertise for e-Health (Nictiz) was established to assist the

Minister with the EHR's development (Tweede Kamer der Staten-Generaal, 2002/2003; Krabben, 2010).[43]

In 2004, a new legislative proposal stipulated the compulsory use of a 'national switching point' (Landelijk Schakelpunt, LSP), which was intended to serve as the basis of the national EHR. This new indexation system was designed to obviate the problem of centralized information storage, and to provide general practitioners, pharmacists, and hospitals with access to a limited summary or core set of patient data. Citizens disapproving of their data being exchanged were granted the possibility of opting out. Despite heated public debates about the opt-out procedure, the proposal was approved by Parliament in 2009. A subsequent study by the national organization for technology assessment revealed persisting concerns among citizens about security and privacy of a national EHR (Ter Berg and Schothorst, 2010).

Similar concerns were echoed by the Senate, who rejected the legislative proposal in 2011 (Ten Ham and Bröer, 2016). In that same year, the Minister put plans for a national EHR indefinitely on hold (Schippers, 2011). A parliamentary report concluded that the involved parties (the Minister and 'the field') had collectively failed to establish sufficiently concrete and feasible goals (Pluut, 2010; Reerink, 2011). In 2012, responsibilities for HIE were delegated to the newly established Netherlands Association of Care Providers for Care Communication (VZVZ).[44] With that, public controversies over EHRs and HIE faded.

Running in parallel to these national developments, new standards and protocols for regional data exchange were being introduced, and many HIE projects were initiated on a regional level. Meanwhile, individual hospitals continued working on their own hospital information systems (Heilbron and Olsthoorn, 2018). Many hospitals experimented with local, small-scale PHR

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[43] Nictiz shared this task with CIBG, an executive agency of the Minister of Health in charge of registries in healthcare and education.

[44] VZVZ is an initiative of general practitioners, general practice centres, pharmacists, and hospitals in the Netherlands. The association developed a national switching point as an alternative for the national EHR. In April 2018 it served approximately 1,900 pharmacists, 3,900 general practitioners, and 79 hospitals (VZVZ, n.d.).

pilots and patient portals, often in collaboration with governmental agencies and external consultancy firms (Otte-Trojel et al., 2015). Increasingly, they contracted domestic and foreign health IT vendors and suppliers who introduced licensed software 'platforms' in the Dutch market (Ten Ham and Bröer, 2016).

In the Netherlands, commercial enterprises including ChipSoft, Epic, Nexus, Cerner, and Alert contributed to a growth of stand-alone (or 'untethered') portals and hospital information systems (Appendix E, Figure 1). Standards for HIE were not centrally regulated or enforced, and problems of national and regional interoperability persisted. In their daily work, healthcare organizations and professionals were confronted with an accumulation of information systems, and with 'hybrids' of licensed products and 'homegrown' systems (Petrakaki and Klecun, 2015). In this context of organizational change, market developments, and shifting political responsibilities and commitments, the Dutch government gradually sought to increase its regulatory control. Amidst these long-term political developments and reconfigurations, health portals were talked about in different ways, and acquired new meanings as technologies for HIE.

2.4 Three ways of framing health portals

In what follows we describe and analyse three technological frames for health portals. Each sub-paragraph refers to a specific frame in internationally oriented medical science literatures, and how that frame reflects in Dutch policy advisory reports.

2.4.1 Portals as a 'gateway' to health information and services

The 'gateway' frame in medical science literatures

Since their inception in the mid-1990s, health portals have been described as technologies providing access to health information and services. A frequently recurring term in that context is the gateway metaphor, which alludes to the etymological origin of the word portal ('like a gate'). We found multiple instances of portals described as gateways in science journals and trade magazines. In some cases, the term gateway featured as a product name for a U.S. based non-profit hospital and physicians network[45] (PM.153, 2007; PM.175, 2006; PM.185, 2004; PM.167, 2008; PM.189, 2004; PM.161, 2004; PM.237, 2005).

The gateway metaphor attributes spatial and architectural connotations to the portal concept. In other words, it conveys the idea of a physical structure that brings remote information within reach of its users. Conceptually, it aligns with the 'information superhighway' metaphor that originated in U.S. policy to emphasize the infrastructural potential of the World Wide Web (Cogburn, 2016; Wyatt, 2004). The term also helps to construe the view of information that 'travels:' in the exchange of health information and services, portal users either send or receive, request or deliver, ask or reply (PM.052, 2008; PM.383, 2007; PM.074, 2005; PM.255, 2001; PM.084, 2004; PM.289, 2009; PM.020, 2010; PM.722, 2011; PM.099, 2001; PM.055, 2008). Texts on access and accessibility attribute a sense of linearity to the flow of information, as the following excerpt from a study on the adoption of health information technology in the Unites States illustrates:

> Much of the data in physician portals are shared in only one direction: from hospital to physician. [...] (S)ome portals have transaction capabilities such as ordering tests or completing and signing medical records that allow data to flow back from physicians to hospitals. (PM.066, 2006: 1633)

Aside from linking portals to information flows, early texts present portals as a search tool and an instrument for information dissemination (PM.551, 2003). Literatures from the mid-2000s include mission statements by government-run portals heralding promises of order and structure in an otherwise over-

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[45] See: https://www.patientgateway.org and http://www.massgeneral.org/services/patientgateway.aspx (accessed 2 September 2022).

whelming e-Health landscape. Phrases such as "providing access to multiple sources", "providing easy access to quality information", and "designed to help you find appropriate, authoritative health information" (PM.082, 2005) help to construe portals as endorsers of content created elsewhere. Viewed from this perspective, portals are "only as good as the websites they lead to" (*ibid.*).

Problem analyses in the gateway frame emphasize (the removal of) access barriers in portal use, such as complex login procedures or unclear user instructions. To some degree, this suggests a 'normalization' of portals as accepted tools in medicine and healthcare (Essén and Värlander, 2019), or a 'stabilization' of health portal technologies (Bijker, 1992): evidently, the problem is in their use. To a lesser extent, the gateway frame includes concerns about a new 'digital divide' in access to healthcare (PM.053, 2008; PM.020, 2010; PM.722, 2011), where different social groups benefit from portals in unequal measure (PM.065, 2006; PM.067, 2006; PM.054, 2008). Describing the problem of access in terms of social disparities often goes hand in hand with calls to action; these 'radicalizing' frames prioritize narratives of democratization and social change over biomedical narratives of evidence and intervention (Essén and Värlander, 2019).

Although these examples point to a blending of normalizing and radicalizing frames in medical science literatures, most discussions about portals as gateways to information and services are firmly planted in biomedical discourses: they configure portals as technological extensions of 'good care' that require no further explanation. In addition, the gateway frame contributes to a view of doctors as experts and patients as lay people, and of hospitals, laboratories, and healthcare organizations as uncontested sites of knowledge and expertise. In this frame, portals act as gatekeepers of trustworthy, timely, and accurate information that travels from one site to another as a black-boxed (and seemingly neutral) entity (PM.142, 2009; PM.759, 2013; PM.784, 2013; see also Adams and Bal, 2009).

The 'gateway' frame in policy reports

In early policy reports by the Institute for Social Research, access to information and services is a prevalent theme. These reports signal a 'convergence' of digital technologies and infrastructures that make people less dependent on each other, while raising new problems as well (SCP.04, 1999; SCP.06, 2000). The unequal distribution of people who are expected to benefit from digital healthcare is one of the main concerns in the early years; reports argue that the 'domestication' of digital technologies (i.e., the extent to which they are incorporated in everyday life) proceeds at different speeds between different social groups (SCP.10, 2004; SCP.16, 2013). The elderly, ethnic minorities, illiterate people, and the long-term unemployed are said to be most at risk of being marginalized as 'participants in the information society' (SCP.10, 2004: 182).[46]

These concerns about a 'digital divide' in access to medical information and services (SCP.15, 2007) are intertwined with broader narratives of digital citizenship and civic engagement in 'the digital world' (SCP.09, 2003; SCP.10, 2004; RVS.16, 2010; RVS.27, 2015). The latter is described as a world inhabited by 'digitally savvy' people – i.e., high-income men under the age of 40 with a personal computer and a fixed broadband subscription (SCP.02, 1998; SCP.07, 2001). In this context, the problem of 'digital literacy' is presented in radicalizing terms as a marker of social inclusion and exclusion (SCP.07, 2001; SCP.08, 2002; SCP.09, 2003; SCP.10, 2004; RVS.18, 2013) and as a new form of capital, or an attribute of the 'healthy wealthy' (SCP.12, 2004).

Reports describe that the rise of customizable weblogs, personal profile sites, and social network sites in the mid-2000s has a 'normalizing' effect on online interactivity, and that engaging with others in the digital world is becoming part of everyday life (SCP.14, 2006; SCP.15, 2007). Some reports explore the policy implications of this changing reality in the context of digital citizenship, social equity, equality, and emancipation (SCP.09, 2003; RVZ.16,

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[46] Interestingly, the Netherlands always featured far above the European average in international surveys on internet use (ITU, 2018); Figure 2 (Appendix E) shows how that average compares with the rest of the world.

2010; RVZ.27, 2015). Increasingly, they describe citizens as skilled internet users, and urge governmental actors to place the quality and reliability of online information on the agenda (RVS.03, 2000; SCP.07, 2001; SCP.11, 2004; RVS.18, 2013). In the specific context of healthcare, they emphasize trust as an important theme in the provision of data and information (SCP.09, 2003).

A related policy concern centres on the ability for citizens/patients to make informed choices based on reliable and trustworthy information. The Institute for Social Research places this problem in the light of political reforms in the Netherlands that contributed to an increased emphasis on personal choice in care provision. These reforms included the introduction of a mandatory basic health insurance scheme provided by competing insurance companies (the 2006 Health Insurance Act) and the decentralisation of social support that requires increasing participation of citizens in informal care (the 2007 Social Support Act):

> In recent years, citizens are increasingly expected to take charge of their own health. Citizens are considered as active, skilled information seekers who welcome the freedom to arrange their own care. Examples can be found in Dutch healthcare policy, which is inspired by a new public management approach, just as in the United Kingdom and the United States […]. The idea behind this approach is that market mechanisms in the public domain will lead to greater cost efficiency for the community, without any negative side effects. Personal responsibility in care is a key element in policy and market developments. (SCP.15, 2006: 190; own translation)

Both the Institute for Social Research and the Council for Health and Society problematize this shift in responsibilities for citizens and patients. While they describe health portals as part and parcel of 'good care', they also warn against a rhetoric of techno-optimism. They seek different solutions in policy interventions, including suggestions to develop criteria and instruments for citizens to assess the reliability of information (RVS.03, 2000; SCP.09, 2003), certification programs for health portals (RVS.09, 2003), and concrete government initiatives such as the comparative website kiesBeter.nl,[47] aimed at helping citizens to make well-informed choices about their care provision (SCP.15, 2007; see also Adams and Bal, 2009; Henwood et al., 2003).

2.4.2 Portals as a commodity

The 'commodity' frame in medical science literatures

A vast body of medical science literatures explores the potential benefits of health portals for individuals, patient groups, professions, healthcare organizations, and society in the light of 'health consumerism' (PM.067, 2006; PM.068, 2006; PM.054, 2008). Editorials in health management journals present health portals as a medium through which healthcare can or should be delivered, as the following excerpt addressing general practitioners illustrates:

> In this era of consumer-driven healthcare, consumers (your current and potential patients) seek healthcare information on the Internet. If your practice doesn't have a Web site, or has one that's static and uninformative, you won't be found, and the patient will move on to the next practice Web site. [...] A practice Web site is a start, but the adoption of a fully functional, interactive Web site with patient portal solutions will not only improve patient-to-provider relationships but will also give the patient access to your practice from anywhere, at any time of the day. Furthermore, these solutions can help practices increase efficiencies and revenue, while reducing operating costs. (PM.128, 2010: 240)

Similar discussions on the strategic use of health portals can be found in different disciplines, ranging from financial management in hospital care (PM.021, 2010) to healthcare informatics (PM.028, 2010). They allude to the commercial exploitation of dedicated, licensed portals for the healthcare *market*,

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[47] https://www.kiesbeter.nl (accessed 2 September 2022).

and describe their advantages to 'end users' in terms of increased efficiency and quality of care delivery. Market analysts, health informaticists, and opinion leaders discuss portals as commercially viable products in a competitive arena, and present them as 'catalysts' of HIE (PM.066, 2006; PM.019, 2010). They attribute economic value to portals by studying their cost efficiency, return on investment, and willingness to pay (PM.066, 2006; PM.021, 2010; PM.036, 2009; PM.063, 2006; PM.038, 2008). In short, they configure portals as strategic assets that can yield profits for healthcare providers.

These narratives of commodification tend to frame doctors as clients, and patients as consumers of HIE technologies (PM.026, 2010; PM.067, 2006; PM.068, 2006; PM.099, 2001; PM.080, 2005; PM.074, 2005; PM.053, 2008). The latter are presented as people who seek to 'empower' themselves (PM.003, 2010), or as active participants in their own care process (PM.099, 2001; PM.036, 2009; see also: Curran and Curran, 2005). The following excerpt from the International Journal of Medical Informatics explains this transformation as the rise of a 'new breed of consumer':

> Healthcare delivery is being transformed by advances in e-health and by the empowered, computer-literate public. Ready to become partners in their own health and to take advantage of online processes, health portals, and physician web pages and email, this new breed of consumer is slowly redefining the physician/patient relationship. [...] First, however, physicians and the organizations that support them must fully understand their role in the e-health revolution. Both must advance their awareness of the new consumers and their needs and define specific action items that will help them realize the benefits of e-health. (PM.009, 2001: 1)

The excerpt illustrates how medical informaticists construe promises and expectations about portals and e-Health, and how they link these to 'raising awareness' about e-Health among the general public. A noteworthy initiative by the U.S. government in this context is the 2013 Blue Button program, a top-down "mechanism for providers" that sought to "engage and empower consumers to be partners in their health through information technology" (Himss.org, 2013).

Within this consumerist frame, portals are frequently linked to implementation problems. They are described as technologies that transform healthcare practices and organizations, but also as 'high-threshold' tools that require investments in research and development to become useful 'consumer products' (PM.067, 2006; PM.068, 2006; PM.054, 2008; PM.170, 2006; PM.155, 2007; PM.282, 2010). In this context, Kreps and Neuhauser speak of the "daunting responsibility to design eHealth tools that communicate effectively with a diverse array of healthcare consumers, providers, and policy makers" (PM.028, 2010: 329). The broader sense of responsibility to create viable and efficient products (PM.199, 2002; PM.032, 2009; PM.067, 2006; PM.054, 2008) suggests a neoliberal approach to HIE, where portal development is presented as both an economic opportunity and a social imperative.

Much like the gateway frame in medical science literatures, the commodification frame presents a blending of radicalizing and normalizing perspectives on portals and their users. The empowerment of citizens/patients is a central theme in this frame, but their voices are rarely heard; instead, doctors and health IT professionals serve as their spokespersons. This frame is embedded in narratives of technological optimism and hubris that show scarce attention for social disparities in health portal access and use. They also create little space for reflections on regulation or government intervention, and sustain the view of doctors as clients and patients as consumers of HIE technologies. Indeed, the commodification frame helps to promote the neoliberal idea that people and organizations in healthcare need to strategically anticipate, invest, and adapt to their changing environment by making use of their own resources.

The 'commodity' frame in policy reports

The policy advisory reports we studied draw heavily on U.S. policies and initiatives in HIE, and place much emphasis on questions of commodification. Most notably, early reports by the Dutch Council for Health and Society on quality of care refer to Kaiser Permanente's plans to develop a large-scale electronic patient record with the aim to provide better 'customer' treatment (RVS.08, 2003). These reports signal a new tendency where "care seeks patients instead of the other way around" (RVS.17, 2011: 26; own translation). They point to a consumerist framing of healthcare that is further elaborated in a series of reports on 'consumer e-Health' (RVS.21, 2015; RVS.22, 2015; RVS.23, 2015; RVS.26, 2015; RVS.28, 2015; RVS.32, 2015). This new concept is presented as part of a shifting paradigm in healthcare:

> Consumer e-Health stretches the concept of 'health' because more and more [digital, networked] products and services allow users to examine certain aspects of their lives (such as their diet, sleeping patterns, exercise, work and stress) from the perspective of health, functioning and well-being. (RVS.28, 2015: 2; own translation)

Highly reminiscent of Eysenbach's (2000) concept of consumer health informatics, the Council for Health and Society champions consumer e-Health (see also Hordern et al., 2011) as an alternative to 'professional e-Health.' Whereas the latter focuses on disease management and cure (and is meant to reach patients or citizens "via medical channels"), consumer e-Health is aimed at "stimulating health competences" and "changing (unhealthy) behaviour", and is said to be easier to implement (RVS.22, 2015: 15). Examples include smartphone applications, lifestyle gadgets, 'health platforms,' and PHRs (RVS.26, 2015: 6). These products and services are offered to citizens "straight from the market [...] without the intervention of healthcare providers" (RVS.21, 2015: 22; own translation).

While the commodification frame in medical science literatures reveals both normalizing and radicalizing features, the 'consumer e-Health' approach in the advisory reports is decidedly radicalizing. Explicitly building on critical theories by Giddens (1994) and Beck (1994), one Institute for Social Research report describes consumer e-Health as an alternative, neoliberal mode of self-control in which market mechanisms are directly invoked (SCP.09, 2003). Here, health portals no longer act as neutral intermediaries, but rather mediate between 'the self' and health(care) as a 'reflexive project' (SCP.09, 2003: 74). This implies a view of portal users as reflexive individuals (be they citizens, patients, clients, or customers) rather than passive recipients of health information and services.

In this frame, the problematization of portals acquires an ethical-philosophical character: consumer e-Health is said to reconfigure the 'life-politics' of modern individuals, which entails the urge to "connect political and societal goals to the 'project of their own life'" (SCP.09, 2003: 76). In our interpretation, this no longer configures the individual citizen as a 'partner of exchange', to use Foucault's description of the 18th-century liberal view of the homo economicus, but as a rational, competent, and calculating 'entrepreneur of himself' (*sic*), and as 'someone manageable' and 'eminently governable' (Foucault, 2008: 270–271).

The consumer e-Health perspective in policy advisory reports situates portals in questions of social change, where the citizen/patient is presented with new responsibilities in an 'uncertain' world (SCP.09, 2003: 75; SCP.13, 2005: 160). While it foregrounds concerns about trust and reliability in relation to HIE, it glosses over political questions of control and accountability over third-party information and services. Although the sense of urgency around these questions is underexposed in the documents we studied (1995-2015), it grew considerably after 2020, when the Netherlands Authority for Consumers & Markets (ACM) asked consultancy firm KPMG to conduct a market survey on hospital information systems and HIE in the Netherlands.[48]

2.4.3 Portals as a 'platform' for personalized care

The 'platform' frame in medical science literatures

Echoing the view of reflexive individuals making informed choices, many references to portals are embedded in narratives of personalization in healthcare – a concept that is rarely problematized in the medical science literatures

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[48] See: https://www.acm.nl/nl/publicaties/acm-start-marktverkenning-naar-informatiesystemen-en-gegevensuitwisseling-ziekenhuiszorg (accessed 2 September 2022).

we studied. In the context of disease management, decision-making, self-help, and consultation, personalization is generally associated with information that is "tailored to the needs" of patients (PM.099, 2001: 2). Here, portals tend to be described as 'platforms' rather than gateways. Like the gateway metaphor, the platform confers spatial and architectural connotations to portals; however, it denotes a site of exchange rather than an access point.

The emphasis on exchange suggests a more symmetrical view of the relation between doctors and patients than in the previous frames. That symmetry is most visible when portals are discussed as 'platforms for PHRs' (PM.602, 2010; PM.722, 2011), and when concerns are raised over data ownership, privacy, and control of 'patient data' in HIE (PM.184, 2004; PM.442, 2006; PM.378, 2008; PM.034, 2009; PM.303, 2009; PM.826, 2012, PM.796, 2012; PM.777, 2013; PM.779, 2013). In these frames, portal users are configured as active participants in their own care. Authors signal a transition from "the old, linear 'expert message sender to receiver' approach" to a situation where 'laypersons' actively contribute to their own medical treatment (PM.028, 2010: 33; PM.719, 2011; PM.799, 2012). More even-handed concepts such as participatory or user-generated health information (sometimes referred to as 'health 2.0') are closely associated with the platform metaphor as well (PM.046, 2008; PM.777, 2013).

The platform metaphor accentuates the distributed character of responsibilities in the production and exchange of patient data, and points to a more disruptive or radicalizing perspective on healthcare than the gateway metaphor. Examples are doctors and patients engaging in the "sharing of distributed patient information" (PM.086, 2004), programs for home care, self-management, and disease treatment (PM.179, 2005; PM.264, 2010), and research collaborations between clinicians, researchers, advocacy groups, and patients (PM.127, 2010). At the same time, the platform metaphor operates within the boundaries of biomedical discourses of 'integrated healthcare' and 'personalized medicine', where patient portals, genomics portals, and molecular experiments in bioinformatics play facilitating roles rather than transformative ones (PM.029, 2010; PM.766, 2013). Similarly normalizing connotations of 'online platforms' occur in relation to local health programs and projects (PM.043, 2008; PM.016, 2005), the screening of individual patients with chronic conditions (PM.051, 2008), the monitoring of patient groups at a distance (PM.188, 2002), and the expansion of knowledge bases (PM.025, 2010). In each of these cases, doctors are still 'in the lead' as experts in the exchange of knowledge and information.

When portals are framed as platforms for personalization, problems are formulated in the light of technical and organizational challenges, and concerns mainly relate to standards, protocols, semantics, security, and interoperability (PM.086, 2004; PM.189, 2004; PM.351, 2009; PM.417, 2006; PM.411, 2007). To a lesser degree, portal users and their ways of 'experiencing' online platforms come to the fore (PM.023, 2010; PM.198, 2003; PM.003, 2010), as do notions of user involvement in portal design and development (PM.378 2008; PM.131, 2010). Crucially, the platform metaphor has a concealing effect on portals: in narratives of personalized and/or integrated care, the platform metaphor often serves as a linguistic substitute of the portal concept. A discursive conflation of 'portal users' and 'PHR users' occurs, in which portals gain an infrastructural character and gradually disappear to the background as tacit or implied technologies (cf. Lampland and Star, 2009).

The 'platform' frame in policy reports

The framing of portals as platforms for personalization in medical science literatures is only vaguely reflected in the context of future technological trends in an early report by the Institute for Social Research on the digitalization of Dutch society (SCP.06, 2000: 86). This report discusses the 'individualization' of services that are thought to emerge "independently from information platforms" in the 2010s (SCP.06, 2000: 94). While links to personalization are made in reports discussing the unmet promises and expectations of PHRs (RVS.08, 2003; SCP.15, 2007; SCP.16, 2013; RVS.20, 2014), the absence of explicit references to portals in these contexts illustrates their aforementioned invisibility as HIE technologies.

Policy reports that reflect the platform and/or personalization frame tend to foreground questions of governance and strategy. The Council for Health and Society frames issues of control, protection, and ownership of (personal) data in PHRs from a predominantly legal and a political perspective. In the former case, control and ownership of medical data are presented as legal barriers to overcome (RVS.24, 2015); in the latter case, questions of patient participation are raised (RVS.18, 2013; RVS.21, 2015). One report stresses that citizens are still not 'in control' of their own treatment, and that they often experience difficulties in accessing their medical record; it laments the slow transition from a 'paternalistic' to a more 'interactive' doctor-patient relationship (RVS.18, 2013: 22). If these insights suggest a radicalizing perspective on HIE, they are also accompanied by a very specific political agenda. The following excerpt shows how the Council for Health and Society champions public-private partnerships in the development of HIE technologies as a shared responsibility between the government and the market:

> [...] the Council advises the government to stimulate the organization of a neutral system of binding agreements and uniform standards for data exchange between consumer eHealth applications and professional eHealth on the basis of public-private partnerships. This could be linked to the adoption of international standards. One of the starting points must be that the consumer/patient has a say in this process. (RVS.21, 2015: 56; own translation)

The excerpt illustrates how the Dutch government's position of detached involvement in HIE is construed in policy advice. By referring to a 'neutral' arrangement for HIE in which different field parties have their say, it simultaneously affirms the long-standing position of the Minister of Health on this matter (Tweede Kamer der Staten-Generaal, 1996/1997), and negates the politics of those arrangements. Elsewhere, the report refers to the use of 'Trusted Third Parties' for authorization and authentication procedures (RVS.21, 2015: 58); while it does allude to complex dependencies between different stakeholders in HIE, it only emphasizes the urgency of a shared commitment between all parties involved. As seen earlier in the context of medical science literatures, the problem of portals is effectively reduced to a problem of PHR implementation.

2.5 Portals as uncontroversial technologies for health information exchange

In our discursive analysis, each frame accentuates and hides different health portal ontologies. The gateway frame in medical science literatures prioritizes the role of portals as neutral instruments in healthcare, be it to gain access to health information from hospitals, general practitioners, or other sources. It largely ignores the transformative role of portals in organizations, and implies a view of patients as passive recipients of care. This frame also glosses over the work required to design and develop portals, and therewith obscures the politics inscribed in those processes (Ellingsen and Monteiro, 2003, 2006; Jæger and Monteiro, 2005). By contrast, the commodification frame foregrounds the impact of portals on the care process. It highlights their embedding in organizations and markets by configuring their users as clients or customers. Although it presents portals as instrumental to innovation and change, the deeper political implications of those processes remain largely invisible (Janssen et al., 2015). Finally, framing portals as a platform places more emphasis on the transformative character of technologies and their users, the (re)distribution of responsibilities between individuals, organizations, and institutions, and questions of standardization. However, the role of governments and markets in those contexts remains opaque.

Compared to the medical science literatures in our study, Dutch policy advisory reports approach questions of access, commodification, and personalization from a more radicalizing perspective. The Institute for Social Research does so by highlighting the importance of *structural* and *cultural* challenges in the governance of HIE (mainly through concerns over inclusivity and participation), whereas the Council for Health and Society primarily underlines the *infrastructural* challenges at play (cf. Bate et al., 2008). It is important to note that in the Netherlands, the Institute for Social Research and the Council for Health and Society have an active role in staging healthcare policy: they have "powerful positions as 'arbiters' of the playing field of policy makers" and "simultaneously legitimize government's attempts to redirect and depoliticize political problems" by means of scientific advice (Van Egmond and Bal, 2011: 112). Our analysis shows that in some instances they call the government and the private sector into action, while in others they provide critiques of technocratic and neoliberal discourses in e-Health. Furthermore, it suggests that policy advisory reports contribute to demarcate the boundaries of the policy debate by (intentionally or unintentionally) circumventing potential political controversies over ownership and control in HIE arrangements. Although these staging and demarcation mechanisms are often less visible in medical science literatures, they occur there as well (Van Egmond and Bal, 2011: 110).

Taken together, the narratives we discerned in Dutch policy advisory reports (1995-2015) paint a picture of portals as uncontroversial technologies for HIE. Whereas in the early years members of Parliament raised questions about monopolization in the health IT market (Tweede Kamer der Staten-Generaal, 1997/1998), the government consistently construed the development of HIE as a shared responsibility between different stakeholders 'in the field.' It is worth adding that healthcare insurers became increasingly active as champions of e-Health services in the Netherlands, and that some insurers announced measures against contracted providers who refused to use those services (Robben et al., 2013; Van Dorrestein, 2014). Questions about their involvement in the funding and development of health portals (or related initiatives) were not raised in the materials we studied. Adding to this, IT vendors and suppliers played an increasingly important role in health portal development in the Netherlands (see Appendix E, Figure 1). Much in the same way, the implications of private involvement in the development of hospital information systems were either circumvented, or not articulated from a political or critical perspective at all (cf. Greenhalgh et al., 2009).

The three frames we discerned in our study helped to construe health portals as uncontroversial technologies for HIE, and to normalize the Dutch government's position of detached involvement in this context. In directing the focus on social inequalities, market opportunities, and strategies for change, policy advisory reports mainly held up a mirror to 'the field,' which hindered reflexive questions about government regulation and commercial interests in health portal development. This is congruent with the analysis by Ten Ham and Bröer (2016) that after failed governmental attempts to introduce a national EHR, Dutch organizations in charge of disseminating new regional HIE protocols were successful in 'depoliticizing' their campaigns – and thus in preventing new public controversies – through strategies of adaptive regulation and governmentality (i.e., by making 'the field' responsible for local protocol implementation).

Overall, our analysis reveals the contours and reconfigurations of neoliberal discourses in the public governance of e-Health in the Netherlands. The Dutch governments' position of detached involvement in HIE fits in a broader neoliberal shift in healthcare and science that originated in the early 1980s (Abraham and Ballinger, 2012; Bal and Halffman, 1998; Cohen et al., 2002) and that entailed "new political commitment to expand market relations into traditionally public arenas" (Lave et al., 2010: 661). In healthcare, that shift found its expression through such concepts as 'evidence-based medicine,' 'benchmarking,' and 'clinical governance' (Winthereik et al., 2007) that we associated with normalizing frames in medical science literatures. Those frames often go hand in hand with rationalist, functionalist, and technocratic solutions that obscure any political implications or consequences.

From a pragmatic perspective, the discursive construction of portals as uncontroversial technologies may be regarded as an accomplishment, given the potentially disruptive effects of controversies on innovation. However, failing to problematize their embedding in public-private partnerships leads to an incomplete picture of the political and sociotechnical challenges at hand. More importantly, it pays little service to solving long-standing problems of fragmentation and interoperability in HIE, or to the further development of portals in that context. Indeed, the increasing presence of commercial IT vendors and suppliers in the Dutch health portal landscape may have obstructed that process by contributing to a dissemination of stand-alone hospital information systems. The rise of licensed 'platforms,' which allowed hospitals to update their internal information systems and to advertise their presence in the healthcare market, was never questioned in that light.

2.6 What's in a frame? Two additional reflections

In this chapter we described different social constructions of health portals between 1995 and 2015 in very broad terms. We do not wish to suggest that there has been, at any time, common agreement on what a health portal 'is' or 'does.' Our study shows how different portal definitions coexist: each one foregrounds some aspects of what a portal 'is' or 'does' while glossing over others. Although our analysis includes texts about hospital portals, patient portals, and generic health portals, it reveals only part of their ontological multiplicity (Strathern, 1991; Mol, 2002), which is produced in a variety of other contexts as well – including government websites, academic repositories, and professionally and privately curated weblogs.

The three frames we discerned in our analysis show continuities and discontinuities in HIE over a period of two decades, where some narratives persisted, and some moved in new directions. What persisted was a focus on organizational and technological concerns on how to develop, organize, implement, and govern HIE in practice. In the Netherlands, these concerns tied in with ambitions of patient-centeredness and empowerment, but also foregrounded the importance of markets and business cases (i.e., questions of ownership, finance, and reimbursement). A change we noticed in Dutch policy narratives – most notably towards the end of our data collection and after 2015 – was an increasing focus on personalization in HIE. This reflected in more attention for self-management, measurement, and quantification as techniques of care and prevention. In that process, the term portal increasingly came to designate patient portals (i.e., tethered to individual hospitals or specific healthcare organizations) or generic health portals for primary care, such as MijnGezondheid.net. In the Netherlands, the 'personal health environment' (*persoonlijke gezondheidsomgeving* or PGO in Dutch) gradually came to replace the portal concept.[49]

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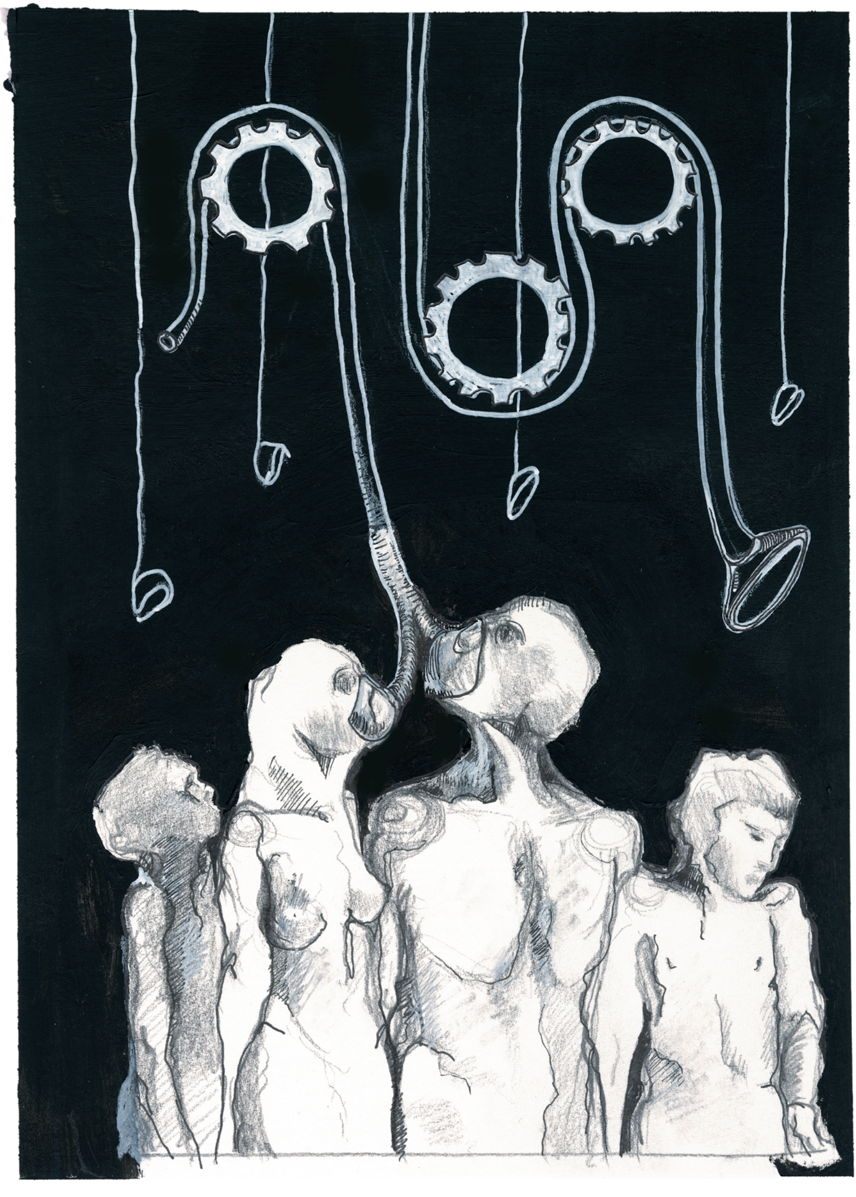
[49] PGO is loosely described as a website or application where one can consult their medical record, and in some cases also add personal health-related measurements (such as weight or blood pressure). See: https://www.pgo.nl (accessed 2 September 2022).

The lack of public controversies about health portals means that we were unable to show clear demarcations between social groups (Bijker, 1987 [2012], 1992; Orlikowski and Gash, 1994; Schön and Rein, 1994); we believe that those differences are more likely to emerge from detailed case studies. As we conducted our data collection and analysis in 2015, we were not aware of (or influenced by) later developments in the Dutch context – including new government funds for improving information exchange in hospitals (Tweede Kamer der Staten-Generaal, 2016/2017: 15), new advice by the Council for Health and Society on the advancement of interoperability in HIE (Karadarevic, 2017), and a legislative proposal for health information exchange (De Jonge, 2021). In our latest revision of this chapter, we avoided adding retrospective layers of interpretation to our analysis in an effort to preserve its contemporary character.

2.7 Concluding remarks

Our analysis of health portal narratives shows that over a period of two decades, dominant discourses on the provision of (or 'access to') information and services were gradually flanked by consumerist approaches to e-Health, where the citizen/patient is configured as an active participant making informed choices, and by related discourses of personalization. The three frames we discerned in medical science literatures and policy advisory reports (i.e., portals as a gateway, a commodity, and a platform) reflect different repertoires of action in the governance of e-Health in the Netherlands, but have shared implications as well. Firstly, they contribute to a normalization of the government's position of detached involvement in HIE, as they (intentionally or unintentionally) help to circumvent potential controversies on market dependencies and government regulation. Secondly, they sustain a narrow scope of problem definitions (i.e., questions of development, implementation, and use) that helps to construe health portals as uncontroversial technologies, or as *normal* elements of healthcare that gradually become invisible in HIE narratives. This normalization translates into scarce critical attention for the underlying mechanisms of portal and HIE development, particularly where it involves the increasing role of markets; the latter are evidently unable to stimulate integration efforts on their own, and are making their clients more dependent on their products and services. By repeatedly calling 'the field' into action, the Dutch government is likely to perpetuate problems of fragmentation and interoperability in healthcare, while contributing to the formation of new monopolies in the health IT market.

We see several benefits in the use of technological frames and frame reflections for policy-oriented research in IS. Firstly, this method can help to reconstruct past controversies and policy challenges, and to identify spaces for dialogue in the present. We called technocratic, rationalized, and 'depoliticized' models of social organization into question, which may help to place alternative, critical approaches to health portal development and implementation on current agendas. Secondly, it allows for an even-handed approach to political and/or normative statements about production, growth, development, implementation, and ethics in technological and infrastructural initiatives in IS. In our results, we placed many terms and expressions between single inverted commas to flag these normativities, and to emphasize their origins in the materials we studied. Thirdly, this method helps to connect pragmatic recommendations for the work floor to organizational challenges and national government policies. While these are often analysed in isolation, the combination of technological frames and frame reflections enables identifying patterns in policy across different levels of abstraction, and showing how they interact and blend in practice.



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Reframing technologies, reconfiguring users

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Introduction

Promises and implications of e-Health and telecare for patients with chronic illnesses have been widely researched in recent years (Langstrup, 2013; Oudshoorn, 2011; Pols, 2012). Much attention has been given to practices of designing and developing such technologies. A small number of researchers carried out this work from a patient-centered e-Health (PCEH) approach (Grandhi and Osatuyi, 2018; Koumaditis et al., 2015; Wilson, 2009; Wilson et al., 2014). PCEH is a conceptual framework in which patients are actively involved in their own treatment through digital technologies – for instance by providing patients direct access to their medical records, or by allowing online interaction with their healthcare providers to support their self-management practices. Touted as "a new way of thinking about how to apply IT for the betterment of patients" (Wilson, 2009: xvi), PCEH differentiates itself from more traditional information systems and applications focused on professional use. PCEH entails new ways of doing care that accommodate professional and non-professional concerns at the same time (Wilson, 2009).

Designing and developing PCEH-oriented technologies requires complex alignments between different people and things. These include patients, doctors, nurses, healthcare managers, and executives, as well as technological and organizational infrastructures, information systems, platforms, financial arrangements, and legal frameworks. In addition, PCEH necessitates strategies for making patients actionable, and making interventions with these applications valuable or meaningful for both providers and recipients of care (Wilson, 2009).[50] Ideally, PCEH starts with active user involvement in the design and development process. A major challenge lies in the "inherent tension between the concerns of clinicians and those of patients," where professional

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[50] Note how this requirement echoes the Meaningful Use program, launched by the U.S. government in 2009. This program was introduced as part of the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act to promote the adoption of EHRs. It was renamed Medicare and Medicaid Promoting Interoperability Programs in 2018. See https://www.healthit.gov/topic/meaningful-use-and-macra/meaningful-use-and-macra (accessed 2 September 2022).

goals (such as treatment compliance) intersect with more idiosyncratic motives (such as negotiating quality of life issues) (Andersen et al., 2018: 1060). Making a technology or program meaningful for both parties asks for a form of participatory design in which these different concerns are somehow brought together. Wilson (2009) stresses that three elements must be foregrounded in this process – "patient-focus, patient-activity, and patient-empowerment" – as they are crucial to the adoption and use of e-Health services and applications (Wilson, 2014: 339). In line with this, Greenhalgh et al. (2010: e1) suggest a design philosophy that builds on "assessing the intended users, observing and analysing tasks and requirements, developing and testing prototypes, evaluating design alternatives, analysing and resolving usability problems, and testing the features and interfaces with users in an iterative manner." What remains unclear in these approaches, is *how* different concerns between doctors and patients are effectively negotiated, aligned, or brought together in practice.

In this chapter we ask: how are doctors and patients enrolled in the development of an e-Health application? Our case is WebPEP, a closed-circuit online video education program that was developed between 2010 and 2011 for cystic fibrosis (CF) patients of the Erasmus MC–Sophia Children's Hospital (SCH) in Rotterdam, the Netherlands. The project initiator, a professor of pulmonary diseases and chairman of the CF Centre at SCH, viewed WebPEP as a possible solution to practical problems in CF education in youth. Our aim is to describe and reflect on some of the challenges we encountered during the development of this patient education initiative, where rational concerns with treatment compliance clashed with the messy, unruly life-world of young adolescent patients. Our study was part of the formative evaluation of WebPEP, and can be described as a form of participatory design (cf. Clemensen et al., 2007; Kanstrup et al. 2017; Kensing and Blomberg, 1998; Nielsen, 2015; Simonsen and Robertson, 2013). We followed the program's development in action, while including our own interventions and contributions to that process. We show that while the program failed to mobilize a sufficiently large group of children with CF between the ages of twelve and eighteen (i.e., its prospective users), and thus failed to adequately integrate patient experiences in the development process, it generated unexpected enthusiasm among parents of young CF patients – a group that had not been taken into account at the start of the project, and that indeed falls beyond the scope of the PCEH framework that informed our research.

