

PATIENT PORTALS  
DEVELOPMENT AND OUTCOMES IN INTEGRATED AND  
FRAGMENTED HEALTH SYSTEMS

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Patient portals

Development and outcomes in integrated and fragmented health systems

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**Patient Portals**  
**Development and outcomes in integrated and fragmented health systems**

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**Patiëntenportalen**  
**Ontwikkeling en uitkomsten in geïntegreerde en gefragmenteerde  
gezondheidssystemen**

Doctoral thesis

to obtain the degree of Doctor from the  
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# CHAPTER 1

*General introduction*

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### Three anecdotes regarding the use of patient portals

A patient logs into a patient portal after having been notified that a test result has been uploaded by the lab. To have a follow-up about the result, the patient books an appointment with her primary care physician via the portal. To be better informed and prepared for the consult, the patient is referred to online educational material about the underlying condition causing the result.

A mother uses a patient portal to securely email her doctor about a non-urgent question concerning her child. After a few clarifying emails, the doctor is able to diagnose the child. The doctor directly sends a prescription to the pharmacy, which the mother picks up. A visit to the doctor was prevented.

A heart patient measures his blood pressure regularly and the results are automatically uploaded to a patient portal. Both the patient and his doctors can view the result in a graph showing the entire measurement history. The cardiologist notices that the trend looks alarming and proposes to change the treatment regiment. The patient's primary care physician asks the patient to come in for an in-person visit to discuss the new treatment regiment.

These anecdotes illustrate how health information technology (health IT), and patient portals specifically, can contribute to improving the quality, efficiency, effectiveness and patient-centeredness of health care delivery. These contributions are the motivations for this PhD research, which is dedicated to studying the development and outcomes of patient portals.

### Introducing patient portals

A patient portal is a secure web site through which patients can access personal health information and typically make use of several communication, self-management and administrative functionalities.[1] Although patient portals may differ across organizations, most include provisions to capture personal health information, provide linkages to convenience tools such as online appointment scheduling, and communication tools such as secure messaging with health service providers.[2] The first patient portals were developed in the 1990s, initially as websites giving access to educational information.[3] However, in the early 2000s, the first couplings to electronic health records (EHRs) were realized.[4], thereby enabling tethered patient portals that linked a patient to his or her personal health information.[5] In this dissertation, we focus on such tethered patient portals that are linked to one or more care providers' EHRs; that is, the health IT systems in which healthcare providers record information

about their patients. A tethered patient portal is often managed by the provider(s) that install it, and who is (are) also accountable for the secure handling of the data. This stands in contrast to universal personal health records, such as 'Microsoft HealthVault' and 'Patients Like Me' for which the patient is the manager, buyer and owner.[6] The benefit of the tethered patient portal is that it serves as an extension of the health service system; it can integrate with providers' EHRs and can support education, self-care, and communication with the health service provider.[7] In this dissertation, we refer to tethered patient portals when we write of patient portals, unless we explicitly state otherwise.

Over the past decade, the development of patient portals has steadily increased, largely as a result of a dramatic acceleration in the adoption of EHRs.[8-10], the foundation upon which patient portals build. In fact, as most EHR vendors also provide patient portals as part of the 'standard EHR package', portals are increasingly becoming a bi-product of most present-day EHR system implementations.[11] This heightened penetration of patient portals is creating unprecedented opportunities for using health IT to deliver health services to patients, paving the way for benefits to patients, providers and the organizations that implement the patient portals.[12] For example, as the introductory anecdotes convey, viewing of test results and reminders may better stimulate patients to manage and monitor their care.[13], something that may be of particular value to patients with chronic diseases.[14]. Further, since patients can carry out more tasks such as appointment scheduling via the patient portal, patients' use of a portal may generate administrative efficiencies.[1] There is also an expectation that secure emailing can substitute for some in-person visits and telephone contacts, especially when it comes to uncomplicated and routine cases.[15]

Numerous research studies have been conducted to assess the actual effects of patient portals on patient outcomes (see for example [14, 16]). In fact, several studies have found use of patient portals to be correlated with better chronic disease management, as evidenced by improved clinical outcome indicators such as blood pressure and hemoglobin levels.[17-18] The effects are especially significant for patients with chronic diseases and when coupled to case management programs.[14]. Also, several studies indicate that use of patient portals may be positively associated with patient satisfaction.[19-20] In fact, there are indications that patients that use a patient portal are more likely to remain members of a care system.[21] The effects of patient portals on other measures of organizational performance, such as healthcare utilization and other operating costs are less clear.[14, 22]

## **Patient portals in light of health service system structure**

Review of the relevant literature reveals that the great majority of published studies of patient portals were conducted within integrated health service systems, and, hence, that the beneficial effects on outcomes described above derive for the most part from portals in integrated delivery systems. This suggests that there is something in the way health services are structured – more specifically the degree of integration versus fragmentation - that affects the penetration and/or the effects of patient portals. In the following, we consider dynamics that likely cause this relationship between health service system structure and reported patient portal outcomes. First, we briefly describe what is meant by integration and fragmentation of the health service system.

### *Health service system structure*

According to Shortell et al. [23], health service system integration occurs along three dimensions: functional, physician, and clinical. Functional integration denotes the “extent to which key support functions and activities (e.g. financial management, human resources management, information technology management, strategic management, quality improvement) are coordinated across operating units so as to add the greatest overall value to the system”. Physician integration is “the extent to which physicians and the organized delivery systems with which they are associated agree on the aims and purposes of the system and work together to achieve mutually shared objectives”. Clinical integration refers to “the extent to which patient care services are coordinated across people, functions, activities, and sites over time so as to maximize the value of services delivered to patients”. These three dimensions of integration enable a network of provider organizations to provide a coordinated continuum of services to a defined population for which it is willing to be held clinically and fiscally accountable.[24] This integrated structure is widely believed to support information continuity, care coordination, system accountability, teamwork, innovation, and easy access to care.[25] One care delivery system scoring particularly highly on the three dimensions of integration is Kaiser Permanente.[26] Since its inception in 1945, Kaiser Permanente has become the largest not-for-profit, integrated health service system in the US, serving almost nine million members.[27]. The Kaiser Permanente Medical Care Program comprises three separate yet interdependent entities: Kaiser Foundation Health Plan, Kaiser Foundation Hospitals, and Permanente Medical Groups in each region. These entities cooperate to organize, finance, and deliver health services under mutually exclusive contracts built on a common vision, joint decision-making, and aligned incentives.[28]

Opposite integrated health service systems such as Kaiser Permanente stand systems with no or little structural integration. A good example of a fragmented health service system currently exists in the Netherlands, although comparable fragmented contexts can also be found in many other countries including the United States. In the Netherlands, health services have historically been strictly divided into primary and secondary care.[29] In addition, there are specialized institutions for mentally and physically disabled, for elderly, for home care, for rehabilitation, et cetera.[30] The fragmentation caused by this organizational specialization is exacerbated by compartmentalized reimbursement arrangements. For instance, hospitals and primary care services are contracted by health insurers under a regulated market setup, other services are reimbursed through national or municipal budgets, each with their own regulations and health service focus.[31-32] Moreover, some provider organisations have religious or cultural identities, and special relationships and arrangements with organisations and individuals sharing their background. Amidst this fragmented structure, there are and have been numerous programs aimed at integrating care in the Netherlands [33], and progress has been achieved in many areas (see for example the continually updated Commonwealth Fund website.[34] Nevertheless, the fragmented structure generally hinders health service organizations from pursuing extensive integration such as is possible in systems like Kaiser Permanente.

### *The implication of health service system structure on patient portals*

The more providers are connected (and tethered) to the patient portals, the more functionality the portal can offer in terms of information access and communication services. If patients see multiple different providers who use distinct patient portals, patients will need to handle several interfaces, authentication procedures and data repertoires, often leading to much confusion and frustration.[35] Moreover, it may be difficult to synthesize all information and coordinate services. In integrated systems, such connectivity occurs automatically when patients receive their care within the system and have access to the system-wide patient portal. In contrast, providing the same functionality through patient portals in fragmented health service systems requires collaboration among managers and professionals from various smaller and independent organizations.[36-37] As such, the concept of inter-organizational collaboration becomes central to patient portal development and delivery in fragmented health service systems.[38-40]

Inter-organizational collaboration implies patterns of social relations among different health service providers (individuals, groups, organizations) who depend on each other to reach their goals and who must coordinate with each other to achieve them.[41] Such coordination is challenged by the fact that the service providers often differ in terms of organizational,

technological and geographical characteristics. Organizationally, they rarely share goals, care management capabilities, or cultures. Technologically, the level of overlapping information technology infrastructures and knowledge, for example about mutual patients, is often low. Geographically, the spatial distance (since they often work in different buildings with at least some geographical spread) may mean that providers seldom share personal relationships that can help them bridge some of the gaps stemming from lack of shared organizational and technological characteristics.[42-43] Integrated systems, glued together by functional, physician, and clinical integration, will likely not encounter these challenges, and at least not to the same degree. The inter-organizational setting may also affect the ability of participating health service providers to muster together and recoup investments. As to the former, due to the lack of a shared financial bottom line, it may be difficult to convince providers in fragmented health service systems to invest in a shared infrastructure. As to the latter, providers can rarely be certain to recoup the benefits of potentially healthier and more satisfied patients, since patients may see many different providers. This is different in an integrated system, which setup makes it possible to capture downstream benefits of better-managed patients, because patients typically stay in the system.[44] Moreover, constructing mutual incentives in fragmented systems is often difficult as providers often are restricted by the compartmental boundaries and may have competing interests.

Hence, solving the problems encountered while developing and providing patient portals is likely to be more difficult in fragmented systems because of the need to work across organizational boundaries. Specifically, solutions that are possible in an integrated health service system are infeasible because of system fragments being managed by separate logics, routines, and financial incentives. This may explain why relatively few comprehensive, multi-provider patient portals are being developed in the Netherlands [45] and why many attempts have failed to produce sustainable patient portals, let alone measurable outcomes. Paradoxically, patient portals may have the highest value in fragmented health service systems, since they can consolidate patient information that is otherwise scattered across multiple health service providers. Thus, a patient portal could be an important instrument with which to overcome fragmentation by giving patients an overview of all their records as well as one place to seek interaction with providers, self management programs, et cetera.

## **Study motivation and research questions**

This problem statement is our motivation for studying the impact of health service system structure on patient portal development and outcomes. The overall objective of this dissertation

is to advance the knowledge base regarding patient portal development and outcomes, with emphasis on portals being developed in fragmented health service systems where they may have the highest value. The following three questions guided the research.

1. What outcomes have been achieved through patient portals and how are these outcomes achieved?
2. How does the health service system context, in particular health service system integration or fragmentation, impact patient portal development and ability to achieve beneficial outcomes?
3. With focus on fragmented health service systems, how can patient portal development and achievement of beneficial outcomes be improved?

As part of the activities involved in answering the third research question, our original research design included empirical work. More specifically, we intended to collaborate with patient portals that were being developed in the Netherlands to implement one or more designs (such as changes in practices or policies) that would emerge as a result of answering these research questions. The research intended to contribute to the evidence base on patient portal development through evaluation of the development processes and the results of the implementations. As our research progressed, however, it became apparent that the patient portals under development in the Netherlands had other priorities and were unlikely to offer fertile empirical research settings. Instead of conducting one or more empirical design studies, we therefore chose to identify effective practices and policies of patient portal development through a literature study. We thus added a fourth research question.

4. How can the existing evidence base inform patient portal development across health service systems and how can this evidence base be advanced?

### **Study approach and outline of dissertation**

We positioned this study in the field of health services research [46], defined as “the multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of health care, and ultimately our health and well-being”.[47] Further, we were informed by organizational theory, especially the strand concerning inter-organizational collaboration and coordination. In using this theoretical lens, we placed our

research alongside other attempts to advance the understanding of an increased role of multi-sector inter-organizational networks in the provision of public services as captured in the new public governance paradigm.[48-49]. Moreover, we drew from information science literature to ensure our research built on and contributed to concurrent work on patient portals and related constructs such as electronic personal health records and EHRs. In turn, our research adds to this literature through our efforts to illuminate the dynamics that occur when developing patient-centered health IT in contexts largely dominated by organizational logics. Last, but not least, we borrowed from design sciences/program design and evaluation literature to assess the ability of the current evidence base to inform patient portal developments.

Due to the centrality of health service system structure in the development of patient portals, we examined portals in integrated and fragmented health service systems in the United States and in the Netherlands. In the United States, we studied Kaiser Permanente's patient portal as well as three portals developed by so-called Health Information Exchange entities that operate in fragmented health service systems. In the Dutch fragmented health service system, we studied three diverse patient portals. The selection of these patient portals was the result of purposive sampling aimed at obtaining representation of a variety of types of patient portals within different health services contexts.[50]. We relied on multiple qualitative methods, including literature review, document analysis, and semi-structured interviews.

We now explain in more detail the steps we took and the methods we used to answer each of our research questions.

**What outcomes have been achieved through patient portals and how are these outcomes achieved?**

## *Chapter two*

We did a systematic review of the scientific literature on patient portal outcomes to examine how portals contribute to health service delivery and patient health. The specific aims were to examine how outcomes are produced, and how variations in outcomes can be explained. We used a realist review method, which aims to describe how “an intervention works, for whom, and in what circumstances” by analyzing patterns between context, mechanism and outcomes. Informed by this method, we asked the following two research questions: (1) By what mechanism(s) do patient portals contribute to outcomes?; and (2) How can variations in outcomes across different contexts be explained? To answer these questions, we reviewed 32 evaluation studies of patient portals published between 2003 and 2013.

Our research initiated a brief methodological discussion in the Journal of the American Medical Informatics Associations, which we believe is insightful and have therefore included as an appendix.

**How does the health service system context, in particular health service system integration or fragmentation, impact patient portal development and ability to achieve outcomes?**

### *Chapter three*

To understand how patient portals work in a truly integrated health service system, we did an in-depth study of the patient portal at Kaiser Permanente. Our aim was to identify and examine the organizational dynamics inherent to an integrated system that influence the impact of the patient portal on organizational performance and patient health. We interviewed eighteen physician leaders and executives particularly knowledgeable about the patient portal, and applied content analytic techniques informed by our analytical framework. This analytical framework centered on two research questions. (1) How does the patient portal impact care delivery to produce the documented effects?; and (2) What are the important organizational factors that influence the patient portal's development?

### *Chapter four*

To gain an understanding of patient portal development in a completely different system, we conducted case studies of three patient portals developed in inter-organizational collaboration in the Netherlands. The aim of this chapter is to identify and describe the main difficulties associated with developing patient portals in a highly fragmented health service system. Specifically, we were interested in the following three questions: (1) What types of patient portal networks have emerged in the Netherlands?; (2) What developmental issues do various types of patient portal networks experience?; and (3) How does patient portal network type affect developmental issues experienced by the patient portal networks? To answer the questions, we collected interviews and documents and applied content analytic techniques to analyze data from each of the three cases.

**With focus on fragmented health service systems, how can patient portal development and achievement of outcomes be improved?**

*Chapter five*

In the United States, the so-called 'Meaningful Use' program offers financial incentives to stimulate Health Information Exchanges to develop patient portals in fragmented health service systems. To advance our understanding of how patient portal development can be stimulated in a fragmented health service system context, we reported on the early effects of this program on patient portal development by Health Information Exchanges (HIEs). Specifically, we examined the following questions: (1) What are the characteristics of early-stage HIE-sponsored portals?; (2) What are the major factors affecting providers' adoption of HIE-sponsored portals?; and (3) What factors will drive the further development and adoption of patient portals in the HIE context? To do so, we identified four HIEs that were developing patient portals as of Spring 2014. We collected relevant documents and conducted interviews with six HIE leaders as well as two providers that were implementing the patient portals in their practices. We performed content analysis on these data to extract information pertinent to our study objectives.

*Chapter six*

Delivering comprehensive patient portals in fragmented delivery systems depends on coordination among a network of health service organizations. However, such inter-organizational coordination is fraught with challenges due to lack of organizational, technological and geographical proximity. These challenges may complicate coordination and lead to high coordination costs. To assess how these challenges can be ameliorated we conducted a conceptual analysis of the usefulness of Relational Coordination Theory and the applicability of the Relational Model of Organizational Change to patient portal networks. The guiding research question was: To what extent can relational coordination help inter-organizational networks overcome challenges to delivering patient portals? In this analysis, we drew upon literature on inter-organizational coordination, and relational coordination in particular.

**How can the existing evidence base inform patient portal development across health service systems and how can this evidence base be advanced?**

*Chapter seven*

Chapter is devoted to scientific understanding and evidence regarding the advancement of patient portals and presents a systematic review of the scientific literature on patient portal development. An emerging evidence base is describing the problems that must be solved to develop patient portals and proposing solutions to ameliorate these problems. Taking a program design and evaluation perspective, we systematically synthesized existing scientific evidence to answer five questions: (1) What categories of problems related to patient portal development have been defined?; (2) What causal factors have been identified by problem analysis and diagnosis?; (3) What solutions have been proposed to ameliorate these causal factors?; (4) How many of the proposed solutions have been implemented?; and (5) How many of the implemented solutions have been evaluated and what learning has been generated? We included 109 articles in the review. The review forms the basis for a reflection on the existing research base and recommendations for further research.

**Conclusion**

*Chapter eight*

We conclude the dissertation by providing concise answers to our four research questions and reflecting on the scientific and practical relevance of our research.

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# CHAPTER 2

## *How outcomes are achieved through patient portals: a realist review*

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## ABSTRACT

**Objective:** To examine how patient portals contribute to health service delivery and patient outcomes. The specific aims were to examine how outcomes are produced, and how variations in outcomes can be explained.

**Materials and Methods:** We used a realist review method, which aims to describe how “an intervention works, for whom, and in what circumstances” by analyzing patterns between context, mechanism and outcomes. We reviewed 32 evaluation studies of patient portals published since 2003.

**Results:** The reviewed evaluations indicate that as a complement to existing health services, patient portals can lead to improvements in clinical outcomes, patient behavior and experiences. Four different mechanisms are reported to yield the reported outcome improvements. These are patient insight into personal health information, activation of information, interpersonal continuity of care, and service convenience. The vast majority of evaluations were conducted in integrated health service networks in the US, and we detected no substantial variation in outcomes across these networks.

**Discussion and conclusion:** Patient portals may impact clinical outcomes and health service delivery through multiple mechanisms. Given the relative uniformity of evaluation contexts, we were not able to detect patterns in how patient portals work in different contexts. Nonetheless, it appears from the overwhelming proportion of patient portal evaluations coming from integrated health service networks, that these networks provide more fertile contexts for patient portals to be effective. To improve the understanding of how patient portals work, future evaluations of patient portals should capture information about mechanisms and context that influence their outcomes.

## BACKGROUND AND SIGNIFICANCE

Health service organizations increasingly implement patient portals based on the belief that patient portals will enhance patient engagement, health outcomes, service efficiency and convenience.[1] A patient portal is a “secure website for patients, typically maintained by provider practices, that offers access to a variety of functions linked to a physician’s EHR [electronic health record] including secure messaging, protected health information (e.g., lab results, medication lists, and immunizations), appointment scheduling, and tethered PHRs [personal health records]; more advanced portals may offer programs for self-management or patient questionnaires”.[1] In 2012, Ammenwerth et al. published a meta-analysis of the impact of patient portals, identifying six types of outcomes or processes to which patient portals can contribute.[2] These include clinical outcomes, health resource consumption, patient adherence, patient-provider communication, patient empowerment, and patient satisfaction. Although providing a synthesis of the contribution of patient portals to these six outcomes and processes, the review method used by Ammenwerth et al. does not explain how patient portals contribute to these outcomes and processes, nor does it explain why some patient portals are successful in doing so while others fail. The variation in outcomes reported by Ammenwerth et al, as well as by others, calls for a scientific analysis to provide explanations for variation in patient portal outcomes. This study seeks to provide such explanations using a so-called realist review method.

A realist review seeks to describe how “an intervention works, for whom, and in what circumstances”[3]. It does so by analyzing the relationships between context, mechanism and outcomes.[4] In adhering to this terminology, we use the word outcome to refer to the six outcome and process measures defined by Ammenwerth.[2] Mechanisms are the often hidden workings of the intervention that cause outcomes.[5] Context refers to the conditions in the environment where the intervention works that activate the mechanisms.[5] Contrary to more traditional literature synthesis methods, the realist approach does not aim to assess the outcomes of interventions, but rather to explain them. This aim allows for including diverse study designs, since each may help explain how the intervention works.[3] A realist approach unravels the workings of complex interventions in their specific contexts.[6] As such, the approach has recently been used on complex and diverse interventions such as joint health and safety committees[7], school feeding programs[8], culturally appropriate diabetes education programs[9], and internet-based medical education[10]. Patient portals are also complex interventions and often continuously adapted to meet the needs of the users and the health care organizations involved.[11] Given such idiosyncratic conditions, the effects of a patient

portal may not be replicated from one context to another.[12] As the number of patient portal implementations increases across a variety of settings, understanding the mechanisms that explain the results achieved in different contexts gains importance.

## OBJECTIVE

Based on the realist line of thinking, the review aims to synthesize and analyze evaluations of patient portals to explain the reported outcomes. Our two main research questions are:

1. By what mechanism(s) do patient portals contribute to outcomes?
2. How can variations in outcomes across different contexts be explained?

## MATERIALS AND METHODS

We adhered to the realist review method described in the RAMESES publication standards, published in 2013.[4] The reporting of our methods and results follows these standards.

### **Exploratory review of how patient portals work**

We started with an exploratory review of background documents and research studies to identify ways in which patient portals may contribute to health service delivery and patient outcomes.[1-2, 13-21]. Based on this review, we identified six main ways in which patient portals may affect service delivery and outcomes. These include improving: patient access to information and services; patient decision-support; coordination of care around the patient; interpersonal continuity of care; health services efficiency; and service convenience to patients and caregivers. The aim of a realist review is to test and refine such 'educated guesses' against the data in the evaluation studies included in the realist review.[10] In the following we describe how these studies were selected.

### **Searching process**

We searched PubMed, LISTA, PsycINFO and Scopus for peer-reviewed literature in English published between January 2003 and August 2013 (see Table 1 for search queries). Assisted by a librarian, we searched for literature on both patient portals and electronic personal health records. We included both these terms, since they are so related that literature often addresses them interchangeably. Given the definition of patient portals presented in the introduction, both entities are relevant to our review: when logged into a patient portal, patients may see their

PHR, which stores data from information exchanges (such as secure messaging) made available via the portal.

**Table 1:** Search queries

Search terms in title/abstract	Restrictions	Hits from combined search with all terms
Patient portal* Patient web portal* Patient online portal* Patient internet portal* Personal health record* AND electronic Personal health record* AND online PHR AND electronic PHR AND online Shared electronic medical record* Electronic personal health record*	Time period: 2003-2013	PubMed: 150
		PsycINFO: 53
	Language: English	LISTA: 48
	Type of publication: Peer-reviewed	Scopus: 279
		Total: 530

### Selection and appraisal of documents

Two reviewers selected the articles to be included in the review through a two-step process. First, each article's title and abstract were reviewed, and articles were excluded if they did not present evaluations of EHR-linked patient portals. The primary reviewer (TOT) reviewed all articles, while the second reviewer (AdB) reviewed a random sample of 10%. The agreement rate was 97.4%, and disagreement was resolved through discussion. In the second round, we read the full text to determine whether our extended set of inclusion criteria was met. Building on Ammenwerth et al.'s review, we included only evaluations addressing the six outcome or process categories classified in that review. In addition, we based our appraisal on whether the studies identified mechanisms by which the interventions were expected to work. The second reviewer received a random sample of 16%, and the agreement rate between reviewers about whether the inclusion criteria were met was 86%. Agreement was reached through discussion and 25 articles were selected. Through snowballing, an additional 7 studies were identified, bringing the number to 32.

### Data extraction

We extracted data from the articles and created six data tables, one for each outcome category. The data used to populate the cells included: article information; study objective;

intervention description; patient portal characteristics; outcomes; contextual factors; proposed mechanisms; evaluation characteristics; and finally, study characteristics. For the studies that reported multiple outcomes, we posted relevant information into multiple outcome tables. However, we did not include information regarding second or tertiary outcomes that were only superficially reported, thus disregarding mechanisms linked to weaker or coincidental outcomes.

## **Analysis and synthesis processes**

For each outcome category, we organized information to bring forward by what mechanism patient portals contribute to outcomes and the variation in outcomes across different contexts. First, we identified the outcomes reported in each study, and organized outcome data according to intervention type and study design (randomized controlled trials (RCTs), observational and qualitative). The organization of data in terms of intervention type was especially important, since we included evaluations of an entire patient portal, a patient portal module, or a program offered through a module. We reasoned that all interventions provide valuable information on the contribution of a patient portal, but were aware that the outcomes should be compared with caution. With respect to study design, we classified the strength of the patient portals' effect on each outcome. (See online supplementary appendix I). For the RCTs, we separated the reported effects into studies reporting no statistically significant effect; those with some significant effect, but lacking consistency across different outcome measures and/or population subgroups; those with a significant effect not sustained over time; and finally those with significant effects across multiple outcome measures and sustained over time.

Second, for each outcome category, we identified the mechanisms mentioned by the authors. Most of the studies did not describe in detail the mechanisms believed to be in play, and careful reading of the text was required to identify the mechanisms proposed to link the patient portal intervention to an outcome. Moreover, we assessed whether these mechanisms were empirically tested; that is, whether the key concepts of the mechanism were operationalized in the studies.

Finally, we gathered information on the organizational and healthcare system context in which the evaluated patient portals operated. Unfortunately, the influence of context on the intervention was rarely described in detail at the service unit level (culture, working relationships, operational policies and procedures, incentive systems) or the personal patient-provider level (guidelines, communication, relationship). Most studies contained some large-scale information, such as the type of organization, the number of providers and patients using the patient portal, the comprehensiveness of the EHR, and existing disease management efforts within the

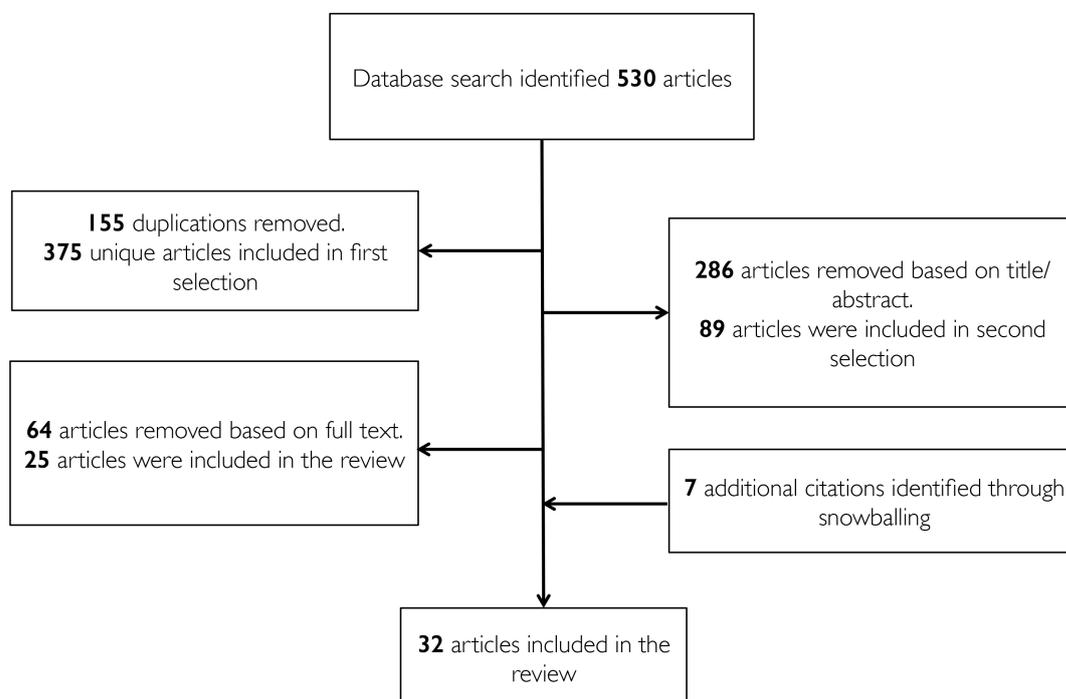
organization. User characteristics such as age distribution, ethnicity, language proficiency, and gender distribution were well described in the studies.

## RESULTS

### Document flow diagram

Figure 1 illustrates the paper selection flow that led to a total of 32 evaluation studies.

**Figure 1:** Paper flow diagram



### Document characteristics

Eleven studies evaluated the effect of a patient portal, portal module, or program offered through a patient portal on clinical outcomes. Eight studies examined the impact on healthcare utilization, and six looked into the effect on patient adherence. Patient-provider communication was an end-point in five evaluations, patient empowerment in eight, and patient satisfaction in five. Eighteen of the studies were RCTs, eleven were observational studies, three were qualitative studies using focus groups or interviews, and one used mixed methods (See online supplementary appendix 1). Thirty studies were from the US, one from Canada and one from the Netherlands. Eleven articles were published before 2010 and twenty-one after, indicating a

recent and steady increase in the evaluations of patient portals and electronic PHRs. (See supplementary online appendix 2 for tables with article information and excerpts from the data about study objective, methods, context, mechanisms, and outcomes).

## **Main findings**

### *Outcomes*

The evaluations indicated that patient portals could lead to improvements in clinical outcomes, patient adherence, patient-provider communication, patient empowerment and patient satisfaction with health services. In total, fifteen of the 18 RCTs demonstrated significant positive effects on these outcomes, albeit in some studies the effects were not strong or consistent over time. The majority of observational and qualitative studies provided indications consistent with these demonstrated effects. No studies found serious adverse consequences of patient portal implementations. However, interestingly, an often-hypothesized potential of patient portals to lower health resource consumption through substitution of services was not validated. On the contrary, of the eight studies that addressed health care utilization, five concluded that higher health resource consumption occurred after the implementation of a patient portal, and two found no change. Only one of the eight studies documented lower healthcare utilization due to a patient portal.[22] However, this finding has been contradicted by a more recent study conducted within the same integrated delivery system.[23] These results suggest that patient portals became complements rather than substitutes to existing health services.

More than half of the patient portal evaluations were targeted at chronic disease patients. This was particularly the case in the clinical outcome category, where all eleven evaluations focused on management of diabetes, hypertension, depression, chronic musculoskeletal pain, or mobility difficulty. This focus on chronic conditions is not surprising since several studies mentioned that the patient portal supported comprehensive self-disease management programs.[24-29]. Interestingly, several studies mentioned a 'ceiling effect' due to the breadth and quality of these existing disease management programs, which could explain why their results were often not strong or consistent. As one study concludes: "As control approaches the upper end of feasibility, further improvements may be limited".[24]

Furthermore, several evaluations suffered from inadequate study samples, relatively short follow-up periods, and used different instruments to assess outcomes. These methodological problems may also have inhibited the strength of results and suggest that caution be taken in generalizing the findings from the studies. However, although the outcomes are important to understanding patient portals' contributions to healthcare systems and the patients they serve,

as noted earlier, assessments and comparisons of outcomes are not key to realist reviews. Rather, focus is on explaining how and why the identified outcomes occur. In the sections below, we attempt to provide answers to those questions.

### *Mechanisms*

By classifying and aggregating authors' hypothesized mechanisms by which patient portals affect outcomes, we identified four such mechanisms. We recognized a mechanism if it was mentioned in at least half of the evaluations within a certain outcome category. Importantly, it should be noted that none of the studies described their hypothesized mechanisms in detail nor did they empirically test whether these mechanisms did in fact lead to the reported outcomes. Further, as a consequence of the research designs used in the respective studies, data were not collected on the actual operationalization of these mechanisms. Hence, the mechanisms we identified are based solely on researchers' hypotheses about the patient portal workings, provided that these were not counter to the corresponding study outcomes. There were no correlations across mechanisms, study designs, or intervention type (whole portal, module, or a program). Below, we describe the four identified mechanisms and provide examples from the data. Worth noting is that the four identified mechanisms do not include care coordination or provider efficiency, which we had identified as possible mechanisms in our exploratory review.

- I. Patient insight into information: Several studies highlighted that having access to personal information will enable and motivate patients and their caregivers to be involved in its application and in ensuring its accuracy and comprehensiveness. This mechanism was mentioned in more than 50% of evaluations of patient empowerment, clinical outcomes, and patient adherence.

Patient empowerment: *"Making electronic health records available across the Internet is viewed as an important step toward consumer empowerment, because without adequate information patients are not able to achieve sufficient levels of desired autonomy and self-efficacy".[30]*

Clinical outcomes: *"Access to effective and tailored patient education, electronic patient-provider communication, and tailored patient education, electronic patient-provider communication, and the wealth of clinical information and web-based resources contained within modern PHRs could lead to improvements in chronic disease outcomes through improved patient-centered care and self-management".[31]*

Patient adherence: *“The use of a secure, interactive personal health record (PHR) tethered to an EHR can provide an avenue for patients to review and update health information and has the potential to improve adherence to guidelines”*.<sup>[32]</sup>

2. Activation of information: Several authors described how decision-support tools provide new and effective ways of using and presenting information. Primarily reminders sent to patients through patient portals were reported to increase the effectiveness and targetability of information. This mechanism was mentioned as being important for achieving patient adherence in more than half of the evaluations.

Patient adherence: *“To act on their choices, patients need written plans and logistical details. They need reminders when services are due, guidance to deal with inconsistent recommendations, and access to decision aids for choices that require shared decision-making”*.<sup>[33]</sup>

3. Interpersonal continuity of care: Easier and improved access for patients to contact their providers was proposed to enhance interpersonal continuity of care. As several studies mentioned, patient portals allow patients to communicate asynchronously with a preferred provider, enabling them to build an ongoing, personal relationship that includes mutual trust and responsibility.<sup>[34]</sup> Interpersonal continuity of care was suggested to improve clinical outcomes and patient satisfaction in some studies, whereas patient-provider communication alone was linked to interpersonal continuity of care in more than 50% of the studies.

Patient-provider communication: *“Our examples illustrate the cases in which patients and providers establish social bonds during the interactions facilitated by the patient portal system. As well, accumulated messages in the portal system about the same patient can provide rich trajectory information that help providers and the patient better understand her illness management from a long-term perspective”*.<sup>[35]</sup>

4. Service convenience: Finally, patient portal services that ease the navigation of the health system, facilitate contact, and decrease patient costs, were believed to bring added service convenience to patients. This mechanism was hypothesized in more than 50% of the studies to impact health resource consumption and patient satisfaction by making it easier to acquire services.

Health resource consumption: *“Internet portals may improve patient health and well-being by providing reliable and trusted MS [multiple sclerosis]-related information and resources, providing easy and reliable*

*methods for patients to navigate an increasingly complex medical healthcare system, and providing a secure avenue for patients to communicate electronically with their MS provider regarding symptoms and disease management”.[36]*

*Patient satisfaction: “The portal was convenient: 81% believed that the portal saved them a telephone call, and 33% believed it saved them a visit to the clinic. The portal allowed patients to send messages at all hours; indeed, 73% of incoming messages were sent during non clinic hours”.[37]*

Authors regularly reported socio-demographic differences in achieving the outcomes. One study, for example, noted that “users were demographically different from nonusers (e.g. fewer minorities and higher education), had more chronic illnesses, and were more up-to-date with care at baseline”.[33] This may suggest a refinement to some or all of the proposed mechanisms. The refinement could point to variations in how mechanisms are triggered in individuals based on their race/ethnicity, geographical location, health and online literacy, and health consciousness.

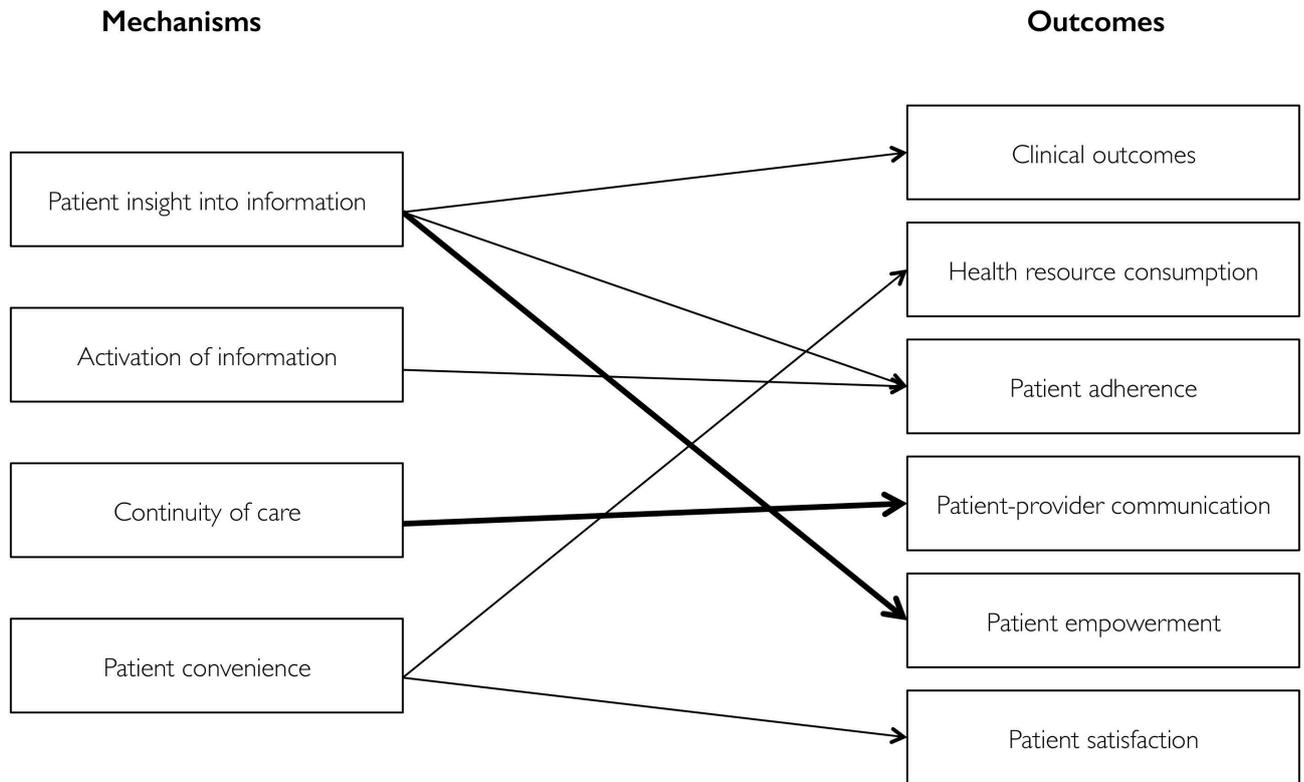
As indicated above, the hypothesized significance of these mechanisms differs per outcome. This is illustrated in figure 2 on the next page. The arrows signify that a least 50% (thin arrows) and 75% (thick arrows) of authors hypothesized that a particular mechanism was in play to produce the expected or observed outcome.

## *Context*

The vast majority of evaluated patient portals included in our review operated within health service networks in the US. These health service networks were integrated delivery networks; academic hospitals providing integrated care; and multispecialty group practices. Although some of these were indeed truly integrated delivery networks, we refer to the three types of networks as ‘organized’. (See online supplementary appendix 3 for a list of these networks). Only two patient portals were from outside the US (Netherlands and Canada) and both distinguished themselves by operating independently within a hospital clinic or a hospital network.

The organized health service networks appeared to share some large-scale contextual characteristics, including the presence of comprehensively used EHRs and a focus upon chronic disease management. The influence of the network configuration on patient portals received some attention in the material, as several research teams noted the impact of integration on the outcomes. One team remarked: “this study was conducted in an integrated health care system

**Figure 2:** Hypothesized links between mechanisms and outcomes\*



\*The thin arrows signify that at least 50% of authors hypothesized that a given mechanism produced a given outcome. The thick arrows indicate that this was the case for at least 75% of authors.

with shared records of medical and mental health care as well as established collaborative relationships between primary care and mental health providers.” Moreover, “the efficiency and clinical benefit of this program might be difficult to replicate outside of an integrated system”. [38]

### *Context-Mechanism-Outcomes patterns*

From a realist perspective, patterns between context, mechanisms, and outcomes of an intervention are central to understanding how and why the intervention had an effect. Based on such patterns, reviewers can explore the impact of the particular context on the mechanisms that were suggested to produce the outcomes. We did not identify context-mechanism-outcome patterns based on the reviewed literature, as we were unable to detect consistent differences regarding the outcomes or proposed mechanisms across contexts. Nor did study design, intervention type, or evaluation methods differ notably across contexts.

## DISCUSSION

### **Summary of finding**

Using a realist lens, we set out to answer (1) by what mechanism(s) patient portals contribute to outcomes, and (2) how variations in outcome across different contexts can be explained.

To the first question, although not empirically tested, patient portal evaluators suggest at least four mechanisms to influence clinical outcomes, health service utilization, patient adherence, patient-provider communication, patient empowerment and satisfaction. This supports our premise that patient portals are complex interventions that work through multiple pathways to generate multiple outcomes. The most frequently reported mechanisms were patient insight into information and interpersonal continuity of care. 75% of authors hypothesized that patient insight was in play to enhance patient empowerment. Similarly, 75% of authors hypothesized that interpersonal continuity of care was a mechanism that explain how patient portals improve patient-provider communication.

Lack of variability in outcomes and mechanisms across relatively uniform contexts hinders a response to our second question. We give three possible explanations for this lack of detectable context-mechanism-outcome patterns in the included studies. First, as indicated above, conditions for patient portals in organized health service networks may be relatively similar, and consequently, the uniformity of evaluation contexts may have inhibited significant differences in mechanisms and outcomes. Second, the effect of a patient portal on outcomes may be limited because of a ceiling effect produced by existing disease management programs. Third, the study designs and evaluation methods did not allow for surfacing measurable differences, especially if these would be marginal due to the ceiling effect.

Nevertheless, the striking tendency of evaluated patient portals to operate within organized health service networks can provide some insights into the contextual characteristics conducive to patient portals. Large and organized health service networks with shared EHRs are well-equipped to make the investment to establish high-functional patient portals that integrate information from the continuum of care.[39-40] The probability that this investment will be returned is high since their large scale facilitates patient traffic, which is necessary to generate outcomes.[41-42]. Moreover, the business case for patient portals remains strong in organized networks, even if costs and benefits appear in different network components. Likewise, organized health service networks suffer less from internal operational barriers which hinder reaping joint benefits as attainable through the higher levels of collaboration and communication enabled by patient portals.[43-45] These attributes are likely to support a culture with a focus on quality improvement and patient-centered care, which may positively affect the application of

patient portals across the care continuum.[39] In addition, existing research and quality improvement traditions incite and permit scientific evaluations of these technologies.[39]

This examination of the impact of organizational aspects on patient portals prompts two reflections. First, the modest outcomes produced by most of the studies may be explained by the fact that the organized health service networks already provide well-established patient-centered health services. As many of the reviewed studies noted, due to existing disease management and patient-engagement programs, the effect of adding a patient portal was only incremental. Furthermore, the high degree of interorganizational coordination found in organized health service networks could explain why the potential of patient portals to improve care coordination did not surface as an important mechanism in the reviewed studies. As care coordination commonly underlies the existing disease management programs, evaluators may have overlooked care coordination as a relevant contextual factor.

Second, the above-mentioned ceiling effect may not apply to fragmented contexts, which may therefore derive higher value from patient portals.[46]. In fragmented contexts, patient portals may become a means to achieving a discontinuous improvement, for example towards care coordination, and thus to generating desired effects.[47]. However, it appears from the lack of reported outcomes from fragmented healthcare systems that these systems are less conducive to achieving such improvements.[48] Patient portals seem to struggle in contexts that need them most.

## **Strengths and limitations**

We found that the studies rarely detail the mechanisms by which an intervention is expected to work. Consequently, the studies are not designed to empirically test the mechanisms that could explain how patient portals improve outcomes. Combined with a scarcity of small-scale contextual information, individual studies tell us little of how and why patient portals create outcomes in different contexts. Thus, our ability to identify and aggregate the proposed mechanisms underlying each intervention is an important step in establishing the evidence base for the implementation of patient portals, and a major contribution of this realist review.

There are a number of limitations to the study. First, we only included evaluations with the six process and outcomes measures identified by Ammenwerth et al., and may thus have excluded evaluations of other end-points. The lack of cost evaluations could, for example, explain why provider-efficiency and productivity was not mentioned as an important mechanism in the reviewed studies. Second, we acknowledge a possible publication bias towards successful

implementations, potentially having led to an omission of information regarding patient portal implementations from less effective contexts.[49]

### **Future research directions**

The reviewed evaluations are likely to be forerunners to a larger body of evaluations that may confirm our preliminary results. Future evaluations should describe the small and large-scale contexts impacting the intervention to make apparent why an intervention may or may not have worked. Furthermore, our understanding of how and why patient portals work will benefit from more attention to the proposed mechanisms underlying patient portal interventions; for example, by empirically measuring whether key concepts to an given intervention mechanism have actually been operationalized as intended.

This review has indicated that patient portals may have even higher value propositions in more fragmented contexts, but that these contexts may be less favorable to patient portals. Therefore, a topic that deserves further exploration is how to implement and derive outcomes from patient portals in healthcare systems that are more fragmented than the ones captured in this review.

### **CONCLUSION**

Patient portals affect clinical outcomes, health service utilization, patient adherence, patient-provider communication, patient empowerment, and patient satisfaction with health services by four mechanism. These mechanisms are: patient insight into information, activation of information, interpersonal continuity of care, and service convenience. The significance of these mechanisms differs per outcome. Reported outcomes of patient portals derive mostly from large and organized health service networks. In highly organized health service networks, patient portals appear to be complements to disease management programs rather than substitutes for these services. Paradoxically, patient portals may have higher impact in more fragmented contexts that are less conducive to patient portal implementation and use.

The complexity of deriving outcomes from patient portals emphasizes the necessity of research that disentangles the mechanisms by which outcomes are produced in relation to their context. Research designs and evaluations reported to date are insufficient for this purpose. Moreover, reports on unsuccessful patient portals, which are equally important for such disentanglement, are lacking.

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# CHAPTER 3

*The organizational dynamics enabling patient portal impacts upon organizational performance and patient health: a qualitative study of Kaiser Permanente*

This chapter was submitted as:

Otte-Trojel T, Rundall T, de Bont A, van de Klundert J, Reed M.  
The organizational dynamics enabling patient portal impacts upon organizational performance and patient health: a qualitative study of Kaiser Permanente

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## ABSTRACT

**Background:** Patient portals may lead to enhanced disease management, health plan retention, changes in channel utilization, and lower environmental waste. However, despite growing research on patient portals and their effects, our understanding of the organizational dynamics that explain how effects come about is limited.

**Methods:** This paper uses qualitative methods to advance our understanding of the organizational dynamics that influence the impact of a patient portal on organizational performance and patient health. The study setting is Kaiser Permanente, the world's largest not-for-profit integrated delivery system, which has been using a portal for over ten years. We interviewed eighteen physician leaders and executives particularly knowledgeable about the portal. Our analytical framework centered on two research questions. (1) How does the patient portal impact care delivery to produce the documented effects?; and (2) What are the important organizational factors that influence the patient portal's development?

**Results:** We identify five ways in which the patient portal may impact care delivery to produce reported effects. First, the portal's ability to ease access to services improves some patients' satisfaction as well as changes the way patients seek care. Second, the transparency and activation of information enable some patients to better manage their care. Third, care management may also be improved through augmented patient-physician interaction. This augmented interaction may also increase the 'stickiness' of some patients to their providers. Forth, a similar effect may be triggered by a closer connection between Kaiser Permanente and patients, which may reduce the likelihood that patients will switch health plans. Finally, the portal may induce efficiencies in physician workflow and administrative tasks, stimulating certain operational savings. Moreover, our analysis illuminated seven organizational factors of particular importance to the portal's development - and thereby ability to impact care delivery: alignment with financial incentives, synergy with existing IT infrastructure and operations, physician-led governance, inclusive decision making and knowledge sharing, regional flexibility to implementation, continuous innovation, and emphasis on patient-centered design.

**Conclusions:** These findings show how organizational dynamics enable the patient portal to affect care delivery by summoning organization-wide support for and use of a portal that meets patient needs.

## BACKGROUND

Patient portals are secure websites that give both ill and healthy individuals (together here referred to as patients) access to personalized health records and typically enable capabilities such as secure emailing with physicians, appointment scheduling, and educational programs.[1] Scholars suggest that patient portals can improve organizational performance, for example by decreasing the need for in-person visits (some of which may be substituted by secure emails), by letting patients manage more activities online (such as through online appointment scheduling and prescription refill), and by reducing the need for paper printouts and postage (enabled by online transmission of test results and care plans).[2, 3] Relatively few studies, however, have documented such effects of patient portals on organizational performance [4, 5] and studies that have examined effects on healthcare utilization show mixed results.[6]

Portals may also positively influence patient health by enabling and stimulating patients to manage and monitor their care [2], something that may be of particular value to patients with chronic diseases.[7] Numerous research studies have been conducted to assess the effects of patient portals on patient outcomes. Several studies have found use of patient portals to be correlated with better chronic disease management, expressed in terms of outcome indicators such as blood pressure and hemoglobin levels (see e.g. [8, 9, 10]). The effects are especially significant for patients with chronic diseases and when coupled to case management.[4] Also, several studies at least indicate that use of the portal may be positively associated with patient satisfaction (e.g. [11, 12]). Yet, the strength of these correlations varies across studies and some studies have not identified statistically significant associations between portal use and patient outcomes.[13]

Despite the potential of patient portals to improve patient health and organizational performance, the varied evidence testifies to the challenge it is to realize and measure this potential. The variety in patient populations, portal functionalities, and contexts in which patient portals are applied may explain some of the variation in results.[14, 15, 16] As the implementation of patient portals is a complex intervention, the dynamics and management of the implementing organizations is likely to play an important role as well. Yet, within the current evidence base, the organizational factors influencing the impact of patient portals on patient health and organizational performance have received little attention. Published studies that document patient portal effects rarely include descriptions of the organizational dynamics that enable these effects.[6]

This study explicitly aims to advance understanding of the organizational dynamics that influence the impact of patient portals on organizational performance and patient health. To this purpose, we conducted a qualitative study at Kaiser Permanente (KP). KP is a prepaid integrated delivery system operating on a global budget.[17] It consists of the Kaiser Foundation Health Plan & Hospitals and Medical Groups in each of the seven regions in which KP operates. The Medical Groups provide care to the 9.5 million members that are insured through the KP Health Plan.[18]

KP's patient portal, accessible through the website and through Apple and Android mobile applications, has evolved over the last 15 years. The portal is integrated with KP HealthConnect, a system-wide electronic health record (EHR) that was fully implemented across KP in 2010.[19] In its current form, the portal gives patients access to parts of their medical records, encyclopedias and self-management programs. Also, it facilitates interaction between patients and physicians via secure email and, in some regions, video consult. Further, the portal offers transactional components including appointment scheduling, prescription refill, and insurance management tools.[20] With 4.4 million registered members as of October 2013, sending 14 million secure emails to 15,000 physicians per year, the KP portal is the most widely used privately owned patient portal in the world.[21] Due to its long running time, extensive patient use, and documented effects, KP's portal makes an ideal case for our study. We now briefly summarize the reported effects of the portal on patient health and organizational performance.

Reported effects of KP's portal include better blood pressure control, scores on the Healthcare Effectiveness Data and Information Set (HEDIS) [22, 23, 24] and use of preventive services for children.[25] Moreover, it has been found to positively influence patient experiences; one study demonstrated that users of the portal were more than two and a half times more likely to stay members of KP, likely due to enhanced satisfaction.[26] In addition, KP is one of the few systems that have reported variations in channel utilization after introduction of a patient portal.[27, 28, 29, 30] Of these four studies, three found that the portal reduced utilization of telephone contacts, in-person doctor's visits and hospitalization, while one documented that the portal led to increased use of these channels. (It may be that some of this inconsistency can be explained by the difficulty of accounting for pent-up demand prior to portal use or the fact that patient portal use may be a predictor for healthcare needs.) Finally, researchers at KP examined how the portal may have lowered use of resources such as paper, postage, and gasoline, thus reducing environmental waste.[31]

## **Analytical framework**

As we have presented, the KP portal has been shown to be able to improve patient health and some measures of organizational performance. The contribution of this study is to advance our understanding of how these effects are realized.

We are not the first to have examined how and why KP performs the way it does. As part of a Commonwealth report series on integrated delivery systems, McCarthy et al. completed a comprehensive case study of KP.[18] The aim of the study was to learn how the organizational context specific to KP supported care delivery to enhance the quality of in-patient care and ambulatory care on a number of parameters. Specifically, the authors examined how KP scored on six organizational attributes believed to be of particular importance to achieving high-quality care delivery. These attributes included information continuity, care coordination, system accountability, peer review and teamwork, continuous innovation, and easy access to appropriate care. Further, the authors examined how these organizational attributes influenced care delivery at KP. As an example of care coordination, they found that the Northern California region used an extensive case management strategy for patients at risk of developing chronic diseases. By offering different combinations of primary and secondary care services to patients stratified by their level of risk, this strategy was successful in improving cholesterol screening, blood pressure control and appropriate receipt of medication while lowering mortality, smoking prevalence, and hospitalization rates for coronary heart disease and strokes. As an example of continuous innovation, KP has set up a Care Management Institute that brings together experts from all the regions to identify causes of variation and establish best practices for regional adoption. One result of the Institute's efforts was an osteoporosis program in the Southern California region that led to significant reductions in the rate of hip fractures and needed treatments. As illustrated through these examples, the authors uncovered how organizational attributes of KP facilitated a number of care delivery processes to improve patient health and organizational performance.

Using a similar conceptual approach, the aim of the study reported here is to understand in detail the impacts of the KP portal on patient care delivery and to learn how the organizational context specific to KP influenced the patient portal's development. Specifically, this study will assess how selected KP practitioners and executives who work closely with the portal believe that it impacts care delivery and how this led to improvements in patient health and organizational performance. By impacts on care delivery, we refer to how the portal alters care processes such as patients' access to healthcare services and the relationships among patients and physicians. Subsequently, we will distinguish and illuminate organizational factors

that have particularly influenced how the portal has been developed within the organization. We focus on organizational factors such as governance, leadership, vision, mission, core values and strategy, and organizational processes that have been shown to importantly influence organizational innovation and change in research or health care organizations.[32] Similar to McCarthy et al, we posit that these factors are of importance to the way a portal is being developed, and thus, its ability to produce effects. Based on these conceptual ideas, we used the following questions to frame our study: (1) How does the patient portal impact care delivery to produce the documented effects at KP? (2) What are the important organizational factors that influence the patient portal's development?

To improve portals' performance, better understanding how they assist care delivery and what organizational factors influence the degree to which they do this is important. This understanding is especially important to health managers and practitioners developing patient portals as well as to researchers evaluating their effects.

## METHODS

### **Data collection**

We conducted semi-structured interviews with key organizational members who have been involved in the development, implementation and evaluation of the KP portal. Specifically, we interviewed 18 leaders, including physician leaders in the Northern California Permanente Medical Group and senior directors at KP's National Program Office, between April and June 2014. Our respondents represented key divisions at KP working with the portal, including information technology, strategy, marketing, policy, and analytics, as well as physicians leaders such as medical directors. By asking respondents to refer us to colleagues they knew to be particularly knowledgeable about the portal, we used the snowball technique to identify our purposive sample of respondents.[33] Each respondent confirmed that he or she directly worked on the development or implementation of the KP portal or was otherwise knowledgeable about the portal. We continued this sampling process until we reached saturation; that is, until we concluded that little new information came out of the interviews and until no new candidate respondents were mentioned as imperative to our investigation.[34] Except for one senior director, all the persons we contacted agreed to participate in our study.

Based on formative research and discussion among the study team [6, 35], we developed an interview guide intended to elicit information relevant to answering our two research questions. Yet, to not let our questions direct or restrict the interviews, we took an

open and exploratory approach, including a broad range of topics in our interview guide. We adjusted the guide to each respondent; however for all respondents the questions explored the following topics: organizational motivation for the patient portal; development and implementation of the portal; organizational processes to develop, maintain and operate the portal; governance, decision-making and funding of the portal; use of the patient portal; and the effects of the portal on patient health and organizational performance. To ensure we did not miss relevant information, we concluded each interview by asking if the respondent could think of topics relevant to the portal beyond those covered in the interview. One member (TOT), and in four cases two members (TOT and TR) of the study team conducted the interviews. The interviews were done by phone and lasted between 45 and 60 minutes. With permission of the respondents, the interviews were recorded and transcribed. Respondents were promised anonymity and all identifiers in our reporting of the interviews have been removed. Copies of the standard interview guide may be obtained from the corresponding author. The research was approved by the Kaiser Permanente Institutional Review Board.

## **Data analysis**

Following principles of content analysis, we coded the interview transcripts according to our two primary research questions.[36] Thus, one category contained information about the portal's impact on care delivery; and one about the organizational factors that influence the development of the portal. Within each of these categories, we subsequently coded the data under headings and subheadings that emerged during the analysis, thereby identifying recurring themes.[37] One member of the study team (TOT) first coded the data. A second member of the study team (TR) reviewed each coded text phrase, reading the phrase in the original text and judged whether the code was applied correctly. This reliability check concluded a 95% agreement rate. Where there were variations in coding decisions, the codes were discussed until agreement was reached.[38] We performed a member check on our qualitative analysis and interpretation of the responses to our questions by sharing and discussing our findings with two of our respondents, thereby seeking to verify the content and the weight we placed on various topics.

## **RESULTS**

We report the results of our content analysis by addressing our two research questions. Below, we identify the themes that emerged from our analysis and use relevant quotes from the interviews to provide specific examples within each theme.

## **How does the patient portal impact care delivery to produce the documented effects at KP?**

We outlined in the introduction that previous research has found that KP's patient portal has improved clinical process measures and member retention and elicited some operational savings and changes in channel utilization. Our analysis of the interview data uncovered six ways our respondents believed that the patient portal affected care delivery to produce these outcomes. As we describe in more detail below, respondents reported that the portal generates the outcomes by affecting ease of access, transparency of information, patient-physician interaction, KP's connection with patients, and operational efficiency.

**Ease of access.** Our respondents emphasized the ability of the portal to ease patients' access to the system. For example, the transactional capabilities simplify the managing of care, since patients do not have to hold on the phone and can perform transactions at their convenience. Especially the convenience of asynchronous communication was emphasized in the interviews; patients can contact their physicians directly with questions when they arise, and outside of regular business hours. As one respondent said, *"I think that the portal does a lot in terms of access by giving patients more direct access to their physicians and reducing the time they have to take off work."* Our respondents assumed that this improved ease of access enhanced patient satisfaction, and by extension, patients' proclivity to remain a member of the delivery system. According to our respondents, for many patients, having new and more convenient ways to access their physicians can also impact channel utilization. Giving patients easy, direct access to their team of physicians via the portal may reduce the perceived need for in-person visits, as some inquiries and transactions can be handled via email. Yet, easy-to-use portal communications may also lower the threshold for seeking contact with physicians so that secure emailing is rather used in addition to these other channels.

**Transparency of information.** Prevalent among the respondents was the notion that by giving patients an overview of their medical records, care plans and lab results the portal educates patients about their health. This transparency of information to patients was thought to make them better able to participate in their care as informed partners. Also, up-to-date information, such as lab results, might activate patients to make positive strides to affect their health or serve as reminders to improve their health habits. Further, follow-up emails reinforce the message given in the physician's office, which can improve patient adherence and understanding. One respondent expressed: *"You're helping them get the information they need to improve their health. You're giving them greater access to information that can help them manage their chronic conditions for example."* According to our respondents, these are mechanisms by

which the portal improves quality scores (HEDIS), clinical process measures, and use of preventive services.

**Patient-physician interaction.** The portal permits physicians to send follow-up messages, reminders about screenings and tests, and other information to make their patients better informed. A respondent expressed that *“they [physicians] can for example see when someone is due for their cholesterol testing and they can send a note reminding the patient and placing an order in the system”*. This reinforcement of messages enabled by secure email may enhance some patients’ adherence to treatment, medications, and lifestyle changes, thereby aiding health promotion or disease prevention or management. One respondent explained that *“Its reinforcing a message, for example that ‘you need to take, stay or get back on this particular drug’. I think it gives an opportunity to engage patients in getting that message and maybe adhering a bit better to some of the protocols”*. Further, some respondents expressed that electronic communication can help physicians notice more issues than if they relied on face-to-face interaction or phone conversations alone. For example, patients can use the portal to reconcile their medication and thereby assist physicians in closing gaps in medication coverage. Through these pathways the portals may improve the quality of patient care. Moreover, several respondents noted that the continuity of contact facilitated by secure messaging improves the interaction between patients and their physicians and thereby *‘augments the connection between patients and their providers’*. Also, since patients and physicians have access to the same information, use of the patient portal can help streamline discussions and improve the quality of communication. This positive influence on the quality of the physician-patient relationship may, according to several respondents, improve patients’ attachment to their physicians, thereby increasing the probability that they will remain members of the health plan.

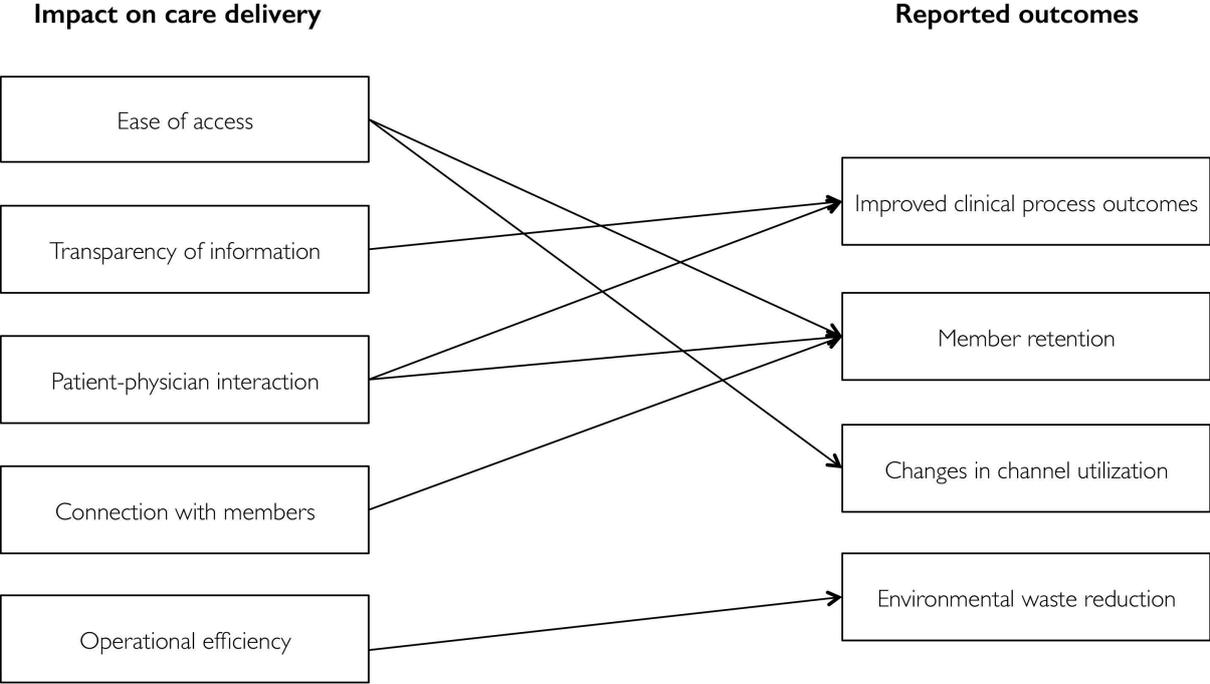
**Connection with patients.** Another way by which the portal can enhance member retention is by helping KP strengthen its connection with its patients. Several respondents explained how the portal enables personalization of services and extension of services into patients’ lives. In the future, this may be reinforced by expanded patient portal capabilities that will allow patients to, for example, upload data from wellness devices onto the patient portal. Moreover, the portal functions as an additional medium for KP to communicate with and engage their patients. One respondent said that *“Digital enables that constant stream of communication where the patients can pull and not just be the result of a push. It can drive engagement to a completely different level.”* More generally, the patient portal is believed to make a positive contribution to KP’s image.

**Operational efficiency.** Our respondents posited that the portal improves operations at KP's operation in several ways, including administration and physician workflow. Firstly, it allows for administrative efficiencies by reducing the need to call patients about test results, book appointments by phone, and to use paper and postage for communication with patients. As one respondent expressed: *"By creating your own appointments - as opposed to having to use up somebody's time on the phone or using up a receptionist's time to create an appointment - by doing self-service, patients can do it for themselves and do it more efficiently. We save paper, postage, because we don't have to mail out the lab results. They can be viewed online. There are enormous efficiencies that come to Kaiser because of the fact that we're online."* Furthermore, some respondents referred to an internal (and unpublished) study that found that patients who book their own appointments through the portal have a lower no-show rate and speculated that the increased number of people that use this feature might reduce this waste. Moreover, the clarity and quality of the information that is inserted in the EHR (at least the portion that is transferred to the portal) tends to be clearer and more accurate since it has to be reported in a way that is understandable to patients. This may reduce inefficiencies stemming from errors or misinterpretation among healthcare professionals as well as between patients and their physicians. Secondly, the portal, and especially the secure emailing functionality, redefines physician workflow. The introduction of secure emailing clearly increased the volume of patient emails that physicians must respond to. However, the general expectation among our respondents was that this extra volume can be balanced by better-managed patient panels, thus reducing the overall patient demand for in-person visits and telephone calls. A respondent explained that: *"The hope is that they'll [physicians] have more accountability for their panel. So the incentive would be that if they are able to better manage their panel through the portal, then maybe they can have more time during the day for email, because fewer patients need to come in, rather than just having the call center loading them up with more and more appointments."* This, in turn *"really frees up the providers' and physicians' time to focus on more of the complex things"*. Further, physicians are able to respond to messages in an asynchronous fashion at their convenience and can avoid of 'playing phone tag' with patients. Our respondents believe that the efficiencies described above result in cost savings, including reduced environmental waste, also reported by Turley et al [31].

Figure 1 summarizes the proposed associations between the portal's impacts on care delivery and documented effects. It should be noted that the arrows signify the associations that most often surfaced from the interview data, and do not mean to imply that other associations

between care delivery impacts and patient portal effects do not exist. Also, our research approach does not support claims about how these associations may play out across different patient sub-populations, such as age or health status groups.

**Figure 1:** Associations between KP's patient portal's impacts on care delivery and reported effects



The purpose of this study was to understand how the KP portal has been able to produce impact upon operational performance and patient health. In establishing these associations, we have focused on the positive impacts of the portal on care delivery outlined in the introduction. Nevertheless, other implications of the portal on the care delivered to patients also surfaced in the interviews. These include risks that patient cannot cope with information online, depersonalization of care, and increased provider workload. It should be noted that these are examples rather than a comprehensive analysis of the negative impacts of the portal.

First, a few respondents described that for some patients, the increased transparency of information can cause anxiety, especially if they have to wait for a response from their physicians to interpret or cope with the information. *“The question is whether the transparency could cause anxiety to the patients. Seeing all that information, does that make patients more informed and active partners in their care, or does it make them feel more worried about a slight and insignificant abnormality?”* Second, another respondent pointed out that some patients are concerned that technology will create a distance from their doctor, since it may replace some one-on-one

interactions. *“There’s a risk that some members could feel distanced from their doctors if they never get to see them. If they feel that too much is being managed electronically or remotely. So we have to be careful about maintaining those relationships.”* Thirdly, some respondents presented accounts that the introduction of secure email has led to a higher workload for some physicians due to the sheer volume of emails that came after the feature became available, and, as one respondent mentioned, some physicians have *“struggled with it and certainly with the feature that we provide where you can e-mail your doctor”*. These struggles may be associated with altered expectations about timeliness of response and the challenge for physicians of finding available time in their day to process the messages.

### **What are the important organizational factors that influence the patient portal’s development?**

Our analysis of the interview data coded under this question exposed seven factors that respondents claimed particularly influence patient portal. These factors include: (1) alignment with financial incentives, (2) synergy with technical and operational infrastructure, (3) physician-led governance, (4) inclusive decision making and knowledge exchange, (5) regional flexibility, (6) continuous innovation, and (7) patient-centered design. These factors are not mutually exclusive.