The concept of 'enrolment' in our central question is borrowed from Callon (1986) to emphasize the negotiated character of role-attributions in technological development. We focus on the enrolment of members of the CF Team (including medical specialists, nurses, psychologists, and dieticians) and young adolescent patients as prospective users of the program. In that process of enrolment, we make a distinction between users and non-users of the video education program (Wyatt, 2003), and describe a relevant social group that was overlooked in the project's design (Pinch and Bijker, 1987 [2012]). We build on the notions of 'configuring the user' Akrich (1995) and 'technological scripts' (Akrich, 1992) to describe the video education program's reframing in relation to its prospective and actual users.

We structured this chapter as follows. We begin by describing the theoretical framework of our study and our methodological approach. We then present a brief overview of the clinical background of CF education, and an elaborate description of the online video education program. Next, we present our empirical findings, in which we focus on the prospective and actual use of the application, how the project initiator reframed the application along the way, and how a single technological artefact was involved in different, coexisting practices of patient-centeredness (Akrich, 1995). In the discussion section, we argue that the changing role of the application in relation to patient education led to different practices of patient-centeredness, as well as different enactments of patient-centered e-health. We conclude with a reflection on how formative evaluation methods can help to configure users in the design and development of PCEH applications.

3.1 Theoretical framework

Developing technologies always occurs in relation to users. Consciously or unconsciously, people anticipate on how technologies will be used in practice. With that, they 'configure' prospective users in their work (Akrich, 1995;

Oudshoorn and Pinch, 2005; Oudshoorn et al., 2004; Woolgar, 1991). This is especially applicable to PCEH, which promises an active role for patients in their treatment (Andersen et al., 2018: 1040). In this chapter we use the notion of 'configuring the user' to describe two facets of design and development in our empirical case. Firstly, we look at how the program initiator construed the knowledge levels and expectations of the patient group a priori (i.e., based on his professional experience), and how this image was adjusted along the way. Secondly, we look at how the program's technological affordances generated different types of users in practice. Crucially, configuring the user is not about determining how users align with technologies or vice versa; rather, it occurs in a gradual process of mutual shaping between technologies and their users. We focus on interactions between various actors in the project, and on different user identities that emerged along the way.

To discuss different types of interaction between the application and its users we build on the concept of technological scripts (Akrich, 1992). This concept has its origins in semiotics, and conveys two basic insights: firstly, the idea of innovators or designers "'*inscribing*' [a] vision of (or prediction about) the world in the technical content [of objects]" (Akrich, 1992: 208; italics in original); and secondly, the idea of technological artefacts that "define a framework of action together with the actors and the space in which they are supposed to act," much like a movie script (*ibid.*). In line with actor-network theory, a fundamental premise of scripts is that human and non-human actors are symmetrically involved in the construction of sociotechnical networks. Another premise is that repertoires of action for so-called end-users are not endless: although they can bypass or ignore the roles envisaged by designers – or indeed define different roles of their own – the affordances of technological artefacts always impose limits and constraints on their use (Akrich, 1992).

We use the concept of enrolment to describe how different user roles are produced in ongoing processes of sociotechnical interaction. With this concept we emphasize that the role attributions in our study are not predetermined, nor conferred by individual actors; instead, they are sociotechnical accomplishments, or negotiated outcomes between technologies and their users (Callon, 1986). Reconstructing them means reflecting with different people in the project, and observing them as much as possible in their daily practices. In the enrolment process, we make a distinction between users and non-users of the video education program (Wyatt, 2003). Non-users are notoriously difficult to engage in research, but they can offer valuable insights regarding design and development choices.

3.2 Methodological approach

We describe our research approach as a form of participatory design, based on a formative evaluation of the WebPEP project. Participatory design is an approach that “seeks to engage users and designers in a mutual learning process to understand current challenges and design new forms of IT support and new ways of organising the work” (Andersen et al., 2018: 1047). Firmly planted in real-world problems, it is closely related to CSCW studies (Kensing and Blomberg, 1998) and “shares many concerns and some of its roots with action research” (Clemensen et al., 2007: 122). The formative evaluation method is strongly related to participatory design; it can be distinguished from summative evaluation techniques in that it takes place during the development phase of a project rather than *a posteriori* (Buse et al., 2012; Scriven, 1967).

We based our research on a combination of ethnographic observations and semi-structured interviews. Starting from November 2009, we followed the WebPEP project in action and made interventions throughout its development. There were no specific results or parameters to be attained or compared,[51] as our evaluation had an explorative character. The first author was granted permission to interview patients of SCH by the Medical Ethics Committee of the Erasmus Medical Center. He attended meetings at Zorgportaal Rijnmond (where a project leader was appointed to develop the ZorgInfoTV application) and assisted in the production of five webcasts at the TV studio of SCH (one test session and four live sessions), which allowed him

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[51] Aside from a description in the Project Initialisation Document of Zorgportaal Rijnmond, no formal documentation was available on WebPEP.

to conduct participant observations.[52] Several encounters took place with the project initiator and members of the CF Team; the first author also attended an educational meeting for parents of CF patients at SCH (March 2011) and a camera training session for presenters.

At the end of each webcast, WebPEP participants were invited to contribute to the study. They also received requests by email, which were sent out by the CF Team. Between May and August 2011, the first author conducted semi-structured interviews with thirteen WebPEP participants; some were recruited at the educational meeting at SCH, others were contacted by telephone using a list provided by the CF Team. The first author was also granted access to the vendor's log data for the WebPEP webcasts, which was generated by the software platform for ZorgInfoTV.

Through regular debriefings we provided feedback and suggestions to the project leader of ZorgInfoTV and members of the CF Team (including the WebPEP initiator). The first author issued a report after each webcast, which included technical and productional issues to resolve, and provided an overview of raw activity data relating to users. These interim reports were forwarded to the ZorgInfoTV project leader, the Zorgportaal Rijnmond program manager, and the WebPEP initiator. In April 2011, we produced a preliminary report based on the first four webcasts. The final evaluation report (issued in August 2011) was based on the first eight webcasts; it was formally presented to members of the CF Team, the project leader of ZorgInfoTV, and the project manager of Zorgportaal Rijnmond in October 2011. In what follows, we subsequently provide background information on the changing approach to CF education at SCH in recent decades, and on the technological and organizational specifics of the WebPEP application.

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[52] The first author was at the studio during the preliminary test (17 August 2010) and for webcasts #1, 2, 3, 4, and 7 (see Appendix F, Table 1).

3.3 CF education at SCH

Cystic fibrosis is a chronic and life-threatening lung disease. It causes the buildup of mucus in the lungs, and can also affect the pancreas, the liver, and the intestine. It can lead to lung infections and serious digestion problems, and requires intensive treatment from the time of diagnosis, which in many cases is established during early childhood. Patients and their parents or caretakers require extensive knowledge and discipline to put the treatment in practice, which makes education indispensable (Naehrig et al., 2017).

At SCH, the treatment strategy and approach to CF education in youth were substantially changed in the 1990s and 2000s. Until the mid-1990s, patients were instructed about therapy, diet, and psychosocial issues related to CF during outpatient visits at the CF Centre. This was perceived as a highly inefficient arrangement by members of the CF Team: they were repeating the same instructions to each individual patient while experiencing great time pressure and busy consulting hours. In the mid-1990s, the CF Team started offering yearly group briefings at SCH. Meetings were open to patients and their parents, and were specifically focused on the prevention of lung deterioration. Around the same time, however, epidemiological studies were indicating that group gatherings could lead to the transfer of bacterial infections between CF patients (Govan et al., 1993). In the wake of growing evidence on this subject, the UK Cystic Fibrosis Trust Control of Infection Group published new guidelines (2001, 2004) for group gatherings. Similar measures were taken in other countries, and around 2005 the CF Team decided to exclude patients from their yearly briefings.

To compensate for what they perceived as a lack of attention to CF education, the CF Centre started issuing a biannual newsletter for patients. However, contact moments with patients were still regarded as too infrequent, and CF Team members found that the education they provided during consultations was too fragmented and not adequately coordinated. To tackle these issues and bypass the problem of physical group gatherings, the CF Centre sought a Web-based solution. In 2006, the parents' association of CF patients and Stichting Vrienden van het Sophia (Friends of the Sophia Foundation) raised funds to enable CF education via the internet. The initiative was named WebPEP, short for Web-Based Patient Education Program. One of the main expectations of WebPEP was that it would allow group gatherings to take place online and more frequently. The project initiator described his vision on this matter as follows:

> WebPEP enables us to offer a more tailored type of education. We have an annual educational meeting, which is primarily attended by parents of young children who don't know much about it. And the entire team is present. Many participants come from [far away], so it's a very inefficient way of providing education. And those who are not attending, like the Moroccan family from Rotterdam-Zuid [a largely immigrant, poor area of the city] are probably the ones that need it most. We are looking for ways to provide more education to specific groups, such as adolescents, who represent a high-risk group. (Project initiator, May 2010; own translation)

The project initiator also stressed the importance of interacting with patients. Drawing from his own professional experience, he explained that doctors gain a better picture of their patients through extensive interaction, and that this ultimately leads to better treatment:

> They [the CF patients] are not CF specialists. They feel things, but feelings tell you very little about your health in five years. […] It's very difficult for us to truly empathize with our patients, and to understand what they really think. The more interaction moments you have, the greater the chance that someone will open up to you, and ask that strange question that makes you realize: 'Huh?! What's that strange idea they have in their mind?!' […] You need to strike the right chord in order to commit them to their treatment. And in each person, it's a different chord. (Project initiator, May 2010; own translation)

Expectations of improved CF treatment through regular online interaction went hand in hand with ideals of patient empowerment. According to the project initiator, WebPEP would enable a type of CF education that was more tailored to the needs and desires of the audience *because* it allowed for interaction with the latter. He expected that patients would actively contribute to the program with their questions and remarks, and that they would feel more in control of their own treatment than if they were to attend the presentations as mere spectators. He hoped that the webcasts – aimed at patients between the ages of twelve and eighteen – would draw the attention of adolescent patients in particular, as they are more susceptible to non-compliance to treatment than younger patients.

Around 2010, the WebPEP approach to patient education was in many ways innovative, but not unique. Similar webcast technologies were being applied to elsewhere[53] and in relation to other chronic diseases[54] to enable a more symmetrical type of doctor-patient interaction – one that was "concordant with the patient's values, needs and preferences" (Epstein et al., 2005: 1516; see also Laine and Davidoff, 1996; Mallinger et al., 2004; Saha and Beach, 2011). A distinctive functionality of the WebPEP application was that it allowed patients and doctors to reciprocally share information in the form of ideas, comments, and feedback through live interaction (cf. Dawson et al., 2009). In the following section, we describe the technical and organizational arrangements behind this interaction.

3.4 An online video education program for patients

The technical contours of WebPEP were first sketched in 2009, when a partnership was established with Zorgportaal Rijnmond (www.zorgportaal-rijnmond.nl), a newly developed portal for healthcare and well-being in the Rotterdam-Rijnmond region. With the support of Zorgportaal Rijnmond

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[53] For example, see the Cystic Fibrosis Foundation webcasts. Retrieved from: http://www.cff.org/LivingWithCF/Webcasts/ (last accessed 4 March 2013; no longer available).

[54] For example, see the Cleveland Clinic webcasts. Retrieved from: http://www.clevelandclinic.org/health/webcast/ (last accessed 4 March 2013; no longer available).

stakeholders, various applications by different vendors in the Netherlands were researched. A contract with a company specialized in online video education platforms was signed in the summer of 2010; subsequently, numerous functional and security tests were performed. The first WebPEP webcast with patients took place in November 2010; it was the first periodic and interactive video education program for patients to comply with Dutch privacy and security guidelines in medical care.

WebPEP consisted of a series of webcasts presented by doctors, nurses, psychologists, and other healthcare professionals affiliated to the CF Centre. The webcasts revolved around treatment compliance and psychosocial implications of CF in youth. They were made available through the online video application ZorgInfoTV on Zorgportaal Rijnmond. Access to the webcasts (either for live participation or "on demand" viewing) was restricted to the CF patients of SCH. Through letters and email messages they were notified about the topic, date, time, and presenter of upcoming webcasts.

The webcasts were produced at the TV studio of SCH, which featured technical equipment such as a camera, spotlights, microphones, and an audio mixing table. An online recorder (provided by the contracted vendor) enabled live interaction between the presenter and participants as well as storage in the ZorgInfoTV video library.[55] During the live webcasts, the technical staff at the studio minimally comprised of an audio engineer and a cameraman (both employed by SCH) and an operator for the online recorder (delegated by the vendor).

The production process followed a standardized scenario that was developed during the first months of the project. To confer a consistent 'look and feel' to the webcasts, the same visual setup was used throughout the project. Typically, a full-scale rehearsal would take place during the last hour before a webcast went live; this allowed the presenter to get acquainted with the setting, while the technical staff made audio and lighting adjustments and tested whether the PowerPoint slides were displayed correctly. The slides were

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[55] See Appendix F, Figure 1, for a schematic representation of how WebPEP participants log in to the application.

shown alongside the video screen during the presentation; the presenter used a laptop to navigate through them.[56] Some presenters also used a graphics tablet, which enabled them to hand-draw arrows and markings on their slides during the presentation.

Presenters took turns in giving educational presentations on medical and psychosocial aspects related to CF. Topics varied from how enzymes work to the yearly patient examination; the content of the presentations was targeted at an audience of twelve years and older.[57] Presenters were asked to contain the tempo of their speech and the length of their presentation, to avoid difficult words, to use an appropriate tone of voice, and to assume a child-friendly demeanour. To improve their presentation skills in front of a camera, several training sessions were organised under supervision of a professional theatre director, who had extensive experience with theatre productions for children.

During the webcast, presenters invited participants to submit questions and to engage in real-time online polls; these functionalities were exclusively available during live webcasts. Participants could enter their questions in a text box and use a dedicated function to answer poll questions. In accordance with privacy guidelines in Dutch medical care, participants did not appear on video and remained anonymous to their fellow participants. Their questions were only visible to the moderator, who was seated next to the presenter. The moderator read and selected incoming questions on his/her laptop and forwarded them to the presenter.[58]

The login procedure for the application was based on a 'single sign-on' principle on the portal. Upon their first visit to Zorgportaal Rijnmond, WebPEP participants needed to create a personal account by providing their name, age, telephone number, and email address. After this registration process, they were required to log into the portal with their personal DigiD, the national authentication and authorization system used for various online government

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[56] See Appendix F, Figure 2, for a screen capture of the WebPEP interface.

[57] See Appendix F, Table 1 for an overview of the topics.

[58] See Appendix F, Figure 3, for a schematic representation of how the presenter, participants, and moderator interact during live webcasts.

services in the Netherlands.[59] Through this step, the system verified the authenticity of the user, and checked whether access to ZorgInfoTV was authorized. Upon login, participants entered a secure Web environment (https://) where links to several ZorgInfoTV services were provided. WebPEP was the oldest of these services, and contained the largest video library (twenty-five webcasts by March 2013). Webcasts went live approximately one minute before the official start of the presentation, thus allowing participants to attend from the start.

3.5 Evaluation: findings and interventions

Our evaluation generated qualitative and quantitative data on the development of the WebPEP project. From the start, the project initiator, the project leader of ZorgInfoTV, and the Zorgportaal Rijnmond project manager were highly interested in numerical data related to live views.[60] They regarded live interaction with WebPEP participants as a crucial feature of the application, and the number of live views as a rough indicator for the degree of success of this interaction. They were disappointed by the alleged low uptake of the project after the first three webcasts: from 22 live participants in the first week, to 25 in the second and 35 in the third week.[61] They knew that part of the live views could be attributed to project stakeholders, and that the actual number of 'non-professional' participants was lower than these numbers suggested. Over time, these numbers became increasingly difficult to interpret. There were seasonal differences to take into account,[62] as well as substantial technological changes in the project, including the introduction of a new

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[59] DigiD is a national authentication and authorization system developed by the governmental agency Logius. During the first seven webcasts login was not based on DigiD, but on the combination of a username and password that were provided to participants beforehand in a sealed envelope.

[60] See Appendix F, Table 1.

[61] At the start of the project, the CF Team sent out invitations to 120 patients. In addition, several project stakeholders were granted access to the webcasts.

[62] Some project members attributed the decrease of live views between June and August 2010 to the summer holidays.

authorization and authentication procedure for participants in week 8 – when the number of live views dropped from 18 to 4.

With insufficient quantitative data to provide useful feedback to the CF Team on the uptake of WebPEP, we focused on *how* the application was being used by analysing interactions between presenters and participants during the live webcasts. In terms of knowledge levels and tone of voice, presentations varied considerably between different topics and presenters. Some were aimed at ten- to twelve-year-olds (such as a tutorial on nebulization in webcast #6), whereas others were directed at young adolescents. According to the presenters, this diversity in the content and presentation of webcasts was largely intentional. We noticed that questions submitted by participants during the live webcasts were equally diverse. In the webcast on antibiotics, for example, they asked such questions as "Why do you always have to finish the course of antibiotics?", "How long can you use antibiotics without becoming resistant?", and "They say that in Germany there is a substance against pseudomonas infection, is that correct?"

While some of the submitted questions were clearly formulated by children, throughout the first four webcasts it became apparent that many questions were actually raised by parents. Typically, the formulation (e.g., "My three-year-old son…") or complexity of the question made this self-evident. We shared this insight with the project members, as the active participation of parents had not been taken into account in the early development stages of WebPEP. This unexpected role of parents was initially viewed as problematic. The aim of the program was emphatically to reach out to children, and members of the CF Team stressed that WebPEP was not the right platform to educate parents or caretakers.

Assessing the project's uptake

Different project stakeholders assessed the user uptake of WebPEP differently. On the one hand, the ZorgInfoTV project leader and the Zorgportaal Rijnmond program manager focused on volume, and grew increasingly concerned about the legitimation of WebPEP in terms of cost-effectiveness. They expressed doubts on the viability of WebPEP over a longer period of time, given the high production costs (approximately 5,000 euros per webcast) and the low number of live views generated by the webcasts. They also questioned whether the WebPEP pilot showed the full potential of ZorgInfoTV in terms of its scalability, as the program was solely focused on CF patients. They argued that a more widespread chronic disease – such as diabetes – would have given access to a larger population and more extensive patient participation.

Stakeholders related to the CF Centre, on the other hand, were more preoccupied with the apparently lacking impact of WebPEP among its prospective users. As a first reaction, the project initiator sought ways to make the webcasts more appealing to children aged twelve to eighteen. He requested a playful template design for the PowerPoint slides, introduced the use of a graphic tablet in his own presentations, and organized training sessions for presenters. After the preliminary evaluation report from April 2011, in which we signalled a gap between prospective and actual users, he started attributing more importance to the number of 'on demand' views in the pilot.[63] He perceived the overview of these cumulative values as a positive indicator for the participants' interest in the WebPEP video library.

Around the time of the preliminary report, we still knew very little about the participants' views on the project. After eight webcasts, we started conducting our interviews with participants. The CF Team had given us ten telephone numbers of patients who were periodically invited to the live webcasts; half of them were adolescents. Recruiting adolescents as respondents proved to be difficult. Most claimed that they had never heard of the project; two vaguely recalled the invitations that had been sent to them, and only one agreed to participate in the study. As one sixteen-year-old stated in a telephone conversation with the first author: "I can't identify with it [the WebPEP project] at all." Adolescents who claimed to be unfamiliar with WebPEP either said that they had no intention of attending future webcasts, or that they were unlikely to do so. Other patients on the list were either too young to consent for an

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[63] See Appendix F, Table 1.

interview, or too young for WebPEP; in both cases, the first author spoke with their parents.

We managed to interview two patients aged ten and fifteen, ten mothers, and one father.[64] The parents were either recruited through the aforementioned telephone calls, or at the parents' meeting. The children gave their views on the usability of the application, its look and feel, and the quality of the presentations. The parents talked about the usability of the application, the quality of the presentations, the duration and scheduling of live webcasts, the respondents' expectations of CF education, and their practices in gathering information about CF.

The two patients in our interview round had been persuaded by their parents to participate in the WebPEP pilot. They struggled to think of the "added value" of WebPEP in their lives, and emphasized what they were missing from the application instead. One suggestion related to the degree of interactivity of the application, which the fifteen-year-old respondent perceived as too limited. When asked what he would change about the webcast, he said:

> Perhaps that people who gave a presentation stay online. Or that they log in occasionally. So that questions can be asked to them. That they answer on a later date. Because sometimes you don't get an answer to your question. […] I think the specialist is the best person to answer those questions. (CF patient, aged fifteen, May 2011; own translation)

He also gathered that his questions on CF would be too specific to be of interest to other participants; he suggested to extend the opportunity to submit questions after the webcast. By contrast, the ten-year-old respondent was too young to have clear questions of her own; she explained that she watched the webcasts together with her mother, who clarified some of the difficult points for her along the way. While both respondents were sympathetic toward WebPEP, it was difficult to determine to what extent they identified with its educational purpose.

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[64] The parents' children were under the age of six.

Parents of young children who participated in our study were openly enthusiastic about WebPEP. Most of them experienced difficulties in gathering reliable information on CF. They distrusted many online sources on CF, and some had grown discouraged by the very practice of seeking CF information online, which often led them to upsetting accounts about terminally ill or deceased patients. All that unfiltered information made them worry about the prospects of their own children. They described WebPEP as having a positive approach to therapy, as well as a reassuring effect on participants. They also appreciated the opportunity of having direct interaction with a specialist, instead of a nurse of the CF Team. Several parents complained that nurses acted as gatekeepers between specialists and parents when they contacted the CF Centre by phone: aside from the face-to-face consultations at SCH, parents rarely got to speak directly with a specialist.

While some parents of young children used WebPEP's interactive functionalities to gain direct access to a specialist, not every respondent felt compelled to do so. One parent explained his reluctance to ask questions through the application as follows:

> I think it's a personal thing… my wife and I, perhaps we're not the kind of people to easily engage with that sort of thing? I'm not exactly sure what it is… just like with social media, some use Twitter very actively and others don't, that's how I'd explain it, some ask questions very easily, and we don't. […] We're more or less sitting there as spectators, you know? Of course we don't have the disease… sure, we do give guidance to our son, he needs our help, but still you're also sitting there as a spectator, to some extent. You learn most from kids who are a little older, and the questions they ask. (Father of a five-year-old patient, August 2011; own translation)

This example illustrates different ways in which different users can engage with a single technology. A commonality among parents with young children is their perceived knowledge deficit in CF education, which they related to their own insufficient experience, and to the lack of an extensive peer network.

One parent viewed the “social” component of CF education as something that could be further explored in the WebPEP project:

> I guess we are also looking for support groups. […] In any case it’s difficult to get in touch with people living nearby. You can check on CF-Café [an online forum for CF patients], but even so, there are not that many people [dealing with CF] in my area. (Mother of a two-year-old patient, August 2011; own translation)

The importance of expanding one’s social network was also emphasized by a mother of adolescents, who argued that parents gradually learn about CF as their children grow older, and that it takes time for their peer network to grow. In her view, educational projects such as WebPEP are less interesting to parents of older children, such as herself:

> I noticed that in the presentation about the lab, I already knew several things… and there are many people asking a question, and then I think well, that was already explained, or I already know what the answer is. […] I thought it looked nice, that’s not the issue, and especially for them [her own children]… and a lot of information was given on the topic, so that was good. But for me it would have to go a step further. And that’s difficult. So you shouldn’t look at me, but at them [the children]. (Mother of two fifteen-year-old patients, May 2011; own translation)

As a mother of adolescent children, this respondent had sufficient basic knowledge about CF as well as an extensive CF network; she stressed that the educational character of WebPEP was not directed at herself. By contrast, many parents of young CF patients regarded WebPEP as a “welcome addition” to their lives, and voiced the hope that the project would be carried on indefinitely. With that, they expressed a need for more education targeted at parents of young patients.

Reframing the project, reconfiguring its users

The final evaluation report of the WebPEP pilot was issued in August 2011. It marked the end of the evaluation period, but also the start of a substantial reframing of the program. In a plenary presentation at SCH in October 2011, we highlighted the observed gap between prospective and actual users, and emphasized the added value of WebPEP for parents of young CF patients. Although the needs of these parents were still not a priority for the project initiator, he suggested using the video library as an extension of the CF Team's consultations:

> One of the things, and that relates to your work process [speaking to the members of the CF Team], is that we should put up something like a poster of available webcasts, so that during a consultation you remember to say 'we talked about this subject, perhaps it's a good idea if you take a look at the broadcast.' (Project initiator, October 2011; own translation)

One member of the CF Team noted that they already started referring patients to WebPEP whenever possible. She gave the example of a young patient who feared the annual clinical examination at SCH. The patient was advised to watch the webcast entitled "Less Afraid to the Hospital" in the video library. Another CF Team member stressed the importance of integrating WebPEP in their own routines toward patients:

> With new children we can inform them right away [of the existence of WebPEP] so that they are accustomed from the start: 'now I give you a lot information, but you can look up some of that information later on.' (CF Team member, October 2011; own translation)

When CF Team members were asked how WebPEP could attract the attention of adolescents, one of them argued that the application looked too dull, and that it required a visual overhaul. Drawing from the comments and suggestions made in the final evaluation report, the project initiator estimated that a visual overhaul would not suffice to solve the issue. He said:

> Still, I don't think that's the point. They are watching flashy things all day, in which all kinds of things happen; I'm afraid it makes this [WebPEP], relatively speaking, an old medium. (Project initiator, October 2011; own translation)

Regardless, the CF Team felt it had to make more efforts to appeal to young adolescents. They had to find ways to work within the boundaries of the application. One of the suggestions was to invite adolescents to present a webcast, or to have them participate in the production process. For the time being, the CF Team wanted to keep WebPEP operational.

In the following months, an extra series of WebPEP webcasts was financially secured by the CF Centre. A total of 23 webcasts were produced between November 2010 and December 2012. Although the frequency of webcasts gradually decreased in this period, the setup and presentation (targeted at children over the age of twelve) largely remained unchanged.[65] Themes continued to relate to treatment compliance and social aspects in CF, and questions from webcast participants were predominantly about young children with CF. Some webcasts now featured a young assistant in the role of moderator.

The reframing of WebPEP as a resource for members of the CF Team suggests that online education had always been predominantly viewed as an act of *sending* information to patients. We found that knowledge exchange between presenters and participants was a subdued part of the CF Team's rhetoric, and that live webcast interaction was to a large extent controlled by the presenter and the moderator. This control over the interaction materialized in the scripts that presenters prepared for each webcast, but was also deeply inscribed in the ZorgInfoTV application. Having visible presenters interacting with

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[65] Webcast #11 (see Appendix F, Table 1) was explicitly directed at the parents of young patients.

anonymous participants made the project compliant with ethical guidelines in Dutch healthcare, but also enabled and sustained the central position of the presenter during the live webcasts. A specific type of user was inscribed in the software – attentive, observant, and passively responsive – that echoed its origins as an educational tool for academic settings. Throughout the evaluation period, this specific design feature of the application was left unchanged. By contrast, the embedding of WebPEP in the CF Centre's educational strategy and its relation to the "end user" were significantly transformed. In the following section we reflect on this reconfiguration of WebPEP and its users in relation to the goal of providing patient-centered education.

3.6 Discussion

The educational strategy envisaged by the CF Centre did not resonate well with the prospective users of WebPEP. The lacking participation and disqualifying comments by adolescent patients about the project made this evident. The two patient-users we interviewed said that the application was insufficiently interactive; they helped us by providing small suggestions on how to improve the content. By contrast, non-users felt no connection to the project, and did not feel compelled to participate in the study. As we did not manage to persuade them, we gained little knowledge about their thoughts and feelings on CF education, or about their motives for not participating in the project. We thus missed an opportunity to learn about design choices from the perspective of non-users (Wyatt, 2003).

Clearly, there was a gap between prospective and actual users in the WebPEP project. Parents of young patients, who were not foreseen in the original 'script' for WebPEP, embraced the program, emphasized its added value, and were decidedly less critical about the technical limitations of the application. A significant difference in their relation toward the project resides in its disciplining character. Although parents were directly affected by the elaborate regime of therapy and exercise that WebPEP prescribes, they were not physically subjected to it. In other words, they engaged with the program as a source of information on their children's condition – not their own.

Through WebPEP they acquired knowledge that could assist them in their caring tasks, which in turn allowed them to enact responsible parenthood. The example of the father describing himself as a “spectator” emphasizes the difference between the intended use of the application (i.e., patients interacting with the presenter via the text box) and the actual practices of its users (i.e., parents watching webcasts as if they were television broadcasts).

WebPEP had been conceived from biomedical concerns about CF education for young patients. The question whether young adolescents were at all open to participate in a voluntary educational program, was never adequately raised. Although the CF Team long acknowledged that adolescents are a “difficult” age group to reach out to, little was known about their perspectives on self-treatment and education before the project started. A better understanding of the plurality of users – and in our specific case, of their spokespersons – could have moved the project in a different technological or organizational direction (Oudshoorn and Pinch, 2005). Our formative evaluation had the potential to give a voice to patients, provided that we consulted them *prior* to the design stage of the project (see also: Wilson and Lankton, 2004, 2009). Indeed, if the WebPEP application qualified as an example of patient-centered e-health in terms of its espoused goals, the execution of its design and development as described it in this chapter suggest that PCEH requires *anticipating* on (and thinking through) the actual use of an envisioned technology.

The non-use of WebPEP by young adolescents and the active participation of parents of young patients did not lead to substantial modifications in the actual format of the application. However, both the non-use and the unexpected use played an active role in the project’s reframing. After the preliminary evaluation, less focus was placed on the interactive character of WebPEP, and more emphasis on its supporting role for the CF Team during patient consultations. While a more active role was envisioned for CF Team members in directing patients to relevant recordings in the video library, the patient was (once again) relegated to a passive role as information recipient in this process. Our failure to follow through a user-centred development process meant that the application remained a mere extension of professional views on CF education and self-treatment: there was little room for even-handed interactions between doctors and patients (cf. Sassene and Hertzum, 2009).

3.7 Concluding remarks

In this chapter we showed how doctors and patients were enrolled in the development of a patient education program in different ways. The doctors (and other members of the CF Team) were coerced into tightly scripted practices under professional guidance. Investing much time and effort after regular working hours, they regarded the production of these videos as an extension of their individual consultations with patients. They regarded it as a challenging but also exciting part of their profession – including feelings of unease and awkwardness when presenting in front of a camera. They took pride in their work, and showed a strong sense of commitment towards the project, which was widely regarded in the CF Team as a valuable addition to patient education. The innovative character of the project, in conjunction with the professional setup at the TV studio of SCH, may have added to the excitement of participating in the project. By contrast, none of these factors were significant to young adolescent patients. As expected, they had a different outlook on the disciplining character of patient education, and did not feel compelled to join a voluntary program about their illness. Unfortunately, their precise motives remained unknown to us, as we did not manage to persuade them to contribute to our study in any other way.

Our study suggests that when an e-health application fails to enrol its prospective users, this does not necessarily imply the end of the project. The gap between prospective and actual users in the WebPEP project was turned into something productive. Without resorting to significant technical modifications, a reconfiguration of the application and its users gave new legitimation to the project. This reconfiguration entailed an alternative way of integrating patients in the CF Centre's education strategy. While the application continued to offer the same webcast functionality directed at children between the ages of twelve and eighteen, the ability to refer patients to the video library served as an important new attribute to the CF Team. The increasing number of recorded webcasts enabled WebPEP to become a repository for "reliable" knowledge about CF, and patients (and their parents) were expected to benefit from this new source of information.

The WebPEP case illustrates how a single technological artefact was involved in different, more or less coexisting practices of patient-centeredness. As we have shown, the program did not lead to symmetrical or even-handed forms of knowledge exchange between doctors and patients, which could have led to a more patient-centered approach to educational practices. Nevertheless, the act of inviting patients to learn more about their condition (in the interest of their own well-being) legitimized it as a form of patient-centered e-health. The CF Team used the video library as a means to structure the CF Centre's education strategy, and to expand the knowledge base at the patient's disposal. These practices entailed different enactments of PCEH, where (failed) attempts to empower patients went hand in hand with new efforts to provide patient education in a more structured and comprehensive way, catering to the needs of individual patients when specific issues or questions arose during their consultation.

Formative evaluation methods can help to integrate users in the design and development of PCEH applications. The lacking participation of young adolescent patients in our study points to the importance of giving an active role to users and non-users in the design and development of PCEH applications. While we were unable to sufficiently explore their views, we stress that understanding people's desires, motives, needs, and practices in relation to their own health and illness is crucial to PCEH. Perhaps more importantly, formative evaluation methods can help to show *what* is at stake in the design and development of a technological artefact, and also *who* are directly implicated. In that sense, our study shows the inherent limitation of focussing on patients in PCEH. In the context of programs or interventions aimed at children in particular, parents and caretakers can not only act as spokespersons for patients, but also reveal barriers or shortcomings in existing communication strategies.

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Of blooming flowers and multiple sockets

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Introduction

Information infrastructures (IIs) are easy to imagine, but hard to describe. They emerge in different ways, and take on different shapes and forms in different domains. In healthcare, the development and governance of IIs have become urgent themes in recent years. The rapid differentiation of e-Health technologies and changing expectations about health communication went hand in hand with new practices, strategies, and policy agendas – all of which generated new challenges of their own. To this day, healthcare organizations and governmental bodies across the world seek to counter problems of 'fragmentation' in health information exchange (HIE), professing aims of increased quality and efficiency through various types of 'integrated' and 'personalized' technological solutions (cf. Detmer et al., 2008). Notable examples are online health portals, hospital portals, and patient portals, which are often championed as 'platforms' for HIE.[66]

In the Netherlands, several attempts have been made to develop patient portals with a regional scope (De Mul et al., 2013). These initiatives varied greatly in terms of their objectives and ambitions, and in the complexity of their organizational and political contexts. A comparative study between three Dutch cases from the early to mid-2010s described the difficulties of achieving implementation, technical interoperability, regulatory compliance, and financial sustainability – especially in decentralized, highly heterogeneous networks of interdependent actors (Otte-Trojel et al., 2015). Taking a closer look at how a patient portal is built in such complex settings can yield valuable insights in the sociotechnical makeup of IIs for healthcare, and in the actual work required to develop and maintain integrated and personalized information systems.

In science and technology studies (STS) and related fields, that work is commonly referred to as infrastructural work. Typically, it pertains to the routinized, mundane, and somewhat boring work that is not accounted for in project documentation, and that remains "invisible to the broader public"

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[66] See Chapter 2 of this study.

(Kuchinskaya, 2012: 90; see also Hanseth et al., 1996; Star and Ruhleder, 1996). Infrastructural work always exists "in relation to organized practices" (Star and Ruhleder, 1996: 113), and encompasses very different forms of development and maintenance work – all of which entail "political, ethical, and social choices" (Bowker et al., 2010: 99). In the context of patient portal development, infrastructural work can be observed in the nitty-gritty of classification and standardization work, but also in the act of translating (more or less complex) ideas and concerns about 'good' care. Indeed, examples of infrastructural work can be found anywhere: from boardrooms, project meeting tables, and conference floors, to secluded computer labs or a nursing home's coffee room.

Anyone who has seen this work unfold in practice, knows that it is inextricably linked to the use of metaphors. The language that managers, engineers, policy makers, and researchers use in these settings is often esoteric: relatively common terms, allegories, and expressions are used in very specific technical contexts that are hard – if not impossible – to grasp by outsiders. In this chapter we take this observation as our vantage point to explore the use of metaphors in the development of a regional patient portal in the Netherlands – a process in which we were actively involved. Our aim is to unravel the role of metaphors and other linguistic attributes in infrastructural work, and to contribute to current knowledge about their politics in IIs. Our focus is on metaphors that circulated among project members and stakeholders in the early stages of the portal's development.

Our research builds on a substantial body of STS literature on practices in the design and development of IIs. Typically, that work aims to understand how science and technology themselves are produced (Monteiro, 2001: 74). Several scholars have paid attention to the role of language and discursive attributes in that process (Walsham, 1991; Hirschheim and Newman, 1991; Monteiro and Hepsø, 2002). We side with the view that discursive attributes have tangible and sometimes far-reaching consequences for emerging IIs, and that exploring their use can help us to understand how agendas in e-Health are shaped, therewith creating "a space for observation, comment and analysis" about alternative strategies (Woolgar and Neyland, 2013: 7).

We contend that metaphors are constitutive elements of IIs and powerful attributes in infrastructural work. Rather than acting as neutral or innocent descriptors of abstract concepts, they can generate new realities by reconfiguring the imagined order of technologies, infrastructures, and their users, and by actively contributing to the manner in which choices are made in relation to architectures, standards, and classification systems. This part of our argument builds on Schön's (1996) work on the enabling and constraining effects of metaphors in practices of policy making. In addition, we view metaphors as mobilization devices that allow ideas to circulate (faster) and that influence the ways in which people argue and convince each other (Latour, 1990: 31; Czarniawska-Joerges and Joerges, 1992, 1996). Through their circulation in networks, metaphors have the potential to (re)configure people, ideas, resources, and technologies.

We develop our argument by describing the use of two metaphors for innovation and infrastructure integration in the portal project: third party e-Health initiatives as 'blooming flowers', and the portal as a 'multiple socket'. The novelty of our approach is that we view metaphors as sociotechnical imaginaries that leave room for ambiguities and interpretative flexibility (Jasanoff and Kim, 2009, 2013; Pinch and Bijker, 1987 [2012]). Sociotechnical imaginaries entail collective images and ideas of a future that is deemed at once attainable and necessary to be attained (Verran, 2001; Jasanoff and Kim, 2009). In our empirical case they consist of promises, hopes, goals, and expectations about 'integrated' and 'personalized' healthcare in a regional context. We present them as expressions of social order that prescribe futures that are at the same time "constituent of the very situation of any doing or action" (Verran, 2001: 37). By reflecting on the consequences that metaphors can bear for agenda-setting and decision-making processes, we cast new light on how language and discursive attributes are tied into infrastructural work in emerging IIs.

4.1 Case description and research questions

Our study draws on ethnographic data collected during the early development of Zorgportaal Rijnmond (ZPR), an online portal for healthcare and wellbeing in the Rotterdam-Rijnmond region of the Netherlands. The portal was inaugurated in 2011, but was gradually abandoned after 2013, as it had failed to live up to its intended purpose. A consortium of public and private partners carried out the development of the portal between 2009 and 2012, and a Regional Health information Organization (RHIO) acted as secretary of the project. We studied and actively contributed to the development of ZPR; our approach can be characterized as a form of action-oriented, engaged scholarship (Bal and Mastboom, 2007; Mathiassen and Nielsen, 2008; Zuiderent-Jerak, 2015). In our role as formative researchers, we were fascinated by the widespread use of metaphors among project members in designating technologies, practices, and processes. The idea of paying close attention to metaphors came from our own disconcertment, as we often struggled to 'spell them out' or to make sense of them analytically (cf. Verran, 2001: 1–20). The blooming flowers and multiple socket metaphors in particular struck us as remarkably playful terms, seemingly contrasting with the serious ambitions that the project embodied. We singled them out as they became prevalent attributes of innovation and integration narratives in the early stage of the project.

In this chapter we ask: what is the politics of language in infrastructural work? How did the enactments of the blooming flowers and multiple socket metaphors sustain the promises, hopes, goals, and expectations in the project? What did these enactments reveal and conceal in terms of the politics of infrastructural work? And consequently, how can an analysis of discursive attributes contribute to the study and development of IIs? In the following two paragraphs, we describe the role of metaphors in infrastructural work, and our research setting and methods. Next, we reconstruct how the metaphors first emerged in the project, and how they were enacted by different people to explore third-party e-Health applications, and to endorse the portal as a neutral and trustworthy platform for integration. We contend that the two metaphors generated a sense of optimism and enthusiasm in the project, but at the same time concealed the politics of infrastructural work. The latter had far-reaching consequences for how the project was carried out. We conclude that metaphors are effective attributes in the development of IIs, precisely because of their ambiguous character. The act of 'spelling out' their meaning can open up a space for new imaginaries and alternative strategies in the development of online health portals, and of technologies and their infrastructures in general.

4.2 The generative character of metaphors in infrastructural work

Since the early 1980s, scholars from various disciplinary backgrounds have studied the social and organizational dimensions of infrastructures in informatics and computing (Bishop and Star, 1996; Kling, 1987; Kling and Scacchi, 1982). STS scholars in particular made noteworthy contributions by theorizing the relational character of information infrastructures (IIs), which became increasingly relevant with the expansion of the World Wide Web and online technologies in the 1990s (Bowker and Star, 2000; Ellingsen and Røed, 2010; Jæger and Monteiro, 2005; Lampland and Star, 2009; Star and Ruhleder, 1996). In the context of healthcare, efforts to make visible the ongoing infrastructural work in IIs led them to focus on the implications and consequences of standards and standardization, the tension between local and global practices, and the politics and work involved in collaborations, alliances, and partnerships in e-Health (Bansler and Kensing, 2010; Bjørn and Kensing, 2013; Hanseth and Ljungberg, 2001; Hanseth et al., 1996).