***Alignment with financial incentives.*** Many respondents pointed out that KP’s capitated reimbursement model has allowed for investments in consumer technology that lead to better patient care and substitution towards use of virtual services. As one respondent explained, *“The capitated model is part of why we were able to be so focused on it [the portal] in the first place. It is the right way to do things, it a cost-effective way to do things, and it provides quality and convenience to our members.”* Furthermore, one respondent pointed out that, in contrast to fee-for-service models, *“Kaiser doesn’t have to pay doctors on an e-mail-by-email basis. Kaiser is incenting the physician to take care of a panel of patients.”* Hence, physicians are believed to be more easily motivated to use the portal to better manage their patient panels and to be unaffected by how emailing is compensated relative to in-person visits.

***Synergy with IT infrastructure and operations.*** The majority of respondents touched upon how the functionality of the patient portal is closely related to the technical and operational infrastructure it ties into. In terms of the technical infrastructure, since it is tethered to an organization-wide EHR, recorded data is constantly and automatically fed to the portal, giving patients up-to-date information from all their providers. In terms of the operational infrastructure, the patient portal creates synergies with existing case management efforts within

KP by supporting better coordination and connecting the patients closer to their care teams. Ensuring such positive interactions between the patient portal and existing operational infrastructures is central. A respondent, who has been closely involved with KP's information system development, noted that even previous to the portal's inception there was a lot of groundwork done to *"better understand the synergies between what Kaiser was trying to accomplish and the emerging capabilities of technology."*

**Physician-led governance.** Many respondents made the point that the portal has been developed and made possible through strong physician leadership. As one respondent said: *"We've had some very bold, and brave, physician leaders who once [...] understanding that the industry was changing and needed to change, said, "this is part of what the medical group will now offer. This is part of how we will offer care."* The CEOs of the KP Health Plan & Hospitals and the Medical Directors agreed that the Medical Groups should be in charge of setting the direction for KP's consumer technology. According to several respondents, this entails both setting the strategic direction for the patient portal, and, on a more practical level, prioritizing the development of clinical features. This governance process takes place within the 'Health Strategy & Governance Group', within which voting members are representatives from each self-governing regional Medical Group. Our respondents explained that, informed by several expert advisory groups, this governance group serves as a 'clearinghouse' for the regions by incorporating regional operational and clinical needs into the priorities that are set for the work done on the portal each year.

**Inclusive decision-making and knowledge sharing.** Although the respondents generally believed that there is alignment of priorities at a high level, some noted that organizational units set priorities through the lens of varying organizational imperatives. As was explained by some respondents, staff in care delivery, for example, tend to be focused on clinical tools and may not see the same value in making financial functions available to patients compared to more administrative staff: One respondent said: *"I think that there are people in care delivery who are not much interested in using kp.org as a marketing tool and device, because they want to focus on care delivery."* Several respondents expressed that this leads to some tension over specific priorities for a year. Hence, an important aspect for KP is to share knowledge among and obtain buy-in concerning the portal from various organizational members. To this end, KP makes use of experience design workshops, decision-making meetings, and a general effort to share best practices, for example via governance and research groups committed to the portal. Furthermore, collaborative decision-making where various groups come together, openly present their interests, and make decisions that benefit the overall strategy is a decision-making

process that is widely used within KP to achieve directional alignment around core goals. This was elaborated by one respondent: *“It enables us to take the input from member experience and panel input in terms of what members want, the regional operations view of what regional operations want, the physician view of what physicians want, the nursing view of what nurses want, etc. It enables us to put all those different interests and objectives into the hopper and to try to solve for all of them together without bargaining or voting on each part individually.”* This, and many other included quotes – with their reference to ‘engaging’, ‘we’, and act ‘without bargaining or voting’ – can even be considered to convey shared values among organizational members, which go beyond inclusive decision-making.

**Regional flexibility.** A recurrent theme in the interviews was that the seven KP regions have different local priorities, resources, operating procedures, and even regulatory environments. Also, although KP has one EHR, most regions still use some legacy systems that were in place before the EHR was adopted. Therefore, some respondents explained how the national portal leadership work with each region to identify their needs and incorporate these into the design, implementation and rollout in each region. Acknowledging that implementing a new capability has differing implications for operations across the regions, the portal leadership uses a centralized and decentralized implementation approach. Each new patient portal capability is made available to all regions, but depending on the individual region’s priorities and operational workflow issues, they may decide whether and how to ‘turn it on’. A respondent described this process: *“Everything that is on the portal is available to all regions if their regional operating procedures, or even their regulatory environment will allow them to have it. So, yes, everything is available, but there are regional differences and that’s just part of the nature of the beast, just because of where they operate in the US.”*

**Continuous innovation.** Several respondents commented that KP was an early EHR and patient portal adopter and has used the portal as a market differentiator. However, since many EHR and patient portal features have now become standard across health systems, KP recognizes the need to differentiate itself by further innovating on consumer technology. One respondent explained that: *“What we’re trying to in terms of the marketplace, so more on the business side and for our customers, is to be able to keep offering rich and new experiences that we can market to those folks and set ourselves up as a differentiator in the marketplace. It has to be useful, helpful, and really great for the current membership. It also has to appeal to attracting, new customers”*. For example, KP is looking to companies in other industries, such as Apple and Amazon, to learn how those organizations manage their online presence and consumer experiences. In fact, continuous innovation is built into the development strategy for the patient

portal; each year the group dedicated to developing the portal, in consultation with its IT counterpart, goes through a process of generating ideas and writing business cases for how to develop the portal in support of the overall strategy. As a result of this process, each year a number of projects are prioritized and receive funding.

**Patient-centered design.** KP uses a patient-centered approach focused on simplifying and enriching the patient experience. According to one respondent *“What I view as going to be key in driving engagement is a personalized, actionable, insightful experience. Even if you have all that data and features, but [...] it doesn't match how consumers want to be able to access it [...] it's not going to drive that experience. We really need to think about how do we create that personalized experience and make it truly actionable”*. For instance, KP is currently focusing innovation on responsive design; building capabilities for all platforms (web, smartphones and tablets) to make the development of the patient portal more streamlined within KP and the user experience more consistent. Especially the respondents involved in designing the portal explained how each new capability goes through extensive usability testing. Also, there is much communication between the developers and member services and advice call centers to ensure a constant cycle of validation of existing features. Moreover, KP actively promotes the portal to its patients and seeks to improve access. Upon registration, each new member is encouraged to sign up and KP monitors use and does outreach to non-users. Further, there are free classes to teach patients how to register and use the patient portal. To include more of its non-English speaking patient base, KP recently launched the portal in Spanish.

Again, we note that in line with our study aim, we have focused on enabling factors in our reporting of the key organizational factors that influence the portal. Nevertheless, some organizational factors that may negatively affect the portal also emerged in the interviews. For example, in general, most respondents acknowledged that the size and complexity of KP, including the multi-state operations, pose challenges to any implementation project. For example, each region is exposed to different regulatory environments. Moreover, the organizational complexity either results in, or is a result of, frequent reorganizations with subsequent changes in the roles and responsibilities of divisions, groups, and people. Some respondents noted that these organizational changes complicate the establishment of working relationships, communication channels, and routines. Nevertheless, it was our perception that our respondents were so used to working under these conditions that they saw these issues as natural consequences of doing work within KP rather than as a barrier specific to the patient portal itself.

## DISCUSSION

### **Summary of findings**

Through interviews with key organizational members, we have described how they perceive KP's patient portal to be affecting care delivery to produce effects, and further, the organizational factors that have influenced the portal's development. Below we combine the results of the research questions to understand how the organization influences the portal's ability to impact care delivery and generate associated effects.

KP has come to believe that investing in the portal would align with its operational goals, such as improved quality and access that lead to retention of better-managed patients with associated cost savings in the long term. Further, the capitated reimbursement of physicians, at least in theory, provides incentives to physician to use the portal to manage their patient panels. The patient portal's linkage to existing IT infrastructure, particularly the comprehensive EHR, powers its functionality and connectivity since patients automatically access to information deriving from all their providers on one patient portal. Furthermore, the use of the patient portal to support existing operations such as care coordination and case management may make its practical contribution to care delivery visible to physicians and other professionals working at the frontline of care. Alignment with organizational and physician incentives, and impacts on care delivery has allowed for large investments in and support of the use of the portal. Both aspects have been vital to developing and deploying a high functional and comprehensive portal, a prerequisite for enabling its impact on care delivery.

The governance process that included 'physician-led governance', 'inclusive decision-making and knowledge sharing', and 'regional flexibility' may have fostered a notion throughout KP that use of the patient portal is consistent with organizational and professional values. The governance process may not only ensure that the portal meets clinical and operational needs, but may also help secure physician buy-in. The inclusive decision-making process that invites the opinion of various organizational members, along with efforts to share knowledge, may facilitate a common understanding about the contributions of the portal to care delivery, such as bringing a better experience to the patient. To the extent that feedback from organizational members with varying interests is taking into account, the functions of the patient portal may better match the needs of these members. Further, the implementation strategy that enables each region to adopt patient portal features in a manner supportive of their priorities and operational realities has likely upheld the belief that the portal is in line with clinical and operational needs pertinent to the individual regions. We posit that the notion that the portal is consistent with organizational and professional values ensures that it is widely used and promoted by physicians

and other staff across the organization. This participation is necessary to stimulate impacts on care delivery processes that rely on an active role of physicians to stimulate workflow and workload changes and to improve their interaction with patients and thereby the quality of care delivered.

Finally, organizational factors concerning the portal's development and design - 'continuous innovation' and 'patient-centered design' - may result in a patient portal that meets patient needs and wishes. The aim of the continuous efforts to improve the capabilities of the portal is to match the potential of IT seen in other industries and to expand its meaningfulness to patients. The patient-centered approach to designing capabilities strives to improve patients' experience of navigating the health system and managing their care. Through this constant improvement of capabilities combined with proactive outreach to non-users, KP hopes to make the portal play a progressively enlarged role in its service provision. Extensive patient use is prerequisite to stimulate the impacts on the care delivery, not just those centered on the patient, but also the ability of physicians to realize workflow and workload changes and for the organization to improve business operations as well as create a stronger connection with patients.

In sum, the dynamics between the organizational factors and the patient portal may trigger improvements in patient health and organizational performance at KP by enabling the embedding of comprehensive and high-functional patient portal services into care delivery throughout the organization.

### **Transferability of findings**

Being a large integrated delivery system, KP is uniquely different from other types of organizational settings such as individual hospitals and physician practices or networks of independent practices. In fact, the integrated setup is widely considered to be supportive of quality improvement and performance on a range of quality and efficiency measures.[39, 40, 41] This may also explain why the majority of research studies on patient portals have been conducted in integrated delivery systems.[4, 6] Thus, it may appear that the integrated care delivery context is particularly well conditioned to realize value of patient portals.

The alignment between the portal and KP's revenue model enables value realization.[42] The alignment has permitted KP to invest in the patient portal on the premise that it increases quality at a reasonable cost.[43] Yet, this may be different for other organizations, especially those operating with fee-for-service payment models.[17] For such organizations, revenues are proportional to patient visits or treatments (at least under models, which do not or only partly

reimburse e-visits.). Thus, offering a patient portal that may substitute for in-person visits and contribute to fewer patient health needs, contradicts this incentive structure.[44]. Also, the high connectivity made possible through the portal's linkage with a comprehensive EHR that covers all 9.5 million KP members and their providers amplifies its functionality, since it gives patients a 'one stop shop' and supports care coordination.[45] Achieving a similar connectivity for patient portals provided by independent practices will depend on integrating information from (typically) distinct information systems.[46] This requires not only technical, but also semantic interoperability to enable the meaningful use of information across practices.[47] Similarly, for each of the organizational factors we have identified, their (direct) transferability from KP to other organizations is unclear.

Nevertheless, even though information about KP's patient portal may not be directly transferable to other types of organizations, the detailed information we provide allows practitioners and managers in any type of organization to distill and translate learning that could apply to their organizations. With this study of one particular portal in one particular system context, we have only started to develop the knowledge base on organizational dynamics influencing patients portals. We welcome research that further explores the impact of patient portals, and especially in more fragmented care delivery settings. Considering the increasing development of patient portals that is currently taking place in various organizational settings [2], research into what works, what does not work, and why, is relevant and timely.

### **Study limitations**

We interviewed only a fixed number of informants. While they largely represented the organizational groups responsible for the portal, they did not represent all of the leadership involved in the patient portal. Moreover, there is a risk that our respondents, due to loyalty to their organization and colleagues, have limited their responses to convey only positive aspects of KP and the patient portal. However, it is our impression that our respondents presented a balanced story, and appreciated the opportunity to reflect on aspects that work well and less well. It is also our sense that the promised anonymity created a comfortable forum for the respondents to share their knowledge with us.

It would have been interesting to complement the perspectives of the organizational members with those of patients. Of particular interest would be an exploration of how and why different patient populations reap benefits from care delivery assisted by a portal, thereby contributing to explaining the variance in effects across these populations. Nevertheless, the aim

of this particular research was to describe the workings of a patient portal from the viewpoint of the organization that provides it.

## CONCLUSIONS

Using semi-structured interviews, we answered two research questions: (1) How does the patient portal impact care delivery to produce the documented effects at KP? and (2) What are the important organizational factors that influence the patient portal's development, and thus, its impact on care delivery? To answer the first question, we identified ways our respondents believed that the portal impacts care delivery to produce reported effects including enhanced disease management, health plan retention, changes in channel utilization, and lower environmental waste. We proposed that the portal's ability to ease access to services improves some patients' satisfaction, and thus health plan retention as well as stimulates changes in the way patients use channels to seek care. Further, the transparency and activation of information makes some patients better able to manage their care. Care management may also be improved through enhanced patient-physician interaction. Improved relationships between patients and providers made possible through enhanced interaction may also increase the 'stickiness' of some patients to their providers, reducing the likelihood that they will switch health plans. A similar effect may be triggered by the portal's ability to improve the connection between KP and its patients. Finally, the portal may induce efficiencies in physician workflow and administrative tasks, leading to operational savings such as reduced environmental waste.

In answering our second research question, our analysis surfaced seven organizational factors of particular influence on the patient portal's development. These factors comprise of the portal's alignment with financial incentives, synergy with existing IT infrastructure and operations, physician-led governance, inclusive decision making and knowledge sharing, regional flexibility to implementation, continuous innovation, and finally, KP's emphasis on patient-centered design. These findings provide insights into how the organization enables the patient portal to affect care delivery by summoning organization-wide support for and use of a portal that meets patient needs. Yet, since these findings originate from a unique integrated delivery system, direct transferability of these findings to other types of care delivery systems may be limited.

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# CHAPTER 4

## *Developing patient portals in a fragmented healthcare system*

This chapter was accepted for publication by the International Journal of Medical Informatics as:

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## ABSTRACT

**Background:** Use of patient portals may contribute to improved patient health and experiences and better organizational performance. In the Netherlands, patient portals have gained considerable attention in recent years, as evidenced by various policy initiatives and practical efforts directed at developing portals. Due to the fragmented setup of the Dutch healthcare system patient portals that give patients access to information and services from across their providers are developed in inter-organizational collaboration.

**Objective:** The objective of this paper is to identify and describe the types of collaborations, or networks, that have been established to develop patient portals in the Netherlands. Understanding the characteristics of these networks as well as the development of their respective portals enables us to assess the enabling and constraining effects of different network types on patient portal initiatives.

**Methods:** We used qualitative methods including interview and documents analysis. In a first step, we interviewed eighteen experts and reviewed relevant national policy and strategy documents. Based on this orientation, we selected three networks we deemed to be representative of inter-organizational efforts to develop Dutch patient portals in 2012. In a second step, we interviewed twelve representatives of these patient portal networks and collected documents related to the portals. We applied content analytic techniques to analyze data from the three cases.

**Results:** The three studied networks differed in their number and diversity of actors, the degree to which these actors were mutually dependent, the degree to which network governance was decentralized, and the dynamics of the network structures. We observed that the portals developed in networks displaying the highest degree of these characteristics experienced most difficulties associated with developing patient portals - such as achieving interoperability, successful implementation, regulatory compliance and financial sustainability. Yet, at the same time, the portals developed in these networks may hold the highest functionality to patients, since they can consolidate information and services from a broad array of health service providers.

**Conclusions:** The early empirical evidence provided here indicates that effective development of patient portals begs a tradeoff between envisioned functionality and ease of development.

## INTRODUCTION

Patient portals are secure websites that give patients access to personal health information and often include functionalities such as secure emailing with providers, online appointment scheduling, and various self-management programs.[1]. Patient portals have been found to produce desirable outcomes including better chronic disease management, patient satisfaction and empowerment, and better patient-provider interaction.[2] Their effects on service operations are less clear. Some evidence suggests that they may induce operational savings and may substitute for some in-person visits and telephone calls.[3] Most of these outcomes have been reported in integrated care delivery systems.[4]

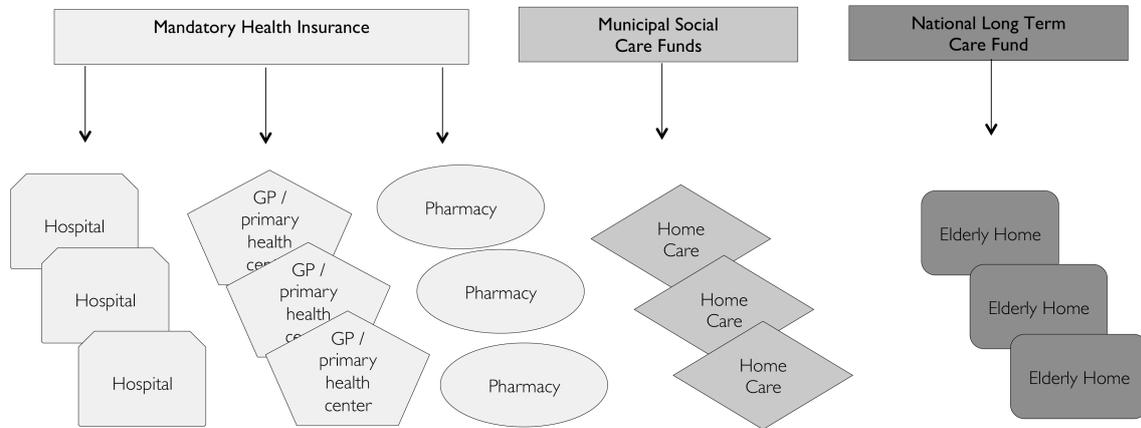
Due to these documented benefits, there is interest in many countries, including the Netherlands, to develop patient portals.[5] In 2014, the Dutch Council for Public Health issued a report outlining the promise of patient-centered health information exchange to mitigate inefficiencies in the Dutch healthcare system caused by information discontinuity.[6] The Minister of Health followed up by emphasizing patient-centered eHealth on the political agenda.[7] Notably, the minister announced three goals: in 2019, 1) 80% of patients with chronic conditions should have electronic access to their medical information; 2) 75% of patients with chronic conditions and elderly should be able to conduct health measurements from home; and 3) everyone who receives care at home should have access to screen-to-screen communication with a care provider, 24 hours per day. Realizing these goals entails establishing patient portals or other eHealth technologies that give patients access to their personal information and tools to manage their care. This agenda is not new, but is following up on several other documents sketching the need for patient-centered eHealth.[8-13] With this paper, we provide insights into patient portal development that can assist the realization of eHealth-related policy objectives in the Netherlands and comparable contexts.

### **Patient portals in the fragmented Dutch healthcare system**

As is the case in many Western countries, health service delivery in the Netherlands has developed in ways that have tended to fragment care and patient information.[14]. Historically, health services have been sharply divided in primary and secondary care. There are also specialized institutions for mentally and physically disabled, for elderly, for home care, for rehabilitation, et cetera.[15] This fragmentation is enforced through compartmentalized reimbursement arrangements: while for instance most hospital services and primary care services are reimbursed on the basis of contracts among insurers, providers and patients under a regulated market setup with mandatory insurance, other services are reimbursed through

national or municipal budgets, each with their own regulations and health service focus.[16-17]

**Figure 1:** Fragmentation and compartmentalization of healthcare in the Netherlands



Due to this fragmented nature of the Dutch healthcare system, developing portals that offer the aspired functionality requires collaboration among independent organizations. When a patient visits multiple provider practices, each of these practices independently records patient information. If each of these providers sets up a portal, the patient could view the information held by each provider in the separate portals, and make use of other portal capabilities such as secure emailing and online appointment scheduling. However, under such a fragmented setup, in order to see all of his or her information and interact with all of his or her providers, the patient must access multiple portals, each with a distinct interface, password, and username.[18] Especially for patients with complex conditions who see multiple providers, this multiplicity of portals and access requirements may complicate their navigation of the system and limit their ability to manage their care.[19] In contrast, patient portals that consolidate input from multiple provider practices give the patient one platform to access their information and interact with all provider practices. This greater functionality that stems from greater connectivity is likely to benefit the effect the portal has on the service provided, as patient portal use (ideally) becomes embedded into the entire care delivery chain.[18] Hence, in fragmented contexts, inter-organizational collaboration around patient data can be used to overcome fragmentation. Such inter-organizational collaboration can be assisted by the existence of a National Health Information Exchange (the National Switch Point), which enables data exchange among health care organizations.[20]

Such collaboration can be between primary care and specialist practices, hospitals, pharmacies, rehabilitation centers, and more. Also, the development of patient portals relies on involvement from information system vendors, insurers, government, and other interest organizations such as regional privacy committees. In this paper we refer to each of these organizations as actors and to the multi-actor collaborations that arise to develop shared patient portals as patient portal networks.

We consider whether this reliance on multi-actor collaboration inhibits the development of integrated patient portals. By patient portal development, we mean establishing relationships and creating capabilities important to the organization's success such as implementing required hardware and software, establishing portal content and capabilities, achieving physician commitment, patient engagement, institutional legitimacy, interoperability across providers, regulatory compliance, and financial sustainability.[21] Establishing such relationships and capabilities in a multi-actor collaboration is particularly challenging. This could explain why integrated patient portals are sparse in the Netherlands [5], at least relative to the country's remarkably high penetration of organizational health ICT.[22] This state of affairs calls for enhanced understanding of patient portal networks in relation to patient portal development. Various authors (see for instance De Bruijn en Ten Heuvelhof [23] and the references therein) suggest that multi-actor networks are characterized by variety, mutual dependencies, decentralized governance, and dynamic structure. For patient portal networks, variety may for instance regard the variety in actors, such as primary care practices, pharmacies, hospitals, physiotherapists, portal service providers, software vendors, et cetera. The actors involved depend on each other for information, resources and the performance of certain activities to bring about integrated functionality.[24-25] Portal development in the fragmented context may then turn out to be a dynamic process requiring negotiations among a variety of actors and other forms of decentralized governance. Moreover, as the network develops, new actors may join while others may leave, and dependence relations may shift. The consequence is a dynamic network structure.[26] Due to these characteristics, activities performed in multi-actor networks tend to be shaped by negotiations among a variety of actors who are constantly facing changing situations and seeking to influence the development accordingly.[27] Consequently, patient portal development via a network approach becomes an intricate social process, relying on negotiation to find common ground among organizational actors.[28] However, not all portal networks will be developed and evolve in identical ways. Local resources, historical organizational ties and other factors will influence a specific portal network's characteristics – the network's variety of actors, mutual dependencies, extent of decentralized governance, and a

dynamic structure. The extent to which these characteristics are present in a network may influence the development of a patient portal.

Despite these theoretical insights, there has been very little empirical validation of how patient portal networks have brought about integrated patient portals to strengthen service delivery. Hence, we set out to study patient portals in the Netherlands, where a variety of patient portals networks have emerged over the past decade. Our aim was to understand how different types of multi-actor networks relate to the patient portal development by investigating how various types of networks have fared in the fragmented Dutch context.

## **Research questions**

We propose the following research questions:

- (1) What types of patient portal networks have emerged in the Netherlands?
- (2) What developmental issues do various types of patient portal networks experience?
- (3) How does patient portal network type affect developmental issues experienced by the patient portal networks?

Approaching the topic from a network perspective may help us explain why some portals fail and others succeed, making it clearer where policy-makers can intervene and providing examples for other patient portal initiatives. This learning is important to advance policy and practice concerning patient portal development, not only in the Netherlands, but also in other fragmented healthcare systems. To our knowledge, this is the first study to have sought to explicitly advance such learning in fragmented healthcare systems. With our focus on networks, our study contributes to the evidence base and theoretical understanding of the increased role of private and third party actors in the provision of public services, as captured in the New Public Governance paradigm.[29-30]

## **MATERIAL AND METHODS**

To answer our research questions, we studied patient portals that were developed by different types of networks in the fragmented Dutch healthcare system, and studied the development of the respective portals. We used a two-pronged approach consisting of an orientation and a case study phase. In both phases, we relied on qualitative data including interviews and documents.

## **Orientation**

We initiated our study in 2012 through interviews with experts and stakeholders who were involved in national and regional developments around eHealth and patient portals. In total we interviewed seventeen people representing major institutes in Netherlands, including the National Patient and Consumer Federation (NPCF), the National Institute for Health Information Communication Technology (Nictiz), and the National Standardization Institute (NEN) as well as directors of Regional Health Information Exchange entities and large eHealth vendors. The interviews were semi-structured and we encouraged our respondents to explain facets of the development of patient portals from their perspectives. We complemented the interviews with reviews of relevant policy documents on eHealth in the Netherlands: using the snowball method, we used the references in notable documents from the National Patient and Consumer Federation, Nictiz and the Institutes behind the National eHealth Agenda (referenced in the Introduction) to identify other important documents on the topic. Also, we conducted searches on websites of Regional Health Information Organizations, insurers, professional associations, Nictiz, as well as on websites specific to eHealth such as NVEH (the Dutch Association for eHealth) and eHealthnu.nl.

In addition to providing us with a thorough impression of the situation around patient portals in the Netherlands in 2012, this orientation gave us an overview of the variety of patient portal networks developing patient portals. Of these, we selected three types of networks for in-depth case study (henceforth referred to as cases) in order to reveal the kinds of developmental issues Dutch patient portal networks face. To select the three cases, we used a purposive sampling technique [31] aimed at selecting the three patient portal network types that we expected to differ most significantly from one another with respect to their degree of variety, mutual dependence, decentralized governance, dynamic structure, and geographic location. Geographically, the cases were distributed across three of the twelve provinces of the Netherlands.

## **Case studies**

Together the three case studies involved semi-structured interviews with twelve people involved in the development of the studied patient portals. The interviews were conducted between April 2012 and November 2012. We interviewed Regional Health Information Organization directors, program-, product-, and/or implementation managers, project leaders, and Chief Medical Information Officers (or their equivalent) of participating health service organizations. We initially contacted the official manager of each portal. By asking these

managers to refer us to colleagues they knew to be particularly knowledgeable about their respective patient portal developments we used the snowball technique to identify our respondents.[32] As a consequence, we did not interview patients since none of the patient portals appeared to involve patients in the development process. To avoid “leading the respondent,” the interviewees were not asked directly about specific portal development issues. Rather, we asked for detailed information about the networks that were established to create the portals, and about the process of developing and implementing the portals. We used a standard topic list for all interviews, with additional specific questions depending on the nature of the work performed by the informant. The standard topic list may be obtained from the corresponding author upon request. The interviews lasted between 40 and 60 minutes. With permission of the participants, the interviews were recorded and transcribed. We also collected relevant documents at each case study site including subsidy applications, project plans, innovation and implementation plans, annual reports, and various research and evaluation documents.

We used content analytic techniques [33] to categorize the case study interview data and the content in the documents into major themes useful to answer our three research questions. One theme concerned characteristics of the networks. Another major theme concerned the development of the portals and the difficulties and corresponding strategies used in each of the networks. We used the answers to the first two research questions to respond to the third question, which joins information about network characteristics and development issues. We did not identify sets of development issues a priori, but, rather, identified the thematic categories as they emerged from the data analysis. Within each of the themes, we ordered data into more specific recurring sub-themes. To validate and refine our analysis, we held a focus group in June 2013, attended by three case study respondents from two of the case study sites. We did not ask specific questions; rather we sought a dialogue with the respondents based on a presentation of initial points and ideas that had surfaced from our analysis. Subsequently, we sent a synthesis of our analysis to each of the case study sites with a request to provide comments. All sites provided final comments on this document. The purpose of these member-checking activities was to discuss and seek feedback on the main themes we identified in our analysis as a final validation of the conclusions. Upon completion of a draft of this manuscript, we did another member check by sending representatives from the case study sites a copy of the draft for verification of the information and analyses presented.

## RESULTS

In this section we report our findings by responding to our three research questions. Thus, we begin with a description of the types of networks we selected. Next, we describe the major issues of the patient portal development process experienced by each of these networks. We then consider how the characteristics of the portal networks impact these development processes. This logic and the main findings are also compactly synthesized in the table presented in the Appendix, which may therefore serve as a reference to the reader.

### **What types of patient portal networks have emerged in the Netherlands?**

As we explained earlier, we considered the various patient portal networks that emerged in the Netherlands and then selected three networks representative of the different types we identified: we label these the 'homogenous', the 'open' and the 'interdependent' networks.

**The homogenous network.** This network was composed of primary care practices, pharmacies, home care providers, rehabilitation centers, physical- and occupational therapy clinics that function under a Care Corporation (Zorggroep [34]) within a municipality. The Care Corporation cares for 80% (170.000) of the citizens in the municipality. The network wanted to introduce a portal into the primary care physicians that were part of the Care Corporation. It is due to this homogenous population of implementation sites and actors that we denote this the 'homogenous network'. By introducing the portal, the Care Corporation hoped to achieve operational efficiencies enabled by administrative relief, mainly due to less phone calls. In turn, the convenience this gave to some patients was believed to enhance the quality of the service offerings.

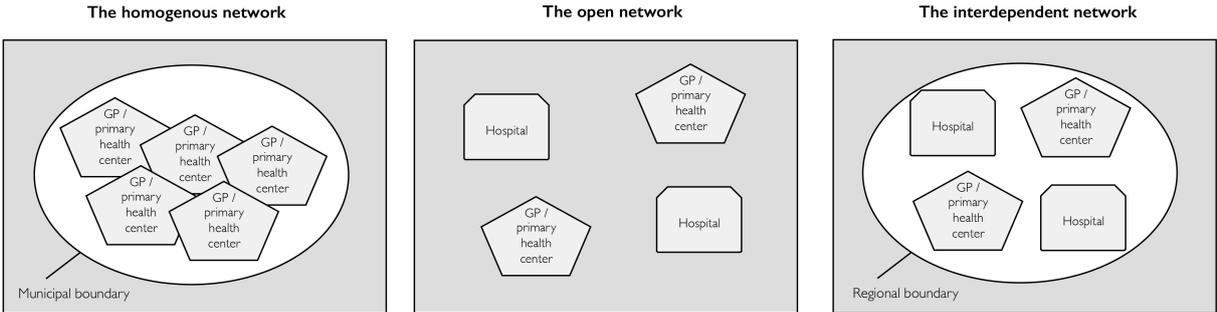
**The open network.** This network was spun around a project management team, which initially was made up of consultants and later on (from 2012) was taken over by designated project staff. In addition to this team, the network consisted of health service providers, eHealth vendors and researchers. The network came together in 2008 to develop a subsidy application, which was successful in procuring grants from the Ministry of Economic Affairs, and the municipality and the province in which the network was based. In addition to these grants, funding came from a regional teaching hospital. The subsidy period lasted from 2009-2012. In contrast to the homogenous network, the purpose of the open network was to develop a commercial portal product that could be scaled up to any primary and secondary care provider in The Netherlands that would wish to connect. Due to this dynamic structure, we refer to this network as the 'open network'. The portal product was envisioned as an integrated web-based

platform that would host an array of independent eHealth applications. An additional network goal was to establish a Center of Excellence for eHealth.

**The interdependent network.** This network comprised of primary and secondary health care organizations (among which a large teaching hospital), public sector entities, eHealth vendors, other for profit entities, researchers, and a regional health information organization (RHIO) within one region. The network came together in a consortium in which the RHIO acted as secretary. The Ministry of Economic Affairs and the municipality granted a subsidy request from the consortium to develop a regional health portal; the network participants also invested in this project, primarily through the allocation of staff and material resources. The subsidy period ran from 2009-2012; the aim was to create an economically sustainable and self-sufficient portal for health care and wellbeing. At the inception, the network included only a handful of health service organizations; however, the network sought to expand itself through a phased development strategy involving participation of more regional health service organizations. The network lacked central governance, which placed emphasis on the mutual interdependencies. The contribution of each participating organization was necessary to develop and sustain the patient portal and the network, which we name the ‘interdependent network’.

We illustrate these three network types in figure 2.

**Figure 2:** Network types



The items included in the figures represent the organizations that partake in the portals. Thus, they do not include organizations that do not partake

These networks differ in their degree of variety, mutual dependence, decentralized governance, and dynamic structures. First, the homogenous network entails the lowest degree of variety, since the portal was only implemented in primary care practices belonging to one Care Corporation. Although primary care physicians were not the only caregivers united under this Care Corporation, these were the only ones coupled to the portal in 2012-2013. Second, the primary care physicians were reliant on the Care Corporation for resources and governance

and therefore shared few mutual dependencies. Third, due to the strategic and financial reliance on the Care Corporation, the primary care practices were receptive to the influence of the Care Corporation including what portal system to implement and how to implement it. Fourth, and finally, the structure of the network was stable: no primary care practices could reject participation in the portal without also leaving the Care Corporation. In comparison, the interdependent network contained a broad inclusion of actors as well as a more intricate network of interdependencies with existing (and sometimes competing) infrastructures. This variety meant that various organizations with different demands, needs, and work processes influenced development and implementation. The actors were highly mutually dependent, since not one organization could develop a portal on its own: the development depended on the commitment from all regional stakeholders. Further, due to the distributed governance with not one organization taking the lead, decisions relied on multi-party decision-making. The expansion strategy focused on regional upscaling meant ever-changing levels of commitments and internal dependence relations, giving the network a dynamic structure. The open network can in many ways be seen as positioned in the middle of this spectrum: the project management team offered some form of centralized governance, and the variety, interdependence and dynamics developed roughly with the modest pace at which new service providers joined the network.

### **What developmental issues do various types of patient portal networks experience?**

#### *The homogenous network*

The development of the portal began in 2009 when a portal was coupled to an existing electronic health record (EHR) shared by the network since the 1990s. The patient portal gave patients access to five applications: e-consultation, e-appointment, e-prescription, access to parts of patients' records, and lab results. The portal also gave patients access to an online physiotherapy support; however, this application was not linked to the EHR. The portal was populated with data from the general practitioner and pharmacy systems. The strategy for portal development and implementation was construed by the Care Corporation's Information Strategy Group, which consisted of selected organizational members who were familiar with technology in their daily work. As part of defining the strategy, this Group had conducted a patient population research, which divided the Care Corporation's patient population into segments based on their socio-demographic characteristics and attitudes towards health care (being a passive or proactive consumer, for example). Informed by this analysis, it was decided that the portal should specifically target the so-called 'result-directed' (20%) and 'quality-

directed' (18%) patients, who were believed to be able and willing to use technology in their care. The remaining patient population was expected to continue to receive care through traditional means. The strategy posited that a 20% usage rate would be sufficient for the portal to realize its efficiency potentials.

From 2012, the portal was implemented into the Care Corporation's primary care physician practices in a graduated fashion, starting with the most enthusiastic practices. Each implementation trajectory lasted 6-7 weeks and followed a uniform approach consisting of technical implementation, staff training, and communication aimed at ensuring physician buy-in. Patients were made aware of the online services through folders at the primary care physician practices. This promotion campaign was also launched in batches to ensure gradual registrations, which could be effectuated in a timely manner. The stepwise implementation approach took into account notable provider resistance in some practices. The technical changes would stir differences in work processes and patient-provider relationships, necessitating both patients and providers to learn to adapt to these changes. Thus, while the portal initiative had started out as a technical project, the implementation team soon realized it had to be managed as an organizational transition project.

In terms of authorization, patient consent was organized via a form with which patients gave permission for their data to be transferred to the portal. In terms of authentication, from 2012, the portal made use of the citizen identity management program, DigiD, which was developed by the Dutch government as an online identity verification tool for citizens in the Netherlands.[10] Since DigiD was a prerequisite for using the portal, only patients who had signed up and registered for DigiD could use the portal. A second consequence, according to the implementation team, was that since family members often have access to each other's DigiD, primary care providers would not be able to control the information flow to patients compared to if the information was provided in person. By 2013, all primary care practices in the Care Corporation were coupled to the portal, and the network was considering expanding the online services to physical therapy- and dietician practices and long-term care institutions.

### *The open network*

The development of the portal began in 2008 when the network submitted the subsidy proposal that was granted in 2009. Key functionalities available on the portal were e-consult, e-appointment, e-prescription, consult preparation and access to parts of records (via a connection to the information system of the implementing organizations). However, the functionalities differed per implementing organization. The idea was that each purchasing

organization would determine how the interface would look and what applications could be accessed through the portal. Notably, the portal was 'white label', meaning that it could be personalized to the purchasing organization. The idea behind the white label was that the portal could capitalize on the existing trust relationship between patients and their providers. The portal product was available to any organization conditional upon it having an existing information system, which the portal could link to. Rather than aiming to disseminate the portal within a locality, the network explicitly served pioneering health service organizations throughout the country. The project management team assisted the purchasing health service organizations in implementing the portal. This entailed helping the purchasing organization integrate the portal into their EHRs, integrate the portal into the workflow, and promote the portal to patients.

The portal was first implemented in a primary care health center in 2009 (version 1), followed by a second primary care health center in 2011 (version 2). A large implementation hurdle proved to be linking the portal to the EHRs that were in place at these health centers, a precondition for the effective integration of the portal into workflow. For example, due to the lack of link with the EHRs, initially information had to be manually transferred to and from the portal, posing a considerable administrative burden. Also, since the health centers' appointment schedules could not automatically be updated, some slots in the schedules had to be kept open for possible online appointments, some of which might not be filled. Due to this uncertainty, there were a limited number of open slots, and thus little choice for patients who booked their appointments through the system. Inefficiencies such as the ones described, reduced the functionality of the portal, limiting the enthusiasm among some providers and patients. In addition to workflow integration issues, many providers expressed concerns, especially regarding accountability. As a result, the implementation team channeled much effort into addressing issues such as timeliness of response to patient enquiries, what and when information should be available to patients, and ensuring that the portal would not be used for emergencies.

For each health service organization, the patient must give permission via a form for their information to be transferred to the portal. The portal did not facilitate exchange of patient information among the underlying applications, so it was not necessary to obtain permission for inter-professional data exchange. Other difficulties in the regulatory domain concerned creating authentication procedures that could support single sign-on, so that patients would not need to log-in a second time when navigating between distinct applications. The portal also used the identify management program DigiD; however, due to a delay by Logius (the government provider of DigiD) a 'group connection' was not yet available. Thus, in 2011

and 2012, the project team hired a 'trusted third party' that could support single sign on through a so-called 'session code'. Where possible, the project team sought to reduce regulatory complexities. As an example, it was decided not to store any data other than profile information on the portal. Instead, each application vendor was responsible for storing data related to the applications. Full implementation of the portal into both health centers (including successful tethering to their EHRs) was realized by 2012 at which time the network had concrete plans to scale it up to more organizations including a hospital.

When the subsidy ended in 2012, the network looked into ways to set up a sustainable business for the portal. For example, in primary care, this model would be based on a fixed annual fee from connected health service organizations. For hospitals and insurers, the network would negotiate an annual fee. The portal would be free for patients (Business Plan 2012). Hence, the revenues would be directly correlated with the number of connected practices and hospitals.

### *The interdependent network*

Begun in 2009, the portal of the third case was envisioned as the regional access point for citizens, patients and caregivers to engage with health service providers through a variety of online applications. These envisioned applications included, at the start, access to a 'Personal Health Record', a 'medical encyclopedia', a closed-circuit 'online video education program', 'self-management diaries', and an 'informal caregiver application'. Only the 'Personal Health Record' application relied upon coupling to an EHR, while the remaining were untethered applications. Like the open network portal in the previous case description, the regional portal was envisioned to be a 'multiple socket' for any new eHealth application, bringing together existing and new technologies on the basis of a unified, accessible architecture. Members of the regional network consortium championed their view of the portal as a not-for-profit project that would 'empower' providers and recipients of care and cure, while at the same time generating economic spinoff by allowing new eHealth businesses to 'blossom'.

The portal platform, which would serve as a gateway to the chosen applications, was first based on a standard product by one vendor. However, in 2011 this collaboration was cancelled due to an inability of the vendor's product to integrate multiple applications from multiple organizations. The network engaged another vendor to create a framework that would fit the portal's technical requirements: several architecture proposals were drafted, based on a 'single sign-on' principle for end users. In general, the portal project was divided into several sub-projects, with a program manager overseeing the development of each application that would

be offered through the portal. The applications were piloted independently of each other on the portal platform with the plan to later upscale applications that had proven successful. As such, the portal project was further removed from practice than the portals developed by the other two networks: only one of the applications was effectively implemented in existing work practices at the teaching hospital.

The portal's unequivocally largest selling point was the 'Personal Health Record', which would allow for information exchange among providers and between providers and patients. To establish a common platform for health information exchange, the network chose the CCR/CCD (Continuity of Care Record/Continuity of Care Document) standard. The actual exchange of data would run via the National Health Information Exchange (the National Switch Point) and no single healthcare organization was in charge of storing data. In September 2011, various health service organizations in/of the region signed a letter of intent to adhere to these standards. The 'Personal Health Record' project was piloted within the teaching hospital, which was also the main stakeholder in this sub-project. A particular issue challenging this process was achieving authorization to exchange personal health information. The Regional Privacy Committee advised that the treatment relation should be determining for authorization, implying that only health service providers that had treatment relationships with patients were allowed to view and exchange those patients' data. Such technical and regulatory issues made problematic the effective coupling of the portal to the hospital's EHR. When the subsidy period ended in 2012, this was still not achieved: problems with the open source platform had greatly delayed the development process, causing new challenges in terms of project management, the allocation of resources, and responsibilities. In addition to authorization issues, patient authentication proved to be more complicated than foreseen. The network had decided that the portal – and particularly the tethered applications such as the 'Personal Health Record' - should be accessed via DigiD in accordance with the single sign-on principle. However, over a space of several months during the subsidy period it remained uncertain how minors could use DigiD. Since minors were one of the target groups of the online video education program, the portal's success largely depended on ensuring access for this group. As it was unclear whether minors between the age of 16 and 18 could apply for a DigiD code without consent of their legal guardians, access to care as guaranteed by the Dutch Medical Treatment Agreement Act (Wet Geneeskundige Behandelingovereenkomst) appeared to be compromised. During a long period of deliberation with legal experts and contacts with the agency that developed DigiD, a pragmatic solution emerged that allowed this age group to apply for DigiD without the aforementioned consent. However, this process also revealed other limitations of DigiD: for

illegal residents, for example, the impediment of access to online care through DigiD persisted. In terms of patient consent for collecting and processing data, there were plans for an opt-in system in which patients would decide who would have access to their records. At the time of data collection, no clear position was taken about how to deal with data processing (for example, for public health purposes).

The hope within the network was that when the subsidy period ended in 2012, fees from participating health service organizations would sustain the portal. However, since the subsidy period did not result in a portal with a set of effective and scalable applications, it was unclear to the participating organizations how the portal complemented their own services. In combination with general budget cuts, organizations in the network decided to set new priorities. As a result, the patient-centered functionality of the portal was put on hold, as the network decided to first focus on facilitating inter-professional exchange under the management of the RHIO.

### **How does patient portal network type affect developmental issues experienced by the patient portal networks?**

Our analysis revealed that respondents frequently mentioned four types of portal development difficulties: achieving interoperability, implementation, regulatory compliance, and financial sustainability. Further, we detected a relationship between network type and the amount of developmental difficulty experienced in the networks. For example, the combination of network characteristics in the homogenous network allowed for the development to largely follow predefined steps and designs. The open network, although it was developing a commercial product, had to do considerable tailoring at each new implementation site to effectively fit the portal product to the given situation. Experiencing the most 'twist and turns,' the interdependent network was largely unable to follow its predefined development strategy. We go into detail with these aspects in the following by providing examples of developmental difficulties in each of the types of networks.

**Interoperability.** All three networks feature a wide range of both national and international standards. The interdependent network, for example, chose to base its health record on the CCR/CCD (Continuity of Care Record/Continuity of Care Document) standard, which has its origins in the United States but is now widely regarded as an international standard. Further, all the networks use HL7, an international standard for the transfer of clinical and administrative data. Yet, the challenges of conforming to these standards differed across the networks. For example, the portal developed in the homogenous network was tethered to a

network-wide EHR. Consequently, the standards used to record information and exchange information was uniform. In other words, the interoperability issue was largely solved prior to the portal add-on. Additionally, the network engaged the same vendor that had installed the EHR to install the patient portal, further simplifying technical integration. This differed from the other networks, where the participating health service organizations owned distinct information systems. In the interdependent network, achieving interoperability between systems was crucial to enabling a common platform for information exchange. Medical information management in the region was highly fragmented and there was no uniformity of language (nomenclature and semantics of medical terminology) and little interoperability between information systems (technical architecture). Thus, standardization was a precondition for establishing a regional health information exchange (HIE) platform.

Standardization depended on achieving agreement within the region, and this was as much a political and organizational challenge, as it was technical: it depended on each organization investing in adaptation of their existing information systems and rearranging data recording all the way down to the individual care providers. The political nature of such technical and organizational arrangements would often become visible when organizations discussed whose standards should be used; some smaller hospitals in the region, for example, regarded their own HIE arrangements as being more advanced than the one envisioned by the (politically more powerful) teaching hospital. Moreover, the need for a platform that could integrate with various information systems also complicated platform construction. As a result, the original vendor's product was inapplicable and the platform development was transferred to another vendor that was able to develop a more suitable product. In the open network, the challenge was of a different nature: the portal was supposed to link to the information systems that were in place at each of the health service organizations that wished to connect to the portal. Especially in the first phase of the portal development, achieving such scalability proved to be a considerable challenge. Due to the difficulties with linking the portal to an EHR, the portal initially had low functionality to the implementing health centers. For this network, the link to various EHRs meant continual negotiation and collaboration with various EHR vendors, each of which had its own agenda and priorities.

**Implementation.** Implementation challenges were highest in the interdependent network, which involved several separate applications and corresponding sub-projects, vendors and health service organizations. Each of these sub-projects consisted of different parties and responsibilities. Also, the extensive task of developing the platform delayed the actual implementation of sub-projects. As a result, only a few of the sub-projects were implemented

and the ones that were, were the standalone ones that required no tethering. The variety of sub-projects took its toll on project management, which had inadequate resources to support implementation of these applications in the region. Therefore, more responsibility was placed on the implementing organizations, further decentralizing the process. The variety of sub-projects also meant that the 'target population' became diffuse. For example, one application focused on children, another on information for caregivers, while yet another sought to provide information to all of the region's patients. This variety of target populations confused implementation: on the one hand it relied on highly targeted approaches, and on the other it tried to create a portal for 'everyone'.

In the case of the open network, the implementation surfaced various issues including workflow integration and provider commitment. In terms of the workflow integration, the lack of EHR tethering in the first years of implementation hindered the realization of envisioned efficiency gains, for example because data transfer to the portal involved a manual step. In terms of provider commitment to using the system, it was difficult to convince providers that the added value exceeded privacy and accountability risks. The homogenous network distinguished itself by allowing for more direct application of implementation experiences. The portal was essentially implemented as a separate project at each of the practice sites, with no significant overlap. Implementation required translational work to embed the portal into each practice; however, along the broader lines, implementation issues were similar for each practice. In batches, the implementation team repeated the implementation trajectories on all practices in the network. The most important factor in the implementation was to effectively embed the portal into practice and secure physician buy-in. As such, the trajectories became more focused on insuring organizational change than technical embedding. Achieving this change was likely helped by the fact each of the primary care physician practices was salaried by the Care Corporation, which eased central management and permitted references to the collective importance of the portal to the network.

**Regulatory compliance.** All three networks confronted issues concerning end user authorization and authentication due to growing privacy concerns within the Netherlands (and Europe) in conjunction with the sensitive nature of medical information. First, ensuring authorization to handle and exchange patient information was more intricate in the networks without a central organization that was a health service provider, since these did not fall under the aforementioned Medical Treatment Agreement Act. Both the open and the interdependent network, which were managed by a product development team and a RHIO respectively, faced this complication. In the open network this ultimately required including an intermediary entity

to act as a 'third trusted party' responsible for data. In the interdependent network, the RHIO acted as intermediary by processing data from the network's health service organizations: no data was to be stored in the portal. This issue of establishing and verifying authority to handle patient data was less pronounced in the homogenous network, where the Care Corporation – formally registered as a health service organization - was clearly responsible under the law. It should be noted that there is current European legislation pending that revises the provisions on protection of personal data, including health data, as well as legislation regarding cross-border care, which largely still needs to be enacted in the Member States. Because this legislation was not in force at the time of the study, it was not considered here, but this type of legislation will be important in the governance of future eHealth developments, as it has bearing on the organizational aspects of interfaces such as the portals discussed here.

Second, the issue of authentication also became more complex as the variety and number of network actors increased. As authentication mechanism, all networks integrated the DigiD standard in their architecture; however, due to the open network and the interdependent network's vision to develop a 'multiple sockets' portal, these networks were dependent on establishing single sign-on. Establishing single sign-on also implied establishing similar authentication requirements for all patients. Resultantly, the organizations in the network had to agree on requirements including who should have access to information and applications and what information and applications they should have access to. These already complex legal questions became more complicated with the number and variance of the participating organizations, which often dealt with different legal requirements (the interdependent network even relied on advice from the Regional Privacy Committee). In practice, this meant modifications and negotiations to ensure that each participating organization complied with legal requirements both with respect to the portal and to their own organization. The degree to which such modifications and negotiations were necessary was correlated with network complexity.

**Financial sustainability.** We note that the more comprehensive the network, the more intricate the investment in creating a common platform. For example, for the portal set up by the interdependent network, investments in the portal platform and applications were highly interdependent. This interdependency can be described by considering the investment in an application as 'building a shop in an empty street'. This metaphor was used by one of our respondents to illustrate that a sole application on a portal has little use, since it alone is unlikely to offer sufficient functionality for patients to spark their sustained interest in the portal. Hence, building a high-functioning portal relies on contributions from a variety of organizations to build

multiple companionable applications. Particularly in the interdependent network this meant creating mutual ownership between health service organizations that essentially compete in the regional healthcare market.

A difficulty for both the open network and the interdependent network was to ensure continued investments in the portals after the subsidy ended. This was largely due to the fact that both portal platforms had been grown out of subsidies. Sustaining investments in the platforms, and well as the applications that ran on them, depended on presenting an attractive business case to investing organizations. For the interdependent network this turned out to be hard – undoubtedly affected by the difficulties in the technical, implementation and regulatory domains – that had hindered the effective implementation of the portal, and thereby a successful ‘proof of concept’. As a consequence, it was unclear to the individual organizations how the portal contributed to their internal eHealth agenda (i.e. the development of their local patient portals). The open network relied on securing further uptake of their portal product. However, this was more challenging than expected, since implementation had taken longer than planned. Because of this longer implementation trajectory, the portal had yet to demonstrate efficiency or effects on patient outcomes, which could be used as selling points to potential buyers. Also, since the functionality of the portal depended upon high uptake in a region or locality (to insure on a minimum amount of connectivity) investing in the portal was risky, since it was uncertain how many others would also adopt the portal. The same risk applied to the EHR vendor that invested in the portal and made adaptations to its own EHR product without knowing if the portal would be a success and thereby expand its market. Similar investment issues did not materialize in the homogenous network, where the Care Corporation carried the investment up front and the portal was operational within a relatively short period of time.

Achieving financial sustainability is not only about ensuring sufficient investments but also about realizing return on these investments. Not all portal applications offered by the homogenous network had an equally clear business case. For example, whereas it was visible how e-appointment could generate administrative savings, it was less clear how giving patients access to personal health information could benefit the organization, let alone when those benefits would materialize. However, since most patients are likely to continue to receive care within the Care Corporation, the rationale was that it might recoup downstream savings stemming from better-managed and healthier patients. Setting up a revenue model was less straightforward in the interdependent network. For example, it was uncertain whether the business case should capture the individual applications, the individual health service provider, or the network as a whole. Furthermore, some organizations in the network were unconvinced

that they would receive sufficient revenues to recover any continued investments. First, this was because the portal was not implemented as planned and successful implementation did not seem immediate. Second, the organizations were not sure that they would reap the benefits of better-informed and empowered regional patients: since the network only constituted a fraction of the health service organizations in the region, and since they had no way of containing savings within the network, benefits might accrue to the healthcare community at large. In the open network, becoming self-sustaining required scaling up the portal product to more health services organizations, because revenues would be dependent on the number of the connected practices that would each pay an annual fee.

A summary of the results of our analysis is provided in Table I at the end of the chapter.

## DISCUSSION

In this study, we have identified and described three types of patient portal networks in the fragmented Dutch healthcare system, varying on key multi-actor network characteristics (variety, interdependence, decentralized governance, and dynamic structure). Our analysis suggests that these four characteristics do not function as independent dimensions; rather it suggests a one-dimensional ordering of network types: on the one extreme is the simple, homogeneous network type with low variety, low interdependence, centralized governance, and a rather static structure. On the other extreme is the comprehensive interdependent network type, with high variety, interdependence, lack of central decision-making, and a network structure that is considerably more dynamic. This relationship between the characteristics may not be coincidental. In the Dutch healthcare context, for instance, patient portal networks with low provider variety will typically have low interdependence, as providers of a same type typically operate in parallel, perhaps even as competitors, rather than in frequent collaboration. Reasoning along the same lines, homogeneity among actors naturally reduces structural dynamics and the development of sub networks and corresponding need for decentralized governance. Conversely, service providers, who interact to provide comprehensive services to a complex patient group, offer a variety of complementary services and interdependencies due to the sharing of patients. Moreover, the dynamics of the patient portal development and the contextual fragmented Dutch health system bring forth structural dynamics and sub networks with decentralized activities and decision-making. Hence, we hypothesize that the characteristics are positively related for patient portal networks, and driven by the comprehensiveness of the health services.

## **Network type, patient portal development, and patient portal functionality**

We used empirical examples to show how network type is related to the development of patient portals by impacting the ability of the networks to achieve interoperability, regulatory compliance, financial sustainability, and effective implementation. Yet, in addition to developmental issues, network type may also be related to the functionality obtainable through a patient portal. We argue in our introduction that portals offered by many providers might obtain the highest connectivity, and thus, functionality to patients, because a variety of applications can be offered in one place. Along the lines of this argument, we find that the interdependent network holds the highest ambitions in terms of connectivity, since it is geared to include the entirety of a region's health service providers. Assuming that most patients receive all their care within a region (except in case of an emergency, of highly complex care), a portal developed in this network could be embedded into most of the care patients receive. In theory, a patient portal developed in this network could largely resemble one developed within an integrated care delivery system (such as Kaiser Permanente and the Veteran Affairs) where most patient portal outcomes have been reported.[35] The open network holds a similar promise of connectivity. However, since the portal is not regionally confined and can be connected to providers distributed across the country, the density of connections is uncertain. Consequently, patients are unlikely to have access to all or most of their providers through the portal. Finally, the homogenous network's restriction to a local Care Corporation at the primary care level inherently limits the connectivity, since no link with hospitals is foreseen.

It thus appears that network type entails a tradeoff between ease of development and patient portal functionality. The homogeneous network type limits portal functionality, as it inherently excludes many of the health service providers visited by complex patients. On the other hand, it appears that the low network complexity and bounded functionality reduce the difficulty of portal development. Conversely, the complex interdependent network envisioned functionality to support comprehensive services for complex patients, yet experienced considerably more difficulties in its development.

In addition to network type, two other factors seem to impact both patient portal development and functionality: geographical bounding and provider density. First, whereas the homogeneous and interdependent networks had clear regional boundaries, the open network was intended to be scaled up, as the portal would be deployed in other regions as well. The economies of scale attainable by regionally unbounded networks were considered promising by some of the actors in the open network, since it might yield a larger return on investment. Also, the non-reliance on commitment from regional actors allowed the portal product to be

marketed to progressive, early patient portal adaptors throughout the country. Second, the proportion of regional health service providers joining the network also appears to have played a role in the networks. Many service providers assessed their value proposition through considering how many of the providers they interact with, typically residing in the same region, was also connected to the portal. In the homogeneous network, all primary care practices automatically joined the network. This was not the case in the other two networks, which appeared to present difficulties, since some actors feared that the portal benefits might accrue to non-participants.

Our identification and description of relevant network factors contribute to an early evidence base from which to understand the development and functionality of patient portals. Yet, the period and breadth of our analysis do not allow for drawing conclusions about which network type is more likely to ultimately provide a integrated patient portal. However, it does suggest that homogeneous networks are more likely to attain short-term objectives than the complex ones. Perhaps they can serve as stepping stone alternatives to development approaches that are comprehensive from the start.

### **Patient co-production**

Worth noting, we observed little of what Osborne & Strokosch [36] have coined 'participative co-production', referring to patient participation in the strategic planning or design stages of public services. We believe that the low level of observed participative co-production in the studied patient portals is a consequence of the intricacy of network management. As we have illustrated by example, network management became a complex social process necessitating actors to devote much of their time interacting with each other. This inherent emphasis on inter-organizational negotiation and decision-making may have inhibited the networks' ability to interact with and involve patients in the development. Again, the constraints of our analysis restrain us from assessing the actual implications of this lack of patient participative co-production. However, we can draw on existing scientific literature to infer that low levels of patient co-production in the portal development risks building portals that fall short of meeting the needs and wishes of patients or fail to support them in their care.[37-38] Hence, patient portal networks would be wise to explicitly recognize patient co-production in the patient portal development as key to achieving desired effects.[39]

### **Transferability of findings**

We believe our findings apply not only to the Dutch healthcare system but also to fragmented

systems more generally. For example, the development difficulties we have described address natural areas of technical, legal, and economic issues, as well as the process management itself. Recognizing these areas and the difficulties encountered therein by the various types, as well as the solutions found by other patient portal networks, may guide network management and policy makers operating in fragmented contexts. As our results present a first exploration of theoretical frameworks and initial evidence, further research on network types and development in the Netherlands and in other fragmented systems is called for to advance understanding of patient portals networks in fragmented contexts. In addition to advancing scientific understanding, such improved understanding can help to improve policy making in the complex domain of eHealth and patient portals. The empirical insights presented here will hopefully serve as a reference for further research on patient portal networks.

### **Study limitations**

We chose three cases that reflect the diversity of network types we saw in 2012. Despite the diversity in this sample of networks, we do not claim that the three identified types are exhaustive. It is possible that analyses of other types of networks may surface other developmental issues not identified here. Furthermore, during our study of the three patient portals, which ended in 2013, we only focused on the processes of network forming and patient portal development. Hence, we have not evaluated actual use or effects of the portals.

Within each case study, we interviewed the persons we understood to hold the most knowledge about and influence on the patient portal development. However, these persons did not represent everyone involved in the development; there is a possibility that our data would have been different had we included other people. For example, we could have included insurers, municipal policy officers, and physicians piloting the portals in their practices. Moreover, it would have been interesting to also interview patients about their role in the network and in the development process. However, as we pointed out earlier, patients were rarely a formal part of the development process. In this study, we therefore decided to focus upon the development from the perspectives of the organizations behind them.

**Table I:** Summary of results

Research questions	The homogenous network	The dynamic network	The interdependent network
<p>What characterizes the networks that have emerged to provide patient portals in the Netherlands?</p>	<p><u>Network participants</u> - Primary care entities (GP, pharmacies, home care, rehab, PT and OT) united by one Care Corporation</p> <p><u>Scope of portal services</u> - Primary care</p> <p><u>Patient portal users</u> - Patients belonging to Care Corporation; primary care physicians</p> <p><u>Investors</u> - Care Corporation</p> <p><u>Project management</u> - Care Corporation's Strategy Group</p> <p><u>Geographical bounding</u> - Restricted to municipality</p> <p><u>Provider density</u> - High participation rate of providers in municipality</p>	<p><u>Network participants</u> - Teaching hospital, primary health centers, IT vendors, consultants researchers</p> <p><u>Scope of portal services</u> - Primary and secondary care</p> <p><u>Patient portal users</u> - Patients belonging to implementing health service organizations; providers working within implementing organizations</p> <p><u>Investors</u> - Government (subsidies), network participants, Product purchasers</p> <p><u>Project management</u> - Consultants; later a designated project team</p> <p><u>Geographical bounding</u> - Available to all providers in the country</p> <p><u>Provider density</u> - Implementation strategy not amenable to achieving density</p>	<p><u>Network participants</u> - RHIO, hospitals and primary care practices, IT vendors, researchers</p> <p><u>Scope of portal services</u> - Primary and secondary care</p> <p><u>Patient portal users</u> - Regional citizens and patients belonging involved health service providers.</p> <p><u>Investors</u> - Government (subsidy), network participants</p> <p><u>Project management</u> - No project manager, later the RHIO</p> <p><u>Geographical bounding</u> - Restricted to region</p> <p><u>Provider density</u> - Not able to ensure participation of all providers in region</p>
<p>What characterized the development of patient portals in the different types of networks?</p>	<p><u>Envisioned functionalities</u> - e-consult; e-appointment, e-prescription, access to parts of PHR, lab results, FysOnline</p> <p><u>Interoperability</u> - Same EHR and portal vendor ensured interoperability</p> <p><u>Implementation</u> - Only primary care</p>	<p><u>Envisioned functionalities</u> - e-consult, e-appointment, e-prescription, consult preparation and access to parts of records</p> <p><u>Interoperability</u> - Link with different EHR for each new implementation site</p> <p><u>Implementation</u> - New implementation</p>	<p><u>Envisioned functionalities</u> - Personal Health Record, self-management diaries (tethered), medical encyclopedia, online video education program, informal caregiver application (non-tethered)</p> <p><u>Interoperability</u> - Each stakeholder used different technologies - Conversion to same</p>

	<p>practices</p> <ul style="list-style-type: none"> <li>- Defined target population</li> <li>- Change management project</li> <li>- Stepwise rollout</li> </ul> <p><u>Regulatory compliance</u></p> <ul style="list-style-type: none"> <li>- Care Corporation was legally authorized to manage patient information.</li> <li>- Used DigiD</li> </ul> <p><u>Financial commitment</u></p> <ul style="list-style-type: none"> <li>- Care Corporation financed the portal up front</li> </ul> <p><u>Financial sustainability</u></p> <ul style="list-style-type: none"> <li>- Care corporation can contain revenues</li> <li>- Satisfied patients may be loyal to Care Corporation</li> </ul>	<p>trajectory for each purchasing organization</p> <ul style="list-style-type: none"> <li>- Many tasks has to be performed manually due to lack of EHR-link in beginning</li> </ul> <p><u>Regulatory compliance</u></p> <ul style="list-style-type: none"> <li>- The consultant group/ project team was not legally authorized to manage patient information and must bring in 'trusted third party'.</li> <li>- Portal must comply to legal framework of each purchasing organization</li> <li>- creating single-sign on with DigiD</li> </ul> <p><u>Financial commitment</u></p> <ul style="list-style-type: none"> <li>- After end subsidies, money must come from purchasing organizations</li> </ul> <p><u>Financial sustainability</u></p> <ul style="list-style-type: none"> <li>- Depends on the ability of the portal to achieve improvements in patient health and organizational performance that can ensure uptake by more organizations</li> </ul>	<p>standard</p> <p><u>Implementation</u></p> <ul style="list-style-type: none"> <li>- Heterogeneous target populations</li> <li>- Each app handled as different implementation project</li> </ul> <p><u>Regulatory compliance</u></p> <ul style="list-style-type: none"> <li>- RHIO was not legally authorized to manage patient information. Could not store data</li> <li>- Defining access requirements</li> <li>- Creating single-sign on with DigiD</li> </ul> <p><u>Financial commitment</u></p> <p>After end subsidies, money must come from network participants</p> <p><u>Financial sustainability</u></p> <ul style="list-style-type: none"> <li>- Network participants not sure they could recoup potential benefits</li> <li>- Each network participant had own eHealth agenda</li> <li>- Apps were not fully implemented, so achieving benefits were not immediate</li> </ul>
<p>How is network type related to portal functionality and the development process of the portals?</p>	<p><u>Potential functionality</u></p> <ul style="list-style-type: none"> <li>- Only connected to primary care</li> <li>- Only apps from one vendor</li> </ul> <p><u>Development process</u></p> <ul style="list-style-type: none"> <li>- Development process was relatively linear</li> </ul>	<p><u>Potential functionality</u></p> <ul style="list-style-type: none"> <li>- Can connect to any provider</li> <li>- Apps from many vendors</li> <li>- Geographical connectivity not guaranteed</li> </ul> <p><u>Development process</u></p> <ul style="list-style-type: none"> <li>- New development process at each purchasing organization, including link with new EHRs</li> <li>- Process was not linear</li> </ul>	<p><u>Potential functionality</u></p> <ul style="list-style-type: none"> <li>- Can connect to any regional provider</li> <li>- Apps from many vendors</li> <li>- Geographical connectivity</li> </ul> <p><u>Development process</u></p> <ul style="list-style-type: none"> <li>- Development process moved in twist and turns</li> </ul>

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# CHAPTER 5

## *Characteristics of Patient Portals Developed in the Context of Health Information Exchanges: Early Policy Effects of Incentives in the Meaningful Use Program in the United States*

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## ABSTRACT

**Background:** In 2014, the Centers for Medicare & Medicaid Services launched the second stage of its EHR Incentive Program, providing financial incentives to providers to meaningfully use their electronic health records to engage patients online. Patient portals are electronic means to engage patients by enabling secure access to personal medical records, communication with providers, various self-management tools, and administrative functionalities. Outcomes of patient portals have mainly been reported in large, integrated health systems. This may now change as the EHR Incentive Program enables and supports the use of patient portals in other types of health systems. In this paper, we focus on Health Information Exchanges; entities that facilitate data exchange within networks of independent providers.

**Objective:** In response to the EHR Incentive Program, some Health Information Exchanges in the United States are developing patient portals and offering them to their network of providers. Such patient portals hold high value for patients, especially in fragmented health system contexts, due to the portals' ability to integrate health information from an array of providers and give patients one access point to this information. We report on the early effects of the EHR incentives on patient portal development by Health Information Exchanges. Specifically, we describe the characteristics of these portals, identify factors affecting adoption by providers during the 2013-2014 time frame, and consider what may be the primary drivers of providers' adoption of patient portals in the future.

**Methods:** We identified four Health Information Exchanges that were developing patient portals as of Spring 2014. We collected relevant documents and conducted interviews with six Exchange leaders as well as two providers that were implementing the portals in their practices. We performed content analysis on these data to extract information pertinent to our study objectives.

**Results:** Our findings suggest that there are two primary types of patient portals available to providers in Health Information Exchanges: portals linked to individual providers' or health systems' EHRs and HIE-sponsored portals that link information from multiple providers' EHRs. The decision of providers in the Exchanges to adopt either one of these portals appears to be a tradeoff between functionality, connectivity, and cost. Our findings also suggest that while the EHR Incentive Program is influencing these decisions, it may not be enough to drive adoption.

Rather, patient demand for access to patient portals will be necessary to achieve widespread portal adoption and realization of potential benefits.

**Conclusions:** Optimizing patient value should be the main principle underlying policies intending to increase online patient engagement in the third stage of the EHR Incentive Program. We propose a number of features for the Program that will enhance patient value and, thereby, support the growth and sustainability of patient portals provided by Health Information Exchanges.