The use of metaphors in information technologies has been researched from various disciplines as well. Covering a wide range of theoretical perspectives, scholars addressed the relevance of metaphors in the design of computer systems (Carroll and Thomas, 1982; Lanzara, 1983; Carroll and Mack, 1985; Carroll et al., 1988; Andersen and Madsen, 1988; Madsen, 1989; Greenbaum and Kyng, 1991; Friedman, 1998), their use in the social construction of internet imaginaries (Wyatt, 2004), their organizing role in information systems (Walsham, 1991; Hirschheim and Newman, 1991; Monteiro and Hepsø, 2002; Ellingsen and Monteiro, 2008; Gillespie, 2010; Constantinides, 2013), and their enabling and constraining effects in IIs (Star and Ruhleder, 1996; Monteiro and Hepsø, 2002).

Our study on the use of metaphors in IIs builds on this work. Our premise is that metaphors structure our understanding of the world, and that they shape expectations in social interaction (Lakoff and Johnson, 1980). We contend that the use of metaphors is inextricably linked to infrastructural work, and that it can have far-reaching consequences for processes of agenda-setting and decision-making. We side with Schön's (1996) argument that metaphors can enable or constrain problem definitions in policy making, and adopt his notion of 'generative metaphor' to contend that the use of metaphors (and the implied act of 'spelling out' their meaning) has real technical and organizational implications for infrastructural work. In his view, metaphors refer "both to a certain kind of product – a perspective or frame, a way of looking at things – and to a certain kind of process – a process by which new perspectives on the world come into existence" (Schön, 1996: 137). Rather than serving as innocent or neutral analogies, metaphors create new realities by contributing to the manner in which problems are formulated – and consequently, how solutions are envisioned.

Taking Schön's explanation as our point of departure, we regard metaphors not merely as linguistic reflections of a given social context, but as constitutive attributes in practices and knowledge production. They act as 'mobilization devices' that allow ideas to circulate (faster) and that influence the ways in which people argue and convince each other (Latour, 1990: 31; Czarniawska-Joerges and Joerges, 1992, 1996). Through their circulation in networks, metaphors affect a growing number of actors – such as the project managers, developers, policy makers, and other stakeholders in our study – and have the potential to (re)configure people, ideas, resources, and technologies. Like material objects, metaphors are enacted in different ways in continuously changing settings. Following Winthereik (2010), who discussed three enactments of systems development in an IT implementation project, we explore how the blooming flowers and multiple socket metaphors were enacted during the early stages of the ZPR project, and how this affected the development of the portal. Our focus on enactment allows us to move away from a strictly representational conceptualization of language (Leonardi and Rodriguez-Lluesma, 2012) and to locate the meaning of metaphors in the act of speaking, rather than solely in "the object for which the word stands" (Wittgenstein, 2009: 5e). Metaphors thus become part and parcel of practices, and of a recursive process of ontological constitution (Woolgar and Neyland, 2014: 38).

We view metaphors as operationalisations of sociotechnical imaginaries that make the latter more discernible, while at the same time leaving room for ambiguities and interpretative flexibility (Pinch and Bijker, 1987 [2012]: 20; Jasanoff and Kim, 2009, 2013). We use the concept of sociotechnical imaginaries to designate collective images and ideas of a future that is deemed at once attainable and necessary to be attained. Rather than treating imaginaries as mere reflections and representations of prospective technologies (cf. Marcus, 1995; Fortun and Fortun, 2005), we regard them as expressions of social order that "prescribe futures" (Jasanoff and Kim, 2009: 120) while being "constituent of the very situation of any doing or action" (Verran, 2001: 37). This conceptualization of imaginaries bears similarities to the notion of 'anticipation work' in computer-supported cooperative work (CSCW), which serves as a "frame to capture practices in the present that cultivate our expectations of the future" (Steinhardt and Jackson, 2015). While the latter's aim is to make 'forward-thinking practices' visible, sociotechnical imaginaries foreground processes of agenda setting; these imaginaries also encompass metaphors that can be "used to call for action in the here and now" (Bijker et al., 2009: 105).

We view our theoretical argument as complementary to existing studies on the development of IIs in information systems (IS) and CSCW literatures, and with studies on the development and implementation of e-Health infrastructures in particular (Ellingsen and Monteiro, 2003, 2006; Jæger and Monteiro, 2005; Ellingsen and Røed, 2010; Sahay et al., 2009; Aanestad and Jensen, 2011; Ellingsen et al., 2013). We adopt a similar approach to human and non-human actors as mutually interdependent entities, and focus on the *work* required to develop and maintain emergent IIs.

4.3 Research setting and methods

We conducted ethnographic research during the early development stage of Zorgportaal Rijnmond (ZPR). Our researchers' role in the project was to evaluate the design, development, and implementation of ZPR, as well as the development and scalability of three applications that were to be offered on the portal: a personal health record for the Rotterdam-Rijnmond region, a closed-circuit video education program, and a web application for social care in the region. The formal task of the first and second author was twofold: to provide timely, intermediate feedback about our findings to project members and other stakeholders, and to assess the pilot phase of each of the applications in three evaluation reports. We conducted our study between September 2009 and August 2012, which coincides with the period in which ZPR was primarily upheld by public funds.[67]

Throughout this 36-month period, the first author attended three-weekly Project group meetings, bimonthly Steering group meetings, and biannual Board meetings, and participated in several Sounding board groups and subproject activities to collect data for the ZPR study. The second author coordinated and supervised the study, and attended the Project group and Steering group meetings as the Research project leader. Like the first author, she was closely involved in the development of the ZPR project. The third author contributed to miscellaneous tasks and issues arising in the project, including the development of pictograms for ZPR's privacy policy. Being less involved in ZPR's daily operations – and having more distance to the project – she was able to signal peculiarities in the overall process, and question issues that were easily overlooked from up close. The fourth author was a member of the ZPR Board, representing the University as a consortium partner in the

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[67] Between September 2009 and August 2013, the Municipality of Rotterdam and the Dutch Minister of Economic Affairs subsidized the ZPR project with the aim to develop a financially sustainable health portal for the Rotterdam-Rijnmond region. During this early development stage, various partners in the ZPR consortium made financial investments in the project as well.

ZPR project. Regular meetings were held between the four authors in which we discussed our ZPR-related research activities and progress.

During our study, the first and second authors' knowledge exchange with project members and stakeholders took on different forms. Aside from actively participating in the aforementioned formal settings, we attended public ZPR events (such as networking meetings and the official launch of the portal in September 2011), wrote reports and memoranda with other members of the ZPR project, joined them in expert meetings, seminars, and trade conferences, and accompanied them on some of their visits to suppliers and other stakeholders. Informally, interactions with project members and other stakeholders took place before and after meetings, either through face-to-face interaction, by telephone, or email correspondence. On numerous occasions the first author joined project members in car rides, lunches, and social activities, alternating small talk with viewpoints on the project.

We drew valuable insights from both formal and informal settings; the latter often allowed us to better understand the political intricacies of the project. At the same time, we were consulted by project members and stakeholders, and shared our own researchers' insights and personal views on the project whenever possible and appropriate. We acknowledge that the formative character of our fieldwork is deeply intertwined with 'intervening' or 'informing design' (Zuiderent-Jerak, 2015), and recognize the importance of critical reflexivity in this process (Bjørn and Boulus, 2011). Our role as participatory researchers merits more attention than the brief reflections we are able to present in this chapter.

Our empirical data includes the first authors' field notes for the ZPR study (September 2009 – August 2012); audio recordings from three Project group meetings, one Steering group meeting, and one Brainstorm session (December 2009 ~ June 2010); and meeting minutes and memoranda from two Steering group meetings (ZPR 2010b; ZPR 2011a) and one Board meeting (ZPR 2011c) in which the metaphors discussed below explicitly occurred or were implicitly alluded to. While the metaphors did not literally recur in the Steering group and Board meetings, we refer to memoranda and meeting minutes from those groups to illustrate how the metaphors contributed in shaping the course of the project. The first author made verbatim transcriptions of relevant excerpts from the aforementioned five audio recordings (up to 25 minutes in length) and coded them following an abductive approach – moving back and forth between the theoretical premises of this study and new insights that emerged from the coding process (Alvesson and Sköldberg, 2018; Tavory and Timmermans, 2014).

To understand the role of the blooming flowers and multiple socket metaphors in the ZPR project we took notice of them as much as possible, described them in our field notes, and reflected on them along the way; this allowed us to retrospectively explore how they were enacted. The two metaphors were part of a management culture in the ZPR project in which the use of analogies, allegories, and idiomatic expressions was profuse. Large and potentially disorderly gatherings, for instance, were referred to as 'Polish Diets' (*Poolse landdagen* in Dutch), which are proverbially linked to a disorderly meeting of the Polish parliament in the sixteenth century; product pitches for vendors went by the English term 'beauty contest,' which – aside from being a synonym of 'beauty pageant' – is informally used to denote any contest decided by popular vote; easily obtainable gains were referred to as 'low-hanging fruit' (*laaghangend fruit*); and a portal or application featuring too many functionalities was likened to a 'Christmas tree' (*Kerstboom*).

In the following section we describe the generative role of the blooming flowers and multiple socket metaphors in the initial phase of the ZPR project. We show how (and by whom) these metaphors were enacted, as well as the consequences of their enactments within the project. We highlight their role in *exploring* its organizational, technical, and economic boundaries, and in *endorsing* the portal as an independent, non-partisan attribute in a newly envisioned technical, economic, and social infrastructure for the region. From our analysis we discerned that narratives about 'exploring innovation' and 'exploring new market opportunities' ran parallel with narratives on how to position ZPR 'in the market' (i.e., how to 'endorse' it as a competitive contender in the Dutch e-Health landscape). This led us to the distinction between 'exploration' and 'endorsement', each consisting of specific enactments of the two metaphors. Although the concepts of exploration and endorsement can be linked to more or less specific imaginaries – which will be explicated below – our distinction between them is not meant to suggest that one type of enactment preceded the other, or that they occurred independently: they are discursively interwoven, and can be linked to a wide variety of practices.

4.4 Flowers blooming in a multiple socket

Before we focus on how the metaphors were enacted by different people in the project, we need to recount how they first emerged. This brings us to the first official ZPR Project group meeting in December 2009, shortly before the Christmas holidays. By that time, several meetings about ZPR subprojects had already taken place, as well as the first meeting of the Steering group. The Project group meeting started with the program manager enunciating four agenda topics while listing them on a display board: "Report from Steering group – Project progress – Project plans/Flowers on the side – Financial report." As the last agenda topic appeared on the board, the project leader in charge of the 'ZPR infrastructure' asked to clarify the meaning of "flowers on the side." The program manager replied that they were "the little flowers blooming in the margins of the project plan, beyond the limits of our raked path."

The notion of 'blooming flowers' is frequently used in the context of business and innovation. It is etymologically rooted in the Hundred Flowers Campaign, which was introduced by the Chinese government in 1956 and was presented as an initiative that would promote the cultivation of new ideas, and grant greater freedom of thought and speech to Chinese artists and scientists. Its specific recurrence in narratives on innovation is explained as follows by Kanter:

> 'Let a thousand flowers bloom.' This slogan, designed to awaken an entire nation to new ideas, offers an apt metaphor for innovation. Innovations, like flowers, start from tiny seeds and have to be nurtured carefully until they blossom; then their essence has to be carried elsewhere for the flowers to spread. (Kanter, 1988: 170)

In the ZPR Project group, the blooming flowers metaphor came to denote e-Health projects in the Netherlands that were deemed appropriate or interesting enough to be ‘offered through’ or ‘integrated in’ the portal. Projects emerging “in the margins of the project plan” thus became known as *bloemetjes* awaiting to blossom;[68] in this chapter we opt for the translation ‘blooming flowers,’ which in our view best conveys the program manager’s description.

The added metaphorical rendition of ZPR’s ‘raked path’ was not clarified by the program manager. It must be understood in relation to ZPR’s five sub-projects existing at that time (one pertaining to the technical infrastructure, one for each of the three applications to be ‘integrated’ in the portal, and one research component) as well as to one of the objectives in the ZPR project: to stimulate the development of new e-Health initiatives and activities in the region (ZPR, 2009). The blooming flowers metaphor thus conveyed ZPR’s envisioned role as a platform for e-Health innovation, and the necessity and willingness to accommodate potentially useful developments beyond the lineaments of ZPR’s project structure – i.e., the neat, orderly, and more or less clearly predefined itinerary suggested by the ‘raked path’.

The notion of ‘integrating’ (or ‘latching on’) e-Health applications in the ZPR portal was conveyed through the view of the portal as a multiple socket.[69] The first occurrence of this term was during the same first Project group meeting in December, when the program manager informed the group about a past meeting with project leaders of another health portal project in the Netherlands:

> Actually they [the project leaders of the other portal project] choose a very different concept; while we are pretty much looking for new

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[68] ‘Bloemetje’ is a diminutive of the Dutch term ‘bloem’ (meaning ‘flower’). In its diminutive form it bears connotations of cuteness and sympathy, which are intuitively recognized as such in the Dutch sociocultural context. In common parlance, ‘bloemetje’ can also denote a flower arrangement as a gift.

[69] A multiple socket consists of a “block of electrical sockets that attaches to the end of a flexible cable (typically with a mains plug on the other end), allowing multiple electrical devices to be powered from a single electrical socket.” See: http://en.wikipedia.org/wiki/Power_strip (accessed 2 September 2022).

> software, their plan is really just to become something like a multiple socket [*stekkerdoos*], where everything that works and is properly developed can be plugged into. So for us it's very important to keep an eye on that, which plugs they will be plugging into their own sockets in the next months, and to plug those in as well. […] We've chosen a slightly different concept, where we say: we have to deliver those things as well in order to generate traffic. (Program manager, 15 December 2009; own translation)

In its first occurrence, the term *stekkerdoos* did not raise questions among the project members. It reappeared verbatim on the agenda of a brainstorming meeting after the Christmas holidays. Several ZPR project leaders, the financial controller, and the director of the Regional Health information Organization (RHIO) were present. As they discussed the potential benefits for other companies to 'plug into' ZPR, the program manager expressed her preoccupations on how to make this work:

> I still have one concern, which is that on a very short term we will need to wheel in money,[70] because I believe that the portal should be made more suitable to also serve as a multiple socket. (Program manager, 7 January 2010; own translation)

In reaction to this, the 'Infrastructure' project leader asked the program manager to clarify his understanding of the term 'multiple socket' in the project's context:

> So in fact, a multiple socket is something that you offer to someone who has a ready-made application {yes! – program manager}[71] with users, administration, on which everything works? (Project leader Infrastructure, 7 January 2010; own translation)

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[70] 'To wheel in money' is a literal translation of the metaphorical expression used by the program manager.

[71] Curly brackets indicate overlapping utterances.

The program manager acknowledged this explanation, adding that the integration between applications and the portal could take on different forms in different cases, and that it would require negotiations with entrepreneurs:

> Yes what you have is… yeah actually it depends, we'll have to talk about it with the entrepreneurs. PatientCom, for example, has a sort of application for diaries, so people can keep their own diary, for diabetes and for ehm… well, they really want to keep data storage to themselves. (Program manager, 7 January 2010; own translation)

Clearly, the program manager was aware of the ambiguity of the multiple socket metaphor: the variation and negotiation she alludes to stand in contrast with the uniformity and rigidity of a multiple socket. Despite this ambiguity, the view of the portal as a multiple socket soon gained currency within the Project group. During our PhD supervision meetings, we reflected on the meaning and use of the blooming flowers and multiple socket metaphors. Our first reflections on these metaphors date back to 20 January 2010 when we tentatively construed the multiple socket as a model of integration, and as a metaphor for the ambition to 'standardize everything.' Rather than firmly hanging on to these ideas, we tried to keep an open view on how the use of this metaphor would develop. However, our choice to frame it as a 'model of integration' persisted and coloured our subsequent observations and interpretations. In what follows, we describe two ways in which the blooming flowers and multiple socket metaphors were enacted in order to gain a better understanding of the relation between metaphors and practices in the ZPR project. We present these enactments in separate sections, each following a chronological order.

4.5 Exploration

The use of the blooming flowers metaphor related to the search for new e-Health applications and market opportunities in the ZPR project. These explorative activities were at their height between February and August 2010, and primarily involved Project group members. While the program manager was planning a collective visit to an ICT fair, she addressed the importance of investigating 'interesting developments' for the multiple socket as follows:

> My thought is: let's go all together, so we can compare notes: what did you see, what did you notice, what can we do with this? I assume that we'll see a number of interesting developments for the multiple socket. (Program manager, 2 February 2010; own translation)

The program manager sought a way to maintain a structured overview of what could be 'plugged into' the portal. An overview of this kind was meant to keep Project group members updated on current findings, while providing a means of comparing different applications as well:

> […] the question is: do we create a single document, and make an entry for each one, and look at the entire list together once or twice a month and say: these are candidates for the multiple socket? And will we say: we can invite so-and-so one for an interview? […] we need a central point where things are directed to, someone who rubricizes them or stores them somewhere so we can come together and say: this looks interesting, if it works well, can we latch it on to the portal? Does it have added value for the portal, or is there something underneath that is useful to us? (Program manager, 2 February 2010; own translation)

A standardized format for keeping track of the blooming flowers would enable a more or less structured exploration of products, activities, and services beyond the aforementioned confines of ZPR's project delineation. In her role as Research project leader, the second author was asked to create a template for a working document, which she divided into twelve descriptive categories: *education*, *prevention and lifestyle*, *self-management*, *support groups*, *e-mental health*, *search and find*, *medication*, *e-learning*, *home automation*, *telemedicine*, *record keeping*, and *internet appointments*. These categories helped to discern different types of e-Health applications based on a standard set of principles. In accordance with this template, each blooming flower was described separately and classified by 'type of ICT tool' (with descriptors loosely based on the aforementioned categorization), 'sector' (such as *prevention*, *cure*, *care*, etc.) and 'target audience' (such as *patients*, *health providers*, *children*, *physiotherapists*). Descriptions varied in length from a few sentences to several paragraphs, and were accompanied by the URL associated with the application or project.

While the Research project leader worked on the template, the Infrastructure project leader set out to explore the technical requirements for a 'good' multiple socket. Having questioned the multiple socket metaphor in the previous meeting, and having recently visited the software vendor who was contracted to build ZPR's technical platform, he reported back to the Project meeting by explaining that the universal character of multiple sockets did not apply to the ZPR case, nor to other portals: "You cannot build one multiple socket for all, it doesn't work like that in software land" (12 February 2010). Noting that it was fundamental to know in advance what requirements ZPR had to meet in order to deliver a technical architecture for ZPR ("the question is: how do you wish to make it available? And not: how do you plug into it?") he added that making different applications interoperable with each other on a single portal would not be a feasible goal.

Interpreted as a literal analogy, the multiple socket metaphor thus revealed its technical and organizational shortcomings: different e-Health applications are based on different 'installed bases' (Hanseth and Ciborra, 2007) which in turn are linked to different standards and infrastructures. Despite these shortcomings, the multiple socket metaphor temporarily configured the relation between applications and the portal as a problem of fit, both in a technical sense (finding a 'fit' between plug and socket) and economically (seeking 'compatible' business models to 'plug into' the portal). However, Project group members continued to discuss the integration of third-party applications as an act of 'plugging into' the portal; in that sense, the metaphor did not help to make the politics of technology and infrastructural work visible. Infrastructure remained a technical challenge, and the main person responsible for its development was the Infrastructure project leader. We will further elaborate on this in the Endorsement section.

Going back to the blooming flowers metaphor, a working document was created that contained formalized descriptions of 41 e-Health applications by the end of February of 2010. Examples included a module for scheduling appointments with health providers, an educational course for adolescents with symptoms of depression, and a Wi-Fi-enabled audio messaging device for young children in hospitals. Typically, these *bloemetjes* were found in online media publications and printed press, through networking gatherings, or by word of mouth. Information and insights about these applications were shared during the three-weekly Project group meetings, and sometimes by email.

Aside from providing project members with a tangible, selected overview of third-party e-Health applications in the Netherlands, the blooming flowers metaphor brought about a classification of innovation that enabled side-by-side comparisons between different initiatives. At the end of February, six Project group members were asked to evaluate the blooming flowers and to rank them. The assessment was based on two generic criteria ('who benefits?' and 'relevance to ZPR goals?') divided in several items,[72] and featured a rating scale from 1 to 10. The form to be filled out for each application became known as the 'blooming flowers form' (*bloemetjesformulier*), and was referred to as such in subsequent Project group meetings.

In the following five months, discussions about the blooming flowers revealed how the exploration work was gradually transforming into decision work – a long and sometimes contentious process. In the Project group meeting in April, a debate arose on how to move from the current working document to the integration of ten applications on the portal by the end of 2010 (as formulated in ZPR's year plan). In her role as Research project leader, the second author pointed out that the working document could help to decide which applications to select for the portal:

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[72] The first criterion contained the items 'citizen', 'patient', 'provider', 'others'; the second 'self-reliance', 'uniformity', 'communication', 'commercial activity', 'value for the region'. Items were scored with '+', '+/-', or '-'.

> You can use that document I made to find out what kind of applications there are… you know, some applications have more of a diary functionality, which you can edit yourself, some are more about communication between healthcare providers and patients, there are applications focused on giving a specific type of information, which can be text-based or visual… and that's a type of ordering that could be helpful. […] It would be nice if there were some sort of balance, if we could offer at least one of each of those types of information on the site. (Project leader Research, 27 April 2010; own translation)

This suggestion not only illustrates the formative interventions we made to the project as researchers (i.e., seeing the working document as an instrument to create order), but it shows how the exploration process was built up – from assessing and classifying innovations to seeking a certain 'balance' in them. A congruent strategy was proposed by ZPR's financial controller, who suggested making a selection of applications based on what could be 'coupled' to the portal relatively easily, without too much effort or high costs:

> Perhaps you should sort out what can be achieved easily, and make something like a global estimate of the time required to couple something like that [a blooming flower] to Zorgportaal, and to make a selection on that basis. (Financial controller, 24 April 2010; own translation)

This hinted at the idea that integrating some applications or initiatives in the portal would require more efforts than others. More precisely, the financial controller felt that the focus should be diverted from what she termed 'experiments.' From this emerges a distinction between established, successful, up-and-running applications and comparatively obscure initiatives by hospital doctors that were still going through trial stages:

> Some of those flowers are, with all due respect, just experiments by people who are not fully dedicated to creating this type of applica-

> tions, like healthcare providers. (Financial controller, 24 April 2010; own translation)

This qualification of some applications or initiatives as 'experiments' adds a new dimension to the view of the "little flowers blooming in the margins of the project plan, beyond the limits of our raked path." Evidently, the blooming flowers now required a 'raked path' of their own in order to be prioritized: simply 'blooming in the margins' was not enough. But the differentiation between 'just experiments' and other initiatives was highly normative: drawing the line between 'experimental' and accomplished applications or initiatives (meaning 'suitable' and 'unsuitable' in this context) was a matter of contention, and the issue of how to draw that line was never settled in the Project group. In response to the financial controller, the program manager argued that any of the blooming flowers in the overview were experimental; she stressed that most of them were actually well-funded, award-winning initiatives. This contestation of the label 'experiment' points to the problematic definition of term itself (who decides what qualifies as an experiment, and on what basis?), as well as to a devaluation of the notion of experimentality: the blooming flowers were not 'just experiments.' The program manager expressed her concern that ZPR would remain an empty portal if they would continue to add new blooming flowers to the overview, and that the focus should be shifted towards ZPR's content. She proposed to create a shortlist containing six or seven blooming flowers that 'already work well' to be made available through the ZPR portal before November 2010:

> The fastest way of creating a lot of content on it [the portal], or interesting activities, is to think about the things that already work well. Meaning flowers that we have already found. (Program manager, 24 April 2010; own translation)

By mid-May the working document contained 57 blooming flowers. The Project group convened again, and the discussion on how to make an appropriate selection continued: who would decide on what to select, and what would be the role of the Steering group in this process? Having discussed the matter beforehand, the Research project leader and the program manager proposed to write a memorandum for the Steering group:

> Those 57 items could all be placed under 'nice health links' […] but in the end it's about making a distinction: what will you be offering through ZPR? (Project leader Research, 18 May 2010; own translation)

> Our proposal is to make some sort of exploration, to write a small plan, and to hand that over to the Steering group. To say to the Steering group: this is what we wish to develop. With these entrepreneurs or these providers we want to talk about a real collaboration, and to connect things to the portal in the right look and feel, which means that we will have to pay for that part of the look and feel for them; and yes, that requires money, can that be paid from the portal or…? (Program manager, 18 May 2010; own translation)

The criteria for this new selection procedure were elaborated in a memorandum entitled 'Acceleration of Zorgportaal development,' which featured on the agenda of the Steering group meeting in June (ZPR, 2010b). In the memorandum, the program manager expressed her opinion that the development of ZPR was not proceeding fast enough: efforts were primarily focused on the technical infrastructure of the portal, and on the three applications developed in association with ZPR. Without further resorting to the blooming flowers metaphor, she wrote: "I believe it is important that we put more energy in collaborations with strong private partners with good services for both care providers and citizens/patients." The memorandum presented three criteria based on which the blooming flowers could be distinguished: *hyperlinks to other sites*; *services for which the visual presentation of the application is integrated with Zorgportaal*; and *services for which the application is integrated in Zorportaal*. This was followed by an overview of the aforementioned twelve categories from the blooming flowers template, and two formal requests to the Steering group: "Agreeing with an accelerated development of content on Zorgportaal Rijnmond, so that it can be presented for decision at the Board meeting; Determining together who decides what services will be offered on Zorgportaal" (ZPR, 2010b).

During the June 2010 Steering group meeting, the memorandum prompted a discussion on envisioned or possible partnerships with private partners. Asked to clarify her view on this matter, the program manager replied:

> I think we need to look at it […] per individual case: what are the costs, what are the returns, what is the short-term business case, the long-term business case. […] It will vary for each… blooming flower, I think. For each… new activity. What are the costs of latching on, and how do you wish to latch on, right? Do you want to be a link from here, or do you really want to be incorporated in the portal… you can imagine that if you really want to be incorporated in the portal, that the costs will be higher. (Program manager, 14 June 2010; own translation)

The Steering group agreed to give a positive advice to the Board regarding the 'accelerated development of content,' which entailed the allocation of a larger share of the program manager's hours to exploring the financial implications of partnerships with private parties. Anticipating future endorsement activities, one of the management delegates summarized the discussion as follows: "How do you market it? Basically, it's all a matter of marketing for Zorgportaal." Between June 2010 and January 2011, the term 'business case' gained prominence on the agenda of the Project group and Steering group. Third party applications were deemed important for the financial sustainability of ZPR, but the project manager did not expect things to go smoothly. In an interview with the first author, she expressed her concerns as follows:

> Look, we obviously face a heck of a problem in about two… one year from now. One year from now [the portal] must be so solid that we can pay for the infrastructure! Thanks to the applications on it, and

> the underlying business cases, if enough traffic is coming in... well, it's all still very exciting! Really exciting! I have no idea! I have yet to see any application in the Netherlands that can support itself based on citizens willing to pay for it. [...] There is an underlying assumption that people are going to use applications, and that there's a business model behind each application, but uh... a lot of the revenue that goes to one [entrepreneur] depends on the investments made by others. (Program manager, 8 July 2010; own translation)

Six months later, in January 2011, a special meeting was held in which five suppliers 'pitched' their products or services to the Steering group; two ZPR project leaders, two project leaders from the largest teaching hospital in the region, and the first author were also invited. Among the presented products were the online diary application for patients with chronic diseases by PatientCom, which allegedly had tens of thousands of users in the Netherlands at that time, and an application for online satisfaction surveys by ResearchCom.[73] All people attending were asked to make notes and reflect on the potential of each proposition. In an interview with the first author (17 January 2011), the RHIO director explained his preference for PatientCom by pointing out the "clear business case in their presentation," and expressed his dislike of ResearchCom for "not having a clear business: how will we pay for it?" Similarly, the minutes of the following Steering group meeting emphasized the 'business case' of both applications, briefly describing the presentations as follows:

> The self-help diaries by PatientCom have been well received. The presentation was very illustrative. It is directly clear for a patient how to use the diaries. Moreover, PatientCom has a clear business case [...]. For the application by ResearchCom we need more clarity about the business case on the longer term. (ZPR, 2011a; own translation)

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[73] The names PatientCom and ResearchCom are fictitious.

This reconstruction shows how the exploration of blooming flowers gained a more economic character as ZPR's own 'business case' and financial sustainability became a more pressing issue. We will elaborate on the marketing-oriented enactment of this metaphor (framing the ZPR portal as a business opportunity) in the Endorsement section. The blooming flowers metaphor contributed in shaping the selection procedure of applications for the ZPR project by articulating the functional and financial dimensions of prospective e-Health innovations. It led to the creation of a standardized form that gave Project group members insight in user-payer arrangements, access procedures, and types of data management and maintenance for different types of applications. Similarly, the multiple socket metaphor enforced the imaginary of a platform for e-Health innovation in which those applications could be 'plugged into.' Table 1 illustrates the different ways in which the metaphors were enacted in light of the view of the portal as a platform for e-Health innovation.

Table 1: Exploration

Imaginary	**Metaphor**	**How it was enacted…**	**… and by whom**	**What it led to**
Portal as a platform for e-Health innovation	Blooming Flowers	***Searching*** for new applications & market opportunities	Project group members	The search led to a selected inventory/overview of e-Health projects in the Netherlands
		Classifying innovation using a standardized working document	Project group members	The working document evolved into a form that contributed to/informed the inclusion and exclusion of potentially useful applications
	Multiple Socket	***Investigating*** ways to build the portal	Project leader 'Infrastructure'	Task of translating the metaphor into technical requirements/specifications
		Searching for new applications to ***plug into*** the portal	Project group members	The derivative 'plug into' metaphor configured the relation between application and portal as a problem of alignment, both technically and economically

4.6 Endorsement

Aside from being viewed as a platform for innovation, the ZPR portal was also heralded as ‘the’ future gateway for healthcare providers and recipients in the Rotterdam-Rijnmond region (ZPR, 2009). Using the blooming flowers metaphor in reference to e-Health developments elsewhere in the Netherlands, the program manager presented her view of ZPR as an inclusive, open, and outwardly oriented project. Project group members and other stakeholders invested substantial effort in mobilizing potential participants in the ZPR project; among those stakeholders was the chief medical information officer (CMIO) of the aforementioned teaching hospital. An avid proponent of the Continuity of Care Record (CCR) standard,[74] the CMIO frequently spoke at medical IT-gatherings, where he championed ZPR as a platform for standardized health information exchange (HIE). His views on how to unify language and semantics in HIE expressed similar narratives of inclusiveness and outward orientation. He deemed cooperation with third parties as crucial, and focused on getting regional hospitals ‘on board’ of the ZPR project. Meanwhile, networking sessions and expert meetings were organized to talk with entrepreneurs about how ZPR could contribute in achieving *their* goals. The prospect of creating new business activities ‘around’ ZPR – or making ‘flowers bloom’ – required sensibilities toward a complex of technical, organizational, economic, and legal challenges. In reaching out to care providers in the region, ZPR was promoted as a not-for-profit gateway to e-Health applications and medical records. With its novel technical infrastructure, the portal would ‘facilitate’ online services as well as improve communication between different parties in the region.

Within the confines of the Project group, the multiple socket metaphor was enacted as a means to discriminate ‘good’ from ‘bad’ e-Health applica-

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[74] The CCR standard was a joint initiative of American-based standards organizations, medical societies, and health IT vendors. When this study was conducted, it consisted of 17 elements summarizing the most relevant, basic health information about a patient. See Chapter 5 of this study.

tions and services. In a landscape cluttered with e-Health initiatives, it was important to be critical about offers or propositions by third parties:

> I think we should be in control [of whom to approach], and think of what company suits us best. So that we only attract the cream of the crop, to which we offer that multiple socket function. And not just any idiot with an idea. (Program manager, 10 February 2010; own translation)

In relation to the outside world, however, the metaphor became instrumental in communicating a sense of unity, suggesting neutral ground, development potential, and a low threshold for participation. The image of the multiple socket meant to convey the notion of a broad platform serving the needs of different groups, and posing no threats or risks to prospective participants. It echoed the promise of a technically accessible and politically 'transparent' infrastructure. In a discussion between the program manager, the RHIO director, and the CMIO on how to facilitate or generate new business activities, the portal's political impartiality was explicated as follows:

> You say that those applications all belong to Zorgportaal. But you can also place those applications elsewhere; we will just be a multiple socket. (Program manager; 10 February 2010; own translation)
>
> No but that's exactly what I mean. […] The business that we develop, it's intended to make Zorgportaal a non-threatening component that you can purchase as your infrastructure; that you don't have the feeling that you need to provide one of your own if you want to do any business at all. […] You have to make sure that you're the party of which I say: that's where I'll place it, and there's no risk for me to lose control over my product (RHIO director; 10 February 2010; own translation)
>
> And that it delivers, it delivers contact between all healthcare providers in the region {yes – RHIO director}, it delivers contact with patients

> {standards! – RHIO director}, it delivers standards {and the multiple socket – RHIO director} yes, but in a secure manner. (CMIO; 10 February 2010; own translation)

The CMIO, who was also a member of the Steering group, never bought into the metaphor as such. By contrast, the representation of ZPR as a multiple socket in which third parties 'plug in' their applications formed a dominant narrative among Project group members, particularly in the early development stage. Although there was still little clarity on the technical and organizational requirements for this model of integration (or on its political and legal implications), the multiple socket complemented the blooming flowers metaphor in endorsing ZPR's envisioned role as an independent and non-partisan attribute in a newly envisioned infrastructure for the region. Like the blooming flowers metaphor, it prioritized a technical and economic framing of ZPR (a 'component that you can purchase') over concerns about its relation to healthcare practices, organizations, and citizens in the Rotterdam-Rijnmond region.

After 12 February 2010, when the Infrastructure project leader openly disqualified the view of the portal as a multiple socket, this metaphor quickly fell into disuse. However, despite its inadequacy as a representation of the 'integration problem' that Project group members were attempting to define, the multiple socket metaphor persisted in derivative expressions such as 'plugging into the portal'. Such expressions continued to recur among project members in discussions about the endorsement of ZPR, where the latter featured as a 'neutral' platform or base where different applications could be *plugged into* or 'latched on to.' This idea was typically visualized in early architecture documents as a series of cylindrical structures positioned on a horizontally placed rectangle, much like pillars on a construction site.

Our descriptions show how different enactments of the blooming flowers and multiple socket metaphors prioritized a technical and economic framing of ZPR, while concealing the politics of technology and infrastructural work. Table 2 illustrates how these metaphors were enacted in relation to the view of the portal as 'the' gateway for e-Health in the Rotterdam-Rijnmond region.

In what follows, we round up this chapter by discussing the generativity of metaphors in our study, and how the analysis of discursive attributes can contribute to the study and development of IIs.

Table 2: Endorsement

Imaginary	**Metaphor**	**How it was enacted…**	**… and by whom**	**What it led to**
Portal as 'the' main gateway for e-Health in the region	Blooming Flowers	Constructing the project as ***inclusive***, open, welcoming, outwardly oriented	Program manager; CMIO	Mobilization of prospective participants and consortium partners; product pitch for e-Health vendors
		Marketing the ZPR portal as a business opportunity	Program manager and Steering group members	
	Multiple Socket	Constructing the portal as ***neutral***, impartial, and non-threatening	RHIO director	

4.7 Discussion and concluding remarks

Metaphors are not 'innocent' or neutral descriptors of abstract concepts. In our empirical description we presented them as operationalizations of socio-technical imaginaries pertaining to 'integrated' and 'personalized' healthcare. As representations of an imagined social and technical order, metaphors can indeed be misguiding conveyors of infrastructural work. Our reconstruction of the multiple socket metaphor's use in the ZPR project shows how the program manager foresaw that the integration between applications and the portal would take on different shapes in different cases. The allegorical 'fit' between plugs and sockets, which suggest a view of 'closed' and 'stabilized' artefacts and standards (Pinch and Bijker, 1987 [2012]: 37), fell short in representing infrastructural work in a decentralized, highly heterogeneous network of interdependent actors (cf. Otte-Trojel et al., 2015).

As a heuristic device, the multiple socket metaphor prompted project group members to "spell out" its meaning by reflecting on the underlying assumptions in the context of infrastructural work (Schön, 1996: 138). Misguiding or not, the metaphor temporarily acted as a "powerful means of organizing work and intellectual practice" by simplifying abstractions, making them manageable, and supporting their circulation (Bowker and Star, 2000: 314; Czarniawska-Joerges and Joerges, 1992, 1996). Viewed from this organizational perspective, the added value of metaphors to project work resides in their ambiguous and versatile character: if they work well, it is exactly *because* they are not precise representations of reality (Ellingsen and Monteiro, 2008).

More importantly, our description of the two metaphors' enactments shows how they configured innovation as a definite, cognizable, and classifiable commodity. As such they were generative metaphors, actively contributing to the way in which Project group members framed problems of exploration and endorsement in the development of the portal. The multiple socket metaphor pre-empted the contours of ZPR as something where things could be 'plugged into,' despite the facetious representation of flowers blooming in a multiple socket. Both the multiple socket and the contiguous plug-in metaphor reduced the concept of infrastructure to a mere arrangement of objects, or a "thing stripped of use" (Star and Ruhleder 1996: 113). They prioritized technical preoccupations and solutions over the social and organizational dimensions of infrastructure, temporarily sustained a deterministic view of the infrastructural work at hand, and concealed the relationship between technology, human work, and users in this process. The blooming flowers metaphor helped to configure ZPR's economic infrastructure by structuring the manner in which ZPR's technical and economic relation to markets and innovation were envisioned. Our reconstruction shows the actual work done to select third-party applications for the portal, and then categorize, order, and rank them.

The blooming flowers metaphor travelled beyond the confines of the Project group, but it required translations to circulate. Its playfulness best suited the Project group setting, where members convened most frequently, and where much of the actual development work took shape. In the Steering group, the project manager chose different terms to address the portal and the third-party applications; our quote from 14 June 2010 nicely illustrates how she takes back the term ‘blooming flower’, and speaks of ‘new activity’ on the portal instead. Similarly, meeting minutes reported about ‘third party applications’ and the ‘accelerated development of content’ (ZPR, 2010b, 2011a). In an open letter to hospital directors in the region, the ZPR Board simply used the term ‘applications/services’ (ZPR, 2012b). In order to enrol actors in more formal settings, such as the Steering group and Board meetings, imaginaries of integrated care and innovation perhaps required more conventional terms in order to be taken seriously.

The blooming flowers and multiple socket metaphors helped to change abstract concepts about markets, business cases, and innovation into comprehensible and non-threatening images. Their playful character may also have helped to sustain a sense of enthusiasm among Project group members, if only temporarily. The blooming flowers metaphor conveyed a witty and endearing view of innovation, exuding a sense of cheerfulness and detachment from the perceived (and often experienced) seriousness and harshness of the project’s technological, economic, and political reality. It helped ZPR project members and other stakeholders to promote the imaginary of an open and inclusive portal project, and then sustained this imaginary by informing the manner in which ‘promising’ or ‘potentially interesting’ e-Health applications were viewed, even when the blooming flowers form was no longer used. The metaphor’s playfulness disguised the fierceness of economic competition, the pervasiveness of conflicting interests and agendas, and practical difficulties in devising a sustainable business model for the portal. In this sense, it helped to conceal the politics of infrastructures (Winner, 1999; Star, 1999). Furthermore, it conveyed a sense of openness and inclusion in the innovation process that masked the normative choices it involves, while obscuring the materiality and politics of infrastructural work (Oudshoorn et al., 2004). As the differentiation between ‘experiments’ and ‘accomplished’ applications illustrates, drawing the line between them remained an implicit problem. Indeed, most applications or initiatives were being tacitly *excluded* from the metaphorical “cream of the crop,” or not included in the *selection* that was deemed necessary to accelerate content development on ZPR.

As an attribute of infrastructural work, the multiple socket metaphor temporarily helped to construct the imaginary of a portal that 'provides' or 'facilitates' a unified and user-friendly technical infrastructure (i.e., based on a 'single sign-on' principle) and to express the anticipation of a future of 'integrated' and 'personalized' healthcare by rendering promises of uniformity, standardization and interoperability through the derivative 'plug in' metaphor. At the same time, its predominantly technological and economic enactment obscured the relationship between technology and human work – an element that has been extensively explored in CSCW literature (Hanseth and Ljungberg, 2001; Aanestad, 2003; Ellingsen and Monteiro, 2003, 2006; Winthereik and Vikkelsø, 2005; Monteiro et al., 2013).

Our analysis suggests that metaphors help to make project imaginaries definite, cognizable, and classifiable, and that in doing so, they can conceal the politics of infrastructural work. More than merely acting as heuristic devices in the development of IIs, we agree with Monteiro and Hepsø that they "act as forceful 'actors' that contribute substantially to the shaping of the technology [...] as a powerful ally" (Monteiro and Hepsø, 2002: 146). Their coerciveness increases as they become more deeply engrained in the project's imaginary. Having described their enactments as elements of sociotechnical imaginaries, we have shown how they contributed to the prescription of futures and agendas for ZPR, while at the same time drawing away the attention from the human work required in developing and maintaining infrastructures, and from questions about the relation between infrastructures and their users.