## INTRODUCTION

### **The Meaningful Use program**

Passed into legislation in 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act included \$30 billion for accelerating and mainstreaming the use of health information technology.[1] The Act incentivizes the adoption of electronic health records (EHRs) by hospitals and physician practices and sets targets for the “meaningful use” of these EHRs to significantly improve patient care.[2] The EHR Incentive Program, also known as the Meaningful Use (MU) program, is a cornerstone of the HITECH Act. The program, which is regulated by the National Coordinator for Health Information Technology (ONC) and administered by the Center for Medicare & Medicaid Services (CMS), authorizes incentive payments through the Medicare and Medicaid Programs.[3] Through three stages, the program rewards providers that meaningfully use ONC certified EHRs by meeting designated objectives and levies a financial penalty on those providers that fail to meet the objectives.[4]

Stage 1 of MU, which was implemented in 2011, provided incentives for eligible physicians and hospitals to adopt EHRs with basic functionalities, such as capturing data electronically and exchanging information among care providers.[5] Subsequent to Stage 1 implementation, the number of providers meeting MU1 criteria with their EHRs sharply increased.[6-7] Up from 4% in 2010, 42% of hospitals surveyed in the 2012 American Hospital Association Health Information Technology Supplement fulfilled core Stage 1 requirements.[8-9] Further, it was estimated that by May 2012, 12.2 % of US office-based physicians had successfully restructured their IT systems and practices to meet Stage 1 requirements.[10-11]

Stage 2 of MU went into effect in 2014 for providers that demonstrated Stage 1 MU in 2011.[12] In addition to using EHRs for continuous data capture and enhanced inter-professional information exchange, the second stage of the program emphasizes building online patient engagement capabilities on top of these EHRs.[13-14] One core objective specific to online patient engagement is that providers give at least 50% of their patient population the ability to view online, download and transmit their health information within four days of the office visit (for physicians) and 36 hours of discharge (for hospitals). Of these patients, the provider must attest that 5% actually access their records online to view, download or transmit information. Providers must also be able to securely message their patients and provide patient-specific educational resources to at least 10% of patients after office visits.[15]

### **Patient portals in light of Meaningful Use**

Patient portals are vehicles for meeting these particular MU2 objectives by enabling secure

messaging with healthcare providers and by giving patients access to their personal health records (PHRs).[16-17] A PHR is a patient-centered tool used for managing health information and engaging in health promotion and management. The individual patient controls his or her own PHR and may also insert information into the record that is not contained in an EHR.[18] A patient portal that is linked to a provider's EHR is called a tethered patient portal.[19] Early evaluations of tethered patient portals suggest that they can improve chronic disease management, patient adherence to medications and preventive services, patient-provider communication, patient empowerment, and patient satisfaction.[20] These outcomes have so far been reported from portals within large and integrated delivery systems, such as Kaiser Permanente and the Veterans Affairs health system, with system-wide EHRs. Through a combination of their comprehensive coverage of a defined eligible population and EHR integration, these portals give patients one access point through which they can view their information and interact with all of their providers in the system. Due to this comprehensiveness and integration, these portals can trigger mechanisms such as enhanced patient insight into their complete health information, inter-personal continuity of care, and patient convenience, which are instrumental to achieving the outcomes listed above.[21]

However, as MU2 introduces financial incentives for online patient engagement, the program is now enabling and stimulating the development of patient portals in health system contexts other than these large, integrated delivery systems, including Health Information Exchanges (HIEs).

### **Patient portals in the HIE context**

Regional or statewide HIEs facilitate information transfer among participating hospitals and physicians' independent and non-interoperable EHRs. In 2013, 90 community-based and 45 statewide HIEs were reported in the US.[22] By facilitating information transfer among independently operating clinicians, laboratories, hospitals, pharmacies, and health plans, these HIEs play an important role in connecting providers in fragmented contexts.[23] According to a Robert Wood Johnson Foundation report [8], by the end of 2012, 30% of U.S. hospitals and 10% of ambulatory practices sent and received data through HIE efforts. This number has increased significantly over the last years, up from 14% and 3% in 2010 for hospitals and ambulatory practices respectively.[8] With information transfer being an ever more crucial component of the ONC's agenda, many HIEs will continue to receive start-up grants, demonstration project grants, and on-going operational support from the Department of Health and Human Services.[24]

As health service providers that participate in these HIEs now seek ways to capture the MU2 incentives, some HIEs will play an increasing role in developing patient portals. Such HIE-sponsored patient portals may enable online patient engagement opportunities not previously seen outside of integrated health delivery systems. By consolidating information, which is typically spread across a range of independent providers' EHRs, patient portals that are developed by HIEs in fragmented contexts can give patients an overview of their health information. Since some patients - especially patients with complex conditions - see multiple providers [25], this single access point alleviates for patients the hassle of accessing their records and using other healthcare services through different portals, each with their own passwords, usernames and interfaces. By achieving comprehensiveness and integration, patient portals in these systems may create patient value comparable to that observed in integrated systems, and thereby trigger outcomes similar to those reported from these systems. As pointed out by Otte-Trojel et al (2014) the patient value of portals that develop in fragmented systems may even exceed that of portals in integrated systems by breaking down siloes in fragmented provider-centric systems.[21]

The achievement of this value from HIE-sponsored portals is challenged by the reality that only 10-30% of providers are currently linked to an HIE. However, as HIE participation rates grow each year, the coverage of HIE-sponsored portals will likely increase at a proportional rate.

## **Study aim**

The potential of HIE-sponsored patient portals to deliver patient value in fragmented health system contexts is significant, especially for patients who see multiple providers. Yet, realizing this potential depends on physicians and hospitals that are members of the HIEs adopting the portals into their practices. The aim of this study is to report on the development and rollout of the first HIE-sponsored portals, and to explore the early effects of the MU incentives on these developments. Specifically, we examined the following questions: (1) What are the characteristics of early-stage HIE-sponsored portals?; (2) What are the major factors affecting providers' adoption of HIE-sponsored portals?; and (3) What factors will drive the further development and adoption of patient portals in the HIE context?

## **METHODS**

Based on the list of HIEs in the 2013 eHealth Initiative report [22], we identified the HIEs that on their websites announced that they were either developing or offering a patient portal. As of

early 2014, such activity was seen in HIEs in Pennsylvania, Kansas, California, and Texas. One of these patient portals has been implemented in a small set of provider practices; one is currently being rolled out in a few practices; and two are still in the piloting phase. Although being a relatively small sample, the four HIEs represent the HIEs that are developing patient portals at present and provide useful experience and information for other HIEs that intend to develop portals as well as for policymakers interested in the effects of MU criteria and incentives on patient portal development. Key characteristics of the four front running HIEs are presented in Table 1.

**Table 1:** Characteristics of Health Information Exchanges that are implementing patient portals

	Kansas Health Information Network (KHIN)	Healthcare Access San Antonio (HASA)	Keystone Health Information Exchange (KeyHIE)	Santa Cruz Health Information Exchange
Founded in:	2010	2005	2005	1998
Service area:	Statewide	22 counties around San Antonio	53 counties in Pennsylvania	Santa Cruz county
Penetration:	6000+ providers 700+ organizations	683,000 providers 29 organizations	1,500 providers 40 organizations	400 providers 200 organizations
Unique patients:	2+ million	860,000	3,7 million	300,000
Patient portal name:	My Health eRecord	MyHASA	MyKeyCare	Santa Cruz HIE patient portal
Patient portal vendor:	NoMoreClipboard	Mana Health	Get Real Health	NoMoreClipboard
Current patient portal users:	2400+			
	Only KeyHIE had active patient portal users at the time of data collection in Spring 2014			

We contacted the directors of these four HIEs in February and March 2014 and all directors agreed to participate in our study. We asked all four HIE directors to refer us to other relevant HIE staff or providers that were in the process of implementing the portals in their practices. We collected data in March and April 2014. As part of our data collection, we obtained documents and conducted ten in-depth interviews with eight people, including four HIE directors, two HIE project managers from two different HIEs, and two providers participating in one of these HIEs. The two providers were from the HIE that had implemented the patient portal in a small set of provider practices at the time of the data collection. In addition, the HIEs provided us with relevant documents, including presentations, training and installation guides,

and annual reports. We conducted content analysis [26-27] of the interview transcripts and acquired documents to extract information relevant to our research questions.

## RESULTS

### **Characteristics of early-stage HIE-sponsored patient portals**

To meet the MU2 requirements, the portals that are currently being developed by HIEs focus on enabling patients to view and download summary of care documents and transmit them to other providers. The HIE-sponsored portals are untethered, since they are not directly linked to an EHR. For two of the HIEs, data will be transferred to each patient's PHR through the ONC's secure emailing system, Direct. As their technical capabilities expand, the ambition is to enable automatic population of the PHRs with data, including summary of care documents, lab results, immunization reports, etc. The other two HIEs already have such automatic transfer capacities, meaning that data can be pulled directly into the PHR. The HIEs have set up procedures to allow providers to flag information in their EHRs that they would not like to share with patients or that they would prefer to discuss with patients before making accessible.

At this early stage of development, patients will be able to store documents and enter information (e.g. about their diet or exercise) in their PHRs, but as the portals evolve, the plan is to also enable transmission of such patient-generated information to relevant healthcare providers. To comply with MU, secure messaging between patients and providers is a standard feature in all the portals.

In addition, individual providers may choose to offer EHR-linked features, such as appointment scheduling, bill payment, patient preregistration, and prescription refill through the portals. In fact, one of the interviewed providers mentioned that they were discussing ways to add a scheduling component and a bill payment component to the portal. However, since the portals are untethered, this will require the providers to install such applications at their end, and subsequently integrate these applications with the patient portal. As several HIE directors and project managers explained, incorporating such features into the portal would require extensive collaboration between the provider and the HIE to achieve the necessary technical and workflow integration. Requiring far less integration work, at least two of the HIEs are also planning to provide non-EHR-linked features through the portals, such as various educational, self-management and wellness applications.

All four portals will be accessible through both the websites of participating providers and a central HIE website. The providers may choose to brand the portal to fit their organization, in which case the portal's interface may differ across these providers. One of the

HIEs aired intentions to eventually also make its portal available on mobile devices, such as smartphones and iPads.

All of the HIEs are planning to incorporate the cost of their portal into the overall HIE provider participation fee, while at least one is considering assigning some of the cost to patients in the form of a \$3-5 monthly service fee. The given HIE had conducted several focus group interviews with patients in the region to learn about their willingness to pay and had concluded that this reimbursement model was feasible. A number of studies have examined patients' willingness to pay for access to patient portals. Results from these studies indicate that 40 -70 % of patients with internet access would be willing to pay a small fee for use of standard patient portal features such as viewing their medical records and secure emailing with their providers.[28-29]

While all the HIEs see vast potential for their patient portals to improve patient health and provider workflow in their state or region, at the time of the interviews none of the HIEs had set specific targets on these areas. The critical milestone for all four HIEs is to be able to attest MU by the start of their providers' reporting periods in either July or October, 2014. Afterwards, the most important success factor is to attain a certain level of provider adoption and patient use of their portals.

### **Factors affecting providers' adoption of HIE-sponsored portals**

The main issue limiting HIE-participating providers' uptake of HIE-sponsored portals is the difficulty HIE leaders have in convincing providers that the value of the HIE portal exceeds that of the EHR-tethered portal that most providers are offered by their EHR vendor. As a result of this competition from the EHR vendors' portals, a HIE-participating provider's decision to adopt the HIE-sponsored portal seems to largely be a tradeoff between functionality, connectivity, and cost.

#### *Functionality*

From our interviews with HIE directors and managers, we identified three main challenges that currently limit the HIE-sponsored portals' degree of functionality. It should be noted that the reported significance of these challenges varies across the four HIEs.

First, the missing linkage between providers' EHRs and the HIE limits the capacities of the HIE-sponsored portals compared to their tethered counterparts in several ways. As noted above, in this early stage, EHR-linked features of convenience for patients (such as appointment scheduling) may not be available through the HIE-sponsored portals. Until full integration

between providers' EHR and the HIE-sponsored portal is realized, one HIE director noted that a solution could be to simply refer patients to relevant providers' EHR features through the portal. However, accessing such features would require patients to use a separate login for each individual provider feature, thus contradicting the rationale behind a shared portal. Furthermore, for the HIEs that are still working on enabling automatic flow of information from the HIE to the patients' records, providers or their administrative staff will have to manually perform this step by sending relevant documents via an email function. While this may be feasible in small practices with small patient volumes, for bigger practices, manually transferring data after each patient visit or discharge is an unsustainable solution.

Second, all the HIEs are challenged by creating the reporting formats required for providers to attest MU. This challenge is augmented by the fact that the HIEs are not tied to the providers' EHRs, which contain administrative data on patient contacts such as when an office visit or discharge took place. Such information is necessary to, for example, generate reports certifying that information was made available to patients in a timely manner. According to the HIEs, no perfect solution is in place yet. For now, attesting MU2 requires that the providers themselves link the data generated by the HIE with information in their own EHR. Since clinical documents are generated through the EHR, many providers have turned to their EHR vendors for advice on meeting MU2. Since these vendors could only guarantee that providers would meet the requirements through the vendors' portals, directors and project managers in two HIEs reported that many providers in their network came to believe that their EHR vendor's tethered portal was a better option than the HIE-sponsored portal.

Third, to varying degrees, the HIEs have yet to fully resolve issues regarding patient matching.[23] When data are exchanged among providers in a given HIE network, data from different providers are matched to a given patient using probabilistic matching algorithms [30]. If available, these algorithms take into account various patient identifiers, such as name, gender, date of birth, social security number, address, and phone number. In fact, one HIE uses 17 patient identifier options for matching. Since the data are being sent only to providers, the threshold for what is considered an adequate match for data with a patient is less than 100% and varies by HIE. When in doubt the providers are able to double-check the data with the patient at the time of a patient visit. However, this situation is different when it comes to populating PHRs, which can be accessed by patients via their portals. Ideally there should be a 100% match of patient identifiers so that patients never receive incorrect data in their PHR. In cases where it is not possible to achieve a match, data cannot be sent to the PHR. This challenge is especially prominent if there is considerable variation in how participating providers'

EHRs format names and addresses, in the quality of data entered in the system at the point of patient registration, and if there are duplicate records for the same patient.[31] Providers with EHR-tethered portals do not share the same challenge, since they can always achieve a full match based on patients' medical record numbers generated within their systems.

### *Connectivity*

The core value of HIE-sponsored portals is their connectivity. According to the MU specifications, to meet the 5% target of patients that view, download, or transmit their information, a provider must have contributed some of the information to the shared portal, but not necessarily the particular information that was viewed, downloaded, or transmitted by the patient. There is consensus among the interviewees that the network externality of sharing credit for patient contacts and thereby collaborating to reach the 5% target is the main selling point of the HIE-sponsored portals to the HIE member provider organizations. As the directors and managers in all four HIEs explained, for many clinics and hospitals this shared incentive makes it more feasible to achieve the 5% target through the shared HIE-sponsored portal compared to having their patient population view records only generated in their respective office, clinic or hospital. A manager from one medical center pointed out that a positive consequence of this incentive mechanism could be that providers will encourage each other to adopt the HIE-sponsored portal.

### *Cost*

A notable advantage of the HIE-sponsored portals is lower costs to providers of acquiring a portal. As explained earlier, most HIEs plan to roll the portal costs into the overall HIE participation fee, regardless of whether a provider actively uses the portal. Especially smaller practices are sensitive to the high cost of EHR-tethered portals and may prefer this more affordable option. Moreover, one HIE director pointed out that the shared portals can operate with a lower overhead, since providers can share certain functions, such as a helpdesk to register patients and respond to patient inquiries.

Nevertheless, this cost incentive is not available for providers that have already implemented a patient portal as part of their EHR. Due to the ONC's certification of 'complete EHRs' that include patient portals, many providers have already implemented an EHR-tethered portal. The 'complete EHR' certification has meant that EHR vendors can only guarantee that their EHR meet MU requirements if a patient portal is included in the package. For providers who have purchased a patient portal as part of their EHR package, the added value of

participating in a HIE-sponsored portal would have to compensate for the (sunk) cost of having an already-purchased portal remain unused (one might note that if the cost of the HIE-sponsored portal is included in the overall participation fee, the expense on a non-used HIE-sponsored portal could also be considered a waste). As one project manager expressed: “MU is kind of the best and the worst of worlds at the same time”.

### **Factors likely to impact the further development and adoption of HIE-sponsored portals**

As outlined above, for HIE-participating providers that are considering implementing a patient portal, their decision to adopt a HIE-sponsored portal may largely be a tradeoff between functionality, connectivity, and cost. Yet, according to the interviewed HIE directors and managers the widespread uptake of patient portals is also inhibited by a general lack of provider interest in sharing information and communicating with patients online. The HIE directors and managers noted that a considerable share of their members express concerns with respect to patient portals, the main points of concern being that secure messaging will lead to a boost in patient contacts and that patients will not be able to interpret or cope with the clinical data in their records. It is worth noting that the literature provides a mixed account of secure messaging's effect on health service utilization. Some studies show that secure emails increase utilization of hospitalizations, in-person visits and telephone contacts [32-35], while one has demonstrated the opposite.[36] There are no good estimates of the proportion of providers that are interested in online patient engagement, and this proportion may vary by state and county. However, the perception among the HIE directors and managers that we interviewed is that a large proportion of providers in their network are not highly motivated by the MU incentives. This perception is supported by reports of the uptake of MU2 requirements. By June 2014, only eight eligible hospitals and 447 eligible professionals had attested to Stage 2 meaningful use.[37-38] Thus, although the HIEs develop patient portals to help their members comply with MU2, this financial incentive may not be enough to guarantee widespread uptake among providers.

Nonetheless, the notion among the HIEs is that as more and more providers include a patient portal in their service portfolio, patients will start demanding that their non-compliant providers offer similar capabilities for online engagement. If the HIEs' predictions about such network externalities hold true, the MU financial incentives may encourage HIEs to provide the infrastructure for patient portals, but ultimately the patients will have to drive the widespread incorporation of the portals into their providers' practices. Most patients recognize the benefits of patient portals: in a 2011 nation-wide survey, 70% of patients indicated that they would want

to access portals with comprehensive PHRs if they were made available to them.[39]

## DISCUSSION

### **Principal findings**

MU2 incentives have ignited interest among some health service providers in fragmented systems to install or further develop patient portals. Such arrangements can be made via EHR-tethered portals within individual provider practices or via portals shared by the HIE network. While both arrangements enable online patient engagement, the latter may lead to more patient value by simulating the connectivity of portals in larger and integrated systems from which outcomes have mainly been reported thus far. Indeed, conversely, development of patient portals solely at the individual provider level could result in sustained fragmentation of patient information. As explained earlier, this fragmentation may have the most serious implications for patients receiving care from multiple providers, who would have to access several patient portals to view all their personal health information and interact with all their providers. However, the functionality of early stage HIE-sponsored portals may be lower than EHR-tethered portals, limiting their adoption. As we have explained, the MU incentives reward connectivity by allowing patient contacts to count towards all providers that contribute to a shared HIE-sponsored portal. Yet, it is still too early to conclude whether this incentive mechanism will be enough to ensure provider adoption of shared portals over individual portals. However, according to our informants, due to a general disinterest among providers to engage their patients online, financial incentives alone may not be enough to drive the widespread adoption of patient portals. Instead, by making online engagement tools a market differentiator, patients themselves may ultimately be the driving force behind patient portal adoption.

Hence, a focus on patient value will be imperative to drive the development of patient portals, and more importantly, to realize the outcomes possible through the use of portals [40]. If the patient portals do not deliver sufficient functionality and meaning to patients, they will likely not be able to generate traction among patients, caregivers, and healthcare consumers to create the necessary demand. Further, if the portals do not adequately engage patients, patients may not capitalize on their online capabilities to spur quality, efficiency and patient safety outcomes envisioned in the EHR Incentive Program.[41] Patient engagement is dependent on patients' perceptions that portal services enrich their current care and patient-provider relationship.[42-43] Thus, identifying ways to optimize and embed patient-valued portal capacities and functionalities into their healthcare services is crucial to achieving desired

outcomes, since achieving these outcomes rely on patients to co-produce the outcomes by appropriately using the services.[44] We have argued that portals that cross providers to give patients only one highly connected portal have the highest value to patient. The improvement of certain process and health outcomes is especially critical for patients with complex or chronic conditions who receive care from multiple providers and who account for an increasingly large part of the burden of disease.[45] Indeed, these patients will likely benefit most from a shared portal that allows them to interact and access information from their entire network of providers.

### **Policy recommendations**

Due to the importance of patient interest and engagement for the success of the program, an important question is whether the prevailing patient portal development that emphasizes provider-centric benefits will lead to portals that rouse the necessary patient demand. We argue that optimizing patient value should be a prime principle underlying efforts to promote online patient engagement in the third stage of the MU program, which is set to start in 2017. The Stage 3 program specifications are now under development, informed by the experience of twelve Agency for Healthcare Research and Quality funded projects that will propose relevant revisions to the program's overall objectives and specific measures [46]. In the following, we point to some MU Stage 3 program features identified in our research that could enhance the feasibility and success of HIE-sponsored portals, including Stage 3 financial incentives, guidelines, and technical requirements.

Shared portals can be promoted through financial incentives that further reward connectivity by strengthening incentives to portals that cross multiple providers. According to one HIE director, "MU3 ought to focus on giving the patients just one portal". The degree of connectivity will also benefit from financial initiatives aimed at increasing the overall rates of HIE participation; as noted earlier, the potential connectivity possible through HIE-sponsored portals may be limited unless HIE participation rates increase. Furthermore, similar incentives could be targeted towards establishing links with other data repositories, particularly the federal Blue Button[47] Developed as part of the ONC's Standard and Interoperability framework, Blue Button gives, among others, veterans and Medicare beneficiaries access to their electronic records and the ability to transmit them to other providers or family members.[48] A link with Blue Button may enhance the value of portals by providing a critical mass of data and thus higher connectivity of patient information in a state or region.

Guidelines and other technical and organizational support mechanisms could assist other

organizations and networks in developing shared, untethered portals, and thereby mitigate some of the challenges faced by the pioneering HIEs. Specifically, the existing ONC specifications for reporting MU poorly match the HIE situation, and further guidance on how to create accurate reporting formats could facilitate this process. Similarly, solving issues around patient matching could also increase the likelihood that providers will adopt HIE-sponsored portals. More generally, such initiatives can be supported by the creation of a HIE collaborative, specifically aimed at disseminating and exchanging successful innovations from HIEs that are developing and implementing patient portals.

Technical requirements could focus on features and capabilities that enhance the functionality of untethered portals to patients. In addition to promoting further integration with providers' EHRs, this could entail giving patients access to more sections of their medical record or more options to interact with providers. Moreover, but likely further down the line, portals could leverage on mobile technology to allow for integration with various wellness and health management applications that could further personalize the portal services. On a more urgent note, the ONC's proposed certification requirements for 2015 [49], which involve revoking the 'complete EHR' certification in favor of a more modular approach, should be effectuated to level the playing field between tethered and untethered portals.

Finally, on a broader level, in consultation with patient representatives, the ONC, CMS and the patient portal-developing HIEs could engage in a dialogue to define realistic targets for developments and outcomes of the HIE-sponsored portals and weave time-specific goals into forthcoming ONC/CMS strategies.

## **Limitations**

This study has a number of limitations. First, our principal findings and policy recommendation are based on experiences of a small number of HIEs. However, these HIEs represent the first ones developing patient portals to take part in MU in early 2014. Second, only early results from MU implementation on HIE portal development are assessed at this time. In fact, only one of the HIEs had a fully operational portal at the time of study, whereas the other three were in the implementation or pilot phases. Thus, a follow-up study two-three years from now would be relevant to understand the longer-term effects of the MU program on patient portal development, adoption, and use. Third, since we do not have information from patients, our results are constrained to the perceptions of the barriers and facilitators of patient portal development from HIE manager's perspective. A follow up study could benefit from including patient users and non-users as research subjects.

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# CHAPTER 6

*Can relational coordination help inter-organizational networks overcome challenges to delivering patient portals?*

An adapted version of this chapter was submitted as:

Otte-Trojel T, Rundall T, de Bont A, van de Klundert J. Can relational coordination help inter-organizational networks overcome challenges to delivering patient portals?

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## ABSTRACT

**Purpose:** Delivering comprehensive patient portals in fragmented delivery systems depends on coordination among a network of health service organizations. However, such inter-organizational coordination is fraught with challenges, mainly due to a lack of organizational, technological and geographical proximity between network participants. These challenges may complicate coordination and lead to high coordination costs. This paper assesses the extent to which application of Relational Coordination Theory can ameliorate these challenges.

**Design/methodology/approach:** We conducted a conceptual analysis of the usefulness of Relational Coordination Theory and the applicability of the Relational Model of Organizational Change to patient portal networks. The analysis draws upon literature on inter-organizational coordination, and relational coordination in particular.

**Findings:** Relational Coordination Theory is applicable to patient portal networks and the Relational Model of Organizational Change may ameliorate the identified challenges. However, some organization redesign interventions posited to strengthen relational coordination in intra-organizational contexts may not be directly applicable to patient portal networks.

**Practical implications:** We propose three hypotheses regarding relational coordination, organizational and technological proximity, and the cost of coordination in portal networks. If future empirical research supports these hypotheses, portal network leaders should implement organizational design and other changes as suggested by the Relational Model of Organizational Change and as appropriate in their network's context to strengthen relational coordination.

**Value:** This analysis contributes to the understanding of Relational Coordination Theory by assessing the extent to which the theory can be extended to inter-organizational collaborations and hypothesizing how relational coordination ameliorates challenges specific to inter-organizational coordination in patient portal networks.

## INTRODUCTION

Patient portals are information systems that give patients access to a personal health record and typically enable functionalities such as secure messaging with providers, appointment scheduling, prescription refill, and programs for self-management.[1] Patient portals can be developed by a single hospital or physician practice. Yet, a comprehensive portal that spans across the continuum of care requires a network of organizations, including, for example, primary and specialist physician practices, hospitals or health systems, rehabilitation facilities, nursing homes, home health agencies, laboratories, pharmacies and other entities. Such a network could be owned by a single corporate parent, be part of a formal alliance or partnership, or composed of largely independent entities.

Comprehensive patient portals have been found to contribute to improved clinical outcomes; health service utilization; patient-provider communication; patient adherence, empowerment, and satisfaction.[2] So far, these outcomes have been reported primarily in a few large and integrated care delivery networks in the United States such as Kaiser Permanente and the Veteran's Health Administration.[3] There have been few attempts to implement comprehensive portals in more fragmented healthcare system contexts. However, this is likely to change as independent healthcare organizations in many states and countries increasingly develop collaborations to improve health service delivery, for example in the form of patient-centred medical homes and accountable care organizations.[4] As these collaborations seek ways to communicate with and engage their patients, they will be likely to develop portals linking patients with the relevant network of independent service providers. Further, in many countries, patient demand, technical standards, and financial incentives, such as the Meaningful Use Program in the United States, encourage independent health service providers to collaborate to engage their patients online.[5]

We define inter-organizational collaboration as two or more organizations working with each other to perform a task and to achieve shared goals.[6] Hence, collaboration is an active, organic process among organizations committed to achieving agreed upon objectives.[7] There are well known benefits to inter-organizational collaboration. Perhaps most importantly, many tasks important to a given organization simply cannot be achieved by the actions of that sole organization. The expertise, technology and other resources of a network of organizations are required.[8] Other benefits of inter-organizational networks include sharing the cost of task work across organizations, exchanging knowledge and expertise, gaining legitimacy, and reducing inefficiencies and competition.[9] Furthermore, by pooling information and knowledge, large networks can collect and analyze large amounts of data with which to incorporate informed

quality improvements to the design and delivery of their portals.[10]

Such inter-organizational collaborations may enable the development of comprehensive patient portals that span the continuum of care in otherwise fragmented contexts. As such, they hold substantial value to patients by consolidating health information from different providers and giving patients one space to access this information. This value is particularly apparent to patients with complex or chronic conditions, who see multiple providers across multiple specialties.[11] Conversely, portals that are provided by a single or few organizations can only connect patients with a few providers. Consequently, some patients must access multiple non-interoperable, and sometimes even competing, portals to manage their health information across all their care encounters. This lack of patient functionality may discourage use, and consequently, prevent desirable outcomes such as clinical improvements and patient satisfaction.

There are major challenges to the delivery of comprehensive portals in organizational networks. Many of these challenges derive from the difficulties associated with achieving inter-organizational coordination among the organizations involved.

### **Patient portals and challenges to inter-organizational coordination**

Achieving the benefits of inter-organizational collaboration requires coordination across boundaries of independently operating and diverse organizations.[12] The development of patient portals typically takes place in a continuous improvement cycle. Portals are constantly evolving based on evaluations of functionality, use, and effects.[13] In addition to agreeing on the portal system and vendor and determining the role and responsibilities of the involved organizational members, delivering a portal requires numerous steps, including continuously seeking integration with workflow, establishing compliance with regulations, implementing the system, training staff, organizing for patient enrolment, and monitoring usage and effects.[14] Successfully accomplishing each step requires key participants to agree on a number of decisions. In the workflow integration step, decisions concern timeliness of response, the breadth of providers who should receive and respond to patient inquiries, accountability arrangements, availability of technical support to providers, and, more generally, embedding the portal into care delivery (e.g. [15]). Establishing compliance with regulation raises a number of questions. For example, who should have access to a minor's health record, what information should be made visible to patients who owns the data, and should consent for exchanging data be obtained? (e.g. [16]) Decisions surrounding system implementation relate to issues such as the preferred degree of outsourcing, agreeing on a project management plan, and training staff to possess needed qualifications (e.g. [17]). Decisions concerning patient enrolment revolve

around defining target groups, marketing the portal, and setting up secure authentication and registration procedures (e.g. [18]). Finally, upon implementation, the portal's use and performance should be monitored to allow for continuous improvements including ongoing tasks of upgrading existing features, adding capabilities, and adjusting care processes.[19] Carrying out activities along these steps within a network of independent providers requires extensive inter-organizational coordination.

For each of these steps, healthy and ill care recipients and their informal caregivers (we refer to such 'patient stakeholders' simply as patients) are a valuable source of feedback, not only in using the portal but also in evaluating and suggesting improvements to enhance its degree of patient-centeredness.[20] Achieving portal effect depends on patients becoming empowered coproducers, thereby igniting potential benefits of better-engaged, informed and satisfied patients.[21] In a worst-case scenario, a portal that fails to meet patient's needs and wishes - for example due to the disruptive nature of fixes and upgrades or poor embedding into the care they receive - can cause frustration and dissatisfaction among patients that prevent their adequate and appropriate engagement. Consequently, the inter-organizational coordination required to deliver a portal occurs throughout portal development, implementation and daily operation and should be achieved through the efforts of the clinical and managerial staff of the organizations involved as well as the patients served by the portal.

Numerous definitions of inter-organizational coordination have been proposed in the literature. The breadth of organizational action encompassed by these definitions varies considerably. For example, inter-organizational coordination has broadly been defined as 'organizations' spontaneous mutual adjustment to their environments', while a more narrow definition is 'controlling organizations' decisions so as to concert their action and achieve mutually beneficial outcomes'.[22] Generally speaking, inter-organizational coordination refers to the extent that a given organization adjusts its behaviour to take into account the actions of one or more other organizations in its network. Regardless of the exact definition used, efforts to achieve inter-organizational coordination are fraught with challenges that must be overcome if the collaboration is to be successful.[23] Moreover, since patients are central to realizing the value of portals, properly engaging patients to coproduce services and effects adds to the challenges of inter-organizational coordination in portal networks.

Knoben & Oerlemans [24] conducted a review of literature on the influence of various dimensions of proximity to the workings of inter-organizational networks. They concluded that three dimensions of proximity are important to such networks: organizational, technological and geographical. Based upon this review, we consider effective coordination in networks formed to

offer patient portals (from now referred to as portal networks) to be challenged by lack of proximity among the network participants along these three dimensions.

**Lack of organizational proximity.** According to Knoblen & Oerlemans, organizational proximity covers dimensions such as cognitive, institutional, cultural and social proximity, and is defined as ‘the set of routines – explicit or implicit – which allows coordination without having to define beforehand how to do so.’ Organizations in the portal network may share only little organizational proximity; participants may have different expertise, professional languages, cultural understandings, and procedures for carrying out tasks. Such differences may result in conflicts and communication difficulties that impede task coordination.[23,25] Shared decision-making may be further complicated if participants see different solutions to problems based on their values, past experiences, or perceived position in the network.[26] With respect to the latter, as any other network, portal networks likely have power imbalances that may cause incongruent expectations of what the coordination demands of each organization, thereby posing a source of conflict and disrespect between organizations.[27] Moreover, although typically the portal network is created by contractual agreements that define overall shared goals, each organization also has performance goals and managerial motivations that may conflict with the network goals.[28] Depending on the organization, these goals and motivations could focus on increasing financial returns, increasing productivity, improving patient outcomes, or other organizational objectives. As organizational leaders prioritize such goals and seek ways to achieve them, their priorities and methods may misalign and give rise to conflict.[29] Further, some organizational goals may remain undisclosed, complicating transparent decision-making in the network.[26] In addition to aligning with the goals and motivations of the network participants, the portal should also adequately match the needs and wishes of the target patient population(s) served by these organizations. This inclusion of the patients – for example directly through board representation and usability panels or indirectly through market research - may likely further augment the coordination challenges, as the ‘patient perspective’ also inserts its influence on the process, for example by suggesting suitable functionalities and usage requirements.

**Lack of technological proximity.** The definition of technological proximity that stems from the review is “the level of overlap of the knowledge bases of two [or more] collaborating actors”.[24] Organizational participants may have little knowledge of the work performed in the other organizations in the network and how this work contributes to the completion of shared tasks.[30] They may also have little knowledge about the patients shared by the network, as recorded in the organizations’ information systems and communicated via the portal.

Consequently, the organizations' information systems are also part of the knowledge base and thus of the technology to which the proximity applies. Yet, information system infrastructures may vary across organizations in the network. Effective coordination may therefore require either developing a shared information system or obtaining interoperability between existing systems.[5] The first of those solutions requires establishing a common platform in the shape of a network-wide electronic health record. The second solution requires setting up means for exchanging information among various electronic health records, for example facilitated by regional or, if possible, national Health Information Exchanges.[31] Also, some organizations may initially be less capable of performing required tasks, such as knowledge transfer and management. Thus, considerable efforts may be needed to align knowledge, infrastructures and competencies to ensure that patients experience a cohesive service. Again, the centrality of the patient experience inherently necessitates inclusion of the patient. There is likely to be great variation across the relevant patient population with respect to understanding how the portal can assist them in managing their care as well as possessing the required digital literacy skills. Thus, portal networks must take this variability into consideration by creating capabilities and interfaces that are not too technologically complicated for those patients with little knowledge of how electronic information and communication systems in health care organizations work, while providing the more sophisticated patient user with the capabilities (such as apps) and options (such as mobile and/or tablet access) they will find useful.