The implications of these observations reach much further than we were able to illustrate in this chapter. Most importantly, we wish to signal that studying the use of linguistic attributes in IIs – and of metaphors and metaphorical expressions in particular – can lead to the insight that "it could be otherwise" (Woolgar and Nyland, 2013: 7). The act of spelling out metaphors can be likened to the 'unpacking' of technologies or interventions (which reveals what is normally hidden or obscured), and thus opens up a space for new imaginaries and alternative strategies (Zuiderent-Jerak and Jensen, 2007). In the context of e-Health integration, alternative ways of framing the problems at stake may be crucial to overcome governance challenges or dilemmas (e.g., regarding the ownership of data, data distribution, surveillance, privacy, etc.). Inquiries into the reconstruction of underlying conflicting frames can help to devise such alternatives, possibly leading to re-conceptualizations of ‘infrastructure’ and ‘integration’ (cf. Schön, 1996: 139).

By focusing on the generativity of metaphors in the development of the ZPR portal, we showed how they contributed in framing the problems at hand in a cognizable yet ambiguous manner. As they divert the gaze from sociotechnical and political complexities, metaphors have the potential to transform contested, disconcerting, or unsettling ideas into seemingly innocuous (or indeed favourable) images. As such, they actively contribute to the manner in which problems are defined, and how people and organizations are called into action. The potentially far-reaching consequences of metaphors as constitutive elements of infrastructures – elements that help to construe their ontological status and their imagined social order, and that are perpetuated and shaped by that order at the same time – deserve more critical scrutiny in research on IIs, as well as in the everyday work practices of project managers, developers, and policy makers. Engaged participatory research can contribute to redirect the gaze on those sociotechnical and political complexities, and to raise timely questions about the implications of imaginaries that bypass the materiality and politics of infrastructure.

The act of spelling out metaphors can open up spaces for alternative strategies in IIs. The use of metaphors and metaphorical expressions is indeed so widespread in e-Health (and in the field of information and communication technologies in general) that it easily escapes the attention of people who ‘live’ with them on a daily basis. Although scholars from different disciplinary backgrounds have long embraced the intertwinement of discourses and practices in their work, continuous research efforts are required to better understand the agency of discursive attributes in infrastructural projects. Aside from their relevance to everyday practices, as illustrated and discussed in this chapter, we believe that metaphors and their use may also provide valuable insights in the *longue durée* of infrastructural development, and in shifting moral, ethical, and political concerns in long-term processes of sociotechnical change.

5

Conceptualizing standards as network extensions

Introduction

Standards lie at the heart of medical practice, and are inextricably linked to the digitalization of healthcare (Timmermans and Berg, 1997, 2003; Berg and Mol, 1998). Scholars in science and technology studies (STS) have given much attention to the politics of standards, their mediating role in professional-patient relationships, the unexpected ways in which they can transform practices, and their intertwinement with information technologies and (material and non-material) infrastructures (Berg, 1996, 1997; Star and Ruhleder, 1996; Timmermans and Berg, 1997; Bowker and Star, 2000; Lampland and Star, 2009; Timmermans and Almeling, 2009). They describe standards as bringing 'different social worlds' closer to one another (Star and Griesemer, 1989; Star and Strauss, 1999), but also as "intensely local […] despite their global reach" (Lampland and Star, 2009: 16). Moreover, they characterize standardization as a situated and reflexive practice that "always requires work and continuous tinkering within the specificities of local contexts" (Felder et al., 2016: 406; see also Bowker and Star, 2000; Lampland and Star 2009; Latour, 1987; Star and Griesemer, 1989; Zuiderent-Jerak, 2007, 2015; Van Loon, 2015).

Many studies have criticized policy and research analyses in healthcare for providing 'hyper-rational' and 'undersocialized' readings of the people and things involved in standardization (Kling, 1998 cited in Jensen, 2008), for overestimating the coordinating role of standards (Jensen, 2008; see also Berg, 1996, 1997), and for suggesting that they act as 'fixed' entities in linear implementation trajectories (Star and Ruhleder, 1996; Timmermans and Berg, 1997; Bowker and Star, 2000; Lampland and Star, 2009; Zuiderent-Jerak, 2007, 2015; Van Loon, 2015; Jensen, 2010). Authors informed by actor-network theory (ANT) emphasize that standards travel by mobilizing actors in heterogeneous networks (Hanseth, 2001; Ellingsen and Monteiro, 2006; Jensen, 2008, 2010), and that they "have to move between practices" in order to have any effect (Jensen, 2008: 11). While they have provided valuable contributions in doing or rethinking standardization in healthcare, their research often pertains to local practices over relatively short time spans.

Our aim in this chapter is to render visible the work invested in medical standards by various actors over a longer period of time, and to reconceptualize that work accordingly. We ask: how is a standard for medical recording integrated in a regional infrastructure for health information exchange? Building on participatory ethnographic research on the development of a personal health record (PHR) for the Rotterdam-Rijnmond region in the Netherlands, we follow the Standard Specification for Continuity of Care Record (ASTM E2369, 'CCR' for short) in action between 2009 and 2012. We use additional desk research to describe how it 'landed' in the Netherlands in 2009, and how it travelled in new directions between 2012 and 2021. Mirroring Jensen's (2008) study we answer three sub-questions: where did the standard come from, and why was it first introduced? Who were involved in its spread? And what happened when it moved between different actors and sites?

We build on ANT to contend that standards act as network extensions: they bring worlds together in non-linear, parallel movements; they make network nodes actionable; and they strengthen the associations between them. We complement this approach with insights from figurational sociology to show how standards lengthen relations of dependency between people and things through different 'frames of relevance' (Couldry and Hepp, 2017; Hepp et al., 2018). Empirically, we describe how CCR was accompanied by other standards in order to travel; how it temporarily reconfigured relations between people and things by extending their networks; how it acquired new meanings as it navigated between different nodes; and how it lost its relevance as concerns about health information exchange shifted in new directions. We round up this chapter by reflecting on the implications of our analytical perspective on standardization in healthcare.

5.1 Theoretical framework

We use ANT to show how standards come into being, travel between settings, mobilize actors, and reconfigure relations between them. We focus on specific network nodes, and describe how more or less durable associations were built between people and things in a regional standardization effort. In ANT, the network metaphor makes visible the "tributaries, allies, accomplices, and helpers" that are implicated in standards as they travel between different nodes (Latour, 2010: 5). We draw on Fenwick's (2010) suggestion to view "standards themselves as a series of networks," and to describe how they mobilize people and things in and around network nodes (Fenwick, 2010: 121). This helps us to trace "how a network [i.e., a standard] becomes extended, through a proliferation of networks and links, to function across far-flung regions of space and time" (Fenwick, 2010: 122). Fenwick's approach implies that standards are never fully settled, stabilized, or fixed, but continuously (re)negotiated and (re)enacted in different configurations of people and things. In practice, these negotiations and enactments entail 'extensions' of organizations, professionals, patients, regulatory bodies, and gatekeepers of various kind; their networks temporarily become 'longer' and the nodes between them 'more connected' (Fenwick, 2010: 122). While these links and associations between network nodes are continuously negotiated and put to the test, they are also under constant threat of being dissolved (Callon, 1986; Latour, 2007).

We propose a slight variation on Fenwick's approach by viewing standards as *network extensions*. This view follows from an observation in our study of a regional PHR pilot project in the Netherlands (2009-2012). The PHR was based on an American development platform that required plug-ins (also known as network extensions or add-ons)[75] to make it work in a Dutch healthcare environment. The plug-ins enabled connections between different elements and systems by overriding 'unwanted' default functionalities in the core of the platform.[76] We were fascinated by their recurrence in project meeting discussions at the teaching hospital's IT department, and learned that building plug-ins required complex negotiations between in-house developers, freelance consultants, and overseas support staff. These negotiations pertained to a wide range of practices, from local habits in project documentation and

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[75] In general terms, a plug-in is a piece of code that serves as an extension of an existing software program. However, different definitions are available. See: https://en.wikipedia.org/wiki/Plug-in_(computing) (accessed 2 September 2022).

[76] See: https://web.archive.org/web/20160315133524/http://robertshoffman.com/tolven-as-an-ehr/ (accessed 2 September 2022).

reporting to invoicing arrangements between different organizations. In our observations we saw an opportunity to translate the empirical concept of plug-ins (or network extensions) into an analytical concept: a particular kind of association between people and things where parts and wholes (or localities and universalities) in standardization processes are linked up or converge through human *and* non-human work.

The concept of network extensions features prominently in the work of Bruno Latour. In *Science in Action*, he discusses the simplification of the Kodak camera as a result of "the extension and complication of Eastman's commercial network" (Latour, 1987: 137), and Alan Shepard's first space flight as "[t]he slow and progressive extension of a network from Cape Canaveral to the orbit of the earth" (Latour, 1987: 248). In *Aramis* he traces associations between heterogeneous networks of officials, economists, engineers, and project spokespersons to conclude that "the network is extended, but its nature doesn't change" (Latour, 1996 [2002]: 134). In *Reassembling the Social* he borrows the plug-in concept from the world of computing to describe how people become 'complete' human actors through network extensions (Latour, 2007: 207–210). In each of these conceptualizations, the network refers to a "transformation in the way action is located and allocated" (Latour, 2010: 3) and to a "mode of inquiry that learns to list […] the unexpected beings necessary for an entity to exist" (Latour, 2010: 5). Extensions of these networks point to the human or non-human attributes of their expansion; they can include individuals, organizations, governments, media, laws, and other elements that link up parts to wholes. Importantly, these actors need to be described in symmetrical relations, rather than in hierarchical orders.

Network extensions increase the scope of different networks and strengthen the links or associations between them. Like the material plug-ins in software programs, they make new relations between people and things actionable. They do so through translation work, or local negotiations that change "something into another form" by displacing it in the network (Stoopendaal and Bal, 2013: 79). In the context of standards, translation work is done by different 'network builders' who tend to organize, treat, and conceive of these standards differently (Fenwick, 2010: 127; Latour, 1983). By consequence, standards "become transmuted at these different sites as much as they transform and mobilize actors" (Fenwick, 2010: 127). Translations continuously take place in parallel movements that reflect different goals, problem definitions, interests, and agendas in standardization (Jensen, 2008: 17). Standards are thus subjected to continuous "ad hoc tinkering, reappropriation, and explanation" (Timmermans and Almeling, 2009: 26). Even in predictable settings, or when "developed with painstaking care," standards are still "incapable of traveling to other places without change" (Jensen, 2008: 27). We use the notion of 'frames of relevance' from scholars in figurational sociology to emphasize that different interpretations of a standard do not replace each other, but are carried over in parallel movements between network nodes, even if only in a fleeting or temporary way (cf. Kuipers, 2018: 433).

In line with ANT and figurational sociology, our first premise is that network extensions do not exist separately from 'social agencies', 'institutions', or 'society' (Dunning and Hughes, 2013: 52).[77] Instead of locating human agency and its constraints in reified social structures or institutions, we view it as an outcome of "the interweaving of multiple lines of action, all colliding with each other in ways that cannot be predicted beforehand" (Van Krieken, 2019: 5–6). This entails a view of social structures as "a site of struggle, a relational effect that recursively generates and reproduces itself" (Law, 1992: 385–386).[78] In that recursive process, "networks become more or less long or more or less connected, performing comparable (if often distinctly different) practices" (Fenwick, 2010: 122). For our study on how standards travel, this means that standardization activities do not trickle down "from standardization committees at the top and down to local hospital practices," but rather occur "in parallel and connected only at certain times and places" (Jensen, 2008: 27).

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[77] Elias criticises sociological representations of 'the individual' and 'society' as antagonistic entities. He argues for a view of society that does not exist outside the individuals that constitute it (Elias, 1978: 119), that focuses on social processes, and that can not be reduced to "unstructured congeries of freely-choosing individuals" (Dunning and Hughes, 2013: 57).

[78] In a footnote to the quoted passage, Law (1992: 386) points to similarities with Elias' figurational sociology, Giddens' structuration theory, and Bourdieu's notion of habitus.

Our second premise is that network extensions can entail more or less uniform and controlled modes of action and ordering, as well as highly ambiguous ones. Closely knit links between network nodes correspond to normalized relations of order, where people and things are clearly categorized and structured by standards – and are thus included or excluded from certain practices, communities, or social groups. By contrast, weak associations and links leave much room for uncertainty, compromise, and improvisation, and entail a wide range of alternative modes of action. Murdoch (1998) refers to these as interrelated 'spaces of prescription' and 'spaces of negotiation' that "cannot exist without one another" (Fenwick, 2010: 126). These spaces are never a rational outcome of 'purposive deliberation' between individual people; instead, they must be understood as fluid relations that reflect "*an order more compelling and stronger than the will and reason of the individual people composing it*" (Elias, 1939 [2012]: 404; italics in original). From these spaces emerges an 'unplanned order' (Elias, 1939 [2012], 1978) or a 'precarious' social ordering (Law, 1992) where associations of people and things "are never settled, but constantly […] re-negotiated, shifting the alignments and forms of the entities that have come together" (Fenwick, 2010: 120).

5.2 Methodological approach

Our reconstruction of how the CCR standard travelled between different actors and networks is based on a combination of ethnographic field work and desk research. Our field work pertains to the integration of CCR in a PHR pilot project for the Rotterdam-Rijnmond region in the Netherlands. This research took place between the fall of 2009 and the summer of 2012, and was part of a broader study on the development of Zorgportaal Rijnmond (ZPR), a regional online health portal. It included participant observations and interviews with ZPR project leaders and managers, PHR developers, hospital staff, and patients. We practiced a form of engaged scholarship by providing direct comments and feedback about the project, and by thinking along with the project leaders, managers, and PHR developers (Aspria et al., 2016; see also: Bal and Mastboom, 2007; Mathiassen and Nielsen, 2008; Zuiderent-Jerak, 2015).

The first author's task in our field work was to evaluate and assist in the scaling of the PHR application from 20 'test users' (primarily hospital staff) to 200 patients of the region's teaching hospital. Between the fall of 2011 and the summer of 2012, the first author had access to the teaching hospital's IT department, where a dedicated PHR Project group convened. For six months he spent approximately four hours per week observing them at work, following their conversations, accessing relevant documents (such as project plans and progress reports), and actively participating in project meetings. He made written notes and audio recordings in project meetings (with permission) and conducted interviews with three project managers, five PHR developers, and eight pilot project participants. Parallel to these interventions at the teaching hospital, the first author attended ZPR Project group, Steering group, and Board meetings at the office of the Regional Health Information Organization (RHIO), which served as ZPR's physical home base. In that context he interviewed nine stakeholders on the political embedding of the portal in the region; respondents included the fourth author, who represented the University in the ZPR Board and discussed the portal's governance in that capacity. The second author was the Research project leader in the ZPR project; she attended Project group and Steering group meetings, where she contributed to ZPR's design and development, and coordinated its overall evaluation.

The second, third, and fourth authors contributed to the analysis of our ethnography by reflecting on our interviews and observations. Our earliest attempt to describe CCR's 'integration' in the region was in 2013; although our work showed conflicting political interests and power relations in the region, it provided little insight in the standard itself. When we revisited our analysis in 2017, we decided to trace how the CCR standard travelled between different networks in the PHR pilot project. We embedded our insights in a wider temporal scope, re-analysed our field notes, audio recordings, transcripts, and project documentation, and expanded our data collection with new observations on the main actor-networks in our reconstruction. Further revisions of our analysis took place between 2019 and 2022. This sequence of revisions added a historicizing element to our work (Asdal, 2012: 379). The combination of engaged and retrospective research enabled us to observe how weak network associations were falling apart, gradually dissolved, and/or reconfigured elsewhere. It also allowed us to reinterpret our theoretical framework and our empirical insights 'in the light of each other' and to adjust our analytical concepts accordingly (Alvesson and Sköldberg, 2018: 5).

Starting in 2017, we supplemented our field work with online desk research on how the CCR standard travelled before and after the PHR pilot project. We downloaded government documents and other publications on the use of CCR in health information exchange, and bookmarked relevant websites and blog posts. We transcribed text fragments from these sources, regularly checked the status of their hyperlinks, and wrote down when we last accessed them. Identifying broken hyperlinks became an important part of our research, as it helped us to identify dead ends and explore new avenues in CCR's travels. Our analysis focused on tracing new associations in regional and national health information exchange in the Netherlands in which CCR was (directly or indirectly) implicated. Our desk research ends with CCR's formal withdrawal by the standards development organization ASTM in 2021.

5.3 A standard emerging from professional concerns in the United States

Medical standards in healthcare – be they quality standards, clinical practice guidelines, review criteria, or performance measures – are intimately interwoven with professional concerns about healthcare provision (Kinney, 2001). Typically, they are tightly coupled to medical professional associations, and pass through a plethora of institutional committees and agencies before they are deployed in practice. The CCR standard for medical recording in our study is no exception. In what follows, we provide a detailed account of CCR's origins to determine where the standard came from, and why it was first introduced.

The Standard Specification for Continuity of Care Record (ASTM E2369) was formally published in 2005 by ASTM International, a standards development organization based in West Conshohokcken, Pennsylvania.[79] It was initiated by Health Care Informatics Committee E31 "to facilitate the interchange of health care data among providers" (Ferranti et al., 2006: 246).[80] The committee developed various iterations of CCR in cooperation with American sponsoring organizations, including nationally oriented medical associations and specialised institutes.[81] The composition of this network illustrates the aforementioned involvement of professional associations in the early development of CCR, and its embedding in professional concerns about U.S. healthcare provision.

The first version of CCR was drafted in 1999, and was based on the Patient Care Referral Form (PCRF) of the Massachusetts State Department of Public Health (Waegemann et al., 2010). The PCRF had been developed two decades earlier for a group of Massachusetts physicians who "wanted a standard, paper-based clinical summary for patients transitioning from hospital care to the care of a nursing home for continued treatment" (Lyniate, *n.d.*). Initially, ASTM developed an electronic equivalent of PCRF in Extensible Markup Language (XML):

> The idea was an electronic patient summary that could be universal, and nonproprietary using XML to take advantage of its characteristics in the growing online environment. (Waegemann et al., 2010: 267)

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[79] ASTM International is accredited by the American National Standards Institute. Before 2001, it was known as the American Society for Testing and Materials.

[80] For details on Committee E31, see: https://www.astm.org/COMMITTEE/E31.htm (accessed 2 September 2022).

[81] The sponsoring organizations included the Massachusetts Medical Society, the Health Information Management and Systems Society, the American Academy of Family Physicians, the American Academy of Pediatrics, the American Medical Association, the Patient Safety Institute, the American Health Care Association, and the National Association for the Support of Long Term Care.

With this digital variation on PCRF, ASTM extended the specific problem of patient referral between hospitals and nursing homes (as defined by Massachusetts physicians) to a wider problem of continuity of care across different healthcare domains. Indeed, ASTM later described CCR as an "outgrowth" of PCRF that is "designed for use in all clinical care settings."[82] The XML standard that accompanied CCR acted as a network extension: it expanded the scope of CCR by enabling it to travel across electronic information systems.

From 2003, CCR was further developed in collaboration with the aforementioned sponsoring organizations, and through consultations with U.S. federal government agencies, clinical specialty societies, State Departments of Public Health, community health programs, and other professional associations and individuals (HL7.org, 2004). In this wider network of healthcare organizations and regulatory bodies, CCR gradually took shape in various forms of documentation: from concept papers to nomenclature lists and spreadsheets that helped to negotiate and refine its formal definitions and delineations. In November 2003, Committee E31 held a meeting to reach consensus on an elaborate draft of the CCR standard specification and its core elements; ASTM members were invited to vote by ballot. One year later, Subcommittee E31.28 (on Healthcare Data Management, Security, Confidentiality, and Privacy) convened "to seek input toward finalizing the draft CCR standard with its accompanying core data elements spreadsheet, XML schema, and Implementation Guide."[83] Aside from the variety of (human and non-human) actors involved in CCR's early development, the work done by Subcommittee E31.28 illustrates how concerns over data security and privacy were added to the network to increase its robustness (Callon, 1986; Latour, 2007, 2010).

CCR now comprised of 17 elements that summarize 'relevant' and 'basic' health information about a patient (see Appendix G, Table 1). Those elements included administrative data (e.g., insurance data and recent appointments),

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[82] Retrieved from: https://www.astm.org/Standards/E2369.htm (last accessed 22 April 2019; withdrawn on 22 January 2021; no longer available).

[83] Retrieved from: https://www.astm.org/COMMIT/E31_CCR.doc (last accessed 22 April 2019; no longer available).

clinical data (e.g., immunizations, alerts, and laboratory results), and the patient's case history. These categories reflected specifically American challenges, such as safeguarding the efficiency of billing procedures in an open healthcare market. Although these categories were thoroughly revised between 2003 and 2004 (see Appendix G, Figure 1 and 2), the main ideas behind the standard were preserved. Most notably, ASTM continued to describe CCR as a 'core data set' for the transfer or referral of a patient, as the following quote from 2019 illustrates:

> The Continuity of Care Record (CCR) is a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's healthcare, covering one or more healthcare encounters. It provides a means for one healthcare practitioner, system, or setting to aggregate all the pertinent data about a patient and forward it to another practitioner, system, or setting to support the continuity of care. The primary use case for the CCR is to provide a snapshot in time containing the pertinent clinical, demographic, and administrative data for a specific patient.[84]

Over time, specific terms and expressions were inscribed in the CCR standard (Akrich, 1992). Most notably, members of Committee E31 and the CCR Steering Committee included the terms 'core data set' and 'snapshot in time' in their presentations and promotional activities (HL7.org, 2004; Tessier, 2004). To legitimize CCR's development and implementation, committee members linked the standard to quality of care, patient safety, efficiency, cost reduction, and integrated care across institutional and regional boundaries. In addition, they construed the standard as an enabler of electronic health record (EHRs) and electronic medical record (EMRs) implementation. These professionally oriented 'frames of relevance' are indicative of the specific audiences (i.e., doctors, managers, and executives) that ASTM was trying to enrol

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[84] Retrieved from: http://www.astm.org/Standards/E2369.htm (last accessed 22 April 2019; withdrawn on 22 January 2021; no longer available).

(Couldry and Hepp, 2017; Hepp et al., 2018). They underline that in its earliest movements, CCR travelled in highly specialized health information exchange networks, far removed from actual practices of healthcare provision.

CCR had to establish itself alongside the Clinical Document Architecture (CDA) standard, which had been issued in 2000 by Health Level Seven International (HL7), a competing standards development organization. CDA is a 'markup language' (a standardized set of notations) that "specifies the structure and semantics" of clinical document exchange between providers and patients (Dolin et al., 2001: 553). By 2004, many health IT vendors had already committed to HL7 and the CDA standard; both represented relatively established and strong networks. CCR overlapped with CDA in several areas, including its purpose and scope, but they were technically incompatible (Ferranti et al., 2006). To avert new problems for IT vendors, ASTM and HL7 initiated joint activities to strengthen the operational ties between them. Paradoxically, these joint activities led to the creation of a new standard: in consultation with Committee E31, HL7 introduced the Continuity of Care Document standard (CCD) in 2007. CCD now served as its coding language and implementation manual for documents specified in accordance with HL7-CDA; without it, CCR specifications could not be implemented by vendors operating in HL7 environments.

Like XML, the CCD standard acted as a network extension for CCR implementations. It strengthened links and associations between different vendors, clients, and their environments, and increased the potential outreach of CCR. Building this new network extension from scratch was the curious outcome of complex relations of dependency between ASTM and HL7, in which CCR and CCD were allies and competitors at the same time: the former being "focused on data and data sets," the latter "more document-focused" (Waegemann, 2010: 267). However, the CCR-CCD node was weaker than HL7-CDA, and more at risk of being dissolved: its associations with other networks were sparse (cf. Callon, 1986; Latour, 2007). Advocates of CCR-CCD proposed to strengthen its legitimacy through local and regional implementation projects. The introduction of the Meaningful Use program[85] by the U.S. government in 2009 expanded the potential outreach of CCR, as it further incentivized the uptake and implementation of CCR and CCD in health information exchange in the United States Although the success of the CCR-CCD pairing was soon debated (Waegemann et al., 2010), their emergence and intertwinement with other networks shows how standardization entails building network extensions: elements that increase the scope of a network to make it actionable and more robust.

5.4 Making the standard 'land' overseas

Challenges in health information exchange were different in the Netherlands, where plans for a national electronic patient record (EPR) had been causing political controversy since the 1990s. Around the mid 2000s, the Minister of Health envisaged a system used and curated by healthcare professionals. Legal restrictions on third-party handling of patient data ruled out the option of centralized data storage, as was current in Denmark and Sweden (Van 't Noordende, 2010). To obviate these restrictions, in July 2009 the Minister inaugurated a national switching point ('Landelijk Schakelpunt', LSP) that authorizes and logs local attempts to access medical information in digital information systems (Klink, 2009). LSP is an indexation system that aims to cover all EPRs in use in the Netherlands; its implementation was supported by a law that made it compulsory for registered healthcare professionals to incorporate the national citizen service number ('Burgerservicenummer', BSN) in all their patient administration and medical data exchange (Van 't Noordende, 2010).[86] BSN had been introduced in 2007 as a unique personal

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[85] Meaningful Use was introduced as part of the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act to promote the adoption of EHRs. See also Chapter 3 of this study.

[86] The BSN law ('Wet gebruik burgerservicenummer in de zorg') was approved by the Senate in April 2008. See: https://www.eerstekamer.nl/wetsvoorstel/30380_wet_gebruik (accessed 2 September 2022).

number for citizens who are registered in the Municipal Personal Records Database (Basisregistratie Personen, BRP).

Dutch Parliament was divided over the introduction over LSP and the prospect of a national EPR: there were concerns about privacy, security, and data ownership, which were echoed by professional interest groups, consumer organizations, and patient federations (Pluut, 2010). The Senate initiated a series of expert hearings, after which national EPR ambitions were put on hold. This incited several groups and organizations in the Netherlands to develop EPRs with a regional scope (De Mul et al., 2013). In September 2009, a consortium of public and private partners started sketching the delineations of Zorgportaal Rijnmond (ZPR), a new health portal for the Rotterdam-Rijnmond region.[87] It was in this region that CCR made its first appearance in the Netherlands.

The ZPR consortium framed the dissent over the national EPR as an opportunity to develop a PHR based on the CCR standard. The system was to be built on the American open-source development platform Tolven, which was purposively designed to support health information exchange systems.[88] By assigning a central role to patients in authorizing access to the PHR, the consortium hoped to bypass existing interoperability problems between healthcare providers in the region. They viewed standardized medical recording practices as a necessary precondition for regional health information exchange. Moreover, they viewed the adoption of CCR as a key to international interoperability: if a patient from the Netherlands were to be admitted in a CCR/CCD-compliant healthcare organization in a foreign country, these standards would allow a basic data set of their medical information to travel along with them.

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[87] The consortium had a remarkably asymmetrical composition: it included the aforementioned teaching hospital – the largest hospital of the Netherlands at that time – as well as the Municipality of Rotterdam, three small consultancy agencies, a diagnostics lab, an internet hosting company, a university department, and the RHIO.

[88] See https://web.archive.org/web/20160315133524/http://robertshoffman.com/tolven-as-an-ehr/ (accessed 2 September 2022).

CCR was introduced in the portal's network by the Chief Medical Information Officer (CMIO) of the teaching hospital, the largest organization in the consortium. He described the importance of structuring medical data according to the CCR standard from a pragmatic point of view:

> [The doctor] just wants to see all the data in one place, and when he [*sic*] sees a patient is being transferred from [hospital A], to name an example, to… I don't know, [hospital B], and he sees those data, uuh... let's say medical history, problem list, medication lab, and then says: 'hey, I see that an MRI was made last week'; then at that moment he must be able to see: last week MRI, [hospital B], the report, and a link to the actual image. And then, as a doctor you'd be happy. How it works behind the scenes with IHE XDS, whatever, no longer matters to the doctor, but he must be able to see it all in one place. Everything needs to run along those 17 items. And for the doctor there should be only one place to see it. If it's in two places, he's not going to look for it! (CMIO, 7 June 2011; own translation)

In professionally oriented presentations about CCR, the CMIO linked this centralizing ambition to the rise of clinical pathways and comorbidity treatments, and to promises and practices of 'integrated care' (cf. Zuiderent-Jerak and Berg, 2010). These new modes of organizing and coordinating work depended on bits of information stored in different databases, and on information systems that were rarely interoperable. Like the members of Committee 31, he spoke of 'snapshots' and a 'core data set' to explain CCR's purpose and added value in healthcare. He espoused the aims and purposes as defined by ASTM and helped to translate their professional frame of relevance to the Netherlands. In addition, the CMIO construed the need for CCR in the region by combining a professional frame with a more 'patient centered' perspective (cf. Dawson et al., 2009). His assumption was that patients would gradually enforce the use of CCR; as 'owners' of their PHRs they would discipline doctors to standardize their registration practices. With that, a new frame of relevance was added to the CCR network: while the focus remained on health information exchange between providers, patients were now discursively configured as gatekeepers of their own medical records. The CMIO envisioned CCR as a means to shift from 'provider-driven' to 'personalized' exchange of medical records between doctors and patients. He described this as 'personalized integrated healthcare,' where patients manage and control their own PHR to make informed choices about their care and treatment.[89]

The ZPR consortium added yet another layer of meaning to CCR by framing the PHR pilot as a pioneering initiative that would place the Rotterdam-Rijnmond region at the forefront of digital health innovation. The consortium endorsed the portal both as a 'platform' for innovation and standardized health information exchange, and as 'the' future gateway for healthcare in the region (Aspria et al., 2016: 79). In a progress report for the ZPR Steering group, this economic frame was formulated as follows:

> Developing a proven concept in which patients can view their electronic patient record and manage it. This project will provide necessary expertise for the portal project on how to exchange medical data between different care providers (Continuity of Care Record or CCR) and knowledge about disclosing it to both citizens and healthcare providers through the portal using the Tolven application. (ZPR, 2010a; own translation)

At that time, CCR's network of documents, specifications, committees, and spreadsheets still needed to be put to the test in actual care practices. Knowledge about CCR and its implementation became a focal point in the PHR pilot; in that process, the standard itself became an object of contestation. At the RHIO's office, a dedicated CCR Subgroup explored architectural, infrastructural, and legal requirements for the PHR. They wrote technical requirements for the PHR's scaling from 20 to 200 patients, and evaluated CCR against competing standards for health information exchange on the

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[89] This aligns with the U.S. government's definition of PHRs. See: https://www.healthit.gov/faq/what-personal-health-record-0 (accessed 2 September 2022).

portal (most notably HL7 and IHE-XDS). They needed CCR to be a solid and implementable standard for different organizations in the region. By contrast, developers at the teaching hospital's IT department worked on a CCR-compliant 'core medical record' ('medisch kerndossier'). They approached the 'mandated core elements of the CCR' (Appendix G, Figure 1 and 2) as an additional feature to their in-house EHR: they based their development work on current principles, procedures, and conventions that kept doctors at the centre of record-keeping practices. Both approaches also differed from the CMIO's view of CCR as an enabler of organizational change, in which patients would gain control of their own health records. Indeed, members of these different nodes clashed over diverging interpretations of the CCR standard and its 'true' purpose: their interpretations of what CCR 'is' reflected different views that often crossed each other's paths, but never quite converged (cf. Jensen, 2008). In what follows, we trace some of these parallel movements in CCR's development from up close.

5.5 Building plug-ins

At the teaching hospital's IT department, a dedicated Project group[90] was established to develop the PHR on the Tolven platform. This platform enabled the assignment of user roles in the PHR, such as 'oncologist,' 'neurologist,' 'nurse,' or 'physiotherapist'. To function in a Dutch healthcare environment, the Tolven platform had to accommodate the aforementioned BSN to identify individual patient records, as well as the unique identification number ('Unieke Zorgverlener Identificatie', UZI) for doctors and nurses, and the national authentication and authorization system DigiD for identifying patients.[91] Having added Tolven's identity management protocols to this network, proj-

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[90] This group consisted of a project leader, a regional coordinator, two developers, a database administrator, an image server specialist, two external consultants for Tolven's technical application management, a staff member in charge of functional tests, and several sub-contractors.

[91] DigiD allows citizens in the Netherlands to access services and websites of the Dutch government, and is directly linked to BSN. In 2010, only two health portals in the Netherlands were experimenting with DigiD.

ect members started referring to the PHR as ‘CCR-Tolven.’ In practice, this expanded network brought together many different nodes (including Tolven, UZI, BSN, and DigiD) that meant to move together across practical, professional, institutional, and disciplinary borders (Jensen, 2008: 19).

While the PHR still consisted of 20 patient records in a test environment that was not ‘aligned’ with the CCR standard, new challenges came to the fore. Firstly, there was a problem of semantics: the 17 CCR elements were in English, and based on practices in U.S. healthcare. In March 2011, a working group under supervision of the national centre of expertise for e-Health (Nictiz) published a manual in which the meaning of each element was (literally) translated, defined, and specified for the Dutch context. A related problem was that some of the generic (American) requirements of CCR’s companion CCD were not applicable to the Dutch context, while local needs and requirements regarding the coding and identification of drugs were missing in the original CCD specifications.[92] Both examples suggest that expanding networks entail repair work: either through a plug-in (as with the Nictiz manual) or through local modifications and adjustments in the PHR test environment.

Another challenge pertained to data extraction. Developers at the IT department prepared two software components for this purpose: one that extracted data from the hospital’s in-house EPR,[93] and one that converted extracted data into a ‘readable’ format for the CCR-based PHR. The Tolven platform arranged health record data entries in a layered queue, allowing prospective PHR users to trace the history of data entry. To make this work, the developers built an algorithmic component that automatically checked the validity of BSNs. In that process, they found that old BSNs (consisting of eight digits) were not recognized by the Tolven platform, which was developed on a nine-digit standard. To override this default mode in the system they wrote a piece of code that extended the platform’s architecture to accommodate old BSN’s. Building this plug-in required translating specialized software

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[92] Retrieved from: http://www.ringholm.com/column/Kerndossier_Nederlandse_CCD_CCR_Dutch_CDA.htm (last accessed 4 May 2019; no longer available).

[93] Retrieved from: https://www6.erasmusmc.nl/47405/patientenzorg-elpado (last accessed 6 April 2019; no longer available).

guidelines to a local context, but also negotiating different ways of 'doing' IT architecture: several meetings and work style adjustments were required between developers at the teaching hospital, freelance consultants, and Tolven's customer support team to put their 'Plug-In Framework' in practice.[94]

5.6 Negotiating different frames of relevance

A central aim of the PHR pilot project was to scale up the system from a test environment with 20 fictitious records to a fully operational PHR with 200 real patients. In May 2011, the first author helped to organize two introductory meetings about CCR and the PHR pilot for doctors and managers at the teaching hospital (Aspria, 2012). These meetings were meant to inform healthcare professionals about the purpose of the pilot and to recruit participants for our study of the PHR in use. Meanwhile, the developers added new patients to the PHR, and gradually made more CCR elements available – as most of these elements were still 'empty' at the start of the pilot. They built a web service to generate patient lists, ran certificate tests and stress-tests on the database, and performed systems adjustments and checks on automated back-ups. Anomalies and adverse events – including a system crash early on in the project – were reported and documented in detail.

The PHR Project group leader saw it as their responsibility to adhere to the formal delineations of the teaching hospital's protocols and regulations: she focused on building a stable and reliable PHR as a potential replacement of the current EPR. However, the CCR Subgroup at the RHIO criticized her lack of openness about the development process, and the CMIO was dismissive of her conservative approach to CCR. The CMIO insisted that CCR's integration in the PHR needed more than a mere alignment of data and systems: it required a new outlook on record keeping that foregrounded the standard's purpose (*why* do we do this?) and its users (*for whom* do we do it?). In his view, that meant exploring how CCR could help patients to actively

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[94] See https://web.archive.org/web/20161217160203/http://www.tolven.org/products.html (accessed 2 September 2022).

participate in their own treatment. He estimated that the PHR Project group was neglecting the prospective role of patients in the PHR, and that it focused too much on the hospital's current systems and infrastructures, or its 'installed base' (Hanseth, 2001). The first author echoed these concerns in meetings with the PHR Project group, adding that it was still unclear how the PHR would be embedded in practice, and what CCR's implications would be for doctors and patients.

By September 2011, when the regional health portal was officially inaugurated, CCR was still largely unknown among Dutch healthcare providers. Shortly after the portal's inauguration, the RHIO hired a 'quartermaster' to accelerate CCR-Tolven's adoption in the region. His task was to explore perceptions and expectations on CCR among stakeholders and potential partners for ZPR in the region. In November 2011 he reported that respondents attributed different meanings to CCR and Tolven in terms of their use: they alternatively constructed CCR as a medical record, a record for patients to consult, or a means to exchange data in care pathways. In addition, stakeholders had different expectations about the practical implications of participating in a CCR-Tolven pilot, such as the time required for its implementation (ZPR, 2011b). These diverging interpretations and expectations emphasize illustrate how standardization initiatives can never be reduced to a single purpose or overarching goal (Jensen, 2008: 26).

These conflicting frames of reference in the region added to the political uncertainty in which the CCR network was now enveloped. Several hospitals declined ZPR's invitation to open up their patient records to CCR-Tolven. They blamed adverse financial circumstances and bad timing, but also questioned the added value of the 17 CCR elements for patients, which they deemed too hard to be interpreted by laypeople. In the PHR pilot, we noted a lack of activity by patients: very few of them had actually accessed their record. Taken together, these were signals that the CCR-Tolven network was weak at best, and possibly on the verge of dissolving.

In April 2012, ZPR and Nictiz organized a regional seminar to promote the implementation of CCR and CCD. The seminar did little to change attitudes in the region: CCR was presented in the context of patient care, in line with the main focus of the ZPR project, and was primarily construed as an asset for hospitals. Domains such as nursing or the broader care sector were strategically glossed over. From ZPR's perspective, expenditures in those domains were not justifiable to the Municipality or the Dutch Minister of Economic Affairs, because it was unclear how they would contribute to economic growth or civic engagement.[95] The seminar was followed by a Nictiz whitepaper on CCR (co-authored by the teaching hospital's CMIO) which explained the standard in accordance with ASTM's specifications. The whitepaper was aimed at professionals in hospitals and other healthcare organisations, general practitioners, and IT vendors. It was accompanied by a dedicated CCR page on the Nictiz website, where it featured alongside other health IT standards.[96] Clearly, the CCR network and the PHR pilot were far removed from the lives of patients and from real-world implementation efforts.

5.7 Falling apart, reconfiguring elsewhere

In the summer of 2012, at the end of ZPR's grant period, the ZPR Board and the PHR Project group leader at the teaching hospital described the PHR's scaling to 200 patients as a success and a valuable experience. By contrast, pilot participants described the system as overly IT-minded and too hard to interpret. In the evaluation report, the first author concluded that it was unclear how the CCR-based information would align with the expectations and needs of patients; the latter were still talked about in abstract terms. The PHR was insufficiently embedded in daily practices, and its design and development lacked the input of real users without vested interests in the project (Aspria, 2012).

Around the same time, it became clear that the PHR pilot would not be extended or followed up. Aspirations of regional health information exchange

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[95] The portal was part of a wider program to stimulate healthcare-related entrepreneurship and innovation in the region; they viewed it as a platform for third-party e-Health innovations, and as a potential site of economic spin-off.

[96] The CCR description page on the Nictiz website qualifies CCR's 'adoption rate' in the Netherlands as low. See https://www.nictiz.nl/standaarden/8029-2/ (accessed 2 September 2022).

were marred by political tensions over the envisioned governance of the portal, and by negative advice by the teaching hospital's Change Advisory Board (CAB). The PHR's integration in ZPR never materialized, and the consortium's ambitions to continue the portal's development gradually faded. Despite these local setbacks, many new developments in health information exchange were taking place elsewhere. On a national scale, the Minister of Health placed the Association of Care Providers for Care Communication (Vereniging van Zorgaanbieders voor Zorgcommunicatie, VZVZ) in charge of the advancement of health information exchange in the Netherlands.

In 2013, the teaching hospital in Rotterdam started building a new PHR for its own patients, based on a simpler architecture and a proprietary development platform. The CCR standard was not incorporated. Before their new PHR was inaugurated in the summer of 2016, a webpage on CCR's implementation was moved from the hospital's portal to a special archive page. By that time, Nictiz reported that 22 hospitals in the Netherlands offered a patient portal, 16 of which used DigiD as their authentication and authorization system. None were based on an open-source platform, none facilitated regional health information exchange, and none were explicitly based on CCR.[97] Evidently, regional integration was not a priority for hospitals, which increasingly focused on individual portals as a way to promote their online presence in a competitive healthcare market (cf. Adams et al., 2015; Lupton, 2014).

While the CCR-Tolven network gradually dissolved, a new standardization initiative emerged that contained traces of the 17 elements of CCR. Between 2013 and 2016, we observed how CCR transmuted into Health Information Building Blocks ('Zorginformatiebouwstenen', zibs), a new concept developed by Nictiz as part of the Registration at the Source programme ('Registratie aan de bron'). The underlying goals and principles of zibs were similar to CCR, in that they meant to facilitate standardized practices of basic medical information registration:

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[97] Retrieved from: https://www.hoeonlineisjouwziekenhuis.nl (last accessed 30 May 2017; no longer available).