**Lack of geographical proximity.** Geographically proximity is “the extent to which two [or more] collaborating actors can have daily face-to-face relations without prohibitive costs”.[24] Portal networks consists of various organizations, including primary and specialist physician practices, hospitals or health systems, rehabilitation facilities, nursing homes, home health agencies, laboratories, and pharmacies. Even though the network might often be confined to a region or community, the organizations are separate entities with at least some geographical distance between each other. Further, given the reliance on information technology that characterize the network, typically, people working with portals make their contributions from within their own organizations such as securely emailing with patients and uploading content to an electronic health record. This may hinder planned and unplanned interpersonal interactions across organizational participants in the networks. A similar distance may be observed with respect to patients that are typically nested in the local or regional community and who may only be in contact with their providers in the event an in-person visit is called for.

The challenges stemming from lack of proximity along these three dimensions may complicate coordination. Overcoming the challenges entails considerable costs, including staff time required to maintain the portals' information base, establish means of exchanging patient information, developing the portals' capabilities, establishing roles and responsibilities, all the while including patients to ensure a patient-centred portal.[32] Further, coordination between organizations implies increased accountability, since organizational members are accountable to other organizations in the network as well as their own organization's governing body.[27] Robust accountability structures may be especially important in portal networks given the liability risks involved with handling sensitive patient information. Due to increased accountability, organizations and their members may give away autonomy in decision-making, which can lead to costly delays in work processes.[29] This sacrifice of autonomy may also be observed in the patient-provider relationship, as patients gain more insight into information and tools to manage their care.[33] Some networks may not be able to overcome these challenges, or the challenges may result in coordination costs that some organizations are not willing or able to pay. This cost of coordination may be particularly high in newly formed networks, in which organizations have yet to build trusting work relationships.[34]

## **Study aim**

These challenges to coordination may impede the development and performance of patient portals developed by networks of health service providers in interaction with their patients. As such, this paper highlights coordination as a precondition for effective portal development. Due to the likely enhanced role of inter-organizational collaboration in the development and use of portals, understanding how to manage the coordination of work within such collaborations, and ameliorating the challenges they face, is important and timely. The aim of this paper is to assess the extent to which application of Relational Coordination Theory can ameliorate these challenges.

We focus on a relatively new promising theoretical model of organizational coordination, Relational Coordination Theory (RCT). The theory has been empirically tested in a variety of organizations, primarily health care delivery organizations in the United States and Europe, and has consistently been found to be positively associated with organizational performance. Motivated by this promise, we critically assess the potential of this theoretical framework to improve coordination among organizations that collaborate to offer patient portals that meet patients' needs and wishes. In particular we assess the extent to which RCT can help ameliorate the challenges to effective coordination in portal networks caused by lack of

organizational, technological and geographical proximity among network participants.

## CONCEPTUAL FRAMEWORK: RELATIONAL COORDINATION

Jody Gittell introduced the concept of relational coordination (RC) in 2000, defining it as a “mutually reinforcing process of interaction between communication and relationships carried out for the purpose of task integration”.[35] RC is believed to be especially important in the coordination of work contingent on high task interdependencies, uncertainty and time constraint, which emphasize the need for mutual adjustment.[36]

These contingencies apply to the work performed to develop a portal and to use it to deliver care to patients. First, mutual interdependencies exist since the actions of one participant rely on the input of others to the portal. Interdependencies can occur when various organizations upgrade their information systems, thereby requiring similar upgrades in other parts of the network to ensure interoperability.[19] They can also emerge, for example, in the coordination of online consults where both the physician and the patient have access to clinical notes from previous health episodes and test results. In such situations, the quality of the consultation relies on the accuracy and comprehensiveness of this information entered by other health service providers.[37] Second, dealing especially with patients with complex conditions involves some uncertainty, for instance when physicians or physician extenders triage and respond to patient requests for online consultations.[38] In such situations, decisions must be made about which types of patients and which types of health conditions could be handled by the nurse practitioner, and which should be referred to the patient’s general practitioner or specialist physician. Further, as we have previously highlighted, there may be differences in patient preferences for online services and the ways patients utilize these services.[39] Third, some tasks must be performed under time constraint, since the timeliness of inputs that are entered in and exchanged via information systems is important for the quality of the portal services. An example is the timing of the posting of a test result, which must be submitted from the laboratory to the portal before a patient’s online consultation with a specialist where the results will be discussed.[19]

Further, we have also argued that properly engaging patients signifies an additional characteristic of the work performed to effectively develop and operate a portal. The RCT framework extends to such reciprocal interrelating between ‘worker’ and ‘customer’.[40] More specifically, the theory posits that embedding relational processes into the interaction between patients and providers can foster attentiveness to the situation and to one another. The result can be improved patient engagement in “coproduction tasks that are critical to achieving

desired health outcomes when performed in cooperation with the care provider team”.[35] RCT points to an interaction between RC and relational coproduction: the higher the degree of RC within the network of providers, the better their ability to engage in relational coproduction with patients. At the same time, the degree to which patients engage in relational coproduction may make visible the lack of RC in the network and incentivize network participants to improve it.[40]

Hence, the work performed to develop, implement and use a patient portal is consistent with the nature of organizational work for which its developers believe RCT is applicable. The mutual adjustment that is enabled by improved RC may help portal networks manage these complexities, and RC thus seems to be a suitable theoretical framework for understanding and managing such networks. In the following, we outline the dimensions of RC and how they can be shaped. We then review the empirical evidence connecting relational coordination with organizational performance within and between organizations.

## **Dimensions of RC**

Relationships and communication are integral to the process of coordination. RCT builds on an understanding that relationships influence the frequency and quality of communication, which in turn influence the quality of relationships.[36] In fact, “this mutual influence between communication and relationships lies at the heart of relational coordination”.[41] The three relationship dimensions are shared goals, shared knowledge and mutual respect, and the four communication dimensions are frequent, timely, accurate and problem-solving communication.

The first relationship dimension is shared goals. Shared goals that transcend organizational participants’ specific functional goals are crucial to facilitating collective and coordinated responses from participants. Effective coordination therefore depends upon a high level of shared goals for the specific work processes since shared goals motivate participants to move beyond sub-goal optimization and to act with regard for the overall work process.[42] The second relationship dimension crucial to coordination is shared knowledge. Coordination relies on interaction among organizational participants with different cultures, disciplines, and expertise. Shared knowledge allows these participants to understand how their specific tasks relate to the overall work process. Further, cultural and professional differences between participants involved in a work process may foster dissimilar ‘thought worlds’. Thus, shared knowledge about the elements of the work process is important for participants to make effective contributions to the work process. The third relationship dimension is mutual respect. Coordination often entails bringing together organizational participants with different

professional identities who belong to different occupational communities. Participants from such different communities may perceive their own role in the coordination process, and their manner of handling tasks in this process, as superior. Such different philosophies can foster disrespect for others, which cause division among participants with different roles and responsibilities. Consequently, improving respect for the competence of others is necessary to overcome professional status barriers to effectively coordinate work processes.[41]

RCT specifies four dimensions of communication that are critical to enhancing performance. The first communication construct is frequent communication, which is believed to support the development of high-quality relationships by fostering understanding and familiarity between organizational participants with different organizational backgrounds and tasks. Second, timely communication is important to decision-making and service delivery as it enables participants to coordinate work based upon up-to-date information. Third, to be helpful, the information must be accurate. Fourth, communications that have a problem-solving character foster constructive, respectful and blame-free communication practices among participants from different cultural backgrounds and disciplines.[42]

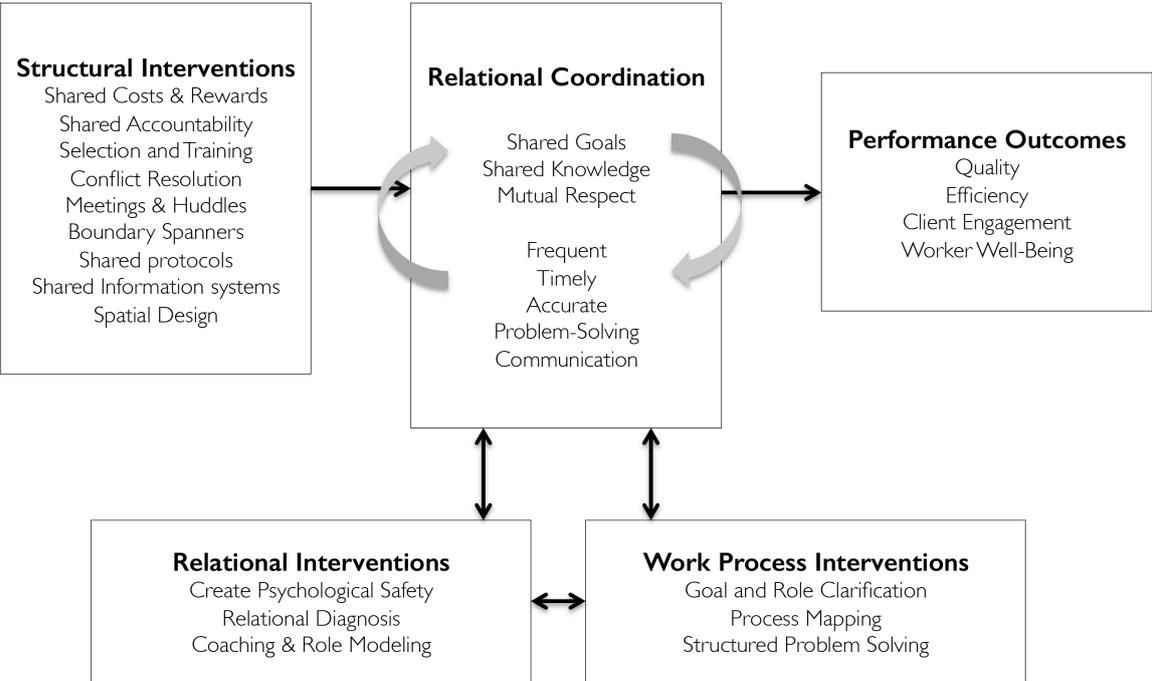
### **Shaping RC: the Relational Model of Organizational Change**

These theoretical ideas lay the basis for a model, the Relational Model of Organizational Change (RMOC), which encompasses a set of interventions aimed at stimulating RC through organization redesign. The model's core premise is that RC is shaped by organizational structures: structures that reinforce functional silos hinder RC and structures that foster cohesiveness and awareness of the work of others stimulate it.[43] As such, the RMOC suggests redesigning organizational structures and practices to strengthen shared goals, shared knowledge, mutual respect, and the important forms of communication by breaking down functional and organizational barriers to coordination.[44] Notably, as explained above, this also involves improving the capacity for relational interrelating with patients to enable coproduction of portal services and effects.

Organization redesign at the structural/systemic level includes interventions such as selecting participants based on their capacity for cross-functional teamwork, constructing measurement and reward systems based on team performance across functions, and creating venues for proactive cross-functional conflict solution. According to the model, structural/systemic interventions should be accompanied by relational interventions and improvement methods. Relational interventions focus on creating psychological safety, coaching and role modelling as well as giving feedback to organizational members about how they score

on RC metrics. Improvement methods can be quality and efficiency improvement processes, process mapping and structured problem solving.[41] The RMOC, which outlines interventions at each of these levels, is illustrated below.

**Figure 1:** Relational Model of Organizational Change



**Evidence on RC’s effect on organizational performance**

Over the past fifteen years, several studies have measured RC in collaborations between people and examined its impact on work performance and outcomes within and between health services organizations.

Evidence from intra-organizational collaborations - RC has consistently been found to improve the quality and efficiency of work processes in intra-organizational collaborations characterized by organizational, technological and geographical proximity. In a large study of hip and knee surgery, RC between physicians, nurses, physical therapists, social workers and case managers within the same hospitals was correlated with patient-perceived quality of care, postoperative pain and functioning as well as length of stay.[45] This study was the first to demonstrate the impact of RC on efficiency and quality of care, but several subsequent studies have corroborated this relationship. Two studies found that higher degrees of RC in cross-functional teams within hospitals were associated with improved quality of health care delivery.[46-47] The former study found that higher levels of RC across functional groups

working to provide integrated care to elderly patients led to increased quality of integrated care delivery. The latter study, which measured the degree of RC between nurses and other provider groups, found that as RC increased, the number of hospital acquired infections and medication errors decreased. Further, self-assessed degree of RC among nurse managers in acute hospitals has been found to be positively correlated with enhanced engagement of these nurses in their work.[48] Nurses who reported a high degree of RC were more likely to consider their job meaningful and that they possessed the job and personal resources required to tackle the demands of their job. Gittel and colleagues also assessed the effect of RC on nurse job satisfaction and residents' quality of life within 15 nursing homes [49], and found a positive relationship between the level of RC and both outcomes. The higher job satisfaction was believed to derive from instrumental benefits for performing tasks and from intrinsic benefits for fostering positive relationships with others. The presence of RC between formal and informal caregiver has also been demonstrated to improve the capacity of the informal caregiver to provide care for discharged patients.[50] A recent study studied the correlation between RC within primary practices and the presence of elements of the Chronic Care Model.[51] The authors found a positive relationship, which they argued might be mediated by reciprocal learning within the practice.

Evidence from inter-organizational collaborations - In comparison to the evidence from intra-organizational collaborations, the application of the theory on coordination between people in different organizations has been meager. We identified two peer-reviewed studies that address RC in an inter-organizational context. First, Bond and Gittel [52] employed RCT to offender re-entry, arguing that successful re-entry necessitates coordination among multiple independent organizations from different sectors. The study, however, did not reach conclusive results about the impact of RC between organizations and re-entry outcomes. Second, Cramm and Nieboer [53] measured the level of RC between people from different organizations who worked together to deliver chronic care in the context of some specific disease management programs. In support of the significance of RC on inter-organizational networks, this study found that RC between people in these organizations was positively associated with components (but not outcomes) of chronic care delivery including self-management support, community linkages, decision support, delivery system design, and information systems.

## FINDINGS AND DISCUSSION: USEFULNESS OF RC AND APPLICABILITY OF THE RMOC ON PORTAL NETWORKS

In fragmented health system contexts, the delivery of comprehensive patient portals requires collaboration among various health service providers and organizations. However, thus far, we observe a lack of reported outcomes from portals in such networks.[3] To improve their outcomes, a relevant question is whether the positive impact of RC on intra-organizational performance extends to the inter-organizational context. Yet, the scarce empirical evidence does not support straightforward extensions of RCT to inter-organizational performance. Hence, we conducted a conceptual analysis of the theory to inter-organizational networks of health-related organizations attempting to coordinate tasks in delivering a portal.

### **Usefulness of RCT on portal networks**

In the following, we provide theoretical justifications for the usefulness of RCT to portal networks by considering how strengthening dimensions of RC may mitigate challenges associated with lack of organizational, technological and geographical proximity among participants in the network.

Lack of organizational proximity - Organizational proximity supports shared norms, goals and respect between people; something that may be less pronounced among participants in an inter-organizational network. We propose that RC may be able to bring the organizational participants closer by stimulating shared goals and mutual respect among participants.

First, organizations in a portal network typically differ with respect to expertise, professional languages, and cultural understandings, which may complicate agreement on shared goals. For example, some participants may focus on administrative capabilities (such as online appointment scheduling) aimed at improving organizations' operational efficiency, while others may emphasize patient education (such as insight into lab results and care plans) aimed at improving the role of patients in their care. RCT proposes ways to foster such shared short and long-term goals among participants, for example by embedding shared reward systems into the organizational structure or by applying relational intervention methods aimed at clarifying participants' goals and roles. These processes are likely to benefit from frequent and timely communication between participants concerning their goals and motivations as they may change over time.[54] Participants may be willing to adjust their goals and motivations if they are committed to the network, as commitment encourages participants to incur short-term sacrifices to demonstrate their reliability and to enhance the performance of the network.[55] Articulation of shared goals may be particularly important in competitive environments where it

takes a clear and mutually reinforcing business case, emphasizing benefits of economies of scale, to bridge oftentimes competing agendas.

Second, differences in expertise, professional languages, and cultural understandings may also result in conflict and disrespect between organizational participants. Disrespect could possibly occur between specialized hospital physicians and administrative staff in primary care practices, who differ considerably in their responsibilities and professional backgrounds. RCT suggests imbedding conflict resolution practices into the structure of the collaboration, and enhancing this through relational interventions that promote psychological safety and improvement methods focused on structured problem-solving. Further, by selecting and training for teamwork, participants are likely to have experiences and personalities supportive of cross-functional and cross-organizational work. The evidence base on the correlation between mutual respect and collaborative performance is considerable (e.g. [56]). For example, in a review of empirical studies, Mattessich and Monsey [57] found mutual respect to be one of the most important relationship components underlying effective collaboration.

Lack of technological proximity - Technological proximity refers to the extent to which organizational participants' knowledge bases overlap and their corresponding ability to transfer knowledge bases and learn from each other. Among the coordination challenges in a portal network may be the adequate transfer of information and knowledge. As an example, one could think of the capacity of the network to capture participants' practical experiences with using the portal and translating them into lessons, for example related to effectively embedding portal services into case management of a specific patient group – something that may have profound implications for the effectiveness of the portal.[2] By promoting shared knowledge among network participants, RCT may be instrumental in mitigating challenges caused by lack of technological proximity. According to the theory, knowledge sharing can be improved through structural mechanisms such as meetings and shared information systems, or through relational interventions designed to identify and level differences in quality or performance. The ability to share knowledge and information has significant effects on collaborative performance, for example by breaking down information asymmetry and facilitating joint conflict-solving arrangements.[58] Especially transfer of tacit knowledge between participants is important in networks characterized by cultural and professional dissimilarity, and in which partners lack a common understanding of non-explicit information by bridging cultural differences and promoting shared understandings.[54]

Lack of geographical proximity - In contrast to the two dimensions addressed above, RC can do little to directly mitigate challenges linked to geographical distance between

organizational participants. That being said, the effects of establishing good relationships and communication practices (including through email and telephone) is likely to make the interaction between organizational participants more fruitful whenever they do meet.

In the above, we have argued that RC mitigates challenges caused by distance along the organizational, technological (and geographical) dimensions. This in turn enables network participants to mutually adjust their work to manage complexities associated with interdependence, uncertainty and time constraint. Further, to the degree it supports relational coproduction, RC may help ensure that the portal develops in accordance with the needs and wishes of patients and is adequately and appropriately used to achieve desired effects. We recall how RCT posits that RC positively influences a portal network's ability to establish coproducing relationships with patients. More specifically, patient coproduction will depend on whether patients understand the benefits associated with using a portal, whether they are able to use it to realize these benefits, and whether they trust that their providers securely handle their personal data or that use of virtual features will not degrade their relationship with their providers.[33] Transferring such elements of shared goals, knowledge, and respect to patients requires mutually supporting efforts among network participants enabled by RC.[21]

We further assert that through building trust, the high-quality relationships enabled by RC reduce the need for formal, restrictive governance mechanisms such as monitoring and contracts.[59] In turn, this reduced need for formal governance mechanisms may lower the costs involved with coordination.[60] Hence, while we do not argue that RC can substitute entirely for formal governance mechanisms, we do believe it may reduce networks' reliance on such mechanisms and thereby enable effective collaboration that would otherwise be costly or impossible.[61]

Based upon this analysis, we propose three hypotheses:

- Hypothesis 1: The greater the level of RC in an inter-organizational portal network, the greater the organizational proximity.
- Hypothesis 2: The greater the RC in an inter-organizational portal network, the greater the technological proximity.
- Hypothesis 3: The greater the organizational and technological proximity, the lower the costs of coordination in an inter-organizational portal network.

## **Applicability of the Relational Model of Organization Change to portal networks**

We have presented theoretical justifications in support of the theory's usefulness to portal networks, which have led to the formulation of three hypotheses about how RC can improve inter-organizational coordination. However, an important question is whether inter-organizational collaborations, such as portal networks, actually do lend themselves to organization design interventions consolidated in the RMOC. According to the founders of RCT, this is the case, as "organizational design can be leveraged to strengthen coordination networks by extending their purview from internal parties to encompass external parties".[30] In fact, according to Gittel and Weiss, interventions that promote RC may be important to cope with increasing integration in health care that requires coordination among mutually interdependent organizations.

However, despite its proposed applicability, a fundamental difference between intra- and inter-organizational collaborations – the difference in geographical proximity - may affect the applicability of the RMOC to portal networks. Thus far, the vast majority of RC studies are from intra-organizational settings. In these studies, research subjects have been individuals on the frontline of care who have frequent interpersonal interaction, such as nurses, physicians and other providers within the same organization. This stands in contrast to portal networks in which most daily tasks are carried out from within each organization. Further, in these networks, most communication between participants may primarily occur through telephone or email and in-person interaction may take place with large intervals. The lack of geographical proximity limits the frequency of interpersonal contact among network participants as well as between network participants and patients. It is likely that this difference in the intensity of interpersonal interaction affects the opportunity for developing RC with the RMOC, particularly the redesign interventions that implicitly assume physical proximity. For example, portal networks may have little opportunity to use meetings/huddles and spatial design to strengthen RC.

Nonetheless, there are interventions that are not dependent on frequent interpersonal interaction between participants. In addition to protocols, information systems, meetings and boundary spanners, structural interventions could be employee selection and training for teamwork, establishing shared accountability for outcomes as well as shared costs and rewards. Also, relational interventions, such as providing feedback to network participants regarding protocol performance metrics, and other improvement methods such as goal and role clarification activities may be able to compensate for the inability of participants to engage in frequent face-to-face interaction and enable portal network participants to develop the routines

of mutual adjustment inherent in RC.[43] Also, new structural and relational inventions may come into play, which are not significant at an intra-organizational level, and not currently contained in the RMOC. For instance, networks may be able to develop financial alignments such as reimbursement schemes that reward participants for achieving network-level performance measures. Other interventions could include personnel rotation, inter-organizational process definitions, performance indicators that take account of inter-organizational performance, and cross-organizational social and professional events. More generally, new forms of communication technology such as Video Conferencing appear to increasingly substitute for geographical proximity, and could also be taken into account in the model.

Furthermore, the difference in interpersonal interaction between participants in intra- and inter-organizational networks may affect the development of RC beyond what is instigated by RMOC interventions. Frequent interpersonal interaction may foster relational capital [62], a form of social capital embedded in relationships. Relational capital is the trust, friendship and respect that comes of continuous interaction at the interpersonal level, and may be a core relationship resource that enables individuals in organizations to manage the “balance between trust and distrust and conflict between their respective organizations”.[63] As a powerful relationship resource between participants that work closely together, relational capital may thus be a supporting mechanism for developing shared goals, knowledge and respect in collaborations. Therefore, due to the physical distance among participants in portal networks, these may not benefit from this possible synergy between the effect of relational capital and the effect of RMOC interventions. Rather than losing importance, we posit that RC may be even more crucial in inter-organizational settings by promoting high-quality relationships that would otherwise not occur.

With this analysis, we question the (direct) applicability of the RMOC to portal networks. Hence, we argue that the model should be tested and possibly adapted to allow for such application. This could be done by implementing RMOC interventions in portal networks and measuring corresponding effects on network performance. Provided that our hypotheses about how RC can improve coordination in portal networks hold true, sharpening the model to such settings can have positive implications for patient portals. Such future lessons regarding the improvement of coordination in portal networks can also be transferable to inter-organizational collaborations with other purposes. For example, although different in the content of the activities that need to be coordinated, establishing a Health Information Exchange network may also likely benefit from RC capacities among vested parties.

## CONCLUSION

Achieving outcomes through patient portals depends on offering a valuable set of services to patients. Comprehensive portals that connect patients with all their health service providers potentially hold the highest patient value, since these portals may succeed to offer patients a single access point to their consolidated information and to connect with their array of providers. In fragmented health systems, developing such comprehensive portals necessitates collaboration among multiple health service providers. Yet, coordination of tasks among providers in such inter-organizational networks brings about several challenges due to lack of organizational, technological and geographical proximity. We have argued that the success of patient portals depends on managing such challenges and fostering effective coordination within the network.

We have examined the usefulness and applicability of a relatively new theory, RCT, to improve coordination within portal networks. The theory has consistently been demonstrated to enhance performance within organizations, while it has been less tested in inter-organizational settings. We have presented theoretical justifications and limited empirical evidence in favour of the relevance of the theoretical framework to portal networks and proposed three hypotheses. These hypotheses state that RC may mitigate challenges caused by lack of organizational and technological proximity, and thereby reduce the cost of coordination in portal networks. The Relational Model of Organizational Change, which intends to improve RC through organization redesign, may therefore be important to managing inter-organizational coordination in the context of patient portals. However, the organization design interventions that can improve RC within organizations may not be directly transferable to portal networks. This is mainly due to physical distance and infrequency of interpersonal interaction, which may restrict the applicability of the (non-adapted) model. Since achieving portals outcomes may increasingly rely on collaborations between health service providers, a test and possible adaptation of the model is pertinent. As inter-organizational health service networks gain importance, so does an advancement of RCT and a corresponding model of inter-organizational change.

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# CHAPTER 7

## *What do we know about patient portal development? A systematic review of the literature*

This chapter was accepted for publication by the Journal of the American Medical Informatics Association as:

Otte-Trojel T, de Bont, A, van de Klundert J, Rundall T.  
What do we know about patient portal development?  
A systematic review of the literature

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## ABSTRACT

**Objective:** Numerous articles have reported on the development of patient portals, including development problems and solutions. We review these articles to inform future patient portal development efforts and to provide a summary of the evidence base that can guide future research.

**Materials and methods:** We performed a systematic review of the relevant literature to answer five questions: (1) What categories of problems related to patient portal development have been defined?; (2) What causal factors have been identified by problem analysis and diagnosis? (3) What solutions have been proposed to ameliorate these causal factors?; (4) Which proposed solutions have been implemented and in which organizational contexts?; and (5) Have implemented solutions been evaluated and what learning has been generated? Through searches on PubMed, ScienceDirect and LISTA, we included 109 articles.

**Results:** We identified five main problem categories: achieving patient engagement, provider acceptance, appropriate data governance, secure infrastructure, and sustainable business model. Further, we identified key factors contributing to these problems and well as solutions proposed to ameliorate them. While about half (45) of the 109 articles proposed solutions, fewer than half of these solutions (18) were implemented, and even fewer (5) were evaluated to generate learning about their effects.

**Discussion:** Due to the lack of evidence on patient portal development processes, our review does not enable formulation of concrete suggestions to inform health care organizations about how to develop portals. However, our findings support a set of recommendations for how the evidence base can be advanced.

## BACKGROUND AND SIGNIFICANCE

A patient portal is a secure web site through which patients can access personal health information and typically make use of several communication, self-management and administrative functionalities.[1] Although patient portals may differ across organizations, most include provisions to capture personal health information, provide linkages to convenience tools such as online appointment scheduling, and communication tools such as secure messaging with health service providers.[2] Patient portals have been found to improve patient health and organizational performance as evidenced by better disease management, patient satisfaction, and enhanced administrative efficiency.[3-7] Patient portals have been introduced in different types of organizational settings including independent hospitals and physician practices, networks of practices, and larger integrated delivery systems.[8] Up until recently, most patient portals were implemented and used within integrated care delivery systems, which have the structure and resources to support internal development and maintenance as well as continuing implementation and deployment efforts.[9] However, now, in response to the Meaningful Use (MU) program and similar national policy efforts to advance use of health information technology, patient portals are increasingly being implemented in a variety of healthcare delivery contexts, including accountable care organizations and multispecialty provider practices.[10-11]

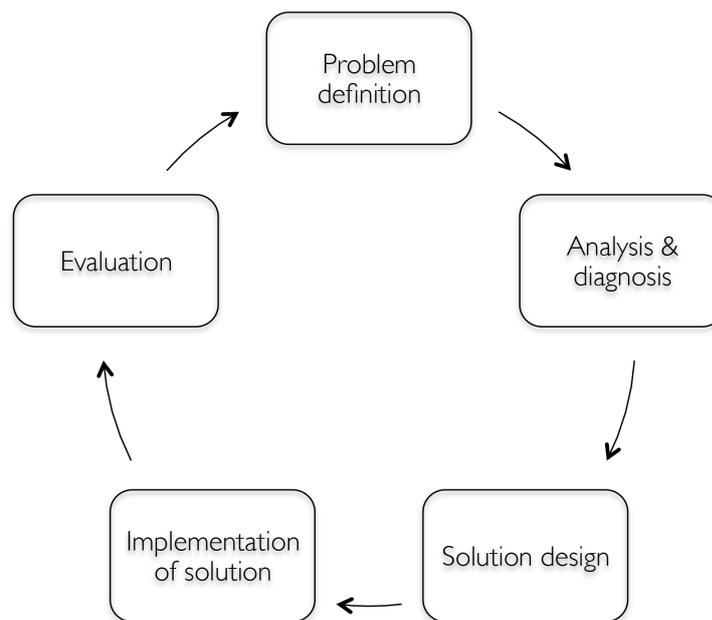
A rapidly growing body of scientific literature addresses the development of patient portals as well as the associated problems regarding, for instance, implementing required hardware and software; establishing portal content and capabilities; and achieving physician commitment and patient engagement, interoperability across providers, regulatory compliance, and financial sustainability in a variety of contexts.[12-13] In addition to addressing these patient portal development problems, some studies have identified, implemented, and evaluated possible solutions. Due to the increasing interest in portals in various healthcare delivery contexts, the time is now ripe to systematically review the literature on these problems and solutions. Not only can such a review inform the development of new patient portals, it can also provide an account of the evidence base that can guide future research efforts.

## OBJECTIVE

As we aim to systematically address the problems encountered in patient portal development, we organize our review using the problem solving cycle depicted in Figure 1. The problem solving cycle forms a core model in design sciences (as well as in related disciplines such as systems/human factors engineering).[14-16] Rather than a single pass solution design process, problem solving in the various inter-organizational contexts of many patient portals - with their

political and cultural complexities - typically requires multiple iterations of the cycle to successfully develop a patient portal. Such a cyclic improvement approach is referred to as a development approach [16], motivating our use of the term 'patient portal development'. The problem solving cycle explicitly facilitates identification of solutions aimed at ameliorating the problems encountered.

**Figure 1:** The problem solving cycle



Following the 'steps' of the problem solving cycle, we formulated five research questions to guide the review of scientific literature:

1. What categories of problems related to patient portal development have been defined?
2. What causal factors have been identified by problem analysis and diagnosis?
3. What solutions have been proposed to ameliorate these causal factors?
4. Which proposed solutions have been implemented and in which organizational contexts?
5. Have implemented solutions been evaluated and what learning has been generated?

## MATERIALS AND METHODS

Our aim with this review was to systematically identify and describe main development problems and solutions. Since only the last of our research questions addresses evaluation of

effects through empirical research, we have not followed a review protocol to systematically review empirical evidence. Instead we adapted the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) checklist [17] to assist us in answering the five research questions. The checklist items (12-16,19-24) regarding the evaluation of effects do not apply to our research questions. We do, however, address the quality of the studies and evidence obtained from evaluation of solutions to problems (research question 5) in the discussion. For an overview of the effects of patient portals, we refer to several systematic reviews.[3-7].

## Search process

We searched in PubMed, ScienceDirect and LISTA in January 2015 using a combination of queries capturing articles about 'patient portals' and 'electronic personal health records'. We included peer-reviewed articles written in the English language and published in the last 10 years. Table 1 shows the search queries.

**Table 1:** Search queries

Queries	Restrictions
<ul style="list-style-type: none"> <li>• Patient portal*</li> <li>• Patient web portal*</li> <li>• Personal health record* AND electronic</li> <li>• Personal health record* AND online</li> </ul>	<ul style="list-style-type: none"> <li>• Time period: 2005-2015</li> <li>• Language: English</li> <li>• Type of publication: Peer-reviewed</li> </ul>

## Selection process

To be eligible for inclusion in the review, articles must concern patient portals that give patients access to their personal health records, must address a problem encountered in the portal development, and/or must present a solution to a problem. Hence, a broad array of articles was captured, including qualitative and quantitative articles reporting primary research on patient portals; population surveys and simulation studies focused on identifying problems or solutions related to patient portal development; and secondary research such as reviews, commentaries and conceptual articles. We included both electronic health records (EHR) tethered portals and 'universal PHRs' as long as the PHRs were clinically integrated; i.e. received information that originated in one or more EHRs.[18] We use the term patient portals to also refer to such PHRs on the grounds that these are accessible through portals.