> A healthcare information building block (zib) comprises agreements about a (medical) concept, such as a diagnosis or a procedure. A zib consists of a number of elements. For example, it has been agreed that the concept of diagnosis also includes the date on which the diagnosis was made, the name of the care provider who made the diagnosis, and the status of the diagnosis. There are various care information building blocks, such as general patient characteristics (for example name, address, contact persons, family situation), measurements to support care (such as blood pressure, weight, pain score), medication use, diagnosis, operations, and care situation (such as wound care, mobility).[98] (own translation)

Zibs were described as relevant information for healthcare professionals and patients.[99] While CCR served as a 'point of departure' for their content,[100] the idea of a 'core data set' was replaced by 'context-dependent' building blocks for EHRs and PHRs:

> Historically, the building block IDs were issued on the basis of the CCR/CCD section numbers in which the relevant building blocks were positioned. Although this classification is no longer leading, the numbering is still maintained to classify the building blocks in classes of related concepts. This classification is not very tight and the numbering in principle has no significant meaning since the IDs are by definition meaningless.[101] (own translation)

These developments illustrate how parts or traces of a standard can be reconfigured and reassembled elsewhere. Zibs were incorporated in MedMij, a nation-wide initiative aimed at organizing health information exchange

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[98] See: https://www.registratieaandebron.nl/wat-is-registreren-aan-de-bron/de-kern-van-registreren-aan-de-bron/zorginformatiebouwstenen/ (accessed 2 September 2022).

[99] See: https://zibs.nl/wiki/ZIB_Hoofdpagina (accessed 2 September 2022).

[100] See: https://zibs.nl/wiki/Issues (accessed 2 September 2022).

[101] https://zibs.nl/wiki/Information_model (accessed 2 September 2022).

around patients.[102] This new arrangement is described as a 'personal health environment' ('persoonlijke gezondheidsomgeving', PGO) that encompasses a new set of agreements on health information exchange, and that is based on existing national and international standards.

By 2019, the CCR standard had come to a standstill in the Netherlands. Several organizations, including two hospitals in the Rotterdam-Rijnmond region, removed references to CCR from their websites. Similar things occurred in other countries – and the United States in particular. The Tolven platform, still touted as "one of the more widely adopted open source solutions for healthcare information technology globally" in 2012,[103] was discontinued only a few years later, when the California-based enterprise Tolven Incorporated was officially dissolved.[104] In January 2021, ASTM silently withdrew the latest iteration of the Standard Specification for Continuity of Care Record (E2369-12) from its product catalogue.[105] ASTM offered neither a replacement for CCR, nor an explanation for its discontinuation. Its quiet exit was indicative of CCR's network weakness; while there were insufficient attachments to strong and durable networks, problems of medical recording and continuity of care were reconfigured and carried over to new networks elsewhere.

5.8 Discussion and concluding remarks: Standards as network extensions

In this study, we traced the early development of the CCR standard, its subsequent integration in a regional PHR in the Netherlands, and its demise and reconfiguration in new Dutch initiatives for health information exchange.

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[102] MedMij is coordinated by the Netherlands Patient Federation (Patiëntenfederatie Nederland) with support from Nictiz and the Minister of Health, and is closely associated with the National Health Information Council. See https://www.medmij.nl/wat-is-medmij/ (accessed 2 September 2022).

[103] See http://www.openhealthnews.com/hotnews/tolven-widely-adopted-open-source-health-it-solution (accessed 2 September 2022).

[104] See https://web.archive.org/web/20161217160203/http://www.tolven.org/products.html (accessed 2 September 2022).

[105] https://www.astm.org/e2369-12.html (accessed 2 September 2022).

We showed how in a period of two decades, CCR was accompanied by a wide range of actors and networks, including other standards (PCRF, XML, CDA, CCD, BSN, UZI, and zib), health information exchange initiatives (the Meaningful Use program, the Dutch national EPR, the ZPR project, the MedMij program), people (standardization champions, project leaders, developers, pilot participants), technologies (LSP, Tolven, DigiD, the PHR test environment), documents (manuals, spreadsheets, progress reports, whitepapers), laws (the HITEC Act, the BSN law) and organizations or institutions (ASTM, HL7, Nictiz, the Minister of Health, the Minister of Economic Affairs, the Municipality of Rotterdam, the RHIO, the teaching hospital, the IT department, the CAB). As CCR travelled through these networks, it reconfigured people and things while being itself transformed: in that process, it came to mean different things to different people.

Zooming in on CCR's integration in the regional PHR, we described the work done by people and things to help CCR move between different networks. This included promotional activities in which old definitions and narratives were reproduced (i.e., CCR as a 'core data set' and a 'snapshot in time'), as well as technical interventions (including literal translation work and writing code) to make the standard actionable. We showed how new frames of relevance relating to innovation, markets, and patient-centered care were added to CCR's network, and how they sometimes clashed with professional concerns about continuity of care. These changes took shape in parallel movements around different network nodes, where professionally oriented frames existed alongside economic frames of innovation. They extended the 'original' ASTM definitions and specifications of CCR in different directions: we described concerns relating to care pathways, integrated and personalized care, and international interoperability. While CCR gained new meanings in this process, it also temporarily extended each of these network nodes by enabling new associations between them.

Zooming out, we described how standards extend and reconfigure existing networks until they stop being relevant. As CCR travelled from the drawing boards of ASTM in Pennsylvania to the teaching hospital in Rotterdam and other places in the world, it was continuously reinterpreted, reappropriated, and moulded to fit new local interests and concerns by different stakeholders (cf. Timmermans and Almeling, 2009). Several network extensions were necessary to make it land in specific times and/or places. For example, XML was required to enable CCR to travel electronically; CCD served as an extension of CCR's network in HL7 environments; and plug-ins were necessary to develop the CCR-Tolven application for the Dutch healthcare context. In our study, these extensions pertained to weak network associations that succumbed to a combination of local tensions and disputes. A reconfiguration in the health information exchange landscape was taking place in which ambitions of hospital-focused regionalization were increasingly competing with nationwide initiatives that were not tethered to hospitals, and with hospital-based portals that had no intention of serving regional functions. CCR's demise materialized in the physical removal of CCR-related documents and descriptions from various websites and hospital portals in the Rotterdam-Rijnmond region, and in its formal withdrawal from the ASTM product catalogue.

The links between actor-networks we described in this study were too weak to keep CCR moving between practices. Over time, important nodes in the CCR network were either dissolved or reconfigured, and the standard failed to extend its 17 elements to real practices of medical recording in the Netherlands. This failure to create durable associations around CCR also reflected in the portal's failure to make itself (and its prospective PHR) indispensable as an obligatory passage point for health information exchange in the region (cf. Callon, 1986). New commercial enterprises reconfigured the health information exchange market by paving the way for simpler, 'untethered' portals and information systems that better suited the current individual needs of hospitals, while leaving little room for questions of regional or national interoperability. Meanwhile, some elements of CCR were carried over to new health information exchange initiatives, as illustrated with the rise of the MedMij program. In that sense, CCR's story is an illustration of standards as "precarious and partial accomplishments that may be overturned" (Law 1994: 1–2), but also of standards as extensions of network nodes that are continuously reconfigured in association with new initiatives or arrangements elsewhere.

Owing to the wide temporal scope of our study, our reconstruction shows how patient-oriented frames of relevance gradually gained some terrain over medical professional frames. In that process, the problem of continuity of care in the CCR standard was itself a moving target. Indeed, we were not only looking at intertwined 'trajectories' of different interpretations of the standard (cf. Bowker and Star, 2000: 186), but at a problem that branched out in different directions as we followed CCR in action. These included questions of fragmentation in healthcare (i.e., integrated care and care pathways); questions of regional and (inter)national interoperability between different hospitals; and questions of patient-centered healthcare provision. We described how temporal extensions of specific interests and sociotechnical dependencies took shape in that process. These entailed a gradual convergence of heterogeneous networks, where healthcare organizations, governmental agencies, commercial enterprises, and patient organizations engaged in new cooperations, and thus grew closer to each other. In this complex 'geometry' of relations in which CCR was more or less prominently implicated (cf. Newton, 2002: 531), we see how new orientations emerged in the approach to problems of standardization in health information exchange (i.e., replacing the notion of a 'core data set' with context-sensitive 'building blocks'). These orientations reflected in projects that were less focused on rigorous implementations of formal standards and more on pragmatic, local interventions.

Combining different strands in social theory, as we have done in this chapter, is itself a matter of building network extensions. While ANT foregrounded the politics of network associations in the making, the concept of frames of relevance helped to describe the changing character of these associations over longer periods of time. It served as a network extension to our ANT approach by adding a more processual, *longue durée* understanding of transformations in health information exchange. Future combinations of ANT and figurational sociology may provide new insights in how standardization relates to changing practices, habits, values, and expectations in healthcare.

6

Tracing phantom networks

Introduction

> *We have been mistaken. What we had called the "technological object" is what lies on the garbage heap, in the scrap pile, abandoned by people and by other projects. (Latour, 1996 [2002]: 214)*

Italo Calvino once described how the spirit of his beloved city of Paris "clings the past to the present, where different eras add up and blend" (Rapetti, 1974, own translation; see also Barral, 2001). He alluded to the interlacing of different temporalities in Parisian infrastructures that configure the city as a reference work: it reads like an encyclopaedia and a newspaper at once (Rapetti, 1974). This strange order of things characterises infrastructures *tout court*: from urban environments to information infrastructures, they build on what is already in place while continuously evolving "along multiple temporal scales" (Aanestad et al., 2017: 29; see also Edwards et al., 2009; Ribes and Finholt, 2009; Karasti et al., 2010). Infrastructures incorporate past, present, and future: they are constituted by imaginaries, expectations, and development, but they equally comprise of memories, destruction, decay, and abandonment. As "possible storytellers," infrastructures can help us to look back in time and rethink unmet hopes and expectations in function of our present and future (Klein Zandvoort, 2022: 16).

Although the normality of failure, loss, dismantling, and phasing out of technological artefacts is widely recognized in science and technology studies (STS), infrastructures and artefacts that "have been neglected, abandoned, and left to deteriorate" are under-researched (Howe et al., 2016: 550; see also Ciborra, 2001; Star, 1999). STS research tends to focus on how infrastructures come into being, how they are used, and how they evolve; it addresses questions of innovation, implementation, and organizational adoption, as well as mundane practices in the design, development, and maintenance of infrastructures in use (Aanestad et al., 2017; Ciborra et al., 2001; Pollock and Williams, 2010; Vertesi et al., 2017). While they do not lack in analyses of failure, studies rarely provide insight in what happens in the afterlife of technologies. This deficiency is not specific to STS alone. Practices of maintenance and repair in abandoned or deteriorated infrastructures "constitute crucial but widely understudied moments within the worlds of new media and technology today" (Jackson, 2013: 226). When sociotechnical networks break down and development activities cease, researchers tend to shift their focus to new subjects. This tendency reflects the "primacy of production and design" in technology and social science that obscures the work done by people and things in the peripheries of sociotechnical networks (Jackson, 2013: 225).

In this chapter, we reflect on technological abandonment in an emergent digital information infrastructure for healthcare. Our aim is to explore what insights we can yield by staying with the abandoned object. We ask: what happens when technologies are abandoned? We started thinking about this question after the abandonment of an online health portal that we had helped to build. It made us realize that on the World Wide Web, signs of abandonment can be found anywhere: from dormant applications to unused or forgotten databases, broken hyperlinks, and websites that are no longer in use, were never completed, or failed to capture an audience. Indeed, the online world is as much a construction site, as it is a digital graveyard (Thomas et al., 2013: 8). We noticed that digital traces and material abandonment on the Web are rarely problematized by researchers and policy makers; notable exceptions are EU legislation on the 'right to be forgotten,' enacted in reaction to the accumulation of personal data on the Web, and grassroots initiatives in the United States to prevent the deletion of climate data from the Environmental Protection Agency (Kansa and Kansa, 2018). We found that overall, little is known about the implications of abandonment in online technological development, or how to study it.

Central to our research is the case of Zorgportaal Rijnmond (ZPR), which started as a publicly funded online health portal for the Dutch region of Rotterdam-Rijnmond in 2009. The portal was festively inaugurated in September 2011, but failed to live up to its intended purpose as a public gateway to health information and services. The consortium behind the portal project was dismantled in August 2012, at the end of a three-year grant period. The material portal was appropriated by the Regional Health Information Organization (RHIO) that had acted as secretary of the project. In the years after 2012, we noticed that new features and applications were added to the portal, amidst clear signs of neglect and decay. Having actively participated in the portal's development, we were increasingly fascinated by its continued online presence. By June 2017, several hyperlinks on the portal led to error pages; by that time, the last news update on the home page was more than a year old. In the months that followed, the RHIO removed all hyperlinks and references to ZPR from its own website. Meanwhile, the portal had been repurposed to serve as a development platform for health information exchange projects in the region. In that process, parts of its content were either deleted or replaced with new features targeted at small groups of people. ZPR remained publicly accessible in that form for two more years. In June 2019, the portal's revised content was completely removed.

Building on actor-network theory (ANT) and affiliated approaches, we describe the portal from up close as it presented itself between June 2017 and June 2019, nested in a grey space between activity and neglect. This specific period in the portal's existence makes visible the peculiarities of abandoned (online) artefacts shortly before they are scrapped, deleted, or removed. Our study is inspired by scholars in organization science, urban geography, landscape studies, anthropology, history, and archival studies (Dale and Burrell, 2011; De Cock and O'Doherty, 2017; Edensor, 2005; Gordillo, 2014; Milligan, 2017; O'Brien, 1999; Qviström, 2012; Schopf and Foster, 2014; Settis, 2011; Stoler, 2013). Their work on the decay, ruination, death, and demise of artefacts and their infrastructures presents abandonment and loss as inherent elements of technological life. It shows how abandoned artefacts materially decompose over time, are reclaimed by nature, blend into new sites, and sometimes gain new purposes. In our reconstruction, we zoom in on the work implicated in those processes.

Siding with Jackson's (2013) 'broken world thinking,' we take the fragility of the worlds we inhabit as our theoretical premise: associations of people and things are not only built, but also continuously fall apart. A similar idea informs STS research on infrastructural ruins, which has been applied to the production of science and knowledge (Howe et al., 2016; Margocsy, 2017; Rankin, 2017) and to questions of human mastery over the world (Beuret and Brown, 2017). These studies emphasize the paradox of infrastructure as "constructive and destructive" at the same time: "it is built and grown, rigid and fluid, meant to last but doomed to be outmoded, ruined, and exceeded" (Howe et al., 2016: 559). Where some scholars focus on the role of 'ruptures' and 'network breakdowns' because they have "the potential to offer a counter-narrative to whiggish narratives" of progress (Margocsy, 2017: 319), others contend that "networks do not break, and infrastructures do not crumble" and that "we should expect networks and projects to diverge, reassemble, and diverge again" (Rankin, 2017: 359, 372).

Following Jackson (2013), we describe repair work in networks of abandoned artefacts and infrastructures, or "the subtle acts of care by which order and meaning in complex sociotechnical systems are maintained and transformed, human value is preserved and extended, and the complicated work of fitting to the varied circumstances of organizations, systems, and lives is accomplished" (Jackson, 2013: 222). Given the relatively narrow temporal focus of our study, we deem this pragmatic approach more suitable than Rankin's (2017) long-term historical view of networks as continuously diverging and reassembling. In Jackson's approach, repair is a form of 'articulation work' over shorter periods of time (i.e., months and years rather than decades or centuries), or a way of temporarily restoring broken and disrupted sociotechnical orders that allows for brief moments and spaces of continuity (Jackson, 2013: 223; Star and Strauss, 1999). In this chapter we distinguish three facets of repair work in our empirical case – anticipation work, erasure, and re-scripting – after which we reflect on the implications of studying repair and abandonment in the context of infrastructural development.

We contribute to existing STS literatures by conceptualizing weak associations of people and things in the portal's afterlife as 'phantom networks.' We view the act of tracing phantom networks as an alternative form of infrastructural inversion that exposes the politics fading "into the woodwork" of technologies and infrastructures in decay (Bowker and Star, 2000: 34; see also Hanseth and Monteiro, 1996; Star and Ruhleder, 1996; Star, 1999). We contend that at the same time, tracing phantom networks is itself a form of repair work with methodological implications: a way of caring for failure and loss that draws attention to the generativity of abandonment, and that helps to piece together the afterlives of infrastructures that are no longer in place.

6.1 Researching abandonment by tracing phantom networks

In STS accounts of technological development, references to abandonment often build on 'symmetrical' analyses of failure and success that aim at an "even-handed treatment of both winners and losers" (Feenberg, 2017: 639; see also Law and Bijker, 1992). Classic examples are the demise of the gas refrigerator (Cowan, 1985) and the high wheel bicycle (Pinch and Bijker, 1987 [2012]), where technological abandonment figures as a process with no clear beginning or ending, and questions of relevance and obsolescence are addressed from a constructivist perspective (Sormany et al., 2017: 116). Hughes' famous description of the battle between direct and alternate electrical current shows how abandonment does not imply "the dramatic vanquishing of one system by the other," but rather "a relatively gentle transition whereby the older system slowly [gives] way over decades, first as the new system supplement[s] it, then as the new replace[s] the worn-out and obsolete" (Hughes, 1983: 121). We build on these insights, and reject a strict analytical dichotomy between triumphs and failures in technological development. In addition, we draw inspiration from feminist STS scholars who described the silenced voices of workers in processes of technological abandonment (Mort and Michael, 1998).

We use ANT to piece together traces of ZPR as an abandoned online health portal, and show how different voices emerged and disappeared amidst its ruins. From an ANT perspective, an analysis of abandonment directs the attention to weakened networks, the collapse of sociotechnical alliances, the displacement of interests, and the absence of intermediaries (Latour, 1987, 1988; Law and Callon, 1992). It makes visible how human and non-human agency is redistributed and reallocated, and lays bare continuities and discontinuities in modes of action (Latour, 2007: 27, 77). The most elaborate illustration of technological abandonment from this approach is Latour's *Aramis*. It is the story of a personal rapid transit system imagined in the 1960s, turned into a project in the 1970s, and "terminated" in Paris in 1987 (Latour, 1996 [2002]: 12–15). Among the story's narrators is Aramis itself, a twentieth-century counterpart of Frankenstein's monster, who is rejected by its own creator and deplores its uncertain fate (Latour, 1996 [2002]: 82). In Aramis' lament we see abandonment as a state of being, denounced by the voice of a marginalized, neglected subject that aspires to become a 'real' object of interest (Latour, 1988, 1996 [2002]). Cut off from its allies, removed from commitment and love, Aramis-the-prototype sees a ghostly image of its own future in shattered fragments:

> No, Aramis is not yet among the powers that be. The prototype circulates in bits and pieces between the hands of humans; humans do not circulate between my sides. I am a great human anthill, a huge body in the process of composition and decomposition, depending. If men stop being interested in me, I don't even talk any more. The thing lies dismembered, in countless pieces dispersed among laboratories and workshops. (Latour, 1996 [2002]: 123)

The failure to transform weak and unstable associations into a dense and durable network means that Aramis is unable to speak for itself, to break free from its creators, and to proceed into the world on its own (Latour, 1996 [2002]: 123). Its abandonment is an attribute of displacement: the mobilization campaign carries on elsewhere, with various actors regrouping under different flags. Their old battle colours are rendered by networks of disparate elements that were once tightly bonded and neatly arranged in contracts, project plans, coordinated activities, and prototypes – as promising technologies of the future. Those elements are now marginalized from robust network nodes, and removed from contestation and dispute.

We propose the concept of 'phantom networks' to describe these weak and marginalized associations of people and things in sociotechnical networks.

Tracing phantom networks means reconstructing how the agency of people and things is redistributed over time. In order to become visible, a phantom network needs to be "traced anew by the passage of another vehicle, another circulating entity" (Latour, 1996 [2002]: 132); only then can it speak to us of a future that never was. Conceptually, it bears similarities with Mort and Michael's (1998) 'phantom intermediaries,' which describe actants or (parts of) networks that have been 'disenrolled' but whose traces remain present despite their physical absence. These displaced intermediaries can be abandoned technological artefacts, but also workers made redundant; while being pushed to the margins, these people and things still have the potential to exert pressure on the remaining actors, or even to put up resistance against the 'predominant network' (Mort and Michael, 1998: 392). We contend that the same applies to phantom networks, or weak associations of people and things: they remain an integral part of infrastructural development, as their agency in the margins of networks is never neutral or inconsequential.

Tracing phantom networks is a form of infrastructural inversion that makes genealogies of artefacts, systems, and their infrastructures visible. It allows us to reconstruct their 'sedimented past,' or a lineage of their precursors (cf. Latour, 1987: 92). It is somewhat reminiscent of the 'biography of artefacts' perspective in information systems (IS) that moves "beyond episodic (short-term single site) studies of settings of technology design or its organisational implementation/use" (Pollock and Williams, 2010: 530–531). However, rather than focussing on "the evolution of workplace technologies over multiple cycles of design and implementation," tracing phantom networks means piecing together what is left behind, and focusing on subtle instances of repair by building and engaging with archives (Jackson, 2013). As places of past memories and imaginaries, we view archives as bringing a specific order to the world, and raising new concerns and problems over time: they act as a mirror through which we understand ourselves (Bradley, 1999; Waterton, 2010). The World Wide Web, which plays an implicit yet very central role in our study, is effectively the largest archive at our disposal: it encompasses online databases, documents, and applications, many of which lie dormant in unindexed websites, private forums, behind security walls, or simply as accessible but forgotten resources. While it can inform us of how things were once organized, valued, and used, it also confronts us with unmet promises, abandoned paths, and other discontinuities and disruptions. Due to the networked, dynamic, and siloed character of the Web in its current form, information about people and things can sometimes be hard to find, or indeed notoriously difficult to erase.

6.2 Methodological approach

Our study is based on a mix of participatory research and archival work, conducted at various moments over a period of ten years. Between 2009 and 2012 we practiced a form of action-oriented, engaged scholarship by contributing to the development of the portal and three of its main applications (cf. Bal and Mastboom, 2007; Mathiassen and Nielsen, 2008; Zuiderent-Jerak, 2015). Our involvement in the portal project gave us a privileged position as observers, in that we witnessed several crucial developments firsthand. The first and second author attended meetings, project events, and conferences, and conducted interviews with project members, regional stakeholders, and prospective and actual portal users. Aside from these formal settings, they gained insights about the project through countless instances of 'informal knowledge sharing,' for example during lunches and car rides with fellow project members (cf. Waring and Bishop, 2010). They documented their involvement in field notes, audio recordings, progress reports, and publications in national and international journals (Aspria et al., 2014, 2016). To complement our research, in 2017 the first author conducted telephone conversations and email correspondence with two portal spokespersons, two former project members, and three other stakeholders (two former, one current in 2017).

In our archival study we tried to be attentive to changing concerns and realities by analysing images and texts in abandoned online spaces. Between October 2010 and June 2012, the first author made screenshots of different versions of the portal as a way of documenting its development process. He did so in an unstructured manner, storing images of published versions of the portal alongside (unpublished) design proposals. His initial intention was to use those images as illustrations in research presentations and project reports. Images were saved in .jpeg or .bmp format and stored in different project folders. After the portal project's end in the summer of 2012, no more screenshots were made for a period of five years. In June 2017, the first author sought to create a current overview of the portal's visual appearance. He used an online tool to capture all publicly accessible pages on the portal; captures were saved in .jpeg format, and the individual documents were named after their relative URLs. These captures were categorized, dated, and filed alongside the aforementioned screenshots in a new folder structure. The archive contained 130 images; new captures were added in January and April 2018 and June 2019, resulting in 165 images in total. All descriptions were recorded in an Excel file, which we refer to as the 'image archive.' The image archive produced various kinds of (reflexive) knowledge and insights about the portal, which were shared between the first, second, third, and fourth author. Most notably, it alerted us to the changing character of our descriptions through time, where initial concerns with functionalities gradually shifted into an interest for silenced voices and missing narratives.

During the image archive compilation, the first author also created an inventory of search results for the bracketed query 'zorgportaal rijnmond' in the Google search engine. The resulting network of hyperlinks and references to ZPR on the World Wide Web, current in August 2017, consisted of 1,250 results and 116 unique page entries which were recorded in a separate Excel file; in this chapter we refer to it as the 'hyperlink network archive'. Each entry contained the name of the webpage or the organization supporting it, a brief description of that organization, the hyperlink to the landing page, the date of online publication (if available), and additional comments. The hyperlink network archive contained publicity and research materials, public announcements (e.g., new partnerships, initiatives, functionalities), and personal opinions about the project; some of these materials were new to us.

In our final analysis, the first, second, and fourth author integrated insights from the image archive and the hyperlink network archive. We complemented these materials with brief telephone conversations and email exchanges on the status of the portal and its applications. Our analysis gave us insights in changing authorization procedures, error pages, and broken hyperlinks on the portal, as well as to changing strategies and organizational developments. We emphasize that our reconstruction is not an objective representation of what we saw, and that our analysis was highly informed by how we experienced the project (cf. Kelly, 1999). This means that we were likely to zoom in on details that may escape the casual observer, and equally likely to run into our own blind spots. In that process, we had to learn how to 'dwell' in ruins by engaging with their materiality (De Cock and O'Doherty, 2017). We did so by carefully documenting our steps for future reference, frequently returning to our materials (including the portal itself), and being reflexive about our observations and interventions. What follows is a summary of the main developments that led to the portal's demise; subsequently, we provide an analysis of repair work in relation to abandonment, and a reflection on tracing phantom networks as a form of repair.

6.3 Birth and demise of a health portal

We start our reconstruction in the fall of 2009, when the Rotterdam-Rijnmond region in the Netherlands comprised of eleven hospitals and a wide range of healthcare organizations on a total population of approximately 1.2 million citizens. Medical professionals from the region had long advocated for a shared information infrastructure, arguing that the countless authentication procedures for different health information systems made their work time-consuming and inefficient. They also viewed the duplication of data-rich images on different hospital servers as a waste of expenses. They argued that building an online portal for healthcare and well-being would raise the quality and efficiency of healthcare provision within and between organizations, and that it would improve public health outcomes (ZPR, 2009).

A regional consortium was formed with the aim to develop a health portal and three applications: an information system for care provision services, a video education program, and a personal health record (PHR) for the region. The consortium comprised of a teaching hospital, a regional hospital, three consultancy agencies, a diagnostics lab, an internet hosting company, a university department, and the RHIO. The latter acted as the project's secretary, and helped to submit a 600,000 euro grant proposal to a special programme for sustainable growth issued by the Dutch Minister of Economic Affairs (Otte-Trojel et al., 2015; Van der Hoeven, 2007). The grant proposal was approved, and the fee was doubled by the Municipality of Rotterdam, who wanted to "gain an important position in national and international health innovation" and welcomed the prospect of a regional health portal in light of the recently introduced Social Support Act (ZPR, 2009).[106]

Details about the portal's early history and development are documented in academic publications and trade journals (Aspria et al., 2014, 2016; De Mul et al., 2013; Groeneveld, 2010; Otte-Trojel et al., 2015; Schop, 2010; Van Dorrestein, 2012). The portal project was related to a digital outpatient clinic pilot for cystic fibrosis, haemophilia, and head and neck cancer at the teaching hospital, and formally started in September 2009 (Luyendijk, 2009).[107] Throughout the three-year grant period, a Steering group of consortium delegates oversaw the Project group's progress, while the Board monitored the project's overall achievements. A program manager presided over daily operations. Around the spring of 2011, in the middle of the portal's development, project members initiated activities to secure its future, and to reach out to new potential partners in the region. In their own words, the consortium's concern was to guide the portal's transition from a funded project (aimed at the future) to a sustainable or exploitable product (anchored in the present). At that time, pilot projects with small user groups were barely starting to provide insights in the added value of some of the applications, and there was little consensus on which problems the portal would (or could) effectively solve in the region. Despite these unclarities, a dedicated working

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[106] The Social Support Act was introduced in the Netherlands in 2007. It implied a transfer of responsibilities for social welfare arrangements from the national government to municipalities.

[107] The outpatient clinic pilot largely involved the same staff from the teaching hospital's IT department, and was based on the same patient-oriented authorization principle as the envisioned PHR on the portal.

group drafted scenarios for the portal's future ownership, its organizational and financial embedding in the region, and its relation to the RHIO.

The portal was festively inaugurated in September 2011, but by February 2012 the first ruptures in its sociotechnical network became visible. As the working group proposed to separate the control of daily operations from questions of financial management and ownership, some consortium members felt that the RHIO's role in the decision-making process was too prominent, and that it was unclear who would effectively own the portal, and who would take place in the two boards (ZPR, 2012a). Throughout the spring and summer of 2012, the portal was little more than a functional prototype with an uncertain future. In July the consortium concluded that there were insufficient funds to guarantee ZPR's running costs and periodic maintenance, and that the search for external commitment had been unsuccessful. The Board approved an ultimate proposal by the RHIO to bridge the financial gap between August and October 2012.

Alongside these ruptures, the first signs of the portal's repurposing became visible. With a smaller group of consortium partners, the RHIO reacted to an international call for implementation pilots in home automation. Together with partners in Spain, Denmark, Italy, and Germany, they submitted a grant application ('Make it ReAAL') to the European Commission's 2012 ICT Policy Support Programme. The grant was approved. In addition, a financial extension for ZPR's repurposing until the end of 2013 was provided by the association of collaborating hospitals in the region (Stichting Samenwerkende Rijnmond Ziekenhuizen, SRZ), two ZPR consortium partners, a home care organization, a cooperative group for stroke treatment, and the Municipality of Rotterdam. By January 2013, the ReAAL project served approximately 1,000 households in the Rotterdam-Rijnmond region. Pilot participants used ZPR to access self-measurement applications, including online registration tools for blood pressure and body weight measurement. Old and new experimental applications on the portal continued to co-exist on the portal for several years.

In 2018, ZPR's home page was redesigned to better serve its purpose as a test bed for regional health information exchange projects. By this time, it only contained a brief allusion to the portal's historical origins as "the place to find correct information about healthcare and wellbeing in the Rijnmond region." The site was available online until June 2019, after which it temporarily served as a mirror site (or 'alias') of the RHIO's website.[108] In 2021, the content and layout of the site were completely replaced, as the site now served as a mock-up template for its new registrar – a domain name provider operating from the city of Zwolle.[109] With that, all traces or references to the RHIO, health information exchange, and the Rotterdam Rijnmond region were cancelled.

In retrospect, we can assert that ZPR failed to serve as a regional health portal, after which it was temporarily used as an experimental platform or test bed for health information exchange. Currently, ZPR exists as a phantom network of physically dispersed non-human actors. These include hyperlinks from other websites, project plans, initiation documents, progress reports, architecture documents, meeting minutes, release schedules, press clippings, media articles, policy reports, promotional items and gifts, emails, audio recordings, memos, personal notes, our image archive, and the current study. Old screen captures of ZPR are accessible through automated online repositories, such as the Internet Archive Wayback Machine.[110] These non-human actors are interlaced with weak associations of people, including project members, doctors, pilot participants, healthcare executives, and others who contributed to the development of ZPR through specific knowledge networks, organizations, and institutions. In different times and places, these people and things were bonded around the health portal project. Currently, they are united by a phantom network of stories, anecdotes, lectures, and academic papers that trace their networks anew (Latour, 1996 [2002]: 132). In what follows, we describe the work done by (some of these) people and things while ZPR was abandoned and its networks ceased or broke down. We view these activities as

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[108] Last accessed as a mirror site of the RHIO's website on 1 August 2019.

[109] As per information available from the Dutch Chamber of Commerce, current on 5 July 2022.

[110] The Internet Archive Wayback Machine is the oldest automated online repository. See: https://archive.org/web (accessed 2 September 2022).

facets of repair, or the (largely invisible) work that took place in the margins of the portal's network between 2017 and 2019 (Jackson, 2013).

6.4 Abandonment and repair

As our reconstruction begins to show, staying with the abandoned object brought practices of appropriation and repurposing to the surface. The RHIO manifested itself as a central hub in these processes; it was there that repairing attempts were made to save the abandoned portal from total loss. In our analysis we discern three facets of repair: anticipation work, erasure, and re-scripting. We present them separately because of their distinct implications and consequences; in practice, they were deeply intertwined.

Anticipation work

The first facet of repair is what we call 'anticipation work.' In relation to infrastructural development, this concept denotes "practices that cultivate and channel expectations of the future, design pathways into those imaginations, and maintain those visions in the face of a dynamic world" (Steinhardt and Jackson, 2015: 443). In the context of ruination and abandonment, we view it as the work done to modify a technological artefact for future purposes, despite its current inactivity or (perceived) failure. This often entails adding or replacing a component to that artefact – a practice known as retrofit. Anticipation work thus follows from the expectation that new opportunities for development, production, or growth will arise, and that (sociotechnical) adaptations or displacements in actor-networks are required. In that process, past and future temporalities are disrupted, taken apart, and reassembled.

To illustrate the complexity of these reconfigurations, we go back to the summer of 2017, when we noticed a video on the portal's home page that looked strangely out of place. The video had originally been published on the RHIO's YouTube channel in May 2009, four months before the official start of the portal project. Eight years later, we found it prominently embedded in the middle of the ZPR home page. The video introduced the portal as a future resource for citizens and health professionals in the Rotterdam-Rijnmond region, and featured seven testimonial speakers: a general practitioner, who calls on her colleagues to adopt the upcoming medical record; a pharmacist, who explains how medical specialists will gain access to pharmacy records through the portal; a board member of a regional hospital, who stresses that healthcare providers will not compete for health information; a representative of the Dutch patient federation, who emphasizes the importance of patient empowerment; a neurologist from a regional hospital, who refers to the benefits of intra-mural medical data exchange; a health entrepreneur, who invites her colleagues to invest in e-Health; and lastly the CMIO of the region's teaching hospital, who expresses his conviction that the portal will become a success.

The video's embedding introduced temporal misalignments in the portal's script by referring to past unaccomplished imaginaries of an indefinite future (Akrich, 1992). Its exact purpose in this context was unclear; it seemed to anticipate on a future repurposing or restart of the portal, and at the same time suggested that the future of ZPR was unclear. The video was later removed from the portal, but remained available on the RHIO's YouTube channel, where it quietly endured as a disenrolled element from the ZPR network.[111] We found similar temporal misalignments and ambiguities on the 'About Zorgportaal Rijnmond' page, where the purpose statement still addressed the same audience as in 2011. It described functionalities of the portal that were either current, past, expected, or exceeded in the summer of 2017: their status was unclear. Like the misaligned video embedding, they illustrated "the ambivalences that emerge when existing projects are touted to enable an uncertain future" (Howe et al., 2016: 555), and the complexity of doing anticipation work in broken or unsettled networks – where each revision to the portal's content seemed to generate new temporal inconsistencies. Although they may strike us as strange, unsettling, or surprising, from a broken world perspective these inconsistencies are normal – and at the same time deeply political – manifestations of neglect and decay (Jackson, 2013).

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[111] See: https://www.youtube.com/watch?v=i7kzwm7ppH4 (accessed 2 September 2022).

Erasure

The second facet of repair is 'erasure,' a term we borrow from organization studies to denote the act of purposefully "filter[ing] out information deemed not worthy of preservation for the organization's future purposes" (Bowker and Star, 2000: 264). In the context of abandoned technological artefacts, erasure becomes visible when historical traces or past affiliations are deleted; it is a form of 'organizational forgetting' where "selective traces in the present" are destroyed (Bowker and Star, 2000: 256–257). Erasure is not necessarily the negative opposite of memory or recollection; indeed, some authors favour erasure over memory "precisely because memorialization has a tendency to tidy up disorderly histories" (Halberstam, 2011: 15).

We observed several instances of erasure on the portal since its appropriation by the RHIO. Most notably, we found that the original sections 'In brief' and 'Partners' had been deleted by 2017, which meant that early descriptions of the portal's historical background were no longer publicly available. We had captured them in our image archive, where they now exist as elements of ZPR's phantom network. The deletion of the Partners page was poignant, as it listed the consortium partners that had actively contributed to the portal's development between 2009 and 2012. Their erasure may be interpreted as a sign of an uncomfortable past, or as a way of not being reminded of the work that had been done in the past – including the thorny process of appropriation initiated by the RHIO. At the same time, it can be regarded as a way to create space for new alliances. In both cases, it shows how repurposing an artefact, system, or infrastructure is as much about forging new alliances, as it is about erasing evidence of ended or broken partnerships.

In ZPR's case, this erasure was a slow and gradual process of revisions that unfolded amidst visual reminders of the site's past as a health portal – including (hyperlinks to) applications for patients and medical professionals. By 2017, these applications were a closed-circuit video education program, online diaries and self-measurement tools, a viewer for electronic medical records (EMR), a medical encyclopaedia, a guide to social care and support for citizens, an embedded portal for general practitioners, and an embedded portal for palliative care. The palliative care portal had been added several years after the end of the ZPR project grant period, and was used as a decision support and coordination tool by general practitioners and palliative care groups (personal communication, 28 September 2017; general practitioner A). The EMR viewer had served as a replacement of the discontinued PHR pilot, and was abandoned by the participating hospitals in 2016 (personal communication, 27 September 2017; hospital manager). Similarly, the registration tools for blood pressure and body weight measurement were no longer in use (personal communication, 18 October 2017; general practitioner B), and the production of webcasts and educational videos had ceased – although all videos were still available in the video library (cf. Aspria et al., 2014; Van Kruijssen, et al. 2015).

Aside from purposeful acts of abandonment and forgetting, erasure is also linked to ongoing processes of decay. By 2017, several application pages on the portal contained deleted videos and broken hyperlinks. Some led to error pages and empty frames as a result of the physical migration of online services provided elsewhere – a phenomenon known as 'link rot' or 'link decay' (Tyler and McNeil, 2003; Hennessey and Ge, 2013). In our study, link rot was indicative of ended partnerships, a lack of maintenance work, or a combination of both; its origins were as much technical as they were organizational and political. At the same time, these error messages and empty frames made visible the embeddedness of a myriad of organizations and infrastructures implicated in ZPR that were "sunk into, inside of, other structures, social arrangements, and technologies" (Bowker and Star, 2000: 35). When the applications were finally removed from the site between January and April 2018, those ties were indefinitely cut off.

By mid-2018, all reminders of patient-centered and integrated regional care that were once inscribed in the portal were erased from the home page. A year later, in the summer of 2019, all content on the portal was erased, and now mirrored the content of the RHIO's website. Indeed, the only reminder of ZPR's past as a health portal was in the name of the active URL. By 2021, the mirror content was replaced with generic healthcare information by its new registrar – possibly a strategy to preserve the domain name for an indefinite future. These examples of erasure in our empirical case illustrate the inherently political character of repair; they primarily pertained to economic interests and investments in technologies and infrastructures for health information exchange. In other contexts of technological development, erasure may equally relate to underlying values, ethics, or moral concerns.

Re-scripting

The third facet of repair is what we call 're-scripting.' We loosely base this term on the notion of 'de-scription' in ANT, which allows "the relation between a form and a meaning constituted by and constitutive of the technical object to come into being" (Akrich, 1992). Whereas de-scription is focused on designers, builders, and the enrolment of objects and users, re-scripting occurs in relation to artefacts that are *not* in use. This means that the focus shifts from dense network nodes and strong associations of people and things to the quiet margins of networks, where re-scripting occurs as an attempt to repair, correct, or redress current narratives about technological artefacts. This work ties in with the aforementioned erasure and anticipation work.

Going back to the summer of 2017, we noticed changes in the visual layout of the portal and in the welcoming texts. Instead of being described as "the main place for health and care in the region" and a "secure website where citizens and healthcare professionals can safely exchange information and quickly and easily find reliable information" (as in 2011), it now welcomed clients and healthcare professionals affiliated with organizations linked to the RHIO. The first author consulted the telephone service desk on the Contact page, hoping to find out more about this change. Although the service desk was indeed in use, the operator refused to disclose information about ZPR's activities to anyone other than the RHIO's clients (personal communication, 6 June 2017; service desk operator). In a follow-up telephone conversation, the RHIO's director confirmed that the portal was being used as a test bed for projects in health information exchange; he explained that he had established new partnerships and subcontracts with health organizations in the region, and that he intended to 'phase out' several applications on a short term, although the site's future was still uncertain (personal communication, 7 June 2017; RHIO director).

Since its appropriation by the RHIO, the portal was subjected to several changes of script. In a first iteration, 'the citizen' and 'the patient' were replaced by local healthcare organizations and specialists in health information exchange; the accompanying texts across the website changed accordingly. This suggested ZPR's transformation from a health portal aimed at the general public, to a closed-circuit test bed for innovation. The news items on the portal's home page, which were posted irregularly between July 2011 and March 2016, explicitly reflected this transformation. In the first two years they consisted of general announcements for citizens and patients, but after 2012 they became entirely focused on professional knowledge networks, and more specifically on innovation managers, medical professionals, and IT developers. Concerns regarding technical interoperability, protocols, and strategy meetings were now on full display; it was a curious form of infrastructural inversion. While the RHIO used abandoned applications on the portal as a professional catalogue of past achievements, it also showcased them in various meetings and conferences. Like the biographical revisions on the portal, these success attributions were de-politicized reconstructions of the past; re-scripting was a way for the RHIO to repair the present order. Amidst abandoned applications and broken hyperlinks, the RHIO seemingly exploited ambiguities in the portal's history with the aim to enrol new allies for their current activities. Here too, we see the political character of repair – this time as a purposeful attempt to change the present, rather than merely concealing or erasing the past.

6.5 Tracing phantom networks as a form of repair

Our analysis of abandonment and repair is based on a combination of ethnographic interventions and building archives. Tracing the portal's phantom network started with actively documenting the portal's gradual abandonment as it happened over time. What began as a way of preserving 'the past' for future reference, or a seemingly neutral intermediary between the portal and ourselves as researchers, quickly became a form of personal engagement. Seeing how ZPR's history was gradually being erased, we felt compelled to side with what was at risk of being lost. The archives we built made visible the (largely hidden) repair work at the fringes of infrastructural development, and the material traces left in the wake of an abandoned artefact. We showed that from the RHIO's perspective, the portal-in-ruins was enabling and constraining infrastructural work elsewhere. As "an insinuation of what once was and of what could have been," it became a reminder of past achievements and political tensions that posed resistance in some places, and created new opportunities in others (Mort and Michael, 1998: 357; see also Bowker and Star, 2000: 258).

Piecing together the portal-in-ruins also made visible how technological artefacts remain consequential or generative even when they "disintegrate" or "lose their existence" in weak network associations (cf. Jensen, 2004: 15). Indeed, infrastructure is not only built on layers of other infrastructures, installed bases, and systems that are already in place, but always emerges amidst traces of abandonment and ruination: disenrolled elements that were once part of a different network, and that can come to represent "the remembered anticipation of a future" in the form of ruins, negative spaces, and absence (Yarrow, 2017: 568).[112] The broken hyperlinks in our reconstruction are compelling examples of what non-durable associations between organizations, systems, infrastructures, and artefacts look like in the online world. They suggest a lack of regular maintenance work (such as restoring perished connections, or redirecting traffic when necessary) that is typical of broken infrastructures. At the same time, they are indicative of political failure: in our empirical case, this is ultimately the failure of national and local institutions to facilitate, organize, and govern a viable form of regional health information exchange.

Tracing phantom networks is itself a form of repair: a way of "connecting threads, mending holes, [and] amplifying quiet voices" that foregrounds the fragility of infrastructures (Mattern, 2018: e1). For us as researchers, staying

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[112] The materiality of absence is nicely illustrated by the perishing of old wooden vessels on the bottom of the ocean: "what remains (the cargo) serves as eloquent proof of the immaterial presence of the ship." (Papadopoulou, 2016: 371)

with the abandoned portal meant being attentive about subtle movements and changes, in an ongoing effort to document what was at risk of being removed. Theoretically and methodologically, building archives became a reflexive practice: a way of engaging with our own interventions in the portal project, and of questioning our own descriptions of the portal as an artefact in ruins. Gradually, the archives also became a way of remembering people, organizations, and things that are no longer with us; this is the affective side of tracing phantom networks, which reflects the pain of abandonment and loss (cf. Mort and Michael, 1998). In that sense, tracing phantom networks also meant caring for failure, and daring to fail – as there were no guarantees that staying with the abandoned artefact would yield valuable insights on a short term.

6.6 Discussion

The concept of phantom networks we introduced in this chapter was partly inspired by Latour's *Aramis*: we thought of weak associations that fail to become durable networks, and wondered how they could inform research on information infrastructures. However, our decision to stay with the abandoned object took our analysis in a different direction: instead of focusing on how 'the object' failed to become a stable fact through processes of translation (Callon, 1986; Latour, 1996 [2002]), we made visible some of the downstream consequences of technological abandonment by focussing on repair work around weak network nodes. We showed how that work helped to create continuity in stronger nodes of infrastructural development elsewhere, while introducing new discontinuities on the portal itself: temporal misalignments and inconsistent scripts that suggested a certain degree of carelessness, yet remained inconsequential precisely because they were removed from strong network nodes. At the same time, directing our focus on weak associations meant bringing back an abandoned artefact from the land of the dead. Viewed in these terms, technology has the potential to haunt us, but may also help us in shaping a better future.

Scholars in STS may notice similarities between our study and feminist analyses of marginality in infrastructure, where the invisible, mundane, and often boring work of maintenance and repair comes to the fore (cf. Mort and Michael, 1998; Star, 1999). Tracing phantom networks indeed prioritizes what is left behind, forgotten, and detracted from view: marginalized elements in sociotechnical networks that tell us how things could have been. As we pieced together information, we looked for changing patterns in what we saw. It resulted in a visual archaeology of sorts, where we peeled off genealogical layers of the portal, and attributed meaning to visible changes based on our own past involvement in its development. We re-interpreted and reassembled the past, rather than reconstructing it in a positivistic sense. Of course, our specific commitment to visual archives meant that we gained little insight in people's motives to intervene. A richer ethnographic approach, based on more extensive interactions with past project contributors, would have provided more insights in the motives for repair work. At the same time, it would have transformed the abandoned, depoliticized portal into a contested object – thus substantially changing the object of research.

As a method, tracing phantom networks helps to unlock infrastructures as "possible storytellers" in relation to our past, present, and future (Klein Zandvoort, 2022: 16). In that process, the archive serves as an entry point to the afterlives of technological artefacts. Building and curating a series of screenshots and automated screen captures as described in this study helps scientists and engineers to explore new ways of ordering sociotechnical networks – moving away from well-trodden paths of innovation, design, and development, and taking ruptures and breakdowns as inherent elements of technological life (Jackson, 2013). At the same time, the archive shows us how past promises and expectations are continuously concealed, erased, and reconfigured; in that sense, tracing phantom networks is a way of countering Whiggish stories of technological development. Based on these implications, and given the ongoing re-scripting of technologies that characterizes the online world in particular, we recommend that engineers and researchers actively contribute to building and curating archives for future studies on repair work (cf. Waterton, 2010).

Scholars in information systems (IS) may view the phantom networks in our study as a conceptual extension of the 'installed base' – an ecology of (sub) infrastructures that are heterogeneous, interdependent, and "layered upon each other just as software components are layered upon each other in all kinds of information systems." (Hanseth, 2001: 59) Typically, the installed base comprises of technological artefacts, rules, regulations, and organizational arrangements that are *already in place*, and that add credibility to new initiatives, products, or standardization efforts (Hanseth, 2001: 62; Jensen and Thorseng, 2017: 210). Similarly, phantom networks are invoked in success attributions, and can constrain or hamper action in new communities of practice. Indeed, the showcasing of bygone accomplishments we described here can be regarded as a way of capitalizing on abandoned artefacts (cf. Jensen and Thorseng, 2017: 216–218). The obvious difference is that phantom networks are *no longer in place* and no longer represent the core of infrastructures. Whereas the installed base shows us how "[n]ew developments need to fit and make use of existing arrangements and at the same time transform them" (Aanestad et al., 2017: 4), phantom networks make visible how abandoned or obsolete arrangements do not simply disappear, but continue to play an active role by contributing to new sociotechnical networks elsewhere through subtle and inconspicuous forms of repair work in the margins.

6.7 Concluding remarks

What happens when technologies are abandoned? In this chapter we described three facets of repair in an abandoned online health portal – anticipation work, erasure, and re-scripting – that pertained to the portal's appropriation and repurposing. These forms of repair occurred incidentally over a period of two years, and unfolded in relation to future-oriented imaginaries and ghostly memories of the past. Where some elements of the portal's ruins were actively invoked to enable new development elsewhere, others put up resistance as reminders of an uncomfortable history. In different situations, contexts, times, or places, we can imagine how repair may also take on other forms: think of the active preservation of abandoned artefacts (Gale and Jacobs, 1987), dismantling obsolete things as a means to survive (Jackson, 2013), or re-writing history by means of archives (Bradley, 1999). We view our conceptualization of repair as fitting to wider themes in healthcare – from questions of quality improvement and patient safety to matters of social inclusion and participation. Indeed, repair echoes Tronto's (1993: 103) definition of care itself as the work that people do "to maintain, continue and repair" the world they inhabit in order to make it liveable (see also Puig de la Bellacasa, 2017).

We described our act of tracing phantom networks as a way of making visible the largely hidden repair work that occurs in processes of abandonment. Much like infrastructural inversion, it foregrounds the work of people and things that is either taken for granted (as in the case of infrastructural development) or simply ignored (as in the case of abandonment). Both approaches to infrastructure are crucial to understand how order, stability, and continuity are maintained in sociotechnical networks over time (Jackson, 2013: 222). For scholars in STS, tracing phantom networks emphasizes the importance of being attentive to questions of abandonment and loss, and of caring for failure while daring to fail. Without romanticizing the things that could have been, or a future that never was, an abandoned object or infrastructure may serve as an empirical entry point for researching technological afterlives, and as a way to shed new light on questions of failure, ruination, and destruction in technological development.

7

Discussion and Conclusion: Plug-in healthcare

Tying it all together

In this final chapter I answer the three central questions in this study: What work is done in the development and demise of an online health portal? How are relations between people and things shaped in that process? And how can insights from this study help us to understand changing sociotechnical figurations in health information exchange? My answer to the first question relates to integration practices in regional health information exchange, and describes the work done by people and things in terms of building network extensions. In my answer to the second question, I reflect on what binds people and things in sociotechnical figurations of health information exchange. My answer to the last question is a critique on the logic of 'plug-in healthcare', and a reflection on what can be learned from repair work. I round up this chapter by discussing the theoretical and methodological implications of my research, and by reflecting on the practical implications of this study.

I start this chapter with a brief reiteration of my main empirical findings. In Chapters 1-6, my co-authors and I addressed the following questions: Where and how did infrastructures for health information exchange originate? How are health portals framed in medical science literatures and policy advisory reports? How are doctors and patients enrolled in the development of an e-Health application? What is the politics of language in infrastructural work? How is a standard for medical recording integrated in a regional infrastructure for health information exchange? And what happens when technologies are abandoned? Taken together, my answers to these questions paved the way for the main argument of this study.

7.1 Main insights from the empirical chapters

Where and how did infrastructures for health information exchange originate?

In Chapter 1 I described the emergence of health information exchange in the Netherlands as an intertwinement of seemingly different, but fundamentally interrelated lines of action, starting by some approximation in the late 1960s. These lines of action include technological developments and infrastructural transformations in healthcare, socioeconomic change, organizational and political reforms, and gradually changing values and perceptions of 'good' care. I showed that knowledge economies played a central role in Dutch innovation policies in the 1960s, and that this emphasis on expanding knowledge – most notably, the ambition to keep up with technoscientific developments in the United States – led to the first experiment with hospital information systems in the Netherlands in the early 1970s.

It was **primarily doctors, hospital managers, and administrators** who addressed and co-construed problems of administrative logistics and billing in Dutch hospitals in the early years. Academic infrastructures and government grants served as central nodes in the first experiments in these areas; commercial enterprises grew increasingly dominant in subsequent decades, and helped to reconfigure existing challenges and problem definitions in hospital care. The rise of the World Wide Web in the 1990s led to new ways of organizing and managing information. In healthcare and elsewhere, it came with new promises of increased efficiency, connectivity, democratization, and personal empowerment, but also called for new approaches to regulation. I characterized the role of the Dutch government in the emergence of health information exchange as a process of **detached involvement**, where the Minister of Health alternately loosened and strengthened its regulatory control, while delegating the development of concrete initiatives to 'the field.'

I situated the emergence of the first regional health portal project in the Netherlands in this context of **regulated competition** in healthcare, the rise of a new health IT market, a more consumerist approach to healthcare by doctors and patients, and a politics increasingly focused on shared decision-making and patient empowerment. The Zorgportaal Rijnmond case in this study is exemplary for how e-Health infrastructures and technologies come into being in largely unpredictable, iterative processes (Ciborra et al., 2001; Zuiderent-Jerak, 2009). My historical reconstruction shows how **old and new lines of action intertwine and persist** in changing figurations of health information exchange. This *longue durée* view of health information exchange helps me to situate the work done in the development of health portals in broader figurations of healthcare (cf. Pollock and Williams, 2010).

How are health portals framed in medical science literatures and policy advisory reports?

In Chapter 2 we presented a discursive analysis of health portal narratives in medical science literatures and policy advisory reports published between 1995 and 2015. We discerned **three technological frames** in medical science literatures: portals as a gateway, a commodity, and a platform. Each of these frames emphasizes specific solutions or problems to be solved, to the extent where the artefact in question can present itself "as essentially different artefacts" to different social groups (Bijker, 1992: 76). The **gateway** frame entails a view of portals as neutral instruments in healthcare; this frame ignores the performativity (or the transformative role) of portals in healthcare, and implies a view of patients as more or less passive recipients in health information exchange. The **commodification** frame foregrounds the organizational and economic impact of portals on the care process; it highlights their embedding in organizations and markets, as well as their instrumental role in innovation and change. It configures their users as clients or customers making active and calculated choices. The framing of portals as a **platform** places more emphasis on the performativity of portal technologies and their users, and on the (re)distribution of responsibilities between individuals, organizations, and institutions.

The main elements of these frames are reflected in policy for health information exchange between 1995 and 2015 (cf. Schön and Rein, 1994). Our analysis shows that early policy advisory reports in the Netherlands addressed questions of access, commodification, and personalization in health information exchange from a **socially critical** approach (cf. Essén and Värlander, 2019). As ideals of patient involvement and shared decision-making gained prominence, these reports warned for new social disparities and unequal power distributions in the digital world. They critiqued technocratic and neoliberal discourses in e-Health, and called the government and the private sector into action over questions of infrastructure and standardization. However, those same reports helped to demarcate the boundaries of policy debates in e-Health. They did so by (intentionally or unintentionally) **circumventing potential controversies** on medical data ownership and control, and by **averting political questions** about government regulation, the role of insurers, and other commercial interests in health portal development. Failing to problematize public-private partnerships in the development of electronic health records (EHRs) and online portals led to an incomplete picture of the (political and sociotechnical) challenges at hand, and was perhaps even counterproductive in solving long-standing problems of fragmentation and interoperability in e-Health.

How are doctors and patients enrolled in the development of an e-Health application?

In Chapter 3 we zoomed in on the development of an online video education program for young adolescent patients with cystic fibrosis (CF). The program was conceived as a tool for live interaction between healthcare professionals and CF patients, and was meant to serve as a substitute for educational group gatherings, which are a potential hazard to CF patients. We focused on the 'enrolment' of members of the CF Team (including medical specialists, nurses, psychologists, and dieticians) and young adolescent patients as prospective users of the program (cf. Callon, 1986). We described how the program's development was largely **decoupled** from the practices, desires, and experiences of young adolescent CF patients. We observed that adolescent CF patients refrained from participating in the live webcasts, but we gained little insights in their motives. Their absence in the project underlines the difference between prospective and actual users in technological development, and emphasizes the importance of attributing an **active role to users *and* non-users** in the design and development of applications (Wyatt, 2003). This presupposes a view on enrolment in sociotechnical networks that not only takes into account the immediate presence of people and things, but also their invisibility or absence.

The live webcasts generated unexpected enthusiasm among parents of very young CF patients: they had little knowledge about CF, lacked a support network of their own, and were disconcerted by the often alarming and inconsistent information provided by other online sources. The project leader enrolled this overlooked group of users in the program by temporarily preserving the live webcasts' functionality, and by repositioning the program as an on-demand video library for patient education. The video library became a repository for reliable knowledge about CF, and legitimized the project as a helpful attribute in the CF Centre's patient education strategy. This shows how **a single technological artefact can be implicated in different, coexisting practices of care** – or more specifically, patient education strategies.

We described the mutual shaping of technologies and their (prospective and actual) users in the video education program as a **reconfiguration of people and things** (cf. Akrich, 1995). In our study, we only scarcely addressed the practical implications of this reconfiguration, such as the logistic and promotional work for the CF Centre's secretaries, the preparation work for the presenters, and the use of professional camera equipment, the studio floor, and the webcast recorder. In that process, figurations of patient education at the CF Centre grew increasingly denser, as people and things grew more dependent on each other. Similarly, we paid scarce attention to the consequences for citizens without a legal status in the Netherlands, who lack the required citizen service number BSN to apply for a DigiD code, and were *de facto* excluded from this type of services and arrangements.

What is the politics of language in infrastructural work?

In Chapter 4 we unpacked the politics of language and metaphors in the portal project. We argued that metaphors act as powerful attributes in infrastructural work: rather than neutral or 'innocent' descriptors of abstract concepts, they can generate new realities by **reconfiguring the imagined order** of technologies, infrastructures, and their users, and by actively contributing to the manner in which choices are made in relation to architectures, standards, and classification systems. We showed how two metaphors for innovation in our study – the portal as a multiple socket and third-party applications as 'blooming flowers' – helped to make imaginaries of 'integrated' and 'personalized' healthcare more definite, cognizable, and classifiable. The multiple socket metaphor configured the relation between third-party applications and the portal as **a problem of fit**, both in a technical sense (finding a 'fit' between plug and socket) and economically (seeking 'compatible' business models to 'plug into' the portal). This metaphor became instrumental in communicating **a sense of unity** to the 'outside world;' it also suggested neutral ground, development potential, and a low threshold for participation. We argued that the blooming flowers metaphor helped to classify and value innovation initiatives, but ultimately concealed the politics of infrastructural work.

We described these metaphors as **operationalisations of sociotechnical imaginaries**: they make those imaginaries more discernible, while at the same time leaving room for ambiguities and interpretative flexibility (Pinch and Bijker, 1987 [2012]: 20; Jasanoff and Kim, 2009, 2013). We showed that metaphors are instrumental in **how problems are defined**, and how people and organizations are called into action (Bijker et al., 2009). The multiple socket metaphor prompted project group members to 'spell out' its meaning by reflecting on the underlying assumptions (Schön, 1996: 138). Viewed from an organizational perspective, the added value of metaphors to project work resides in their **ambiguous and versatile** character: if they work well, it is exactly *because* they are not precise representations of reality (Ellingsen and Monteiro, 2008).

Our study also made visible the **performativity of language**. Words are never neutral, and have consequences for technological development; they are part and parcel of infrastructural work. Moreover, our observations remind us that metaphors do not travel alone: they require actors that help them to move between different networks. We suggested that the playfulness of the blooming flowers metaphor best suited the Project group environment, as the program manager chose different terms in relation to third-party e-Health applications when she addressed members of the Steering group – where she spoke of *new activity on the portal* instead. This stresses the **contextuality of metaphors**; to enrol actors in more formal and remote settings, references to third-party applications evidently required more ‘conventional’ language in order to be taken seriously.

How is a standard for medical recording integrated in a regional infrastructure for health information exchange?

In Chapter 5 we further elaborated on the notion of travelling and reconfiguring relations by focussing on standardization in health information exchange. Our study showed how the Continuity of Care Record (CCR) standard for medical recording travelled between different actors and settings in the early stages of the portal’s development. It was enacted in different ways as it moved between network nodes, and reconfigured people and things while being itself transformed in the process. In doing so, the standard extended various nodes in the portal project and temporarily strengthened the technical, organizational, political, and economic associations between them.

We followed Fenwick’s (2010: 121) suggestion to view “standards themselves as a series of networks,” and proposed the notion of **standards as network extensions** to describe expanding sociotechnical figurations of health information exchange. Rather than emphasizing their coordinating character, we showed how standards bring worlds together in non-linear, parallel movements; how they make network nodes actionable and strengthen the associations between them; and how they lengthen relations of dependence between people and things through different ‘frames of relevance,’ or shared meanings and orientations that gradually shift in changing **sociotechnical figurations** (Jensen, 2008; Couldry and Hepp, 2017; Hepp et al., 2018). In our empirical case, definitions and narratives by the American standardization organization were reproduced in seminars, presentations, and promotional activities, and circulated widely in documents about health information exchange. We showed how the CCR standard temporarily **reconfigured** relations between people and things by bringing different social groups together. Meanwhile, it was itself **transformed** in that process, as it acquired different meanings in different times and places.

We operationalized network extensions as a mode of association in which different networks continuously converge and diverge around specific nodes to produce new sociotechnical orders. We zoomed in on the construction of different frames of relevance in those associations, and argued that standardization is about **taming different or competing frames of relevance**. We also showed that like the metaphors in the previous chapter, the CCR standard did not travel alone: as it moved between different nodes, it was accompanied by other standards to make its technical and semantic components actionable in new networks.

What happens when technologies are abandoned?

In Chapter 6 we described Zorgportaal Rijnmond in a state of abandonment and decay. Our aim was to explore what insights we could yield from staying with the abandoned portal. The case served as an example of infrastructural discontinuities, with the portal nested in a **grey space between activity and neglect** for a period of several years. During that period, it was difficult for us (as relative outsiders, and no longer 'in the middle of things') to establish if the portal was still operational, and indeed whether it still qualified as a health portal. As the first and last regional health portal in the Netherlands to date, Zorgportaal Rijnmond left behind a phantom network of material traces – including blog posts, newspaper articles, scientific papers, and emails – that remind us of a past experimental initiative in regional health information exchange. That experiment failed to become a strong and sustainable infrastructure in the region, but contributed to newly emerging infrastructures elsewhere.

We showed how the portal's phantom network continued to have an impact on success attributions in new project work through **repair**. We discerned anticipation work, erasure, and re-scripting as three forms of repair that supported the RHIO in subsequent projects. We argued that the RHIO depoliticized the portal by concealing its roots in a publicly funded consortium of semi-public and private partners. Tracing the portal's **phantom network** was a way of gaining insight in how the agency of people and things was redistributed during the portal's abandonment. However, it can also be regarded as **a form of repair** in itself: a normative intervention that draws attention to organized practices in the margins of networks, and that helps to piece together a genealogy of infrastructures that is continuously at risk of being forgotten, lost, or strategically erased.

Our focus on displacements in the afterlife of Zorgportaal Rijnmond showed how infrastructure is not only built on layers of other infrastructures, installed bases, and systems that are already in place, but that it always emerges amidst **ruins**: disenrolled elements that were once part of a (more) tightly knit network, and that come to represent "the remembered anticipation of a future" in the form of 'negative spaces' and absence (Yarrow, 2017: 568). Indeed, the portal kept revealing its history of past associations through broken links, empty video frames, and a promotional video that was temporally misaligned. In this context, repair entailed various forms of content editing that were meant to create a sense of coherence and continuity in the RHIO's new approach to regional health information exchange. We interpreted this as a form of '**organizational forgetting**' where "selective traces in the present" are destroyed to create new room for political manoeuvrability, cooperation, and negotiation between different network nodes (Bowker and Star, 2000: 256–257).

7.2 Answering the central questions of this study

7.2.1 What work is done

My answer to the first central question – What work is done in the development and demise of an online health portal? – follows from my analysis of Chapters 3-6. These chapters reveal different types of infrastructural work implicated in the development and demise of an online regional health portal. They range from reframing, reconfiguring, and rescripting relations between people and things on a local scale, to repurposing existing technologies and their infrastructures, and erasing inconvenient traces of the past. I view infrastructural work as an ongoing process of '**building network extensions**.'

I contend that like plug-ins in software programs, network extensions enable new relations between people and things by increasing the scope of different networks and strengthening the links or associations between them. In what follows, I elaborate on this point.

Building network extensions is the work that people do to **make things actionable**, or the local negotiations and translations that change "something into another form" by displacing it in the network (Stoopendaal and Bal, 2013: 79). Typically, this displacement occurs when technologies are developed and 'scaled up' by adding of new elements to their sociotechnical network (Tsing, 2012); indeed, the scalability of technological projects is a recurring theme in the empirical chapters of this study. From an infrastructural perspective, building network extensions contributes to the expansion of existing infrastructures and their installed bases; in this study, these include the "organizational, institutional, regulatory, [and] sociotechnical arrangements that are already in place" in Dutch infrastructures for e-Health (Aanestad et al., 2017: 29). Typically, these are **closely knit links** between local and national network nodes in healthcare, information technologies, and public services. These closely knit links correspond to normalized relations of order, where people and things are clearly categorized (and thus included or excluded from social groups and practices).

Dense webs of people and things can relate to infrastructures, as well as to institutionalized arrangements. An example of the latter is the obligation for healthcare professionals to maintain medical records for their patients. This obligation builds on well-established rules and regulations, ubiquitous standards, and protocolized procedures. Dense webs and closely knit links between network nodes are about order, stability, efficiency, and robustness; although their character changes over time, they are only slightly reconfigured or transformed by local network extensions. By contrast, **weak associations** entail a wide range of alternative modes of action, and leave much room for uncertainty, compromise, and improvisation. In this study, weak associations took on many different forms. For example, they came together in imaginaries, experiments, individual champions, and organizations for the advancement of regional health information exchange. But they also comprised of people and things that were overlooked or left behind in **network displacements**; think of the aforementioned problem of access to online services and arrangements for citizens without a legal status.

Coming back to infrastructures, we see that infrastructural work entails ongoing attempts to make weak associations of regional health information exchange stronger and more durable; this happens by displacing people and things in networks, and then reconfiguring them. But these displacements and reconfigurations have other implications as well. The examples of the patient education program and the regional PHR show that organizing care around digital technologies is – at least to some extent – **a scripted practice** (Akrich, 1995; Star and Griesemer, 1989). This means that it can inscribe new affordances in technologies, or generate new roles for their users. Of course, there are **limits to the malleability** of organizations and organizing practices; for example, there were not endlessly different ways for the CF Centre to reconfigure the webcast application or to solve problems of secure access with DigiD.

While network displacements create strong associations between some nodes, they weaken other relations. Murdoch (1998) refers to these weak relations as interrelated 'spaces of prescription' and 'spaces of negotiation' that "cannot exist without one another" (Fenwick, 2010: 126). According to Star (1995), these **'spaces in between'** the filaments of networks are what the network metaphor itself tries to hide. She describes them in a poem that "calls for attention to see those spaces" and that invites us to engage with "the interruptions in overconnected networks that reveal fissures in technoscientific cultures" (Puig de la Bellacasa, 2016: 3):

network

and the word flares trumpets
shining webs
connect me
dissolving time and space

[...]

oh seductive metaphor
network flung over reality
        filaments spun from the body
        connections of magic
        extend
        extend
        extend

who will see the spaces between?
(Star, 1995: 29–31)

It is in these technoscientific gaps and fissures that new ideas, technologies in progress, and broken infrastructures exist; they are part of an 'unplanned order' (cf. Elias, 1939 [2012], 1978) or a 'precarious' social ordering (cf. Law, 1994) in which associations of people and things "are never settled, but constantly […] re-negotiated, shifting the alignments and forms of the entities that have come together" (Fenwick, 2010: 120). When these weakly associated elements are mobilized, they are tested against rigid structures and dense network nodes, such as rules and regulations, path dependencies, and the obduracy of infrastructures and their installed bases (cf. Hanseth and Ciborra, 2007; Aanestad et al., 2017).

The 'spaces in between' the filaments are also where **repair work** takes place. In this study, repair refers to unplanned, ad-hoc interventions in health information exchange: acts of care by which people try to preserve continuity and order in a messy and disorderly reality. Repair can take on many forms; from mundane workarounds in information exchange, such as the invisible work that people do to exchange medical records when information systems do not align, to the reframing of an application that does not catch on with its intended users. From an infrastructural point of view, repair always mediates between the broken present we inhabit and the futures we aspire to:

> Here, then, are two radically different forces and realities. On the one hand, a fractal world, a centrifugal world, an always-almost-falling-apart world. On the other, a world in constant process of fixing and reinvention, reconfiguring and reassembling into new combinations and new possibilities – a topic of both hope and concern. It is a world of pain and possibility, creativity and destruction, innovation, and the worst excesses of leftover habit and power. (Jackson, 2013: 222)

As suggested in Chapter 6, repair helps us to invoke the past to reconfigure the present. By tracing phantom networks, and actively engaging with empty spaces and abandoned artefacts, the past has the potential to come back and haunt us, or indeed to enlighten us; it may even do both things at the same time. In the context of health information exchange, it can show us how infrastructural arrangements could have been, or how assumptions about prospective users misaligned with their actual needs and practices. In what follows, I briefly return to this conceptualization of repair; I reflect on it more elaborately in the subsequent segment, and in the theoretical implications.

7.2.2 What binds people and things

My answer to the second central question – How are relations between people and things shaped in the development and demise of an online health portal? – follows from my analysis of different ways in which people and things became implicated in mutual relations of dependence in figurations of health information exchange. To answer this question, I combine a *longue durée* approach to health information exchange (see Chapter 1) with my insights on infrastructural work (see Chapters 4-6). I argue that technoscientific order is produced – and continuously expands – in intensifying relations of interdependence; that this reflects in increasing dependencies on IT platforms, markets, and government arrangements; and that this tightening of networks has different consequences for different people. I conclude this section by contending that repair is a form of caring for people and things at the margins of this process.

Looking at how technoscientific order is produced in health information exchange, we see that in a period spanning more than five decades, **different lines of action** gradually came together through local and national infrastructural work, and by building network extensions in and between healthcare organizations, government agencies, and markets. The examples of order I described in this study pertain to ideals of integration, innovation, and economic valorisation in e-Health, as well as to more specific ambitions of regionalisation, personalization, and patient empowerment. These ideals cannot simply be attributed to 'structural' or 'cultural change' in society; rather, they are the result of the work that people and things do in continuously expanding sociotechnical networks.

Describing a changing order in health information exchange means tracing an **increasing variety of associations** between people and things in different networks over time; some of these associations became strong and durable, others weakened and became redundant. An example of a historically durable association is the relation between academic researchers and teaching hospitals in the Netherlands, which started with small-scale, publicly funded experiments between specific departments (see Chapter 1). In these early experiments, commercial enterprises still played a relatively marginal role as suppliers of hardware and maintenance. As described earlier, collaborations between universities and hospitals intensified, and some of the more successful experiments were privatized; with that, a new specialized health IT market emerged. This caused a gradual, but also messy and largely unintentional redistribution of infrastructures, technological resources, and expertise in health information exchange; a process that was further accelerated by the advent of the World Wide Web in the 1990s, and by political reforms in the Netherlands in the 2000s.[113]

As different lines of action come together over longer periods of time, we see that **relations of dependence** between people and things are reconfigured. In health information exchange, the old order of centralized archives and paper-based records was increasingly challenged by the emergence of digital records, networked archives, and new promises of personalization and empowerment. In practice, these orders continue to coexist in complex, artful arrangements. Still today, archives for patient records in Dutch primary and secondary care are hybrid assemblages of heterogeneous technologies and storage media. But in the archive's displacement, we see that healthcare professionals and policy makers increasingly configured patients in new ways: for example, as owners of their medical data, and as partners in health information exchange (see Chapter 2). With that, the categorical distinction between providers and recipients in health information exchange became problematic, and there were increasing pressures to delegate tasks and responsibilities from healthcare professionals to patients, which went hand in hand with a need for new rules and regulations.

In these displacements of old and new network nodes, webs of people and things **grow increasingly dense**. In this study we described an accumulation of heterogeneous elements in sociotechnical figurations of health information exchange: from the introduction of competing health IT vendors to new governmental agencies, regulators, and payers. Computers, operating systems, development platforms, and programming languages became new intermediaries in the doctor-patient relationship, and helped to shape values and expectations of 'good' care. A remarkable trait of these new values and expectations is the implied view of *the patient* as a persona in the singular.

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[113] These reforms include the introduction of a mandatory basic health insurance scheme provided by competing insurance companies (the 2006 Health Insurance Act) and the decentralisation of social support that requires increasing participation of citizens in informal care (the 2007 Social Support Act). In the wake of this, public-private cooperations became more important in funding new e-Health initiatives, with insurers taking on a more prominent role in the development of health portals and related initiatives.

Current narratives about ‘personal health environments’ in the Netherlands often configure the patient as a rational individual that carves out their own care trajectory.[114] This is congruent with representations of ‘the patient in the driver seat’ of a car, or as a director ‘staging’ their own care, where medical-professional frames of patient-centeredness and empowerment are combined with economic frames of efficiency and personal choice (cf. Gerads, 2010). These representations build on a rhetoric of urgency and user-friendliness, and further contribute to a normalization of ideals of personalization and responsibilization in health information exchange. This new outlook on ‘good’ care lacks a view of patients as ‘homines aperti’ as described in the Introduction: social, open, and inherently bound to each other (Elias, 1978).

This tightening of networks has **different consequences for different people** that are bound together in the same figuration. Looking back at Chapter 3 and Chapter 5, we see how the development of the patient education program and the PHR entailed a strengthening of ties with the national authentication and authorization system DigiD and the citizen service number BSN. The latter was already mandatory for patient administration and medical data exchange among professionals, and made patient records traceable to their individual ‘owners.’ Through their association with DigiD, the patient education program and the PHR became part of a growing number of (mostly public) services and arrangements in the Netherlands that shared the same authentication and authorization procedure.[115] As mentioned earlier, there were practical inconveniences for citizens who had to procure a DigiD code, and more fundamental consequences for citizens without a legal status who were *de facto* excluded from participating in these online arrangements. This example illustrates how in dense and tightly-knit networks, gaps

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[114] This individual frequently appears in brochures by Dutch government agencies and healthcare organizations. For example, the information brochure ‘Handreiking voor (informatie) reizen in de zorg’ by the National Health Information Council features six ‘client types’ developed by research and consultancy agency Motivaction. See https://www.informatieberaadzorg.nl/publicaties/brochures/2018/09/10/boekje-informatiereizen-in-de-zorg (accessed 2 September 2022).

[115] These include municipal services, health insurers, the tax office, the employee insurance agency, the social insurance bank, and the police.

often manifest themselves in the further **social exclusion** of people who were already marginalized.[116] Thinking about *the patient* in the singular prevents us from addressing these and other social consequences of technological and infrastructural arrangements.

From this emerges a view of the work done in the development and demise of an online health portal as a double-edged sword; on the one hand, it is a process of **building network extensions**, where people and things 'plug into' new initiatives, programs, and arrangements in health information exchange – including all the promises, expectations, and mobilization efforts that infrastructural work entails. On the other hand, it is a process of **repair**, where discontinuities and displacements in sociotechnical figurations are identified, attended to, and cared for. Of course, repair is not limited to projects that fail, technologies and services that are abandoned, communities that dissolve, or knowledge and techniques that are threatened to be lost. Indeed, the examples of ruination, abandonment, and exclusion in this study show us what happens at the margins of sociotechnical figurations. As I contend in the following section, repair closely aligns with Tronto's (1993: 103) definition of *care* as the work that people do "to maintain, continue and repair" the world they inhabit in order to make it liveable (see also Puig de la Bellacasa, 2017).

7.2.3 What can be learned from repair

In my answer to the third central question – How can insights from this study help us to understand changing sociotechnical figurations in health information exchange? – I focus on what can be learned from repair. In generic

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[116] In a critical commentary on DigiD's development, the director of the Dutch organization Waag emphasized how software vendors, the tax authority, and e-commerce representatives were involved in its early design phase, and that no-one stood up for the interests of citizens: "Of course, the user-friendliness of the end product has been tested, but that offers no guarantees and I wonder how DigiD got through that inspection. Even then, testing for user-friendliness is something fundamentally different from focusing on the personal experience, legal position and interests of the individual" (Stikker, 2019: 199; own translation). Note that the use of DigiD as a precondition for access to the patient education program and the PHR conflicted with the Medical Treatment Agreement Act (Wet op de geneeskundige behandelingsovereenkomst, WGBO).

terms, I view **repair** as the (often invisible and undervalued) **articulation work** that people do to restore broken orders and maintain relations; it is about seeking stability in a fundamentally unstable, fragile world. This work is commonly explored in STS, anthropology, and related disciplines, but is also increasingly visible in policy agendas – for example, in relation to questions of sustainability. Indeed, repair can take on many different guises. In Chapter 6 I described it as a set of strategic interventions to depoliticize the portal while it was being repurposed. In a very different context, it applied to the reframing of an educational program, where repair was both a strategic intervention and a way of providing care for parents of young patients (see Chapter 3). In both examples, repair shows a side of technological development and infrastructural work that is easily overlooked.

Repair always takes place in relation to past infrastructural choices and decisions. In that sense, it invokes the past to reconfigure the present. Chapter 6 shows how the past has the potential to haunt the present, for example by making visible how health information exchange was once problematized and approached. Repair then acts as a way to learn from infrastructural gaps and discontinuities, and to rethink current development strategies in the light of a politicized past. Through negative spaces and disenrolled people and things we see **the past talking back to the present**: old alliances, failed strategies, and lost opportunities that have the potential to become relevant by shedding a new light on current assumptions. Viewed from this perspective, disruptions in technological development help us to trace (dis)continuities in health information exchange, and reveal the paradox of infrastructure as being "constructive and destructive" at the same time (Howe et al., 2016: 559).

Disruptions in complex ecologies of infrastructure – and the subtle instances of repair we described in this study – are crucial to understand how order, stability, and continuity are maintained in sociotechnical networks (Jackson, 2013: 222). Our decision to stay with the abandoned object (see Chapter 6) meant '**staying with the trouble**' of a world in perennial decay, and making sense of the present by engaging with the unorderly, messy ruins that surround us (cf. Haraway, 2016). As a way of mending ruptures and broken orders, repair is open to various forms of sociological analysis. Instead of seeking patterns in ruins, I suggest that we focus on how repair is done, and study how ambiguities in ruins unfold over time and in different places. In this study, I did so by thinking of development and abandonment as intertwined trajectories in continuously reconfigured sociotechnical orders, where neglect and preservation, maintenance and vandalism, mending and dismantling are deeply interwoven lines of action. In the following section I discuss the theoretical implications of these insights. I focus on the notion of building network extensions, the logic of 'plug-in healthcare,' and the importance of studying repair work in technological and infrastructural development.

7.3 Theoretical implications

7.3.1 Building network extensions

Describing what people and things do as 'building network extensions' has far-reaching theoretical implications. As suggested by Star in her poem on the 'spaces in between,' the network metaphor is a forceful analytical abstraction ('flung over reality') that prioritizes connectivity and extension over other relations between people and things. In this study, the concept of building network extensions foregrounds the **social and political character of infrastructural work**. While it directs the attention to modalities of creation, association, and growth, it is less productive as an analytical lens for processes of abandonment, ruination, and loss as described in Chapter 6. To avid readers of science fiction, building network extensions may conjure images of William Gibson's 1984 novel *Neuromancer*, where computer hacker Case 'jacks into' cyberspace and immerses himself in a virtual world built on mathematical concepts, graphic representations, and constellations of data. With that imagery of 'plugging in' and 'out' networks in mind, building network extensions may indeed be seen as a way of bringing different worlds into being, or a poetic interpretation of people become 'complete' human actors through network extensions (Latour, 2007: 207–210). In the context of health information exchange, such processes of 'subjectivation' and 'desubjectivation' would merit a study of their own.

In this study, building network extensions is about **making people and things circulate faster** in a network, and then **fixing them in place** through various forms of standardization, formalization, and regulation. In early ANT literatures, this process has often been described as 'heterogeneous engineering' (Law, 1987 [2012]: 108). It is about achieving order, stability, and homogeneity in actor-networks, where people and things are tangled up with each other in complex networks of (human and non-human) actors with different goals and interests (Law, 1987 [2012]: 108). The notion of heterogeneous engineering emphasizes that these relations require more than sociological explanations, and that technologies and their infrastructures are inherently layered: they build on a past of more or less obdurate artefacts and installed bases that leave material traces in their wake, and that can be analytically pieced together.

The network extensions I described in this study are also **accomplishments**: they require human and non-human work to be continuously built and maintained against the background of changing sociotechnical relations. In that sense, they should not be confused with McLuhan's view of technologies as 'extensions' of our body that rearrange patterns of human association (1964 [2005]: 3), or with Freud's conception of man as a prosthetic god with 'auxiliary organs' (1930 [2002]: 29). Network extensions are not 'external' to networks, but exist as associations between and within people and things. The *inability* to create durable associations is often described in ANT as a problem of 'interessement;' this can be a failure of actors to make themselves indispensable as an 'obligatory passage point' (Callon 1986), or as a failure to defend themselves against network displacements (Star and Griesemer, 1989: 391). At the same time, building network extensions also requires adaptations to other networks; in that sense, the portal project in this study is an example of a network that failed to adapt to changing network associations and new sociotechnical dependencies.

Network extensions are **never rigid or stable**; indeed, they are "precarious and partial accomplishments that may be overturned" (Law 1994: 1–2). Consequently, the notion of building network extensions presumes a processual view of technological development, where people and things are always in flux: they are bound together in mutual (and always changing) relations of dependence. In the next section, I expand on the unbridled belief in technological progress that the notion of building network extensions can engender. I refer to this as the logic of plug-in healthcare.