The included articles were selected through two steps. First, each article's title and abstract were reviewed and articles excluded that did not meet the just-mentioned eligibility criteria. The primary reviewer (TOT) reviewed all articles, while the second reviewer (AdB)

reviewed a random sample of 10%. The agreement rate measured in Cohen's Kappa was 0.75 and disagreement was resolved through discussion. In the second step, we used a liberal accelerated approach [19] where the first reviewer read the full text and rejected articles that did not comply with the criteria (including 17 articles for which the full text could not be accessed). The second reviewer then received the list of rejected articles for validation. After reading these articles in full, the second reviewer concurred with all but three of the decisions, which were discussed until consensus was reached, resulting in two articles being added back. We chose the liberal accelerated approach for the second phase because it requires fewer resources compared to having two reviewers read the full text of all papers, while maximizing inclusion.[20]

### **Data extraction and synthesis**

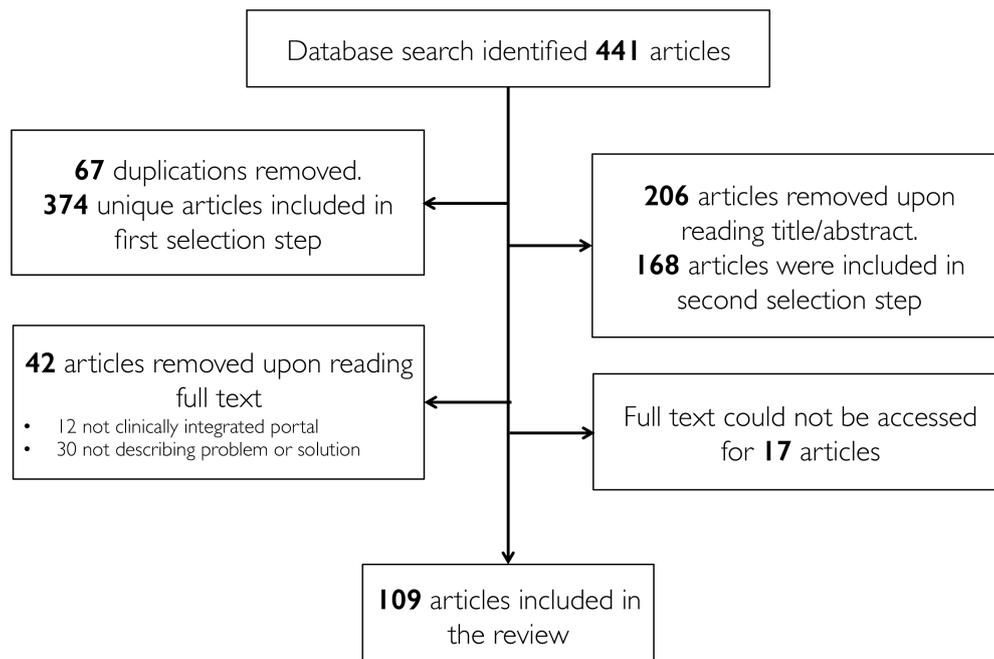
One reviewer extracted information from the articles regarding each of the five steps of the problem solving cycle. The extracted information was sent to the other members of the research team to solicit feedback and comments. The majority of the articles mentioned only one problem. However, some articles mentioned multiple problems in which case we extracted information about each of the addressed problems. Taking an abductive analysis approach that strives to find the most simple and probable explanation of a given observation [21], we then first combined information about problem definitions into 'problem categories'. This categorization was based on the problem definitions of the articles. We verified that we had not omitted key categories by comparing our categories with two relevant frameworks on patient portal development [13, 22]. Second, we combined information about factors causing each of the problems in the categories. Third, for each of the problem categories, we ordered information about proposed solutions into themes, each describing a type of solution. Fourth, for the solutions that had been implemented, we gathered information about the solution and the organizational context within which the solution was implemented, specifically the type of healthcare system setting. According to the problem solving framework, factors inherent to the organizational context profoundly affect the development process. Thus, we believed it was useful to understand, at a minimum, in which types of systems solutions were implemented. Fifth, for the implemented solutions that had been evaluated, we took note of evidence from the evaluations.

## RESULTS

### Study selection

The number of articles retrieved from the initial search was 441. The flow diagram displayed in figure 2 details the selection process, which resulted in 109 included articles.

**Figure 2:** Flow diagram



### Study characteristics

61 of the articles presented primary research on actual patient portals, while 27 reported on primary research not specific to a portal such as population surveys and simulation studies focused on identifying problems or solutions related to patient portal development. The remaining 21 articles conveyed secondary research such as reviews, commentaries and conceptual articles. Non-experimental studies dominated in the pool of selected articles with only three quasi-experimental studies and no RCTs. The vast majority of authors were from the North America (#85) and Europe (#14), with only 10 from Asia, Australia and South America. 34 of the articles were published between 2005-2010, while 75 are from between 2011-2015, indicating a considerable increase in research on the topic in most recent years. The online supplementary file displays basic information about the articles<sup>1</sup>.

<sup>1</sup> The numbering assigned to each article in the appendix is used in this text for referencing the articles.

## Synthesis of results

### *Problem definition*

Our categorization of data led to the identification of five main problem categories: achieving patient engagement, health service provider engagement, appropriate data governance, security and interoperability, and a sustainable business model. These problems were defined in both primary and secondary research articles.

### *Problem analysis and diagnosis*

For each of the identified problem categories, we provide an account of the factors causing the problems as they have been described in the included literature.

**Patient engagement.** Seventy-one articles addressed patients' use of patient portals, several of which remarked that use is generally low (#9,15,22,37,40,45,46,49,50,58,74,96). The articles placed in this problem category offered three explanations for this low use. First, as several articles noted, patient use is limited by patient concerns about confidentiality of their personal health data (#6,7,9,15,22,28,33,35,36,37,38,48,50,56,72,84,98,99). Second, some patients are unaware that they have access to a portal or do not recognize the usefulness of using one (#2,4,6,7,15,29,38,51,58,61,95,108). Also, some patients have tried using a portal but have had negative experiences, perhaps due to lack of user friendliness (#2,22,33,84). Third, a major hindrance to engaging patients described in many articles is lack of digital access (#2,3,7,29,36,38,41,45,51,55,58,99) and/or health literacy (#2,3,7,23,28,41,45,47,49,50,51,55,56,58,70,79,85,90,91,109). Patients facing these constraints may not be able to access a patient portal or feel empowered to retrieve and apply information. A central topic in the literature is whether some patients, based on demographic and socio-economic characteristics, are less able and prone to use portals than others (#2,3,22,23,24,28,29,38,40,42,44,49,52,53,54,66,67,69,71,73,74,75,78,80,83,85,86,94,98,101,102,103,104,106,107), generally associating use with being female, young, white, affluent, and having a chronic disease.

**Health service provider engagement.** Twenty-two articles described concerns held by providers that hinder them from adopting or using a portal. An often-mentioned aspect is providers' fear that use of portal features, especially secure email, will increase their workload and disrupt their workflow (#20,21,27,43,63,65,92,97,102)<sup>2</sup>, especially in light of inadequate

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<sup>2</sup> This is despite a recent study, which found that, on average, secure e-mailing with patients has not substantially impacted primary care provider workloads [23]

compensation (#7,21). A related concern among providers, as expressed in these and other articles, is that they do not possess the skills and capacities to adjust to technical requirements and new models of patient care induced by electronic means of interacting with patients, which give patient more control as well as responsibility (#7,21,56,75,76). A third aspect revolved around liability in case of breached privacy or harmful patient behavior (#7,16,39,62,64,65,92,97,105); for instance, providers could fail to respond in a timely way to patient inquiries or be required to base clinical decision-making on patient-entered data, which they cannot be sure is accurate or complete. Further, providers have a concern about their possible liability related to patients who may not be able to interpret clinical content, leading to anxiety, confusion and perhaps inappropriate or harmful behavior. Lastly, two articles note that some providers are hesitant to give up autonomy, a consequence of giving patients control over activities traditionally arranged by the providers such as booking appointments (#82,92).

**Security and interoperability.** Twenty articles touched upon the challenge of establishing secure and stable technical infrastructures on which portals can operate. Two articles made explicit that this problem should be seen in light of non-standardized technical and semantic language and rules for setting up and managing health information system infrastructures (#41,57). To avoid portals becoming 'information islands', it was explicitly recognized in four articles that patient portals should be able to receive and transmit data to and from several EHRs (#23,32,41,92). Thus, an important problem is achieving data exchange, especially in contexts with non-interoperable EHR systems (#38,92,41). The data exchange problem also extends to establishing bi-directional flow of data between the EHR and the portal as well as between the portal and external web sources (#5,32,92). For systems to exchange data, they must be able to identify and verify the owners of data and corresponding records, making the establishment of robust authentication mechanisms a focus of several articles (#37,48,57,75,81,89,92). Another aspect, which was described in two articles, is the importance of protecting against security breaches from, for instance, hacking or inappropriate system use (#18,38,68). At the same time, five articles noted that ramping up security measures typically lowers the flexibility and friendliness of use (#7,17,37,75,92).

**Data governance.** Appropriate data protecting and handling was the focus of 16 articles. A notion in some of these was that national data regulations (such as the HIPAA in the United States) do not cover patient portal developers and the hosting organization, causing uncertainty about appropriate data governance (#38,41,64,77). This uncertainty centered on three main aspects. The first is data transparency; that is, what data (such as clinical notes, test result, and problems lists) should be included in the PHR, when to make these data available,

and in what way to convey them (#7,13,19,32,26). This problem is augmented by the fact that data have traditionally been recorded for an expert audience as opposed to lay people (#26). A second aspect of uncertainty concerned authorization/privacy control; who should have access to records and who should be able to determine such access rights (#13,16,19,26,32,38,77). Examples are whether minors should have access to portals and whether patients should be able to assign proxy access to their informal caregivers. Several of the articles point out that, in situations where patients can choose to extend access to other people, some patients may not be able to properly manage the activities of the people to whom they have extended access (#16,77). A third aspect is how to guarantee data integrity; that is, the accuracy and completeness of data (#16,19,57,87). The question often raised was that when data in the record can be altered and complemented, how well such revisions would be visible in the record.

**Sustainable business model.** Nine articles concerned the problem of developing a sufficiently sound business model for patient portals. Two main topics were discussed under this problem category. First, there are inadequate and often contradictory reimbursement structures for services provided electronically (#19,21,22,36,38,60,93). Even with the MU program, the incentives are often too modest (and the thresholds too high) to create an adequate business case (#60). The second issue is the lack of documented cost-savings from using patient portals, attainable for example through better-managed patients or administrative efficiencies (#7,19,38,59).

### *Design of solutions*

Forty-five articles reporting on both primary and secondary research proposed solutions to ameliorate these problems.

**Patient engagement.** Seventeen articles discussed how to better engage patients to use patient portals, the majority of which mentioned using participatory design approaches (#12,23,31,33, 36,46,52,70, 72,75,84,88,100,108). Designing portals to meet needs defined by patients' characteristics, preferences, and capacities, as opposed to the most easily operationalized features of the technology, is believed to result in portals with high patient-perceived usefulness and usability. One example is translation of content to minority languages (#36). As described in many of these articles, such patient-centered designs are achieved through patient interviews, surveys and focus groups or through actual usability testing where patients are observed while using the portal. A second way to engage patients, with particular emphasis on those lacking access and skills, is via training these patients in the use of portals

(#2,26,33,47,55,67) or providing access through, for example, onsite kiosks (#2). Three articles reported on actual training programs offered to patients, and especially to vulnerable patients with low Internet skills (#47,55,67). Lastly, a couple of articles mentioned promotion initiatives as helpful to attracting patient attention and increasing awareness. This can be either through encouragement by providers (#2,52), through providing written or visual materials (#33,46,61,102), or follow up registration reminders (#29).

**Health service provider engagement.** Ten articles suggested ways to enhance provider engagement by improving their attitudes toward patient portals. Four articles suggested providing communication and practical training to providers to equip them to handle technical, interpersonal, and workflow aspects of portal use (#20,26,56,92). Three out of these four articles also suggested introducing information about the use EHRs and PHRs into the medical and nursing school curricula (#20,56,92). Three articles described how using workflow engineering to mirror current workflow and capitalize on existing provider roles can inform minimal burden workflow revisions (#11,30,34). As a concrete example, one article explained how completed care plans were not transmitted to a relevant provider until two weeks prior to scheduled visit (#3). Two of the ten articles made explicit that involving providers in this process is important to fully understand their work environment and tasks (#11,75). Ways to appease providers' liability-related concerns were addressed in two articles. One suggested notifying providers if patients had not opened an email, while the other proposed designing the system to detect messages that signal medical urgency [62,64].

**Security and interoperability.** Thirteen articles suggested ways to improve the security for patient portals. Of these, several discussed the feasibility of setting up various types of authentication mechanisms (#17,25,48,57,75,81,89), such as the so-called Public Key Infrastructures<sup>3</sup> (PKIs). Three articles expressed the importance of standardizing interoperability guidelines to allow for data exchange among organization, such as the international HL7 standard (#7,8,68). Two articles proposed achieving data exchange by setting up (Regional) Health Information Exchanges that can standardize data and facilitate exchange among different organizations (#23,38). One article suggested circumventing the need for inter-organizational data exchange by letting patients act as mediators (#39). A few articles discussed ways to improve system security through encryption tools, firewall, and audits of adherence to security protocols (#17,75).

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<sup>3</sup> Public Key Infrastructures are sets of hardware, software, people, policies, and procedures needed to create, manage, distribute, use, store, and revoke digital certificates.[24]

**Data governance.** Nine articles suggested solutions to data governance problems. Of these, the majority addressed policies for data availability and timing (#10,13,26,30,32,64), four of which described actual policies defined in organizations that have implemented portals (#10,30,32,64). In these cases, as much data as possible (except for test results prohibited by state laws such as for cancer and HIV) were made available to patients. In at least two of these organizations, the timing of certain test results was tuned to provider workflow to allow for quick provider follow-up. Four articles suggested ways to authorize patients to view data (#8,16,32,64). In most cases, patients had to show identification in person before gaining access to a portal, while an electronically signed user agreement sufficed in others. One article explicitly mentioned that patients were allowed to delegate access to one proxy (#64). Lastly, with regards to data integrity, three articles commented that systematic use of electronic signatures could be a viable way to clearly determine who had revised the records (#1,8,57).

**Sustainable business model.** Two articles addressed solutions to ensure a sustainable business model. One article advised organizations to negotiate a trial period before committing to purchasing a portal. This would allow organizations to test usability and be better able to estimate financial and organizational effects of using a portal (#59). The other article was committed to developing and testing reimbursement criteria for secure messaging, which could be used by payers to determine whether and by how much to reimburse an online encounter (#93).

### *Implementation of solutions*

Eighteen of the studies reported some form of implementation of solutions in an actual patient portal, which is the only requirement we imposed for a solution to be classified as 'implemented' (#5,8,10,11,12,20,30,32,39,46,55,61,64,67,70,88,100,102). The most commonly implemented solutions were aimed at solving problems in the patient engagement category, followed by solutions in the provider engagement, data governance and security and interoperability categories. There were none in the sustainable business case category. Interestingly, in terms of the organizational context, 14 of the solutions were implemented in portals within single organizations or organized care delivery systems, while four of the portals were provided in collaboration between individual organizations.

### *Evaluation of solutions*

Of the 18 solutions implemented in actual portals reported above, five (#20,46,55,61,67) reported on (perceived) effects of the implementation. All of these were in the patient and

provider engagement categories. These five evaluations collected data on implementation of secure messaging curricula in residency training (#20), strategies to promote portals to patients (#46,61), and patient training and guidance (#55,67) and demonstrated that these solutions can ameliorate problems of achieving patient and health service provider engagement. Only one (#61) of the studies involved a controlled design, while the remaining four were uncontrolled qualitative or quantitative before-and-after studies.

Table 2 summarizes the findings of the review.

**Table 2:** Summary of review findings

<b>Development problems</b>	<b>Solutions</b>
Patient engagement <ul style="list-style-type: none"> <li>• Privacy and confidentiality concerns</li> <li>• Awareness</li> <li>• Usefulness and usability</li> <li>• Digital access</li> <li>• Health literacy</li> <li>• Socio-economic disparities</li> </ul>	<ul style="list-style-type: none"> <li>• Patient centered design</li> <li>• Training and education*</li> <li>• Promotional initiatives*</li> </ul>
Health service provider engagement <ul style="list-style-type: none"> <li>• Workload and workflow</li> <li>• Skills and capacities</li> <li>• Liability</li> <li>• Autonomy</li> </ul>	<ul style="list-style-type: none"> <li>• Workflow engineering</li> <li>• Workflow training*</li> <li>• Notifications and signaling of urgency</li> </ul>
Security and interoperability <ul style="list-style-type: none"> <li>• Data exchange</li> <li>• Authentication</li> <li>• System robustness</li> </ul>	<ul style="list-style-type: none"> <li>• International communication standards</li> <li>• Access control mechanisms</li> <li>• Encryption, internet firewalls, audits</li> <li>• Health information exchanges</li> </ul>
Data governance <ul style="list-style-type: none"> <li>• Data transparency</li> <li>• Authorization/privacy control</li> <li>• Data integrity</li> </ul>	<ul style="list-style-type: none"> <li>• Policies for data availability and timing</li> <li>• In person authorization /user agreements</li> <li>• Provider and patient electronic signatures</li> </ul>
Financial sustainability <ul style="list-style-type: none"> <li>• Inadequate reimbursements</li> <li>• Uncertainty about cost savings</li> </ul>	<ul style="list-style-type: none"> <li>• Trial period to establish business case</li> <li>• Appropriate reimbursement criteria</li> </ul>

\* Effect of solution has been evaluated

## DISCUSSION

The review provides valuable insights into problems, diagnosis, and possible solutions described in an emerging field of research. Held up against the problem solving cycle, we note that of the 109 articles, 45 reported to have made it past the problem analysis and diagnosis to propose solutions. Of these, eighteen reported implementation, of which five reported evaluation, thus

evidencing to have gone “full circle” at least once. None of these articles described the problem solving process in enough detail for the reader to understand the iterations and dynamics of the process. This does not necessarily mean that the problem solving process was not completed. The stages not reported, may simply have been disregarded in the publication. Yet, in view of the modest number of evaluated designs, and the relatively weak evidence, we refrain from presenting evidence-based suggestions for solving the problems encountered in patient portal development. We also refrain from assessing the quality of the solutions that have been proposed but for which no implementation is reported. That being said, the review does provide a basis for further reflection on the nature of the evidence base and recommendations for how it can best be advanced to inform practice. Moreover, the references and appendix may direct the reader to relevant studies of interest.

### **Further reflection on the evidence base**

There appears to be a great deal of attention on patient engagement in the scientific literature. Especially, we note that a large proportion of articles are dedicated to examining socio-economic factors associated with portal use. Fewer, but still a considerable number of articles, address problems and solutions related to securing provider engagement, appropriate data governance, and security and interoperability. In comparison, few articles deal with the financial sustainability of patient portals.

Furthermore, aside from patient engagement and provider engagement, we have noted no evaluated solutions in the other categories. The uneven nature of the evidence-base hinders portal developers from comprehending and solving for all problems that affect patient portal development, problems that may be interrelated; for example, lack of financial sustainability will likely hinder provider engagement, even if providers think positively about using a portal. As such, it appears that the current evidence base informs only part of an effective development process.

Further, according to the problem-solving framework, the development process is affected by the organizational context. For instance, it is likely that implementing solutions in portal developments within fragmented care delivery contexts is most difficult, since several organizations typically must join forces to develop a comprehensive portal. While achieving patient engagement, health service provider engagement, security and interoperability, appropriate data governance, and a sustainable business model is challenging within one organization, this challenge is likely exacerbated by the necessity to solve problems across organizations with varying patient populations, provider attitudes and incentives, existing

technical infrastructures, internal regulatory policies or beliefs, and short- and long-term objectives and profit motives. However, we found that the vast majority of the implemented solutions was from within single organizations or organized care delivery systems. Thus, these types of organizational contexts appear to provide the test bed for most patient portal developments, which may limit the relevance of current research to other organizational contexts.

### **Recommendations for future research**

Future research should seek to systematically improve our comprehension of what patient portal solutions actually work, for whom, and in what contexts. We offer three main recommendations for such research efforts.

1. Where available, we encourage researchers to base their designs on existing evidence, and report implementation and evaluation, so as to validate, advance and generalize existing evidence. Where there is no evidence, such as on how to secure financial sustainability, we encourage research that identifies and analyses problems, in addition to designing, implementing and evaluating solutions, so as to create a more well-rounded evidence base.
2. Patient portal development occurs through multiple iterations of the problem solving cycle. Hence we call for studies with an extended 'unit of analysis' in terms of a longer time horizon and several iterations of the process.
3. To be able to inform portal development across contexts, the evidence base could benefit from research that accumulates knowledge from different types of patient portals, patient populations and across organizational contexts (and especially within fragmented care delivery contexts where portal development problems may be most severe).

### **Study limitations**

By only including articles written in English, we have excluded many articles published in their authors' native languages. Further, we restricted our review to peer-reviewed studies, foregoing sources such as websites of specific patient portals or high-level policy and strategy documents issued by governments or large knowledge institutes. To advance the depth of understanding about development problems and solutions in various contexts, our review could have benefitted from inclusion of such grey literature from several countries.

The dominance of articles addressing user engagement may be explained by the fact that we excluded articles that focused on EHRs and Health Information Exchanges more

broadly; since patient portals typically tie into existing health information technology infrastructures, insight into earlier design and development stages of these infrastructures are important to fully comprehend portals (see for example [25-32]). Hence, while it was outside of the scope of this review, we might have obtained a more even distribution of insights across problem categories if we had opened up the review to also include EHRs and Health Information Exchanges.

Finally, by focusing on development problems, we may have excluded some articles that solely report on successes and that could also provide important guidance to patient portal implementers. In addition, there is a probability of publication bias towards studies of implemented solutions with clear results. Consequently, the evidence base included in this study may underreport on development successes as well as non-implemented or poorly implemented solutions.

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# CHAPTER 8

*Conclusion*

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We conclude the dissertation by providing concise answers to our four overall research questions.

1. What outcomes have been achieved through patient portals and how are these outcomes achieved?
2. How does the health service system context, in particular health service system integration or fragmentation, impact patient portal development and ability to achieve beneficial outcomes?
3. With focus on fragmented health service systems, how can patient portal development and achievement of beneficial outcomes be improved?
4. How can the existing evidence base inform patient portal development across health service systems and how can this evidence base be advanced?

### **What outcomes have been achieved through patient portals and how are these outcomes achieved?**

We have shown how patient portals can lead to improvements in clinical process outcomes, patient adherence, patient empowerment, patient satisfaction, health plan retention, patient-provider communication as well as changes in health resource consumption and reductions in environmental waste. These outcomes are achieved through multiple mechanisms including enhanced patient insight into health information and access to services, transparency and activation of information, interaction and interpersonal continuity of care, service convenience, stronger connection between patients and their health plan, and efficiencies in physician workflow and administrative tasks. The usability of these findings is limited to organizational contexts, which enable the triggering of these mechanisms. Since most existing evidence is produced within integrated health service systems, our findings do not directly support decisions and actions outside of this particular health service system context.

### **How does the health service system context, in particular health service system integration or fragmentation, impact patient portal development and ability to achieve beneficial outcomes?**

We found that the organizational context plays a considerable role in activating these mechanisms. Contextual factors conducive to patient portals include alignment with financial incentives, synergy with existing IT infrastructures and operations, physician-led governance, inclusive decision making and knowledge sharing, regional flexibility to implementation,

continuous innovation, and emphasis on patient-centered design. These contextual factors are most easily achieved in integrated health service systems, which may explain why the overwhelming proportion of reported patient portal outcomes are documented within integrated systems such as Kaiser Permanente. These factors are less present in fragmented health service systems where numerous independent providers and organizations deliver services. In these systems, developing integrated patient portals entails collaboration across these health service providers and organizations. This means establishing networks, networks that are characterized by variety, mutual dependence, decentralized governance, and a dynamic structure. Given these characteristics, solving issues associated with patient portal development - such as achieving interoperability, successful implementation, regulatory compliance, and financial sustainability – becomes a complex social process relying on inter-organizational negotiation and coordination. Thus, although these issues must be solved to effectively develop patient portals in any type of system, the difficulties of doing so appear to be much greater in fragmented health service system contexts. We conclude that effective development of patient portals in fragmented health service systems entails a tradeoff between functionality and ease of development: highly integrated patient portals that connect with a wide array of providers and organizations have higher functionality to patients. However, achieving such integration necessitates complex networks, which will be confronted with many developmental difficulties.

### **With focus on fragmented health service systems, how can patient portal development and achievement of beneficial outcomes be improved?**

While acknowledging that there are many more, we identified and assessed the viability of two specific approaches to advancing the development of patient portals in fragmented health service systems.

First, using a theoretical framework to improve relational capacities for coordination among organizations is a viable approach. Specifically, we found that the Relational Coordination framework can guide the tuning of organizational structures and dynamics to enhance relational coordination in a network. Our results showed that improved relational coordination can help networks mitigate challenges caused by organizational and technological differences between the participating providers and organizations. However, the framework needs to be applied, tested, and possibly adapted to an inter-organizational setting. If successfully adapted to an inter-organizational network setting, Relational Coordination Theory and its associated Relational Model of Organizational Change can be instrumental in improving the effectiveness of inter-organizational patient portal networks.

Second, the development of patient portals in fragmented health service systems can be stimulated through national fiscal incentives such as provided through the Meaningful Use program in the United States. So far, the Meaningful Use incentives have stimulated some providers to adopt integrated patient portals by rewarding connectivity. Yet, the incentives have not been effective enough to insure widespread uptake, since other factors – including functionality and costs – also weigh in on providers' decision-making. In general, the financial incentives are not enough to drive adoption. Rather, patient demand for access to patient portals will be necessary to achieve providers' widespread adoption. Therefore, we assert that to truly advance the development and adoption of integrated patient portals, the Meaningful Use program – and other comparable programs for that matter - should focus on ways to enhance the value health IT has for patients.

### **How can the existing evidence base inform patient portal development across health service systems and how can this evidence base be advanced?**

From a review of 109 articles, it appears that patient portal development efforts are confronted with five main problems: achieving patient engagement, provider acceptance, appropriate data governance, a secure infrastructure, and a sustainable business model. Each of these problems are caused by an array of factors such as (but not limited to) patient concern about the confidentiality of their data; fear from health service providers that secure messaging will increase their workload; lack of standards for, for instance, authentication; difficulty with ensuring data integrity when multiple actors can edit data; as well as the absence of clear reimbursement arrangements for electronic means of communication. The current evidence base offers several solutions to how these factors (and more) may be ameliorated. Yet, of the 109 articles, only 18 reported implementation of the proposed solutions. Even fewer (5) of these solutions reported evaluation. Hence, few of the articles report on the more advanced stages of the 'problem solving cycle' generic to design science research. Consequently, we were not able to achieve our aim of using existing evidence to propose designs to assist the development of patient portals. Yet, the review supported a reflection on the current evidence base and allowed formulation of a set of recommendations to systematically advance it. We are convinced that these recommendations can spur the generation of evidence that patient portal developers can put into practical use, be it a network of providers, a large integrated care delivery system, or an individual hospital or provider practice.

## Relevance of research

The main relevance of our research lies in its illumination of the organizational context and mechanisms that influence patient portal development and outcomes. We have achieved this through exploration and comparison of international cases, enabling us to offer specific and in-depth explanations for the dramatic differences in patient portal development and outcomes across regions and countries. For example, in the Californian Bay Area, organizations see a patient portal as a necessity to be in business, as patients have come to expect and demand one. In other geographical areas, such as in the Netherlands and other parts of the United States, patients are much less aware of patient portals and therefore do not exert the same demand on the health service system. We believe that our analysis of and explanations for why we see these differences can contribute towards closing the gap that currently exists between patient portal development in those systems in which patient portals have become an institutionalized norm and those in which patient portals are now beginning to emerge. Since patient portals hold considerable potential benefits to patients, providers and the organizations that implement them, we see closing this gap as an important and warranted pursuit.

As we have argued and showed throughout our research, the reason behind this gap cannot be explained loose from the organizational context: while integration of the health service system has an enabling influence on patient portals, fragmentation, and the increased complexity it triggers, hinders their development and achievement of outcomes. We have therefore dedicated a large share of our research to studying the complexity caused by fragmentation and to assessing ways to support patient portal development amidst this complexity. At the very core, we suggest that effective development of a patient portal requires appropriate structuring of the system in which the portal is to be embedded. In other words, the organizational context and the effectiveness of a patient portal development are so deeply interwoven that effective development necessitates at least some adaption of the organizational context. Accordingly, through our empirical cases, we have identified and described contextual factors conducive to patient portal development and achievement of outcomes. Although this learning does not qualify for direct translation to and implementation in complex, fragmented systems, it may inform major or minor tweaks in a given organizational context in support of a patient portal. Furthermore, we have considered organizational strategies for strengthening coordination between distinct organizations, and have evaluated the ability of national, fiscal policy initiatives to stimulate organizations to develop and/or adopt patient portals in fragmented health service systems. We have also pointed to common, and possibly perilous, attributes of patient portal developments in fragmented systems. For example, the strong

organizational focus we see in many developments entails a risk that the patient perspective is ignored. Yet, if not firmly rooted in a patient perspective, a patient portal may not stir the patient demand that is required to truly drive widespread development in a geographical area.

These insights are of practical relevance to policy-makers, health service providers and patient portal developers, particularly in fragmented health service systems. At a minimum, we are convinced that such stakeholders, after having read the results of our research, will have a better understanding of what to consider and reasonably expect when attempting to develop a patient portal in a fragmented health service system. Our research also bears significant scientific relevance. By mapping and synthesizing evidence on this emerging and important field of research, we have created an overview of a field that appears to be advancing quickly, yet rather unsystematically. We have complemented the synthesized evidence with insights from conceptual investigation and empirical exploration. In these endeavors, we have aimed to carefully integrate theoretical perspectives and to avoid cornering ourselves between academic disciplines. This is visible in the variety of journals in which we have published our results.

We are hopeful that the knowledge and evidence brought forward by our research will assist practical and scientific efforts in creating value through patient portals for patients, organizations, and the health service system as a whole.

### **Ideas for future research**

Despite these arguments in favor of the relevance of our research, we acknowledge that our study only illuminates certain areas of a large field of research and that there are several areas worth of further exploration and consideration. Perhaps most notably, we have chosen a strong organizational focus examining dynamics between care delivery components, organizational attributes, and facets of the health service system context. In doing so, we have inevitably placed less emphasis on the patient and how patient factors affect and/or interrelate with organizational dynamics and decisions. Future research that would seek to compensate for this could focus on two main issues. First, it is important to get a clearer grasp of 'patient value' in relation to patient portals. How precisely should this construct be defined and operationalized? Such clarity will be crucial for the patient perspective to effectively play a role in the development of patient portals and their embedding in care delivery, and ultimately, to enhance patient value through patient portals. Second, like we have sought to distinguish and explain patterns in organizational dynamics, similar efforts could be directed at patient dynamics. It is likely that patient characteristics and beliefs influence the development and organization of patient portals as well as the mechanisms through which outcomes are achieved; that is, that patient factors interact

with technological, professional, and organizational factors. Future research could aim to identify and map such dynamics, and thereby help to produce a more wholesome picture of patient portal development and outcomes.



# SUMMARY

## Introduction

In **Chapter 1**, we introduce patient portals and describe our study objectives and questions. Patient portals can give patients access to a personal health record and enable interaction with the health care system. Patient portals are creating unprecedented opportunities for using health IT to deliver care to patients, paving the way for benefits to patients, providers and the organizations that implement the portals. The organizational context plays a large role in the realization of these benefits: whereas integrated health service systems are conducive to portals, the context of fragmented health service systems appears to have an inhibiting effect. The result has been relatively few comprehensive patient portals being developed in fragmented health service systems such as the Dutch. Hence, the objective of this dissertation has been to explore the role of the organizational context by identifying and describing factors affecting portals in different types of health service systems. Moreover, we have sought to detect and assess ways to advance the development of patient portals in health service systems with a fragmented nature.

We have let the following four questions guide the research.

1. What outcomes have been achieved through patient portals and how are these outcomes achieved?
2. How does the health service system context, in particular health service system integration or fragmentation, impact patient portal development and ability to achieve beneficial outcomes?
3. With focus on fragmented health service systems, how can patient portal development and achievement of beneficial outcomes be improved?
4. How can the existing evidence base inform patient portal development across health service systems and how can this evidence base be advanced?

In answering these questions, we studied portals in integrated and fragmented health service systems in the United States and in the Netherlands. We relied on multiple qualitative methods, including literature review, document analysis, and interviews. We structured the research according to the four research questions.

### **Research question 1: What outcomes have been achieved through patient portals and how are these outcomes achieved?**

To form a basis for answering this question, in **Chapter 2** we describe a realist review we did of the literature on patient portal outcomes. Through a review of 32 relevant publications, we established that patient portals can lead to improvements in clinical outcomes, patient adherence, patient empowerment, patient satisfaction, patient-provider communication as well as changes in health resource consumption. We found these outcomes to be achieved through multiple mechanisms including patient insight into personal health information, activation of information, interpersonal continuity of care, and service convenience. We were interested in examining the role of the organizational context in activating these mechanisms. However, the vast majority of evaluations were conducted in integrated health service networks in the US. Thus, we were not able to detect patterns in how patient portals work in different contexts. Nonetheless, it appeared from the overwhelming proportion of patient portal evaluations coming from integrated health service systems, that these systems provide contexts most conducive to patient portals. We concluded that to improve the understanding of how patient portals work, future evaluations of patient portals should capture information about mechanisms and context that influence their outcomes.

### **Research question 2: How does the health service system context, in particular health service system integration or fragmentation, impact patient portal development and ability to achieve beneficial outcomes?**

We contributed to this understanding by conducting a case study of Kaiser Permanente's patient portal, which we report on in **Chapter 3**. As the results of our review indicate, health system integration appears to positively affect the ability of organizations to develop and achieve outcomes through portals. To gain more in-depth knowledge about how outcomes are achieved and about the role of health system integration on achieving these outcomes, we considered a study of Kaiser Permanente's patient portal ideal. We conducted semi-structured interviews with 18 organizational members who played key roles in the development, implementation and evaluation of the portal. Our study had two main results. First, we described the mechanisms by which this specific portal achieves outcomes. Largely consistent with the mechanisms identified through our realist review, these included enhancing access to services, transparency and activation of information, patient-physician interaction, the connection between Kaiser Permanente and patients, and efficiencies in physician workflow and

administrative tasks. Second, we identified seven key organizational factors inherent to Kaiser Permanente that enable these mechanisms. These are alignment with financial incentives, synergy with existing IT infrastructure and operations, physician-led governance, inclusive decision-making and knowledge sharing, regional flexibility to implementation, continuous innovation, and emphasis on patient-centered design. Although the findings may not be directly transferable to all types of health service system contexts, they can inform patient portal developers about how to tune organizational factors in support of achieving outcomes.

The previous chapter provided a thorough understanding of what and how outcomes can be achieved under favorable conditions. Going forward, we were interested in learning about patient portal development under less – seemingly – advantageous conditions, which we believe fragmented health service systems provide. To comprehend the dynamics related to patient portal development in fragmented systems, we collected empirical evidence – including interviews and documents - from three patient portals developed in networks of provider organizations in the fragmented Dutch system. We report on this study in **Chapter 4**. The three studied networks differed in their number and diversity of actors, the degree to which these actors were mutually dependent, the degree to which network governance was decentralized, and the dynamics of the network structures. We observed that the networks displaying the highest degree of these characteristics experienced most difficulties with developing patient portals. We identified the most important difficulties to be achieving interoperability, successful implementation, regulatory compliance, and financial sustainability. At the same time, we found that the portals developed in the most complex networks likely hold most functionality to patients, since they can consolidate information and services from a broad array of health service providers. Based on these findings, we suggested that effective development of patient portals likely begs a tradeoff between envisioned functionality and ease of development.

### **Research question 3: With focus on fragmented health service systems, how can patient portal development and achievement of beneficial outcomes be improved?**

So far, our research has led to a thorough comprehension of the role of the organizational context, including factors enabling and hindering patient portal development and outcomes. Particularly, based on the realization that fragmentation has an inhibiting effect on patient portals, our ambition became to seek and assess ways to mitigate this effect. In the next two chapters, we describe two potential approaches to doing this.