7.3.2 Plug-in healthcare as a modernist illusion

The **logic of 'plug-in healthcare'** is a logic of creation, production, and growth that prioritizes technical, legal, and economic preoccupations and solutions over the social and organizational dimensions of healthcare. Analytically, it can be regarded as a 'metacultural frame,' or a "broad, culturally shared [system] of beliefs" that contains the frames "from which institutional actors derive the policy frames they use to structure a wide range of problematic policy situations (Schön and Rein, 1994: 33). In practices of technological development and policy-making, plug-in healthcare entails a pervasive focus on standards, protocols, architectures, governance codes, laws, and technologies that **conceals the complex relationships between technology, human work, and people**. These relationships have been amply described in implementation studies in healthcare, where time and again a "lack of sensitivity to clinical work, the naive optimism about ICT in health care, and the complete disregard for the experiences of patients" comes to the fore (Zuiderent-Jerak, 2015: 185). In this study, this translates to a fundamental lack of engagement with actual practices of health information exchange.

The logic of plug-in healthcare echoes decade-old hopes and beliefs in networked technologies, self-regulating markets, and individual autonomy. It is a logic of expansion that conceals the actual work of building network extensions. Seconding Tsing (2012), it is a naturalized way of thinking about how we inhabit the world: a modernist logic that incorporates ideals of *scalability* without change, where a project is extended, but its relations – and the nature of what it does – are not transformed (Tsing, 2012: 507–508; see also Latour, 1996 [2002]: 134). In Western countries in particular, the logic of plug-in healthcare inconspicuously reproduces neoliberal forms of ordering the world based on ideals of bureaucratic homogeneity and market-driven standardization (cf. Scott, 1998: 3–8). It also reflects the 'corporatist mode of governance' that characterizes current healthcare policy in the Netherlands (Grit et al., 2012). It is a logic that **does not account for the heterogeneity of people, things, and practices** in real life; instead, it coerces them into formal classifications and abstractions, and tries to structure messy practices into well-delineated 'raked paths.' It entails continuous simplifications and reductions of social and technological complexity; reductions that help to improve the 'legibility' of healthcare systems, but that translate individual patient experiences in crude, aggregated data (Scott, 1998: 80). It is a logic that forgets to learn from the unstructured chaos of care, the noise it produces, the in-betweens of rigid categories, and the ruins it leaves in its wake. In short: it forgets to learn from the subtle instances of repair in sociotechnical orders as described in this study.

The **first implication** of this logic is that it black-boxes the politics of infrastructural work. It is a mode of thinking about management and governance in healthcare that translates infrastructural challenges into discernible, justifiable, and accountable decisions and interventions (cf. Clegg and Courpasson, 2004). As it cannot account for the heterogeneity of people, things, and practices in real life, it presents crude and aggregated versions of reality through continuous reductions of social and technological complexity.[117] With that, it coerces diffuse and heterogeneous actors into formal classifications, and structures messy practices into well-delineated 'raked paths' (see Chapter 4). What is lost in that process is the 'inside' of the black box: a space containing all the practical difficulties of making abstract ideas actionable in the real world – including the unstructured chaos and noise of everyday practices in health information exchange. The use of plug-in metaphors in the Zorgportaal Rijnmond project is a prime example of this black-boxing of infrastructure. By prioritizing technical preoccupations and solutions over the social and organizational dimensions of infrastructure, and by sustaining

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[117] This echoes the idea that governments resort to reductionisms (such as taxation schemes) to improve the legibility of systems, and thus gain control over their population: "[n]o administrative system is capable of representing *any* existing social community except through a heroic and greatly schematized process of abstraction and simplification" (Scott, 1998: 22).

a deterministic view of the infrastructural work at hand, it closed the lid on a box filled with ethical and political questions on current and future relations between doctors and patients, and on democratic values in health information exchange.

The **second implication** of the logic of plug-in healthcare is that it detracts the attention from dependencies between healthcare organizations, governments, and markets. If we look at the empirical case in this study, explaining the failure to 'plug in' different hospitals into a regional health portal needs to take into account the figuration of regulated competition in which these hospitals were (and indeed still are) bound to each other (cf. Schut and Varkevisser, 2017). The political and economic context in which they operated sparked the development of new hospital portals in the region; instead of an integration of information systems, it led to an increasingly fragmented landscape. Evidently, 'the field' was unable to solve this problem on its own. Meanwhile, local government actors (most notably the Municipality) played a relatively subdued role in this process. Indeed, ambitions of regional unification and integration in health information exchange were increasingly competing with nation-wide programs for health information exchange, which were facilitated and financially sustained by the national government.

The **third implication** of the logic of plug-in healthcare is that it places citizens in a position of increased responsibility, and that it normalizes the view of citizens as owners and managers of health information – without genuinely attending to their needs or concerns. In doing so, it inadvertently helps to transform health information from a *clinical utility* into a *personal utility* (cf. Bunnik et al., 2015). As a clinical utility, health information belongs to the professional domain: it is accessed by doctors and managers as an attribute of medical and managerial work, and also serves as a correlate of hospital indicators and quality improvement initiatives (such as the Meaningful Use program for electronic health records).[118] With the deployment of portals and applications that provide patients access to their 'personal' health records, health information becomes a *personal utility*. Although personal utility is an ethically contested concept (Bunnik et al., 2015), it points at an increasing commodification of health information, in which professional perspectives on the value of health information exchange are complemented by (and merge with) consumerist perspectives. Being in control of one's medical information and data thus becomes a civic concern: a right to which citizens are morally entitled, but one that produces new obligations as well. This, in turn, requires co-constructive and socially inclusive approaches to technological development.

From a *longue durée* perspective, we see that welfare state arrangements in education, health, and social care in the Netherlands have been gradually 'plugged out' to give way for participatory arrangements over the past decades. By analogy, the health portal in this study acted as a plug-in or network extension for participatory forms of healthcare (i.e., self-management and shared decision-making programs). In that process, it configured citizens not as groups or communities, but as active individuals who make their own calculated, rational, and informed choices. It not only reflected a transformation of health information into a personal utility, but helped to normalize the gradual abandonment of communal arrangements in healthcare (such as traditional waiting rooms and office windows) by offering information and services 'tailored' to individual, allegedly in a more efficient manner.

The logic of plug-in healthcare reflects decade-old beliefs in networked technologies, self-regulating markets, and individual autonomy that are be-

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[118] The Meaningful Use program is a U.S. government initiative linked to the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act. It entails "the use of certified EHR technology in a meaningful manner (for example electronic prescribing); ensuring that the certified EHR technology is connected in a manner that provides for the electronic exchange of health information to improve the quality of care; and that in using certified EHR technology the provider must submit to the Secretary of Health & Human Services (HHS) information on quality of care and other measures." Retrieved from: https://www.cdc.gov/ehrmeaningfuluse/introduction.html (last accessed 8 September 2018; no longer available).

ginning to reveal their flaws and limitations. In health information exchange, triumphant promises of unification and control go hand in hand with broken promises, and with increasingly opaque constellations of suppliers, vendors, facilitators, regulators, and payers. In the following section I describe the importance of repair in this context, most notably as a way to bring back the politics of health information exchange in the public debate.

7.3.3 Researching repair

Like building network extensions, researching repair requires a pragmatic focus on what people and things do. Both concepts revolve around the notion of work, and alert us to gaps in technoscientific orders. But as the previous segment started to show, these concepts also have distinct analytical implications. One of their differences pertains to **temporality**. The concept of building network extensions led to a chronological reconstruction of changing sociotechnical figurations. Examples are my description of emerging infrastructures for health information exchange in Chapter 1, and how the CCR standard travelled between network nodes in Chapter 5. Both reconstructions suggest a certain degree of linearity and progress in relations between people and things. By contrast, researching repair entails a non-linear relation to temporality; the example of technological abandonment in Chapter 6 is a case in point. Here, repair revealed itself in the form of anticipation work, erasure, and re-scripting, where past imaginaries clashed with the present; these acts of maintaining, protecting, and preserving current arrangements and new plans emphasize that histories and futures are inextricably linked:

> Repair is about space and function – the extension or safeguarding of capabilities in danger of decay. But it is also an inescapably timely phenomenon, bridging past and future in distinctive and sometimes surprising ways. Repair inherits an old and layered world, making history but not in the circumstances of its choosing. It accounts for the durability of the old, but also the appearance of the new […]. (Jackson, 2013: 223)

Like the local interventions described in Chapters 3 and 6, repair is often ad hoc and unplanned, and likely to yield unforeseen or unexpected results. As a way of caring for marginalized people and things, repair can refer to mundane practices of everyday life (i.e., tinkering and improvising with people and things that do not fit), and to the resilience of wider technoscientific orders that are at risk of falling apart. Typically, repair occurs in the 'in betweens' of project work, and is easily overlooked in the evaluation of policy instruments:

> They [the policy instruments] do not work because of their intrinsic characteristics but because of the context in which they are applied, and in particular, the amount of repair work that is done at other levels. This helps to articulate the global notion of steering-from-the-inside and adds the possibility that success derives from repair work elsewhere in the overall system. (Rip, 2006: 89)

We see an example of this 'steering-from-the-inside' in the development of the live webcasts in Chapter 3, where unexpected actors (i.e., parents of young CF patients) introduced new challenges, while also generating new opportunities to reconfigure and expand the scope of the patient education program (see also Aspria et al., 2012). While the project did not produce the expected results, its continuation can be largely attributed to repair work in the background. Failing to acknowledge this type of invisible work fits in the logic of plug-in healthcare, or what Arie Rip called a 'modernist illusion' in policy and regulation:

> Such repair work happens all the time, and unavoidably so, but it tends not to be recognized because of the **modernist illusion**. I have argued a number of times that the apparent effectiveness of some modernist policies (in science policy, in risk regulation) derives from the repair work done during implementation and ongoingly in local practices. Thus, acceptance of local 'repair work' in order to keep things going is necessary, and the one component of non-modern steering is to ensure its quality rather than try to control it from a distance. [...]

> 'Non-modern' then does not negate modernism, but draws attention to its actual practices. (Rip, 2006: 89)

Researching repair is then about tracing the ad hoc, reflexive practices of actors who challenge or question the boundaries of modernist programs or arrangements, or problematize existing orders. These actors sometimes reside in dense networks, and sometimes dwell in their margins. Assessing policy interventions through the lens of repair means looking beyond the modernist illusion of 'plugging in' and 'out' of networks, and focussing instead on the actual work invested in establishing new, local associations and undoing old ones.

Another distinct characteristic of researching repair is that it makes visible **relations of affect** in the gaps, fractures, and interruptions of technoscientific orders. Once again, the case of the patient education program in Chapter 3 illustrates this point. The work done to preserve the live webcasts for parents of young CF patients can be explained as a rational strategy; but if reconfiguring the program meant solving a practical problem in the organization of patient education at the CF Centre, continuing the production of live webcasts was also a costly financial operation that was not easily legitimized. Emotional appeals by parents in our evaluation of the pilot played an important role in the advice I formulated for the CF Centre regarding the preservation of the webcasts, and the repair work that ensued. Viewed from this perspective, repair alerts us to affective investments and 'emotional labour' in engaged and participatory forms of research (Lenette et al., 2019). To some extent, this sensitivity to affect and emotions echoes the love of technology (or indeed the lack of it) as described by Latour (1996) in *Aramis*: if the technology did not succeed, it was ultimately because it was not loved. With the concept of building network extensions, which entails a more rationalizing approach to the social and political character of infrastructural work, such affective relations between people and things are more easily overlooked.

Like any analytical concept, repair has its drawbacks and limitations. A notable risk is that it can engender a conservative view on technological development. If we take the example of staying with an abandoned object, and tracing its phantom network as a form of repair (see Chapter 6), we need to beware of insidious (or indeed dangerous) attachments to the past. Without the aforementioned element of care, repair can easily translate into reactionary or regressive political strategies, or the advancement of dubious moral values. If care for people and things is taken seriously, repair can be the starting point for researching technological afterlives, and a way of attending to the people and things that are forgotten, left out, or overlooked in current technoscientific orders. Without romanticizing things that could have been or a future that never was, a focus on loss, abandonment, and repair may lead to new ways of problematizing or rethinking technologies and their infrastructures as open and uncontained, continuously moving between alternatives, and never quite finished.

7.4 Methodological reflections

In what follows I start by describing my own position as a researcher in a field that was novel to me. I discern two types of knowing that helped me to navigate uncertainties – I call them *knot-knowing* and *not knowing* – that required learning and unlearning things, as well as ongoing justifications of my work. I further reflect on the implications of my research approach by addressing two methodological challenges: engaging with partially existing objects, and intervening and making knowledge actionable. The first relates to the elusiveness and ambiguity of some of the things I was researching; the second pertains to the difficulties of setting people and things in motion.

7.4.1 Knot-knowing and not knowing

When I started my research in 2009, I had little knowledge of practices and institutions in healthcare, and knew nothing about technical infrastructures and systems for health information exchange. I had no affinity with healthcare organizations in the city of Rotterdam, and my experience with policy advice was sparse at best. Due to my academic training, I was familiar with sociological theories on what binds people: I call this ***knot-knowing***. This abstract, and perhaps somewhat disengaged form of knowledge was intertwined with my ***not knowing*** many things: I stepped into the project with some theoretical baggage, unhindered by preconceived notions or assumptions about the concrete problems at hand. In retrospect, I think of my *not knowing* as a variation on what Halberstam calls *stupidity*: a form of knowing that "could refer not simply to a lack of knowledge but to the limits of certain forms of knowing and certain ways of inhabiting structures of knowing (Halberstam, 2011: 12). In my daily work as a researcher, I had to learn the language of consultants, managers, and healthcare professionals, and familiarize myself with more pragmatic approaches to research.

I used my academic duties as a teaching assistant to get acquainted with theories of management, organization, and governance in healthcare, and to gain more insights in relevant institutions and arrangements in the Netherlands. As I immersed myself in worlds that were new to me, I disclosed my inexperience to my project co-workers and respondents, and took notes of my doubts and disconcertments. I am careful not to characterize 'the field' I entered as a mysterious site of esoteric knowledge or heroic experts, or even as a well-delineated space "that pre-exists the study and lies out there just waiting to be discovered" (Henriksen, 2002: 32). I worked with different people who often had different ideas about what we were doing, or why it was important. Together, we took a leap into the unknown, not knowing what lied ahead of us, or which strings to pull. In a Latourian sense, I was looking at a technoscientific process rather than a product, and at 'warm' and unstable artefacts rather than 'cold' black-boxed ones (Latour, 1987).

In my everyday work, not knowing helped me to proverbially break the ice with the people I encountered, and to engage with them in open-ended discussions about the problems I was studying. From an analytical perspective, not knowing helped me to **denaturalize** concepts such as integration, personalization, and patient empowerment, and to explore some of their underlying assumptions and normativities (Verran, 2001: 205). Admitting to not-knowing rarely posed a problem in small or informal settings, but was sometimes met with reserve or scepticism in larger groups, especially when discussing our approach to the project's evaluation. I moved in a world where scientific interventions were predominantly viewed from a positivistic light, and where people held the principle that *to measure is to know*. Having committed to a **formative research** approach, I argued against baseline measurements and comparative analyses, and defended a more process-oriented, practice-based research approach to understand what we were doing, why we were doing it, and what alternatives we had (cf. Scriven, 1967; Aspria et al., 2014). That said, it took time to make that approach my own, and to turn it into concrete or useful advice. Doing formative research meant convincing others *and* myself that I was moving in a productive direction, even when I sometimes felt that I had little to show for it. I was not very successful in mobilizing audiences, and my approach to project evaluations sometimes raised doubts among the people I was studying. In that sense, my inexperience was not very helpful.

Despite these limitations, my knot-knowing and not knowing were also complementary to each other. Most notably, I was not inhibited by preconceived notions about problems of health information exchange. Meanwhile, I managed to engage with new analytical approaches when necessary. As an integral part of my research approach, I had to unlearn my inclination to focus on *people*, and learn to include *things* in my observations and analyses: this meant embracing a **sociotechnical perspective** in which artefacts, standards, and protocols pose resistance, talk back, enable and constrain behaviour. In this study, I alternatively described them as generative and consequential things, but also as indefinite, continuously in the making, multiple, and distributed. The things I studied were sometimes technologies in progress, but often little more than ideas on paper. It took time to learn how to engage with partially existing objects (Latour, 1999; Jensen, 2004), but it helped me to realize how closely technological development ties in with abandonment, and gave me a clearer view on the ambiguous character of emerging infrastructures (Jackson, 2013).

7.4.2 Engaging with partially existing objects

From my earliest involvement in the portal project, I struggled to explain what exactly I was doing in my research. I was exploring the development of a regional health portal that was *unable to speak for itself* (cf. Latour, 1996 [2002]). Project proposals and initiation documents speaking on its behalf configured the region as an alternative to national health information exchange initiatives; new forms of organizing care, and new enactments of citizenship and entrepreneurship were meant to unfold in the Rotterdam region before anywhere else in the Netherlands. Different views of regionality were interspersed, and not easy to follow in practice: *where to start?* Should I embrace the views of the CMIO at the teaching hospital, who seemed to represent the interests of doctors and patients? And how many other perspectives, interests, or agendas should I follow? In other words, it was equally difficult to establish *where to end.*

Defining the material boundaries of the portal project was not straightforward either. Initially, reading about portals and speaking about them with healthcare professionals made things less clear. The word 'portal' turned out to have different meanings, and still serves as an umbrella concept for various technologies in health information exchange. A discursive analysis of health portals (see Chapter 2) helped me to turn this elusiveness into an empirical insight. I found that the words 'health portal,' 'patient portal,' and 'PHR' were increasingly conflated in policy and medical science literatures. Over time, I adopted the frame of portals as a 'platform for health information exchange' in my own study, as it seemed to align well with questions on infrastructure. However, Zorgportaal Rijnmond's ontological status remained problematic: what made it a portal? And how or when did it stop being a portal?

I had to resist the misguiding intuition of "pre-determining what an entity must be at the beginning of an inquiry" (Jensen, 2004: 11). This applied to the portal as well as to the standard for continuity of care, the PHR, and many other things in the project that existed on paper, but that were not easy to identify in practice. They were heterogeneous things, spatially and temporally distributed over different networks and nodes, and only rarely presented themselves as – or perhaps pretended to be – whole and well-rounded things. By focussing on practices and materialities, I managed to reconstruct different ways in which they came into being and then disappeared again (cf. Jensen, 2004: 9; Mol, 2002). At the same time, I frequently forced a closure, for example when I described the portal as "little more than a functional prototype with an uncertain future" in Chapter 6. By doing so, I primarily disclosed my own perspective as the person describing it. The thing I tried to fix in place was, of course, much more than the 'prototype' of something else. In other instances, I resorted to narratives and texts to show how the portal, the standard for continuity of care, and the PHR were material and discursive objects at the same time, or "different material and discursive ways of ordering practice, which sometime go by the same name" (Jensen, 2004: 14). I tried to show *how* they were real in their material and discursive consequences, for example by describing how they helped to mobilise political agendas of integration, standardization, and personalization.

I was looking at '**partially existing objects**' that moved through the hands of many different people, and that ordered practices differently in different times and places (Jensen, 2004: 14; Latour, 1999). Capturing their ontological multiplicity often meant reconstructing their more stabilized versions, and showing how they were reconfigured and continued in other networks; an example is the integration of elements of the CCR standard in Health Information Building Blocks (see Chapter 5). If much of my research focused on continuities in and between networks, in 2017 I decided to pay more attention to discontinuities by 'staying' with the portal in its apparent state of inertia. By that time, Zorgportaal Rijnmond had lost many of its network allies, and its ontological status as a portal could be called into question (see Chapter 6). I was engaging with an object in the margins of dense network nodes. It was no longer clear what this object 'was:' a portal in ruins, a past project, a repurposed site operated by the RHIO, or perhaps all these things at once.

Tracing phantom networks was one of my more tangible engagements with partially existing objects. It allowed for a form of 'online time travelling' in my research by making backups of online content (Stikker, 2019: 81).

'Staying' with the abandoned portal made visible some of the very local repair work that took place in its background since 2017. It showed how technological artefacts remain consequential or generative, even when they 'disintegrate' or 'lose their existence' in weak network associations (cf. Jensen, 2004: 15). At the same time, these broken artefacts and their respective infrastructures serve as illustrations of political failure – as argued earlier in relation to the inability of 'the field' to build its own regional infrastructure for health information exchange in Rotterdam Rijnmond. Viewed in this light, Zorgportaal Rijnmond's phantom network can be invoked to challenge decades of neo-liberal politics in the Netherlands, or to question the belief in markets and regulated competition in healthcare. More than plainly providing critique, failure can thus become a site where "dominant history teems with the remnants of alternative possibilities, and the job of the subversive intellectual is to trace the lines of the worlds they conjured and left behind" (Halberstam, 2011: 19).

Archives play an important role in questions of infrastructure and repair. As places of past memories and imaginaries, they come to act as a mirror through which we understand ourselves (Bradley, 1999; Waterton, 2010). In our empirical case, building archives began as a way of preserving 'the past' for future reference, and then gradually transformed into a conservation of silenced voices and narratives. Seeing how the portal's history was being actively erased, the archives became part of a normative intervention: a way to bring back the portals' past to the present, and to repair some of the gaps in its written biography. Aside from a site of reflexivity and political resistance, archiving was a personal way of remembering people, organizations, and things that are no longer with us; this affective side of tracing phantom networks brought up dear memories, as well as the pain of abandonment and loss (cf. Mort and Michael, 1998). It suggests that tracing phantom networks is itself a form of repair work: a way of "connecting threads, mending holes, [and] amplifying quiet voices" that foregrounds the fragility of technologies and their infrastructures (Mattern, 2018: e1). If ruptures and breakdowns are all too often associated with disaster, catastrophe, calamity, or crisis, there is still much room for researching technological abandonment in relation to innovation and development.

7.4.3 Intervening and making knowledge actionable

Doing formative, participatory, or engaged research means moving between different network nodes, where conflicting ideas, views, and problem definitions circulate. In practice, I acted as an intermediary between various people at the RHIO, Sophia Childrens' Hospital (SCH), the teaching hospital's IT department, and my academic supervisors. The ways in which I related to my co-workers in the portal project changed over time: I was sometimes one of *them*, and sometimes took my distance. Depending on the time and situation I was a colleague, an ally, a nosy parker, a stranger, or an outright intruder. I had to find ways to **make knowledge actionable**, or translating it in such a way that it becomes helpful to people in practice (Argyris, 2005).

I used my formative research approach as a way of bringing empirical sensibilities to the fore. In my feedback to project members at the RHIO, SCH, and the IT department, I tried to articulate our practices in project work, and what we were missing in that process. People in key positions in the project – including the program manager, the RHIO director, the CMIO, and several board executives – shared the view that the 'real' challenge of building a regional portal was organizational and political, and argued against it becoming a 'technically oriented' project. In my own presentations I spoke of 'sociotechnical' challenges instead; I wanted to stress the relationality of people and things, and to preserve the role of technology in our analyses, rather than explaining it away. However, I often struggled to convey the practical benefits of my theoretical perspective, and grew increasingly worried that my holding on to this form of knot-knowing prevented me from doing 'good' interventions. It felt like being caught in a classic sociological problem of **detachment and involvement**.

Detachment and involvement (or distance and engagement) are often viewed as opposing categories, where the work of the researcher becomes a balancing act of sorts. In his study on situated interventions in healthcare, Zuiderent-Jerak (2015) seeks a way out of this dichotomy. He contends that researchers tend to be overly attached to 'pre-given problem spaces', while other actors in the field often overlook alternative repertoires of action (Zuiderent-

Jerak, 2015: 184, 187). He advocates for an ‘artful contamination’ between researchers and their environment: a two-way-street in which “sociological attachments and the health care practices under study get entangled,” and where the researcher’s normative concerns and the normative practices being researched are mutually shaped and reconfigured (Zuiderent-Jerak, 2015: 187). As discussed earlier in relation to the patient education program (see Chapter 3), my interventions at the CF Centre had an affective component: I felt emotionally involved in the concerns of parents with young CF patients. Given my affective attachments, I foregrounded their emotional appeals in my advisory report, and found an opportunity to think *with* them rather than *for* them. Here, making knowledge actionable meant giving the project leader sufficient reasons to warrant a continuation of the live webcasts, despite their high costs for the CF Centre.

One of the main places where insights about the project were made actionable was Zorgportaal Rijnmond’s ‘research platform’ (2010-2011), a knowledge network where people from various disciplines and academic backgrounds were invited to share their experiences with evaluation and implementation in health portal projects. As pilot studies in that area were rapidly increasing, it was important to learn from those interventions, and to discuss how theories of user participation, co-creation, and experience-based design were *made* to work in practice. The research platform was physically hosted by the Erasmus University Rotterdam, and served as a place for researchers to reflect on, tinker with, and rethink their repertoires of action.

My participation in the research platform made me aware of the strong coupling between research approaches and development strategies, and of notable differences between e-Health evaluations in primary and secondary care. As an example of a portal for primary care, the PAZIO project invested heavily in patient-centeredness and co-creation, and prioritized content development over questions of security (Van Well, 2021). By contrast, Zorgportaal Rijnmond was rooted in secondary care, and thus more bound to hospital regulations and centralized protocols on the handling of medical data. This reflected in different ways of translating research insights in development strategies. In Zorgportaal Rijnmond, the primary emphasis was on building a secure infrastructure for health information exchange; by contrast, the PAZIO project was more focused on offering valuable e-Health applications. In that sense, PAZIO seemed to create more room for translating ideals of patient-centeredness and co-creation in the research and evaluation design. In the Zorgportaal Rijnmond project, fundamental choices in the portal's architecture and infrastructure were only scarcely based on user experiences – the aforementioned patient education program being a notable exception.

7.5 Practical implications and concluding remarks

How should we think about technology? In this study I described the pervasiveness of deterministic and rationalistic approaches to technological development in the context of health information exchange. I argued that these approaches pay insufficient attention to the fundamentally social and political character of technologies and their infrastructures; this negation is what I called the logic of plug-in healthcare. From the discussion of my findings, I discern the following suggestions.

First, formative research interventions in technological development should not be built around problems of 'fit' between technologies and their users, but rather **start with fundamental questions of purpose**: whose problem(s) need(s) to be solved? Whose interests need to be addressed in the design of possible solutions? And who needs to participate in that process? This questioning of political and ethical choices in infrastructural work requires an open approach to technologies (i.e., viewing them as flexible and configurable), a commitment to tinkering along the way, and the realization that design choices inscribe new behaviour in people – behaviour that can gain different values and meanings over time.

Second, **changing relations of dependence** between old and new actors in figurations of health information exchange **need to be made more explicit and visible**. While Dutch government agencies do a commendable job in publishing status updates, monitors, posters, videos, and infographics about the progress achieved in project work, questions on the governance and control in new sociotechnical arrangements are discussed behind closed doors, subtracted from public view. How open and legible are these arrangements? Who participate in their development and implementation, and who are excluded? And who will be held accountable when they fail? In this study I described how triumphant and utilitarian promises of unification and control went hand in hand with increasingly opaque constellations of suppliers, vendors, facilitators, regulators, and payers. The current distance between citizens and hyperspecialized, market-driven associations in healthcare in the Netherlands is problematic, and requires new forms of civic engagement:

> The question is not what we think of technology in retrospect, but who decides in advance what technology we will develop. If we want technology to work for people, and not the other way around, we should not leave the design process to the owners and producers of that technology, but also to its future users and all other stakeholders. (Stikker, 2019: 135; own translation)

A good example in this context was the development of a national contact tracing app for COVID-19. For this purpose, the Dutch Minister of Health organized an 'appathon' with experts from different fields. This three-day event in April 2020 featured livestreams, which were for a large part accessible to the general public. Thousands of people watched these livestreams, and some used social media platforms (most notably Twitter) to actively contribute to discussions on the development of the contact tracing app. In many ways, the appathon was an unprecedented example of civic engagement in technoscience that foregrounded the politics and ethics of design choices.

Third, we need to explore ways to **undo the growing dependencies** of healthcare providers on health IT vendors and markets, and repair the damage that has been done in that context in the past decades. The need for experimenting with new participatory models of technological development remains, and fundamental questions need to be raised about the current lack of civic engagement in infrastructural projects in e-Health. We are experiencing a 'sociotechnical transition' in health information exchange that includes "changing skills, infrastructures, industry structures, products, regulations, user preferences and cultural predilections," as well as new expectations regarding ownership and distribution of medical data and health information (Schot and Steinmuller, 2018: 1562). This transition entails more than a simple 'plugging in' and 'out' of networks; it calls for tentative modes of governance that engage with uncertainty and doubt, that are "provisional, revisable, dynamic and open," and that include "experimentation, learning, reflexivity, and reversibility" (Schot and Steinmuller, 2018: 1563).

Fourth, in policy for health information exchange (and technological development in general) we need to **address people in the plural**. The widespread tendency to think of *the patient* or *the citizen* in the singular – as a rational actor, or a self-contained entity – prevents us from overseeing the social and political consequences of technological and infrastructural arrangements. The plural is a way of attending to diversity and difference in populations, and emphasizes dependencies between people. More importantly, it is a way of protecting democratic values: health information exchange is not an individual, but a public concern. It requires learning from what people do and need in practice, instead of thinking *for* them; and it requires the realization that 'producers' and 'users' of health information exist in very different capacities – the boundaries between them are not always clear (cf. Ritzer and Jurgenson, 2010).

Fifth, we need to think of **sustainable ways of preserving data**. On the one hand, we see how current developments in information systems go hand in hand with increasing demands for digital storage capacity – think of the construction of new data centres that are increasingly becoming a public concern. On the other hand, we see that abandoned online databases and archives rapidly become inaccessible, and that we are losing our digital past. Whether that past needs to be saved – and if so, at what cost – is a normative question that begs to be answered. The emerging discipline of digital archaeology can yield interesting insights in this area. It has already demonstrated its value during the Trump administration in 2017, when U.S. civil servants 'rescued' climate science data at risk of being deleted from federal information systems (Kansa and Kansa, 2018). Similarly, digital archaeology may become a relevant resource in healthcare in the near future.

To conclude, a brief return to where this study began: Katie Paterson's 'Moon-altered piece' of the Moonlight Sonata. Much like the Moon talking back to Earth, the artefacts in this study talked back to me in a strange and sometimes unsettling way. In my effort to make sense of this, I developed a language of my own; one that consistently refers to people and things instead of actors or actants; that speaks of sociotechnical figurations rather than configurations; that includes building network extensions and tracing phantom networks; that values knot-knowing as well as not knowing; and that looks at the politics of technological development through the lens of repair. I leave it up to the readers to engage with the concepts, ideas, and reflections I proposed here, and to fill in the gaps as they please. Ultimately, this study is an invitation to come back down to Earth, and to embrace and let go of theoretical attachments: feet firmly planted on the ground, without a sense of betrayal or regret of what may be lost in translation.

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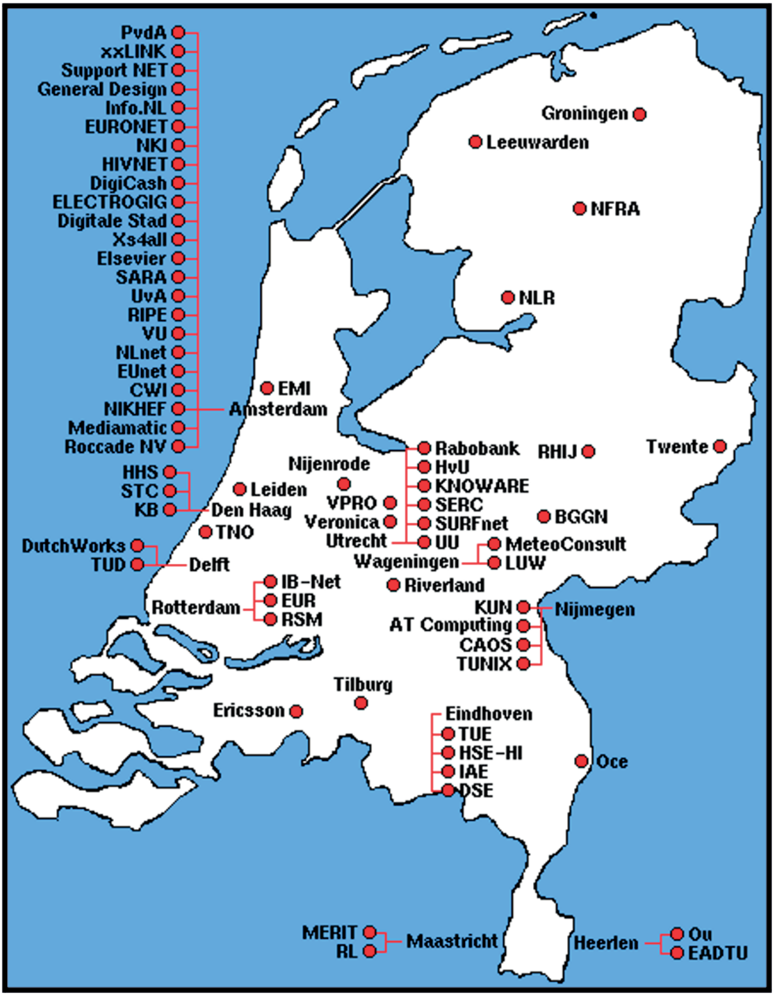
Appendices (A~G)

Appendix A

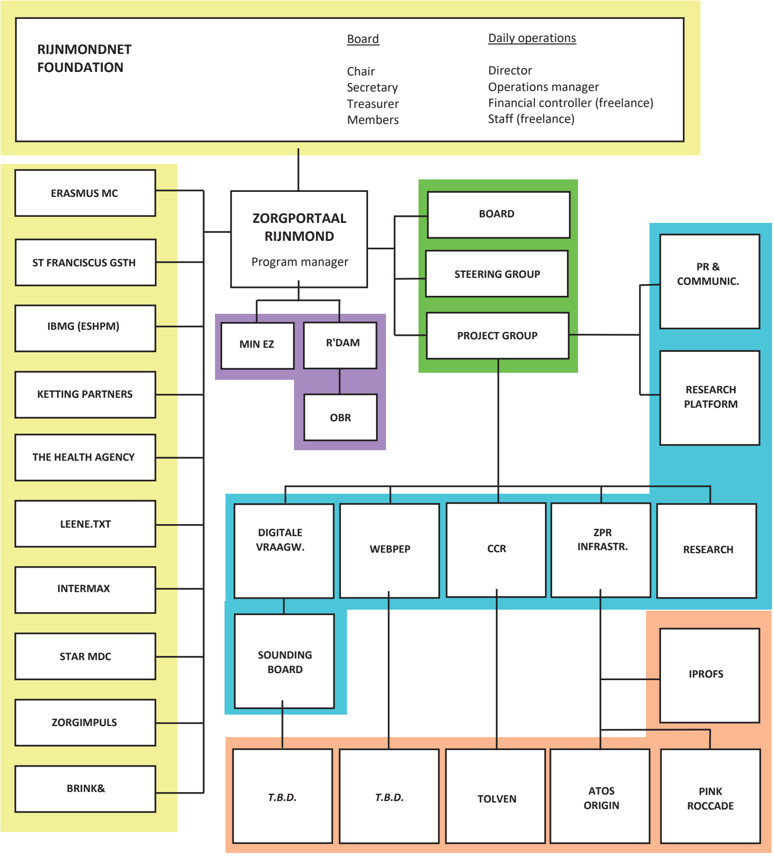
Figure 1: Directory of WWW access points in the Netherlands (1994)



Source: Eindhovenfotos.nl. Retrieved from: https://www.eindhovenfotos.nl/dhp.nl.html (last accessed 22 April 2018; no longer available)

Appendix B

Figure 1: Organization chart of the Zorgportaal Rijnmond Project (November 2009)



Appendix C

PubMed/MEDLINE database

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Appendix D

SCP & RVS policy reports

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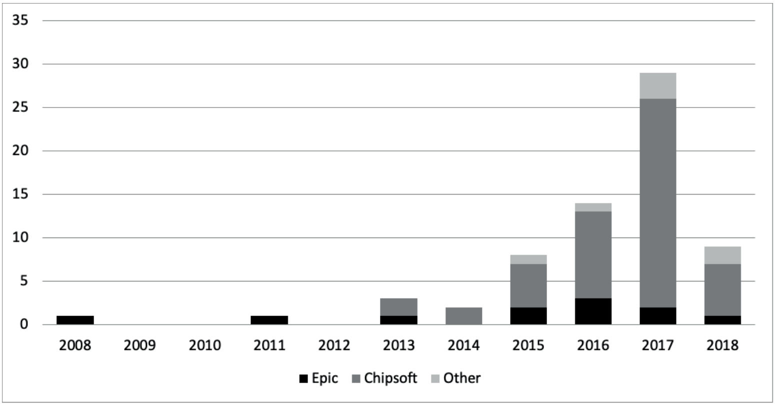
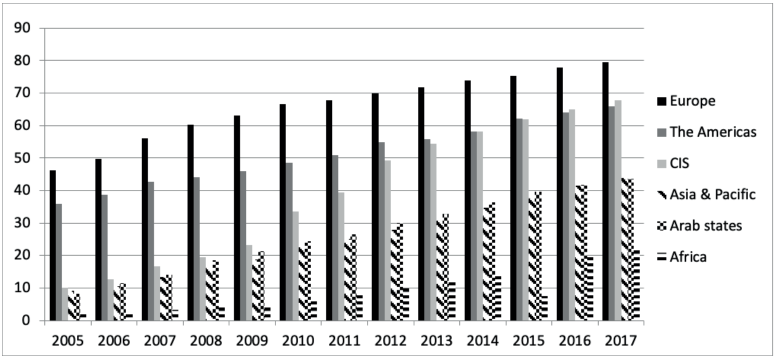
Appendix E

Figure 1: EHR implementations in Dutch hospitals, 2008-2018



Source: *M&I Partners*, 2018. 10 undated EHR implementations are missing from this overview. Data reflect the situation as of 28 February 2018.

Figure 2: Percentage of individuals using the Internet worldwide, 2005-2017



Source: *ITU*, 2018. CIS = Commonwealth of Independent States. Data for 2017 are estimates.

Appendix F

Table 1: Webcast topics and number of views per 17 November 2011

Title	Description	Live	On demand
Drugs and Compliance	On CF medication and the importance of therapy compliance. Presented by a paediatrician specialized in pulmonology (A) 17 November 2010	22	84
Enzymes, etc.	On enzymes and how they work. Presented by a paediatrician specialized in gastrointestinal and liver diseases (B) 16 December 2010	25	70
Where Does Slime Go When You Swallow It?	On the physiology of lungs and breathing techniques. Presented by a children's physiotherapist (C) 27 January 2011	35	59
What's Growing in My Sputum	On the characteristics of bacteria and the prevention of infections. Presented by a medical microbiologist (D) 24 February 2011	49	48
Less Afraid to the Hospital!	On the various steps that a young patient undergoes during the yearly check-up. Presented by a health psychologist (E) 31 March 2011	15	51
How Do Drugs Enter the Lungs?	On nebulization instruments and techniques. Presented by a paediatrician specialized in pulmonology (A) 28 April 2011	11	53
Antibiotics	On antibiotics and whether they can be harmful. Presented by a paediatrician specialized in pulmonology (A) 26 May 2011	18	35
Obstipation	On obstipation, its causes and remedies. Presented by a paediatrician specialized in gastrointestinal and liver diseases (B) 30 June 2011	4	41
Why Breathing for Lung Function?	On the importance of lung function tests. Presented by a paediatrician specialized in pulmonology (A) 25 August 2011	6	41
What Is DNA?	On chromosomes, DNA, and the hereditary nature of CF. Presented by a researcher in clinical genetics (F) 29 September 2011	2	30
Why the Annual Examination?	On the reasons for yearly physical examinations at the CF Centre. Presented by a paediatrician specialized in pulmonology (A) 27 October 2011	9	9

Figure 1: How WebPEP participants log in to the application

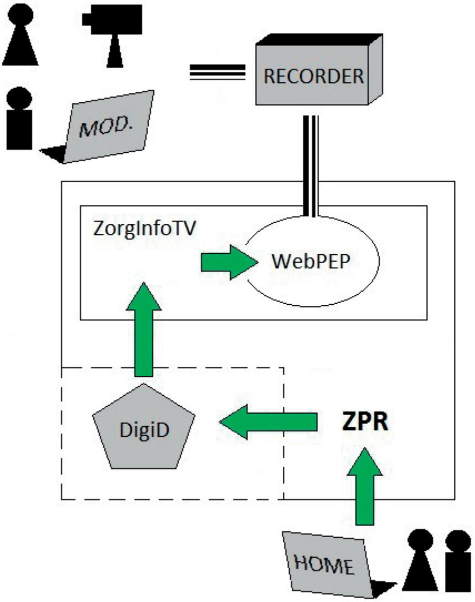
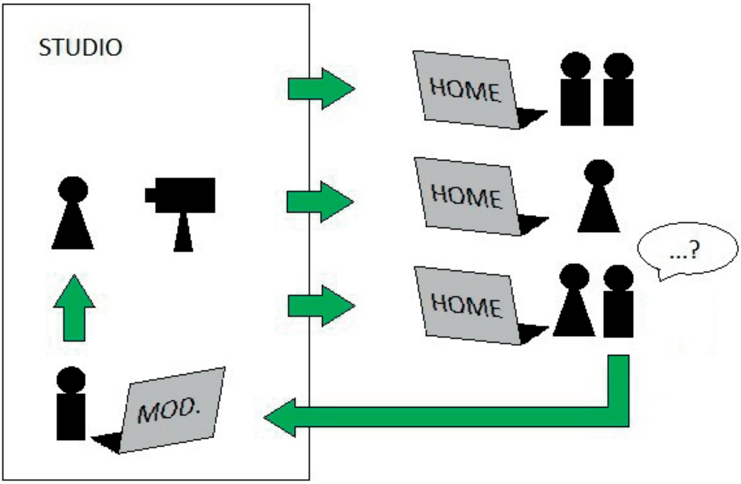


Figure 2: Screen capture of the WebPEP interface (on demand view)


Vernevelen: hoe doe je dat?

- Langzaam en diep ademen:

Figure 3: Live interaction between presenter, participants, and moderator

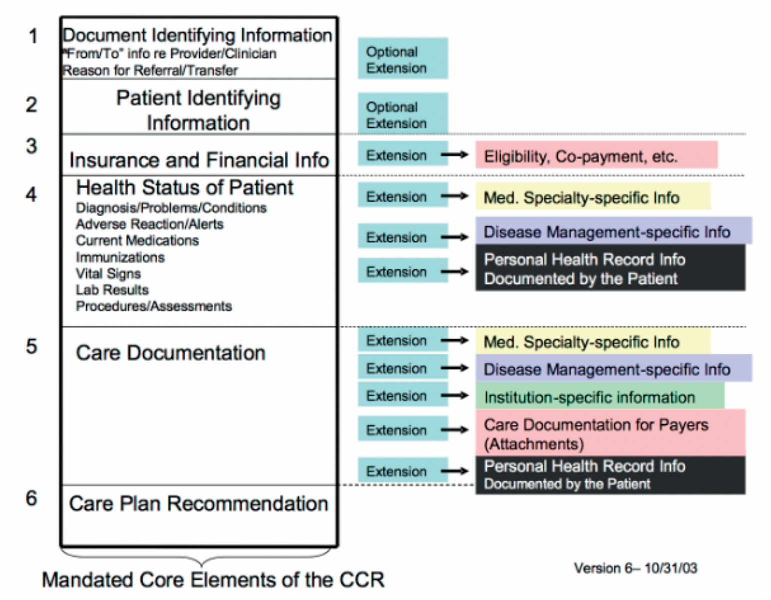


Appendix G

Table 1: Seventeen elements in CCR

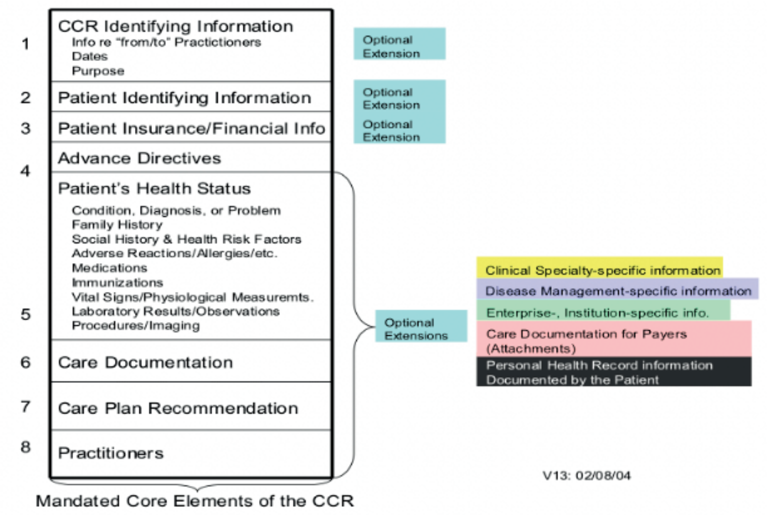
1	Patient Demographics	10	Medication
2	Immunizations	11	Procedures
3	Vital Signs	12	Results
4	Problems & Diagnoses	13	Necessary Medical Equipment
5	Insurance Information	14	Social History
6	Health Care Providers	15	Statistics
7	Encounter Information	16	Family History
8	Allergies/Alerting Data	17	Care Plan
9	Appropriate Results		

Figure 1: The Continuity of Care Record, conceptual model V.6 (10-31-2003)



Source: *ASTM International*. Retrieved from: www.astm.org/COMMIT/E31_ConceptPaper.doc (last accessed 22 April 2019; no longer available)

Figure 2: The Continuity of Care Record, conceptual model V.13 (02-08-2004)



Source: *Continuity of Care Record*. Presentation by Claudia Tessier, co-chair ASTM E31 workgroup on CCR. July 2004. Retrieved from: www.astm.org/COMMIT/E31_CCRJuly04.ppt (last accessed 22 April 2019; no longer available)

SUMMARY

This dissertation explores the work done by people and things in emerging infrastructures for health information exchange. It shows how this work relates to processes of development, production, and growth, as well as to abandonment, ruination, and loss. It argues for a revaluation of repair work: a form of articulation work that attends to gaps and disruptions in the margins of technological development. Often ignored by engineers, policy makers, and researchers, repair sensitizes us to different ways of caring for people and things that do not fit, fall in between categories, and resist social norms and conventions. It reminds us that infrastructures emerge in messy and unevenly distributed sociotechnical configurations, and that technological solutions cannot be simply 'plugged in' at will, but require all kinds of work. With that, repair emphasizes the need for more democratic, critical, and reflexive engagements with (and interventions in) health information exchange.

Empirically, this study aims to understand how 'integration' in health information exchange is done in practice, and to develop concepts and insights that may help us to rethink technological development accordingly. It starts from the premise that the introduction of IT in healthcare is all too often regarded as a neutral process, and as a rational implementation challenge. These widespread views among professionals, managers, and policy makers need to be addressed, as they have very real – and mostly undesirable – consequences. Spanning a period of more than ten years, this study traces the birth and demise of an online regional health portal in the Netherlands (2009-2019). Combining ethnographic research with an experimental form of archive work, it describes sociotechnical networks that expanded, collapsed, and reconfigured around a variety of problems – from access to information and data ownership to business cases, financial sustainability, and regional care. It puts a spotlight on the integration of standards, infrastructures, and users in the portal project, and on elements of collapsing networks that quietly resurfaced elsewhere. The reconstruction of these processes foregrounds different instances of repair work in the portal's development and subsequent abandonment, repurposing, and erasure.

Conceptually, this study contributes to academic debates in health information exchange, including the politics of technology, practices of participatory design, and the role of language in emerging information infrastructures. It latches on to ethnographic studies on information systems and infrastructural work, and brings together insights from actor-network theory, science and technology studies, and figurational sociology to rethink and extend current (reflexive and critical) understandings of technological development. It raises three questions: What work is done in the development and demise of an online health portal? How are relations between people and things shaped in that process? And how can insights from this study help us to understand changing sociotechnical figurations in health information exchange? The final analysis includes five key concepts: the act of *building network extensions*, the method of *tracing phantom networks*, the notion of *sociotechnical figurations*, the logic of *plug-in healthcare*, and *repair* as a heuristic device.

Chapter 1 sketches a historical background to the empirical case. I describe how people and things fundamentally redefined medical recording practices in healthcare since the late 1960s, and how they reshaped the conditions under which health information is exchanged. In recent decades, medical professionals and policy makers in the Netherlands sought ways to contain the growing differentiation of information systems in use, and to align or unify different technologies, infrastructures, and practices in health information exchange. While preoccupations with efficiency and innovation increasingly intertwined with questions of patient empowerment and shared decision-making, the Dutch Minister of Health alternately strengthened and loosened its regulatory control in health information exchange, while delegating the development of patient-centered initiatives to 'the field.' I describe the case of Zorgportaal Rijnmond (ZPR) in this context, alongside contemporary health portal initiatives in the Netherlands. I contend that ZPR served as an intermediary between a period of experimentation and uncertainty on the one hand, and the rise of a market for health information systems on the other. My *longue durée* reconstruction dispels the view of health portals as a purely 'technological' innovation, and emphasizes how their development not only paved the way for new standards and initiatives, but raised more fundamental, societal questions about data ownership, inclusion, governance, and control in health information exchange.

Chapter 2 is the first of five co-authored studies in this dissertation, and introduces health portals in relation to policies for health information exchange. We explore narratives relating to online health portals and electronic health records in internationally oriented medical science literatures between 1995 and 2015, and how they reflect in Dutch policy advisory reports from the same period. We discern three ways of framing health portals – as a *gateway*, a *commodity*, and a *platform* – where each frame casts a different light on infrastructural work in health portal development. We describe the construction of technological futures, the negation of the politics of health portals, and the lacking problematization of public-private partnerships. We contend that absences and silences in these narratives helped to avert potential controversies in e-Health policies, and to expand the role of commercial enterprises in health information exchange.

Chapter 3 shifts the focus from discursive practices to techniques of governing people on a micro level. Zooming in on the development of an online video education program in a children's hospital, we explore how technologies are invoked to steer the conduct of patients, and how those patients are more or less successfully 'integrated' in project work. We discern users and non-users of the video education program, as well as a relevant group of people that was overlooked in the project's design. Building on the notion of *configuring the user* we describe the video education program's reframing in relation to its actual users, and show how a single technology can be implicated in different, coexisting practices of care. In doing so, we unpack some of the challenges of technologies in search of an audience. This is a first attempt in this study to address questions of success and failure in technological development, and to reflect on how formative evaluation methods can help to configure users in the design and development of e-Health applications.

Chapter 4 marks a return to the use of language in health information exchange. This chapter is based on the early development of ZPR as a regional infrastructure, and focuses on the politics of metaphors in infrastructural work. We describe how they were enacted in practice, and how they shaped present-and future-oriented work and imaginaries in health information exchange. We view metaphors as mobilization devices that allow ideas to circulate (faster) and that influence the ways in which people argue and convince each other. Through their circulation in networks, metaphors have the potential to (re) configure people, ideas, resources, and technologies. We regard them as real attributes of infrastructural work, and as operationalisations of sociotechnical imaginaries that leave room for ambiguities and interpretative flexibility. We contend that two recurring metaphors in the project – promising applications as blooming flowers and the portal as a multiple socket – concealed the politics of infrastructural work in our empirical case, and that collectively 'spelling out' their meaning can open up a space for new imaginaries and alternative strategies in health portal development.

Chapter 5 contributes to existing conceptualizations in science and technology studies on how standards travel in actor-networks. We do so by introducing the notion of *building network extensions*. Using a combination of participatory ethnography and desk research, we describe how the Continuity of Care Record (CCR) standard for medical recording was enacted in different ways as it moved between different network nodes, and how it reconfigured people and things while being itself transformed. We show how CCR was accompanied by other standards in order to travel; how it temporarily reconfigured relations between people and things by extending their networks; how it acquired new meanings as it navigated between different nodes; and finally, how it lost its relevance as concerns about health information exchange shifted in new directions. Based on our reconstruction, we contend that standards act as network extensions: they bring worlds together in non-linear, parallel movements; they make network nodes actionable; and they strengthen the associations between them. Like the act of building plug-ins in software programs, building network extensions is required to make new sociotechnical arrangements actionable; this happens by displacing people and things in networks. Describing the work implicated in these displacements from up close (and over longer periods of time) helps to understand how relations between people and things are shaped in practice: the character of their associations changes as they converge around specific network nodes.

Chapter 6 explores what happens when technologies are abandoned, and describes ZPR as a project in ruins. We introduce the method of *tracing phantom networks* as an experimental form of infrastructural inversion that exposes the politics of technologies and infrastructures in decay. Our method draws attention to (more or less) organized practices in the margins of the portal project, and pieces together broken and erased infrastructures from the past. As a fundamentally normative and political intervention, tracing phantom networks casts a new light on abandoned, premature, or foolish plans, and can help to reimagine future infrastructures accordingly. We use the concept of *repair* to describe what happens in weak associations of people and things – from gaps and ruptures in technological development to abandoned places, empty spaces, and other things that are left behind when a project comes to an end. We discuss three facets of repair in the abandoned health portal – anticipation work, erasure, and re-scripting – and reflect on how various forms of repair work (including the method of tracing phantom networks) can be used as a way of intervening in ruins.

Chapter 7 draws together the main themes from this study. In this final chapter, I unravel the notion of *sociotechnical figurations* to describe the pattern of forces that bind people and things as they travel between networks, compete for supremacy, and build on, work against, or dominate each other. I contend that these forces are not external to people and things; rather, they *are* the (continuously shifting and changing) relations of dependence between them. Subsequently, I point out a pervasive logic of creation, alignment, and expansion among engineers and policy makers in the Netherlands that coerces people and things into formal classifications, and structures messy practices into well-delineated 'raked paths.' I call this the logic of *plug-in healthcare:* a logic that does not question the values and assumptions embedded in technological artefacts, and that largely ignores the social and organizational dimensions of healthcare. I argue that *repair* provides an alternative to modernist accounts of development and growth, where deficits are fixed by 'plugging in' ready-made technological solutions. In this study, repair denotes the subtle – and often invisible – work that is required to articulate differences, negotiate gaps, and translate interests in health information exchange. This work includes the ongoing tinkering and negotiating in the margins of technological development; the precarious work that goes undocumented in project plans and reports; the seemingly negligible, situated interventions that help to shape and mould technologies over time; but also, tracing phantom networks as a normative form of attachment to what is at risk of being lost.

In short, this dissertation alerts us to the fluid, unstable, and unsettled character of sociotechnical relations, and to brief moments of continuity in the fragile world(s) we inhabit. I call for participatory modes of design and development in e-Health that include engagements with failure, breakdown, and loss. Repair helps to expose the logic of plug-in healthcare and its consequences, including the continuous expansion of hyperspecialized, market-driven, and monopolizing networks and infrastructures for health information exchange. Empirically and conceptually, this study moves between distance and proximity; from those movements, repair emerges both as a pragmatic way of addressing the inherently social and political character of technologies and their infrastructures, and as an attempt to revalue attachments to messiness, unruliness, instability, and decay.

SAMENVATTING

Dit proefschrift onderzoekt het werk dat door mensen en dingen wordt verricht in opkomende infrastructuren voor gegevensuitwisseling in de zorg. Het laat zien hoe dit werk zich verhoudt tot processen van ontwikkeling, productie en groei, maar ook tot verwaarlozing, verval en verlies. Het pleit voor een herwaardering van herstelwerk: een vorm van articulatiewerk rondom hiaten en leegtes in de marge van technologische ontwikkeling. Herstel wordt door ingenieurs, beleidsmakers en onderzoekers vaak over het hoofd gezien; het hangt samen met het zorgen voor mensen en dingen die niet in de pas lopen, tussen categorieën vallen, en zich verzetten tegen sociale normen en conventies. Het herinnert ons eraan dat infrastructuren ontstaan in rommelige en ongelijk verdeelde sociotechnische configuraties, en dat technologische oplossingen niet simpelweg kunnen worden ‘ingeplugd’ maar allerlei vormen van werk behoeven. Tevens benadrukt het de noodzaak van meer democratische, kritische en reflexieve betrokkenheid bij (en interventies in) gegevensuitwisseling in de zorg.

Empirisch beoogt deze studie te begrijpen hoe ‘integratie’ bij gegevensuitwisseling in de zorg in de praktijk tot stand komt, en om concepten en inzichten te verschaffen die een hernieuwde blik werpen op technologische ontwikkeling. Het uitgangspunt van dit onderzoek is dat de invoering van informatietechnologie in de zorg nog te vaak wordt beschouwd als een neutraal proces en een rationeel implementatieprobleem. Beide opvattingen zijn wijdverbreid onder professionals, managers en beleidsmakers; ze dienen te worden bevraagd omdat ze zeer reële – en veelal onwenselijke – gevolgen hebben. Deze studie beslaat een periode van ruim tien jaar waarin de opkomst en ondergang van een online regionaal zorgportaal in Nederland centraal staat (2009-2019). Op basis van etnografisch onderzoek en een experimentele vorm van archiefwerk schetst het een beeld van sociotechnische netwerken die zich uitbreidden, uit elkaar vielen en zich herschikten rondom uiteenlopende vraagstukken – van toegang tot informatie en eigenaarschap van data tot businesscases, financiële borging en regionale zorg. Het onderzoek richt zich specifiek op de integratie van standaarden, infrastructuren en gebruikers in het portaalproject, en laat zien hoe elementen van vervallen netwerken elders stilletjes weer opdoken. De reconstructie van deze processen toont verschillende voorbeelden van herstelwerk in de ontwikkeling – en de daaropvolgende verwaarlozing, herbestemming en ontmanteling – van het portaal.

Conceptueel draagt deze studie bij aan academische debatten over gegevensuitwisseling in de zorg: van de politiek van technologie en praktijken van participatief ontwerp tot de rol van taal in opkomende informatie-infrastructuren. Het sluit aan bij etnografische studies over informatiesystemen en infrastructureel werk; het verenigt inzichten uit de actor-netwerk theorie, wetenschaps- en techniekstudies, en figuratiesociologie om bestaande (reflexieve en kritische) opvattingen over technologie te bevragen en aan te vullen. Het onderzoek omvat drie vragen: Wat voor werk wordt er verricht bij de ontwikkeling en teloorgang van een online zorgportaal? Hoe worden relaties tussen mensen en dingen in dat proces gevormd? En hoe kunnen inzichten uit dit onderzoek ons helpen om veranderende sociotechnische figuraties rondom gegevensuitwisseling in de zorg te duiden? De slotanalyse omvat vijf sleutelconcepten: het bouwen van netwerkextensies (*building network extensions*), het natrekken van fantoomnetwerken (*tracing phantom networks*), de notie van *sociotechnische figuraties*, de *logica van de stekkerdoos* (*plug-in healthcare*), en *herstel* als heuristisch instrument.

Hoofdstuk 1 schetst een historische achtergrond van de empirische casus. Hierin beschrijf ik hoe mensen en dingen sinds het einde van de jaren zestig praktijken van medische registratie in de zorg grondig hebben geherdefinieerd, en hoe ze de voorwaarden hebben herschapen waaronder zorg-gerelateerde informatie wordt uitgewisseld. In de afgelopen decennia hebben medische professionals en beleidsmakers in Nederland gezocht naar manieren om de groeiende differentiatie van bestaande informatiesystemen te beheersen en om verschillende technologieën, infrastructuren en praktijken op elkaar af te stemmen of te integreren. Kwesties rondom efficiëntie en innovatie raakten steeds meer verweven met vraagstukken over gedeelde besluitvorming en de ‘empowerment’ van patiënten; in dat proces werd de regulering van gegevensuitwisseling door de minister van Volksgezondheid afwisselend strakker aangetrokken en versoepeld. De ontwikkeling van gerelateerde patiëntgerichte initiatieven werd daarbij overgelaten aan ‘het veld.’ Tegen deze achtergrond beschrijf ik de opkomst van Zorgportaal Rijnmond (ZPR) naast andere zorgportaalinitiatieven in Nederland. Ik betoog dat ZPR diende als intermediair tussen een periode van experimenteren en onzekerheid enerzijds, en de opkomst van een markt voor zorginformatiesystemen anderzijds. Met deze reconstructie tracht ik tegenwicht te bieden aan het beeld van zorgportalen als een puur ‘technologische’ innovatie, en benadruk ik dat hun ontwikkeling niet alleen de weg vrijmaakte voor nieuwe standaarden en initiatieven, maar ook meer fundamentele, maatschappelijke vragen opwierp over eigendom van data, sociale inclusie, en bestuur en beheer bij gegevensuitwisseling in de zorg.

Hoofdstuk 2 is de eerste van vijf gezamenlijk geschreven studies in dit proefschrift, en bespreekt zorgportalen in relatie tot beleid voor gegevensuitwisseling in de zorg. We onderzoeken narratieven met betrekking tot online zorgportalen en elektronische patiëntendossiers in internationaal georiënteerde medisch-wetenschappelijke literatuur tussen 1995 en 2015, en laten zien hoe die narratieven zich weerspiegelen in Nederlandse beleidsadviezen uit dezelfde periode. We onderscheiden drie manieren om zorgportalen te framen – portalen als *toegangspoort*, als *handelswaar* en als *platform* – die elk een specifiek licht werpen op infrastructureel werk bij de ontwikkeling van portalen. In die context beschrijven we de constructie van technologische visies op de toekomst, de ontkenning van de politiek van zorgportalen, en de gebrekkige problematisering van publiek-private partnerschappen. We stellen dat deze lacunes en stiltes hebben bijgedragen aan het voorkomen van mogelijke controverses in e-Health-beleid, maar ook aan het versterken van de positie van commerciële ondernemingen bij gegevensuitwisseling in de zorg.

Hoofdstuk 3 verlegt de focus van discursieve praktijken naar technieken om mensen aan te sturen op microniveau. Door in te zoomen op de ontwikkeling van een online video-educatieprogramma in een kinderziekenhuis, onderzoeken we hoe technologieën worden ingezet om patiënten aan te sturen in hun gedrag, en hoe die patiënten min of meer succesvol worden ‘geïntegreerd’ in projectwerk. We onderscheiden gebruikers en niet-gebruikers van het educatieprogramma, evenals een relevante groep mensen die over het hoofd was gezien tijdens het ontwerp van het project. Voortbouwend op de idee van het configureren van gebruikers (*configuring the user*) beschrijven we de heroriëntatie van het educatieprogramma in relatie tot de daadwerkelijke gebruikers, en laten we zien hoe een enkele technologie betrokken kan zijn bij verschillende, naast elkaar bestaande zorgpraktijken. We gaan daarbij dieper in op een aantal uitdagingen bij technologieën op zoek naar een publiek. Dit is een eerste poging in deze studie om kwesties van succes en falen in technologische ontwikkeling te duiden, en om na te denken over hoe formatieve evaluatiemethoden kunnen helpen om gebruikers te betrekken bij het ontwerp en de ontwikkeling van e-Health-toepassingen.

Hoofdstuk 4 brengt ons terug naar het gebruik van taal. Dit hoofdstuk beslaat de vroege ontwikkelingsfase van ZPR als regionale infrastructuur, en richt zich op de politiek van metaforen in infrastructureel werk. We beschrijven hoe metaforen in de praktijk werden toegepast, en hoe ze praktijken en verbeeldingen met betrekking tot gegevensuitwisseling in de zorg vormgaven. We bespreken metaforen als mobilisatieinstrumenten die ideeën (sneller) doen circuleren en die invloed hebben op de manier waarop mensen elkaar overhalen of overtuigen. Wanneer ze circuleren in netwerken hebben metaforen het vermogen om relaties tussen mensen, ideeën, hulpbronnen en technologieën te ordenen en herschikken. We beschouwen ze als daadwerkelijke onderdelen van infrastructureel werk, en als uitwerkingen van sociotechnische verbeeldingen die ruimte laten voor ambiguïteiten en interpretatieve flexibiliteit. We betogen dat twee opvallende metaforen in het project – veelbelovende innovaties als ‘bloemetjes’ en het portaal als ‘stekkerdoos’ – de politiek van infrastructureel werk in onze empirische casus verhulden. Het gezamenlijk ‘uitspellen’ van hun betekenis kan ruimte creëren voor nieuwe denkbeelden en alternatieve strategieën bij de ontwikkeling van zorgportalen.

Hoofdstuk 5 draagt bij aan conceptuele inzichten in de wetenschaps- en techniekstudies over hoe standaarden reizen in actor-netwerken. Wij introduceren hiertoe het *bouwen van netwerkextensies* als analytisch begrip. We combineren etnografie met documentenonderzoek om te beschrijven hoe een standaard voor medische registratie op steeds nieuwe manieren werd opgevoerd terwijl het zich tussen verschillende verknopingen in netwerken bewoog, en hoe het relaties tussen mensen en dingen herschikte terwijl het ook zelf transformaties onderging. We laten zien hoe deze standaard in zijn reis werd vergezeld door andere standaarden; hoe het de relaties tussen mensen en dingen tijdelijk herschikte door hun netwerken uit te breiden; hoe het nieuwe betekenissen kreeg door te bewegen tussen verschillende verknopingen; en ten slotte, hoe het zijn relevantie verloor toen nieuwe vraagstukken rondom gegevensuitwisseling in de zorg een prominentere rol kregen. Op basis van onze reconstructie stellen we dat standaarden werken als netwerkextensies: ze brengen werelden samen in niet-lineaire, parallelle bewegingen; ze maken verknopingen werkbaar; en ze versterken hun onderlinge associaties. Net als het bouwen van plug-ins in softwareprogramma's is het bouwen van netwerkextensies nodig om nieuwe sociotechnische arrangementen werkbaar te maken; dat gebeurt door ordeningen van mensen en dingen in netwerken te herschikken. Door van nabij (en over een langere periode) het werk te beschrijven dat plaatsvindt in deze herschikkingen, kunnen we beter begrijpen hoe relaties tussen mensen en dingen in de praktijk worden gevormd: het karakter van hun associaties verandert naarmate ze samenkomen rond specifieke verknopingen.

Hoofdstuk 6 onderzoekt wat er gebeurt wanneer technologieën worden verlaten, en beschrijft ZPR als een project in staat van verval. We presenteren het *natrekken van fantoomnetwerken* als onderzoeksmethode: een experimentele vorm van infrastructurele inversie die de politiek van technologieën en infrastructuren in verval blootlegt. Met deze methode vestigen we de aandacht op (min of meer) georganiseerde praktijken in de marge van het portaalproject, en voegen we delen van gebroken en verdwenen infrastructuren samen. Als normatieve en politieke interventie werpt het een nieuw licht op (af)gewezen, premature of dwaze plannen, en kan het helpen om ideeën voor toekomstige infrastructuren bij te stellen. Aan de hand van het *herstel*-begrip beschrijven we wat er gebeurt in zwakke associaties van mensen en dingen – van hiaten en verstoringen in technologische ontwikkeling tot verlaten plekken, lege ruimtes en andere dingen die achterblijven wanneer een project ten einde loopt. We bespreken drie facetten van herstelwerk in het verlaten zorgportaal – anticipatiewerk *(anticipation work)*, uitvlakken (*erasure*) en herschrijven (*re-scripting*) – en reflecteren op hoe verschillende vormen van herstelwerk (waaronder het natrekken van fantoomnetwerken) zich verhouden tot ruïnes en verval.

Hoofdstuk 7 brengt de belangrijkste thema's uit dit onderzoek samen. In dit laatste hoofdstuk werk ik de notie van *sociotechnische figuraties* uit, waarmee ik het patroon beschrijf van krachten die mensen en dingen binden terwijl ze tussen netwerken reizen, strijden om overheersing, en elkaar helpen, tegenwerken of onderdrukken. Ik betoog dat deze krachten niet extern zijn aan mensen en dingen; het *zijn* de onderlinge (en voortdurend veranderende) afhankelijkheidsrelaties tussen hen. Vervolgens wijs ik op een logica van creatie, uniformering en expansie die wijdverspreid is onder ingenieurs en beleidsmakers in Nederland; een logica die mensen en dingen dwingt tot formele classificaties, en rommelige praktijken structureert tot duidelijk afgebakende 'aangeharkte paadjes.' Ik noem dit de *logica van de stekkerdoos*: een logica die impliciete waarden en onderliggende aannames in technologische artefacten niet bevraagt, en die het sociale en organisatorische karakter van zorg grotendeels negeert. Ik betoog dat *herstel* een alternatief biedt voor modernistische vertogen over ontwikkeling en groei, waarin problemen worden verholpen door naar believen kant-en-klare technologische oplossingen 'in te pluggen.' In deze studie verwijst herstel naar het subtiele – en vaak onzichtbare – werk dat bij gegevensuitwisseling nodig is om verschillen kenbaar te maken, kloven te overbruggen en belangen te vertalen. Bij dit werk is voortdurend sprake van knutselen en onderhandelen in de marge van technologische ontwikkeling; het onzekere werk dat onbeschreven blijft in projectplannen en rapportages; de ogenschijnlijk verwaarloosbare, gesitueerde interventies die helpen om technologieën te vormen en te kneden; maar ook het natrekken van fantoomnetwerken als een normatieve gehechtheid aan dingen die we dreigen te verliezen.

Kortom, dit proefschrift wijst ons op het vloeiende, onstabiele en rommelige karakter van sociotechnische relaties, en op spaarzame momenten van eenheid en cohesie in de fragiele wereld(en) waarin wij leven. Het roept op tot participatieve vormen van ontwerp en ontwikkeling in e-Health die ruimte bieden voor falen, verval en verlies. Herstel legt de gevolgen bloot van de logica van de stekkerdoos, zoals de voortdurende uitbreiding van hypergespecialiseerde, marktgestuurde en monopoliserende netwerken en infrastructuren voor gegevensuitwisseling in de zorg. Empirisch en conceptueel beweegt deze studie tussen afstand en nabijheid; uit die beweging komt herstel naar voren als manier om het sociale en politieke karakter van technologieën en hun infrastructuren zichtbaar te maken, en als herwaardering van nieuwe vormen van gehechtheid aan rommeligheid, weerbarstigheid, instabiliteit en verval.

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Back in Rotterdam, I thank all my past colleagues at *instituut Beleid & Management Gezondheidszorg*, now *Erasmus School of Health Policy & Management*. I was perhaps a little out of place in the Health Services Management & Organisation section in terms of the research I was doing; nonetheless, I made friends with many people. I was lucky to share an office space with Mahdi Mahdavi: I will never forget your kindness and support. The same goes for Kirti Doekhie and Terese Otte-Trojel Antonsen: you were always there for a lending ear or a talk.

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Thanks to Hester van de Bovenkamp and Iris Wallenburg for coming to my rescue. Hester, you gave me the keys to your house when you temporarily moved to Norway in 2020. We were still in the middle of pandemic times, and my small apartment felt like a prison. It was in your house that I came back to my senses. Iris, we had our first walks in Amsterdam after the peak of the pandemic. I still struggled to return to my abandoned dissertation: all I saw was a manuscript in ruins. You convinced me to pick it up again, and you motivated me to continue. The support you both gave me in that period was crucial.

Rik Wehrens, what can I say? Aside from being a great colleague, you gave excellent feedback on a previous version of Chapter 6. That was in a distant past, but you really helped me to fine-tune my train of thought. The same applies to Bethany Hipple Walters, who read a previous version of Chapter 4, and provided meticulous and clear comments. Bethany, I also have fond memories of our motorcycle rides with your husband.

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Dear Dara, you have a special place in my heart. Thank you for being there when it mattered, and for being who you are. I enjoy learning from you; I enjoy seeing your talent at work. From our countless afternoons in perfume shops to our time spent in Paris, *de tijd vliegt altijd voorbij*. I'm happy to call you my friend, and I'm proud to have you by my side as my paranymph.

To my loving parents, to whom I owe everything, and who are always there for me: *grazie di cuore*. To my dear brother Giovanni: I could not have done this without you.

PORTFOLIO

Conference presentations

2019 Nordic STS Conference (Tampere)

2016 4S/EASST *Science & technology by other means* (Barcelona)

2011 The King's Fund *International congress on telehealth and telecare* (London)

2010 EASST *Practicing science and technology, performing the social* (Trento)

Workshops and training

2019 University Teaching Qualification (EUR/Rotterdam)

2018 PhD Workshop *Digital governance and the distributed self* (Amsterdam)

2018 CLI MicroLab *How to create an educational video* (EUR/Rotterdam)

2017 WTMC Writeshop with Sergio Sismondo and Chunglin Kwa

2015 English Level Statement level C2 (EUR/Rotterdam)

2014 Swedish STS Summer School *STS as an Engaged Program* (Vadstena)

2013 WTMC Dissertation Day with Aant Elzinga and Andrew Webster (Utrecht)

2013 WTMC Summer School *Participation and the politics of difference* (Utrecht)

2013 PhD Workshop *Infrastructures for Healthcare* (Tromso)

2012 PhD Workshop *Innovation in Information Infrastructures* (Edinburgh)

2012 WTMC Workshop *Assessing technology assessment* (Soeterbeek)

2012 WTMC Summer School *Seeing through numbers* (Soeterbeek)

2012 WTMC Workshop *Science and citizenship* (Soeterbeek)

2012 WTMC Workshop *Normativity as object and as practice* (Soeterbeek)

2011 PhD Course *Trusting information: Technology, truth and transparency* (Copenhagen)

2011 Training *Tutorvaardigheden in probleemgestuurd onderwijs* (EUR/Rotterdam)

2011 Academic Writing for PhD students (EUR/Rotterdam)

2010 Klaar in 4 jaar (!) (EUR/Rotterdam)

2010 WTMC Workshop *Research for development* (Soeterbeek)

Teaching (EUR)

Coordinator

2023 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2022 Quality & Safety of Healthcare (Master; in English)
2022 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2021 Quality & Safety of Healthcare (Master; in English)
2021 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2020 Blok 3 Integratieopdracht (Bachelor; in Dutch)
2019 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2018 Critical Studies of Management & Innovation (Bachelor; in English)

Tutor

2023 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2023 Governance & Strategy (Master; in English)
2023 Verdelingsvraagstukken en Gezondheidszorgbeleid (Pre-Master; in Dutch)
2023 Afstudeerproject (Bachelor; in Dutch)
2022 Quality & Safety of Healthcare (Master; in English)
2022 Advanced Research Methods (Master; in English)
2022 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2022 Afstudeerproject (Bachelor; in Dutch)
2022 Governance & Strategy (Master; in English)
2021 Quality & Safety of Healthcare (Master; in English)
2021 Advanced Research Methods (Master; in English)
2021 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2021 Afstudeerproject (Bachelor; in Dutch)
2020 Quality & Safety of Healthcare (Master; in English)
2020 Advanced Research Methods (Master; in English)
2020 Kwalitatieve Onderzoeksmethoden Gezondheidszorgonderzoek (Pre-Master; in Dutch)
2019 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2019 Verdelingsvraagstukken en Gezondheidszorgbeleid (Pre-Master; in Dutch)

2018 Kwalitatieve Onderzoeksmethoden Gezondheidszorgonderzoek (Pre-Master; in Dutch)
2018 Advanced Research Methods (Master; in English)
2018 Critical Studies of Management & Innovation (Bachelor; in English)
2017 Critical Studies of Management & Innovation 2017 (Bachelor; in English)
2016 Quality & Safety of Healthcare (Master; in English)
2016 Kwalitatieve Onderzoeksmethoden Gezondheidszorgonderzoek (Pre-Master; in Dutch)
2015 Quality & Safety of Healthcare (Master and part-time Master; in Dutch and English)
2015 Methoden & Technieken 1 (Bachelor; in Dutch)
2015 Management and Innovation Studies (Bachelor; in English)
2015 Healthcare Governance (Master; in English)
2015 Beleids- en Bestuurswetenschappen (Bachelor; in Dutch)
2015 Advanced Research Methods (Master; in English)
2015 Kwalitatieve Onderzoeksmethoden Gezondheidszorgonderzoek (Pre-Master; in Dutch)
2015 Mentoraat (Bachelor; in Dutch)
2014 Veranderen en Vernieuwen (Bachelor; in Dutch)
2014 Quality & Safety of Healthcare (Master; in Dutch)
2014 Methoden & Technieken 1 (Bachelor; in Dutch)
2014 Management and Innovation Studies (Bachelor; in English)
2014 Beleids- en Bestuurswetenschappen (Bachelor; in Dutch)
2014 Advanced Research Methods (Master; in English)
2014 Introductie in de Gezondheidswetenschappen (Bachelor; in Dutch)
2013 Veranderen en Vernieuwen (Bachelor; in Dutch)
2013 Advanced Research Methods (Master; in English)
2012 Veranderen en Vernieuwen (Bachelor; in Dutch)
2012 Methoden & Technieken 1 (Bachelor; in Dutch)
2011 Veranderen en Vernieuwen (Bachelor; in Dutch)
2010 Veranderen en Vernieuwen (Bachelor; in Dutch)

Supervisor

2010-2023 Bachelor and Master thesis supervision
2020-2023 Master thesis reading committee

Lecturer

2023 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2022 Quality & Safety of Healthcare (Master; in English)
2022 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2021 Quality & Safety of Healthcare (Master; in English)
2021 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2019 Kritische Studies van Management en Innovatie (Pre-Master; in Dutch)
2017 Critical Studies of Management & Innovation 2017 (Bachelor; in English)
2017 Kritische Studies van Management en Innovatie (Schakel; in Dutch)
2016 Kritische Studies van Management en Innovatie (Schakel; in Dutch)
2015 Health informatics - minor (Master; in Dutch)
2015 Kwalitatieve Onderzoeksmethoden Gezondheidszorgonderzoek (Pre-Master; in Dutch)
2015 Management and Innovation Studies (Bachelor; in English)
2014 Health Informatics (Master; in English)
2014 Management and Innovation Studies (Bachelor; in English)
2014 Veranderen en Vernieuwen (Bachelor; in Dutch)
2012 Minor Medische Technologie (Master; in Dutch)
2011 Minor Medische Technologie (Master; in Dutch)

Teaching (other)

Coordinator / teaching assistant / adjunct faculty instructor

2021 Kwalitatieve onderzoeksmethoden, Erasmus MC (Master; in Dutch)
2020 Kwalitatieve onderzoeksmethoden, Erasmus MC (Master; in Dutch)
2018 PSYC3000 Thesis writing course, Webster College Leiden (in English)
2018 PSYC4825 Senior thesis, Webster College Leiden (in English)
2017 PSYC4825 Senior thesis, Webster College Leiden (in English)
2017 PSYC3000 Thesis proposal writing course, Webster College Leiden (in English)
2017 BUSN3100 Thesis proposal writing course, Webster College Leiden (in English)
2017 Science, Technology & Society, Erasmus University College (in English)
2017 Minor Health Care Management, Vrije Universiteit Amsterdam (Master; in English)

2016 PSYC3000 Thesis writing course, Webster College Leiden (in English)

Peer-reviewed publications (this thesis)

Aspria M, De Mul M, Adams S and Bal R (2016) Of blooming flowers and multiple sockets: The role of metaphors in the politics of infrastructural work. *Science & Technology Studies* 29(3): 68–87.

Aspria M, De Mul M, Adams S and Bal R (2014) Integrating users in an interactive video education project: Reframing the patient-centered strategy of a cystic fibrosis centre. *Communications of the Association for Information Systems* 34: 439–452.

Otte-Trojel T, De Bont A, Aspria M, Adams S, Rundall T, Van der Klundert J and De Mul M (2015) Developing patient portals in a fragmented healthcare system. *International Journal of Medical Informatics* 84(10): 835–846.

Publications (other)

Aspria M (2019) Herstelwerk. *Wijsgerig Perspectief* 59(4): 46–47.

Aspria M, Tiddens H and Visser F (2012) Web-tv cystic fibrosis half geslaagd. *Medisch Contact 67*(6): 328–30.

De Mul M, Adams S, Aspria M, Otte-Trojel T and Bal R (2013) *Hart voor de regio: Patiëntenportalen en regionale ontwikkelingen in Nederland*. Rotterdam: Erasmus University Rotterdam & ZonMw. Available at: https://repub.eur.nl/pub/50495/Metis_194888.pdf (accessed 2 September 2022).

Other activities

2010-2012: Secretary to the Board of the Norbert Elias Foundation

Awards

2021: Kees van Wijk Education Award

ABOUT THE AUTHOR

Marcello Aspria (1974) studied Sociology (MSc) and Gender & Sexuality Studies (MSc, cum laude) at University of Amsterdam. Before starting his PhD, he worked in translation and technical documentation for more than a decade. At Erasmus University, Marcello has been teaching, coordinating, and (re)developing various courses (bachelor, pre-master, and master level) and supervising students since 2009. He also taught at Erasmus University College (2017), Vrije Universiteit Amsterdam (2017), and Webster College Leiden (2016-2018). He obtained his University Teaching Qualification in 2019 and received the Kees van Wijk Education Award in 2021. He was involved in the evaluation of Zorgportaal Rijnmond (2009-2012) and in phase two of the ZonMw research project *Centrale Evaluatie Goed Werkende Aanpak Verward Gedrag* (2020-2022). He currently works as a teaching assistant at Erasmus School of Health Policy & Management. His research interests include digital infrastructures, health information exchange, technological abandonment, ruination, and repair.

In his spare time, Marcello likes to read about the lives and times of famous dead philosophers and social scientists. He has a fascination for theorists from the 1920s and ’30s, and enjoys sensorial art, classical and contemporary dance, the city of Paris, and all kinds of music. During weekends, he can be found nosing around in bookstores or pottering along the open roads on his motorcycle.

Health information exchange is a complex matter. There is a growing variety of health-related information systems in use, but they are seldom interoperable. Doctors and policy makers have sought ways to contain this growing differentiation for decades. Efforts to integrate large-scale information systems rarely succeed.

This study explores the work done by people and things in emerging infrastructures for health information exchange. It shows how this work relates to development, production, and growth, as well as to abandonment, ruination, and loss. Rather than offering quick fixes or smart solutions, it argues for a revaluation of repair work: a form of articulation work that attends to gaps and disruptions in the margins of technological development. Repair happens all the time, but is rarely described as such. It sensitizes us to different ways of caring for people and things that do not fit, fall in between categories, and resist social norms and conventions. It reminds us that infrastructures emerge in messy and unevenly distributed sociotechnical configurations, and that technological solutions cannot be simply 'plugged in' at will: they require work by people and things that is often overlooked. With that, repair emphasizes the need for more democratic, critical, and reflexive engagements and interventions in health information exchange.