First, as we outline in **Chapter 5**, we studied the effect of a national policy initiative, the Meaningful Use program, on stimulating the development of patient portals in fragmented health service systems in the United States. We selected four Health Information Exchanges that – inspired by the Meaningful Use incentives - were pioneering in developing patient portals in 2014. We conducted semi-structured interviews with the directors, project managers and providers. Through our analysis of these interviews, we found that the Meaningful Use incentives stimulated comprehensive portals by encouraging connectivity. Other factors weighing in on adoption decisions were functionality and costs. A general finding, however, was that the financial incentives are not enough to drive widespread adoption. Rather, patient demand for access to patient portals will likely be necessary to achieve widespread portal adoption and realization of potential benefits. Hence, we suggested that optimizing patient value should be the main principle underlying policies intending to increase online patient engagement in the third stage of the EHR Incentive Program. We proposed a number of features for the Program that will enhance patient value and, thereby, support the growth and sustainability of patient portals provided by Health Information Exchanges.

We had observed that, generally, an important underlying cause for the observed difficulties of developing portals in fragmented contexts is reliance on collaboration among organizations with different organizational, technological and geographical properties. Hence, as described in **Chapter 6**, we first did a theoretical analysis to assess the usefulness of Relational Coordination Theory to mitigate these differences. In the analysis, we drew upon literature on inter-organizational coordination, and relational coordination in particular. We found that relational coordination can help mitigate challenges caused by lack of organizational and technological proximity among participants in a patient portal network. The Relational Model of Organizational Change is a useful tool to improve relational coordination. However, some organization redesign interventions proposed in the Model may not be directly applicable to patient portal networks due to lack of geographical proximity among network participants.

#### **Research question 4: How can the existing evidence base inform patient portal development across health service systems and how can this evidence base be advanced?**

In **Chapter 7**, we reviewed the existing evidence base on patient portal development to not only learn more about how the two above-mentioned approaches have been used and have fared, but also to identify additional approaches for effectively developing patient portals in various health service system contexts. We believed this review would be valuable to inform

practice and guide future research. Rooted in a design science framework, we reviewed the results of 109 relevant articles. This review led to the identification of five main development problems: securing patient engagement; health service provider acceptance; appropriate data governance; a secure infrastructure; and a sustainable business case. Further, we discerned solutions that have been proposed to ameliorate these problems. Workplace interventions such as Relational Coordination and economic interventions such as the Meaningful Use incentives were addressed in some of these articles, but many other types of solutions also surfaced. Yet, very few of these solutions have been evaluated, hindering the identification of a set of concrete solutions to assist patient portal development. Hence, to advance the evidence base we suggested three main recommendations. First, where available, researchers should base their designs on existing evidence, and report implementation and evaluation, so as to validate, advance and generalize existing evidence. Where there is no evidence, we encourage research that identifies and analyzes problems, in addition to designing, implementing and evaluating solutions, so as to create a more well-rounded evidence base. Second, patient portal development occurs through multiple iterations of the problem solving cycle. Hence we call for studies with an extended 'unit of analysis' in terms of a longer time horizon and several iterations of the process. Third, to be able to inform portal developments across contexts, the evidence base could benefit from research that accumulates knowledge from different types of patient portals, patient populations and across organizational contexts (and especially within fragmented care delivery contexts where portal development problems may be most severe).

## **Conclusion**

In **Chapter 8**, we conclude on the findings of our research. We argue that our research output is relevant for practitioners and scholars committed to developing and using patient portals, especially in fragmented health service systems.

# SAMENVATTING

In **Hoofdstuk I** introduceren we patiëntportalen en beschrijven we onze onderzoeksvragen en doelstellingen. Patiëntportalen kunnen patiënten toegang geven tot hun persoonlijk gezondheidsdossier en interactie met het zorgsysteem faciliteren. Ze maken nieuwe IT-toepassingen in de patiëntenzorg mogelijk, wat gunstige uitkomsten kan opleveren voor patiënten, zorgaanbieders en organisaties die portalen implementeren. De organisatorische context speelt daarbij een grote rol: daar waar geïntegreerde zorgstelsels bevorderlijk zijn voor portalen, heeft de context van gefragmenteerde zorgstelsels een remmend effect op hun ontwikkeling. Een gevolg daarvan is dat er tot op heden relatief weinig grootschalige patiëntportalen zijn ontwikkeld in gefragmenteerde zorgstelsels, zoals bijvoorbeeld in Nederland. Het doel van dit proefschrift is om de rol van die organisatorische context te onderzoeken door factoren te identificeren en te beschrijven die van invloed zijn op patiëntportalen in verschillende zorgstelsels. Tevens beschouwen we verschillende manieren waarop de ontwikkeling van patiëntportalen in gefragmenteerde zorgsystemen bevorderd zou kunnen worden.

Ons onderzoek komt voort uit de volgende vier vragen:

1. Tot welke uitkomsten hebben patiëntportalen geleid, en hoe worden die uitkomsten bereikt?
2. Hoe beïnvloedt de context van een zorgstelsel, met name in termen van integratie of fragmentatie, de ontwikkeling van patiëntportalen en de mogelijkheid om gunstige effecten te bereiken?
3. Hoe kan de ontwikkeling van patiëntportalen in gefragmenteerde zorgstelsels en het bereiken van gunstige effecten worden gestimuleerd?
4. Hoe kan bestaande wetenschappelijke evidentie bijdragen aan de ontwikkeling van patiëntportalen in verschillende zorgstelsels, en hoe kan die evidentie worden verstevigd?

Om deze vragen te beantwoorden hebben we patiëntportalen bestudeerd in geïntegreerde en gefragmenteerde zorgstelsels in de Verenigde Staten en Nederland. We hebben gebruik gemaakt van meerdere kwalitatieve methoden, waaronder literatuuronderzoek, documentenanalyse en interviews. We hebben ons onderzoek gestructureerd op basis van de vier onderzoeksvragen.

## **Onderzoeksvraag 1: Tot welke uitkomsten hebben patiëntportalen geleid en hoe zijn die uitkomsten bereikt?**

Ter beantwoording van deze vraag geven wij in **Hoofdstuk 2** aan de hand van een 'realist review' een beschrijving van literatuur over behaalde uitkomsten van patiëntportalen. Op basis van 32 relevante publicaties hebben we vastgesteld dat patiëntportalen kunnen leiden tot verbeteringen in klinische resultaten, therapietrouw, empowerment van patiënten, patiënttevredenheid, communicatie tussen patiënt en aanbieder, en veranderingen in het gebruik van zorgdiensten. Ons onderzoek wijst uit dat deze resultaten worden bereikt door meerdere mechanismen; deze mechanismen omvatten patiënt-inzage in persoonlijke zorginformatie, het activeren van informatie, continuïteit van zorg op interpersoonlijk niveau, en gebruiksgemak. Onze interesse ging vooral uit naar de rol van de organisatorische context in het activeren van deze mechanismen. Het merendeel van de evaluatiestudies bleek echter te zijn uitgevoerd binnen geïntegreerde zorgsystemen in de Verenigde Staten, waardoor wij niet in staat waren om patronen te ontwaren in de wijze waarop patiëntportalen in verschillende contexten functioneren. Niettemin kan uit de meerderheid van patiëntportaal-evaluaties in geïntegreerde zorgsystemen worden afgeleid dat de organisatorische contexten van deze systemen het meest bevorderlijk zijn voor patiëntportalen. Onze conclusie luidt dat om de werking van patiëntportalen beter te begrijpen, toekomstige evaluaties van patiëntportalen inzichten zullen moeten verschaffen in de mechanismen en contextuele factoren die van invloed zijn op uitkomsten.

## **Onderzoeksvraag 2: Hoe beïnvloedt de context van een zorgstelsel, met name in termen van integratie of fragmentatie, de ontwikkeling van patiëntportalen en de mogelijkheid om gunstige effecten te bereiken?**

Antwoorden op deze vraag hebben we verkregen door het uitvoeren van een casestudie van Kaiser Permanente's patiëntportaal, waarover we verslag doen in **Hoofdstuk 3**. Zoals de resultaten van onze literatuurstudie hebben aangetoond blijkt dat integratie van een zorgstelsel van invloed is op de mogelijkheid van organisaties om resultaten te bereiken aan de hand van patiëntportalen. Om ons te verdiepen in de wijze waarop resultaten worden bereikt en welke rol de mate van integratie van het zorgstelsel daarin speelt, hebben wij onderzoek gedaan naar het patiëntportaal van Kaiser Permanente, dat in onze optiek een ideale casus vormt. We hebben semigestructureerde interviews uitgevoerd met 18 leden van de organisatie die belangrijke rollen hebben gespeeld in de ontwikkeling, uitvoering en evaluatie van het portaal.

Onze studie heeft twee belangrijke resultaten opgeleverd. Allereerst hebben we de mechanismen beschreven waarmee dit specifieke portaal resultaten heeft bereikt. Deze omvatten verbetering in de toegang tot diensten, transparantie en activering van informatie, arts-patiënt interactie, verbinding tussen Kaiser Permanente en patiënten, en efficiëntie van de workflow en administratieve taken van zorgaanbieders; dit is grotendeels in overeenstemming met de mechanismen zoals beschreven in onze 'realist review'. Ten tweede hebben we zeven belangrijke organisatorische factoren bij Kaiser Permanente geïdentificeerd die deze mechanismen mogelijk maken. Deze factoren zijn de afstemming met financiële prikkels, synergie met bestaande IT-infrastructuur en operaties, governance-structuren waarin een leidende rol voor artsen is weggelegd, participatieve besluitvorming en kennisdeling, regionale flexibiliteit in de implementatie, continue innovatie, en nadruk op een centrale positie van de patiënt in het ontwerp. Hoewel de bevindingen niet rechtstreeks toepasbaar zijn op alle zorgstelselvarianten, kunnen ze ontwikkelaars van portalen informeren over de wijze waarop organisatorische factoren kunnen bijdragen aan het bereiken van gestelde doelen.

Het vorige hoofdstuk heeft diepgaande inzichten opgeleverd over welke resultaten op welke manier kunnen worden bereikt onder gunstige omstandigheden. In het verlengde daarvan wilden we kennis opdoen over de ontwikkeling van patiëntportalen onder (schijnbaar) minder gunstige omstandigheden, die volgens ons zijn toe te schrijven aan gefragmenteerde zorgstelsels. Om de dynamiek van het ontwikkelen van patiëntportalen in gefragmenteerde zorgstelsels te begrijpen hebben we empirische data verzameld – waaronder interviews en documenten – bij drie patiëntportalen die zijn ontwikkeld door netwerken van zorgorganisaties in het gefragmenteerde Nederlandse zorgstelsel. We doen verslag van dit onderzoek in **Hoofdstuk 4**. De drie onderzochte netwerken verschilden in hun aantal en diversiteit van actoren, de mate waarin deze actoren afhankelijk van elkaar waren, de mate waarin het netwerkbestuur was gedecentraliseerd, en de dynamische natuur van de netwerkstructuur. We beschrijven hoe de netwerken met de hoogste graad van elk van deze kenmerken ook de meeste problemen ondervonden met de ontwikkeling van hun patiëntportaal. Als voornaamste uitdagingen noemen we het bereiken van interoperabiliteit, een succesvolle implementatie, de naleving van regelgeving, en financiële duurzaamheid. Tegelijkertijd vermoeden we dat portalen die ontwikkeld zijn binnen de meest complexe netwerken ook de meeste functionaliteit kunnen bieden aan patiënten, aangezien informatie en diensten uit een breed scala van zorgverleners samengebracht kunnen worden. Op basis van deze bevindingen suggereren wij dat een effectieve ontwikkeling van patiëntportalen een afweging behelst tussen beoogde functionaliteit en gemak bij de ontwikkeling.

### **Onderzoeksvraag 3: Hoe kan de ontwikkeling van patiëntportalen in gefragmenteerde zorgstelsels en het bereiken van gunstige effecten worden gestimuleerd?**

Tot dusverre heeft ons onderzoek geleid tot een grondig begrip van de rol van de organisatorische context, waaronder de factoren die de ontwikkeling en uitkomsten van patiëntportalen belemmeren. Uitgaande van de idee dat fragmentatie een remmende werking heeft op patiëntportalen besloten wij om manieren te verkennen en te beschouwen die dit negatieve effect zouden kunnen temperen. Daartoe beschrijven we in de volgende twee hoofdstukken twee mogelijke benaderingen.

Zoals geschetst in **Hoofdstuk 5** hebben we ons allereerst gericht op het effect van een nationaal beleidsinitiatief, het 'Meaningful Use'-programma, op het stimuleren van de ontwikkeling van patiëntportalen in gefragmenteerde zorgstelsels in de Verenigde Staten. We hebben vier 'Health Information Exchanges' geselecteerd die – geïnspireerd door Meaningful Use-prikkels – als pioniers golden in de ontwikkeling van patiëntportalen in 2014. We hebben semigestructureerde interviews uitgevoerd met directieleden, projectmanagers en zorgverleners. Onze analyse van deze interviews wijst uit dat de Meaningful Use-prikkels de ontwikkeling van uitgebreide portalen hebben gestimuleerd door het aanmoedigen van connectiviteit. Andere factoren die worden meegewogen bij besluitvorming omtrent adoptie waren functionaliteit en kosten. Een algemene bevinding was echter dat financiële prikkels niet volstaan om een brede invoering te borgen. Onder patiënten zal er daadwerkelijk vraag moeten zijn naar toegang tot patiëntportalen om de adoptie van patiëntportalen en het bereiken van mogelijke voordelen op grote schaal te kunnen realiseren. Om die reden stellen wij voor dat het optimaliseren van de waarde voor de patiënt het belangrijkste onderliggende principe moet zijn in de derde fase van het Meaningful Use-programma. We hebben een aantal aanpassingen van het Programma voorgesteld die de waarde voor patiënten kunnen vergroten, en daarmee de ontwikkeling en duurzaamheid van patiëntportalen binnen Health Information Exchanges ondersteunen.

Ons onderzoek wijst uit dat de afhankelijkheid van samenwerking tussen organisaties met verschillende organisatorische, technologische en geografische eigenschappen een belangrijke onderliggende oorzaak is van de waargenomen problemen in het ontwikkelen van patiëntportalen in gefragmenteerde zorgstelsels. . Zoals beschreven in **Hoofdstuk 6** hebben we allereerst, aan de hand van een theoretische analyse, de bruikbaarheid van de Relational Coordination Theory getoetst om deze verschillen te temperen. In de analyse baseren we ons op literatuur over inter-organisatorische coördinatie, en relationele coördinatie in het bijzonder. Daaruit bleek dat relationele coördinatie kan bijdragen bij het temperen van problemen die hun

oorsprong vinden in de organisatorische en technologische proximateit tussen participanten in een portalen-netwerk. Bovendien is het Relational Model of Organizational Change een bruikbaar instrument om relationele coördinatie te bevorderen. Een deel van de redesign-interventies die in het Model worden voorgesteld zijn mogelijk niet rechtstreeks van toepassing op inter-organisatorische patiëntportaal-netwerken vanwege de geografische kloof tussen organisaties in het netwerk.

#### **Onderzoek vraag 4: Hoe kan bestaande wetenschappelijke evidentie bijdragen aan de ontwikkeling van patiëntportalen in verschillende zorgstelsels en hoe kan die evidentie worden verstevigd?**

In **Hoofdstuk 7** hebben we bestaande wetenschappelijke evidentie onderzocht over de ontwikkeling van patiëntportalen, met als doel om niet alleen meer informatie te verkrijgen over de wijze waarop de twee hierboven genoemde methoden gebruikt zijn, maar ook om meerdere benaderingen te identificeren waarmee op effectieve wijze patiëntportalen kunnen worden ontwikkeld binnen verschillende zorgstelsels. Ons uitgangspunt was dat deze literatuurstudie waardevol zou zijn om praktisch toepasbare kennis te genereren en toekomstig onderzoek te ondersteunen. Op basis van een 'design science'-kader hebben we de resultaten van 109 relevante artikelen onder de loep genomen. Onze review leidde tot het identificeren van de vijf voornaamste ontwikkelingsproblemen: het borgen van patiënt-betrokkenheid, de acceptatie van zorgaanbieders, het vinden van een geschikte vorm van data governance, een veilige infrastructuur, en een duurzame business case. Verder hebben we oplossingen ontwaard die werden voorgesteld om deze problemen te verlichten. Interventies op de werkvloer (zoals relationele coördinatie) en economische interventies (zoals het Meaningful Use-programma) werden in een aantal van deze artikelen behandeld, maar daarnaast werden er ook vele andere soorten oplossingen genoemd. Slechts weinig van deze oplossingen zijn echter geëvalueerd, en dat belemmert het aanreiken van concrete oplossingen voor patiëntportaal-ontwikkelaars. Om de wetenschappelijke evidentie te bevorderen hebben we drie aanbevelingen voorgesteld. Ten eerste: onderzoekers dienen hun ontwerpen (indien beschikbaar) op bestaande bewijsvoering te baseren en verslag te doen van de implementatie en evaluatie, om zo bij te dragen aan de validering, bevordering en generaliseerbaarheid van bestaande evidentie. Indien er geen sprake is van bestaande evidentie raden we aan om onderzoek te initiëren dat naast het ontwerpen, implementeren en evalueren van oplossingen ook problemen identificeert en analyseert om een meer solide en complete wetenschappelijke evidentie te creëren. Ten tweede voltrekt de ontwikkeling van patiëntportalen zich door middel van meervoudige iteraties in een

probleemoplossende cyclus. Daarom moedigen wij studies aan met een brede reikwijdte, zoals een langere tijdsspanne en meerdere iteraties binnen het cyclus. Ten derde: om portaalontwikkelingen in verschillende contexten te kunnen ondersteunen zou de vorming van wetenschappelijke evidentie gebaat zijn bij onderzoek waarbij op cumulatieve wijze kennis wordt vergaard uit verschillende soorten patiëntportalen, patiënten-populaties en organisatorische contexten (en in het bijzonder binnen gefragmenteerde zorgstelsels, waar de ontwikkeling van patiëntportalen het moeilijkst blijkt te zijn).

## **Conclusie**

In **Hoofdstuk 8** reflecteren we op de bevindingen van ons onderzoek. Wij betogen dat onze onderzoeks-output relevant is voor artsen en onderzoekers die zich hebben toegelegd op de ontwikkeling en het gebruik van patiëntportalen, met name in gefragmenteerde zorgstelsels.



# SAMMENFATNING

Introduktion

I **Kapitel 1** introducerer vi patientportaler og beskriver vores forskningsmål- og spørgsmål. Patientportaler kan give patienter adgang til egne sundhedsdata og facilitere interaktion med sundhedsvæsenet. Patientportaler skaber hidtil usete muligheder for at få digital adgang til sundhedsvæsenet, hvormed de kan skabe værdi for patienter, sundhedsudbydere og de organisationer, der udbyder portalerne. Den organisatoriske kontekst spiller en stor rolle i opfyldelsen af dette potentiale: hvor integrerede sundhedssystemer virker fremmende, lader fragmenterede sundhedssystemers kontekst til at have en hæmmende virkning på potentialet. Resultatet er, at relativt få omfangsrige patientportaler er blevet udviklet i fragmenterede sundhedssystemer, herunder det hollandske. Målet med denne afhandling har derfor været at undersøge, hvilken rolle kontekst spiller. Vi har gjort dette ved at identificere faktorer, som påvirker portaler i forskellige typer af sundhedssystemer. Derudover har vi søgt at definere og vurdere måder, hvorpå udviklingen af patientportaler kan fremmes i fragmenterede sundhedssystemer.

Vi har ladet de følgende fire spørgsmål lede forskningen.

1. Hvilke resultater kan opnås gennem patientportaler, og hvordan bliver disse resultater opnået?
2. Hvordan påvirker sundhedsvæsenets organisering patientportalers udvikling og evne til at opnå resultater?
3. Med fokus på fragmenterede sundhedssystemer, hvordan kan patientportalers udvikling og evne til at opnå resultater fremmes?
4. Hvordan kan det nuværende vidensgrundlag hjælpe patientportalers udvikling og evne til at opnå resultater, og hvordan kan dette vidensgrundlag forbedres?

For at kunne besvare disse spørgsmål studerede vi patientportaler i integrerede og fragmenterede sundhedssystemer i USA og Holland. Vi benyttede flere forskellige kvalitative metoder, herunder litteraturgennemgang, dokumentanalyse og interviews. De fire forskningsspørgsmål dikterer strukturen i forskningen.

### **Forskningsspørgsmål 1: Hvilke resultater kan opnås gennem patientportaler, og hvordan bliver disse resultater opnået?**

Som grundlag til at besvare dette spørgsmål, lavede vi et 'realist review' af artikler vedrørende resultater af patientportaler. Vi beskriver dette i **Kapitel 2**. Via en gennemgang af 32 relevante

artikler, fandt vi, at patientportaler kan lede til forbedringer i patienters helbred, patienters overholdelse af behandlingsråd, patientbemyndigelse, patienttilfredshed, patient-læge kommunikation samt ændringer i brug af sundhedsydelser. Vi udledte, at disse resultater kan opnås gennem adskillige mekanismer, herunder patienters indsigt i deres egne sundhedsdata, automatisering af information, personkontinuitet samt tilgængelighed af sundhedsydelser. Vi var interesserede i at undersøge, hvilken rolle den organisatoriske kontekst spiller i aktiveringen af disse mekanismer. Det viste sig dog, at størstedelen af evalueringerne var blevet foretaget i integrerede sundhedssystemer i USA. Dette gjorde os ude af stand til at finde et mønster i, hvordan patientportaler virker i forskellige kontekster. Det kan dog udledes fra den store del af patientportal-evalueringer fra integrerede sundhedssystemer, at disse systemers kontekst er fremmede for patientportaler. For at forbedre vores forståelse af, hvordan patientportaler virker, konkluderede vi, at fremtidige evalueringer bør indhente information omkring mekanismer og kontekst, som påvirker patientportalers resultater.

## **Forskningsspørgsmål 2: Hvordan påvirker sundhedsvæsenets organisering patientportalers udvikling og evne til at opnå resultater?**

Vi bidrog til at forbedre denne forståelse ved at foretage et casestudie af Kaiser Permanentes patientportal, hvilket vi beretter om i **Kapitel 3**. Som resultaterne af vores realist review indikerer, lader integration af et sundhedssystem til positivt at påvirke organisationers evne til at opnå resultater gennem patientportaler. For at skabe en mere dybdegående forståelse af, hvordan resultater opnås, og hvilken rolle integration af et sundhedssystem spiller for at opnå disse resultater, vurderede vi, at et studie af Kaiser Permanentes patientportal ville være ideelt. Vi foretog semistrukturerede interviews med 18 organisatoriske medlemmer, som varetog nøgleopgaver i udviklingen, implementeringen og evalueringen af portalen. Vores studie havde to hovedresultater. For det første beskrev vi de mekanismer, hvormed denne specifikke portal opnår resultater. Hovedsageligt i linje med de mekanismer vi identificerede gennem vores realist review, indbefattede disse mekanismer forbedret adgang til sundhedsydelser, gennemsigtighed og automatisering af information, patient-læge interaktion, forbindelsen mellem Kaiser Permanente og patienter samt effektivisering af lægers arbejdsgange og administrative opgaver. For det andet identificerede vi syv organisatoriske faktorer uløseligt forbundet med Kaiser Permanente, som muliggør disse mekanismer. Disse er afstemning mellem portalen og økonomiske incitamenter, synergi med eksisterende it-infrastruktur og drift, læge-ledet styring, inkluderende beslutninger og vidensdeling, regional fleksibilitet i implementering, kontinuerlig innovation samt vægt på patient-tilpasset design. På trods af, at disse resultater ikke kan

overføres direkte til alle slags sundhedssystemer, kan de vejlede patientportal-udviklere om, hvordan organisatoriske faktorer kan justeres for at understøtte patientportaler.

Det foregående kapitel gav en grundig forståelse af, hvilke resultater der kan opnås under gunstige forudsætninger og hvordan. Vi var nu interesserede i at lære mere om patientportaler under mindre – tilsyneladende – fordelagtige forudsætninger, som vi anser fragmenterede sundhedssystemer for at have. For at forstå dynamikkerne forbundet med udviklingen af patientportaler i fragmenterede sundhedssystemer indsamlede vi empirisk materiale – herunder interviews og dokumenter – fra tre patientportaler, som bliver udviklet i netværk af sundhedsorganisationer i det fragmenterede hollandske system. Vi beretter om dette studie i **Kapitel 4**. Disse tre netværk differentierede sig fra hinanden i deres antal og forskellighed af aktører, graden hvormed disse aktører var gensidigt afhængige, graden hvormed netværksstyring var decentraliseret, og graden hvormed netværksstrukturen var dynamisk. Vi observerede, at de netværk, der udviste den højeste grad af disse karakteristika, oplevede størst besvær med at udvikle patientportaler. Vi fandt, at de mest fremtrædende besværligheder var forbundet med at opnå interoperabilitet, succesful implementering, overholdelse af regulativer og økonomisk bæredygtighed. Samtidig fandt vi, at portalerne, der blev udviklet af de mest komplekse netværk, sandsynligvis er mest funktionelle for patienter, idet de kan sammenføre information og ydelser fra flere sundhedsudbydere. Baseret på disse indsigter fremsatte vi, at effektiv udvikling af patientportaler sandsynligvis forudsætter en afvejning mellem funktionalitet og simplicitet i udviklingen.

### **Forskningsspørgsmål 3: Med fokus på fragmenterede sundhedssystemer, hvordan kan patientportalers udvikling og evne til at opnå resultater fremmes?**

Indtil nu har vores forskning ledt til en indgående forståelse af, hvilken rolle den organisatoriske kontekst spiller, herunder fremmende og hæmmende faktorer for patientportal-udvikling og resultaterne heraf. Især grundet indsigt i at fragmentation har en hæmmende indflydelse på patientportaler, blev vores ambition at finde og vurdere måder, hvorpå denne indflydelse kan mindskes. I de følgende to kapitler beskriver vi to mulige tilgange til at gøre dette.

Først, som vi beskriver i **Kapitel 5**, studerede vi effekten af et nationalt politisk initiativ 'Meaningful Use'-programmet, der handler om stimuleringen af udviklingen af patientportaler i fragmenterede sundhedssystemer i USA. Vi udvalgte fire 'Health Information Exchanges', som – motiveret af incitamenterne fra Meaningful Use – var banebrydende indenfor udviklingen af patientportaler i 2014. Vi foretog semistrukturerede interviews med direktører, projektledere og

sundhedsudbydere. Gennem vores analyse af disse interviews fandt vi, at incitamenterne fra Meaningful Use-programmet stimulerede udviklingen af integrerede portaler ved at opfordre til tilslutning fra adskillige sundhedsudbydere. Øvrige faktorer, som spillede ind på beslutninger vedrørende optag af integrerede portaler var funktionalitet og omkostninger. En generel erkendelse var dog, at incitamenterne ikke var nok til at fremdrive gennemgribende optag af patientportaler. Derfor fremsatte vi, at et fokus på værdi for patienten bør være det underliggende princip i tiltag, der forsøger at øge online patient-involvering i Meaningful Use-programmets tredje stadie. Vi foreslog et antal ændringer i programmet, som ville kunne øge værdi for patienten og, derved understøtte væksten og bæredygtigheden af patientportaler, der bliver udviklet af Health Information Exchanges.

Vi var os bevidste om, at en vigtig underliggende årsag til meget af det besvær, der er forbundet med udvikling af patientportaler i fragmenterede sundhedssystemer, er afhængigheden af samarbejde mellem organisationer med forskellige organisatoriske, tekniske og geografiske egenskaber. Som vi beskrev i **Kapitel 6** lavede vi derfor først en teoretisk analyse for at bedømme anvendeligheden af the 'Relational Coordination Theory' til at mindste disse forskelligheder. I analysen brugte vi litteratur inden for inter-organisatorisk samarbejde og især 'relational coordination'. Vi fandt, at relational coordination kan hjælpe til at mindske besvær forårsaget af organisatoriske og teknologiske forskelligheder mellem deltagere i netværket. The 'Relational Model of Organizational Change' er et brugbart redskab til at styrke relational coordination og kan derved reducere omkostninger forbundet med inter-organisatorisk koordination. Dog kan nogle af de organisatoriske redesign-interventioner, som modellen foreslår, muligvis ikke direkte overføres på patientportal-netværk grundet geografisk afstand mellem deltagere i netværket.

#### **Forskningsspørgsmål 4: Hvordan kan det nuværende vidensgrundlag hjælpe patientportalers udvikling og evne til at opnå resultater, og hvordan kan dette vidensgrundlag forbedres?**

I **Kapitel 7** gennemgik vi eksisterende evidens vedrørende udvikling af patientportaler, ikke kun for at lære mere om hvordan de to ovennævnte tilgange er blevet benyttet og har klaret sig, men også for at identificere yderligere tiltag for på effektiv vis at udvikle patientportaler i forskellige sundhedssystemer. Vi mente, at denne litteraturgennemgang kunne hjælpe til at vejlede praksis og guide fremtidig forskning. Med udgangspunkt i design science research gennemgik vi 109 relevante artikler. Dette førte til identifikationen af fem hovedproblemer i patientportal-udviklingen: at sikre patientinvolvering, accept fra sundhedsudbydere,

hensigtsmæssig datahåndtering, en sikker infrastruktur og en bæredygtig forretningsmodel. Derudover identificerede vi fremlagte løsninger, der kan mindske disse problemer. Arbejdspladsinterventioner (såsom relational coordination) samt økonomiske interventioner (såsom Meaningful Use-incidenterne) var nævnt i nogle af disse artikler, men mange andre løsninger dukkede op. Meget få af disse løsninger er dog blevet evalueret, hvilket hindrer dannelsen af et sæt konkrete løsninger til udvikling af patientportaler. For på systematisk vis at fremme vidensgrundlaget for udvikling af patientportaler gav vi tre overordnede anbefalinger til fremtidig forskning. For det første, hvor vidensgrundlaget eksisterer bør forskere basere deres designs på eksisterende evidens og rapportere om implementering og evaluering for således at validere, videreudvikle og generalisere det eksisterende evidensgrundlag. På områder, hvor der ikke er evidens, tilskynder vi forskning, der identificerer og analyserer problemer samt designer, implementerer og evaluerer løsninger for derved at skabe et sammenhængende vidensgrundlag. For det andet, sker udvikling af patientportaler gennem flere gentagelser af 'the problem solving cycle'. Vi tilskynder således studier med længere analyseenheder, for eksempel i form af en længere tidshorizont eller gentagelser af udviklingsprocessen. For det tredje, for at kunne informere udviklingen af patientportaler i forskellige sundhedssystemer kan vidensgrundlaget drage nytte af forskning, der indsamler viden fra forskellige typer af patientportaler, patientpopulationer og i forskellige organisatoriske kontekster – især i fragmenterede sundhedssystemer, hvor besværet med udviklingen af patientportaler sandsynligvis er størst.

## **Konklusion**

I **Kapitel 8** konkluderer vi på resultaterne af vores forskning. Vi argumenterer for, at vores forskningsoutput er relevant for akademikere og praktikere, som er dedikerede til at udvikle og bruge patientportaler, særligt i fragmenterede sundhedssystemer.

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I'm sure the fingers of most PhDs have itched for the moment when they get to write thanks to all the people who have contributed personally and professionally to their PhD trajectories. But then, when the time comes, no words seem adequate to capture all the thoughts, feelings and experiences that have come and gone through so many years. And yet, we are all charged with trying. Here's my best attempt.

This dissertation could not have been accomplished without the love and support, hard work, and intellectual contributions from numerous people. One thing is certain, without them it would not have been the fun and meaningful adventure it has been. Most central to the process has been my team of supervisors consisting of Joris van de Klundert, Antoinette de Bont, and Thomas Rundall.

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Tom, I think it's rare one comes across another person that impacts one's life as significantly as you have mine. Over the last couple of years, you've been not only a great mentor but also an

extraordinary friend. I have you to thank for my experiences in the US and for making them so valuable. It is with a smile that I think back on our numerous work meetings in Berkeley, often over coffee or lunch and always with many laughs. I reflect warmly thinking back on my recuperation at your and Jane's home – thank you for taking me in. I feel humble that you decided to devote time in your well-deserved retirement to work with me on my dissertation. Although (knowing your generosity) you expect nothing in return, I am deeply indebted to you. Thank you for everything.

Many other people have been involved in my research in one way or another. I am appreciative to all who have participated in my research by offering insights into the work they do. I am also thankful to the several people I've collaborated with, especially Mary Reed at Kaiser Permanente's Division of Research and Jan Hazelzet at the Erasmus Medical Center. Last, but not least, I am grateful to the members of my doctorate committee for reading this work and joining me for my defense.

I would like to extend my appreciation to my colleagues at iBMG, and especially in HSMO. A special thanks to my 'kamergeroepjes' Carien, Willemijn and Judith for always making me look forward to coming into our office. It has been a space to laugh, share frustrations, and motivate each other, for example through our 'boot camps'. I appreciate your patience as I have progressed in my Dutch skills and for providing a safe environment to practice. Also a very special thanks to Marcello and Marleen. You were always there to listen, talk and offer a helping hand.

My time living abroad, both in the Netherlands and in California wouldn't have been so amazing had it not been for a lot of incredible people who have let me become a part of their lives. I get truly overwhelmed when thinking of all the fun times we've had, places we've seen, and things we've learned from each other. I value our friendships so much and look forward to many, many more moments with you.

The only reason I've been able to live abroad for so many years is because I have such a strong home base. My dear friends in Denmark, thank you for always encouraging me and for being there for me. I'll always appreciate you visiting me in the Netherlands and California, and for making time for me when I've been back for short or long visits. I know how lucky I am to have you as my friends. Tusind tak for det!

My family – Mormor, Ditlev, Tine, Frederik, Mor og Far – you mean the world to me. I've enjoyed so much having you there with me throughout my PhD: clapping when an article was

submitted, booing when one was rejected and celebrating when one was accepted. Mor og Far, how do I thank the people who have given me everything? Jeg elsker jer og er så taknemmelig for, at jeg lige præcis er jeres datter.

I would like to dedicate this book to my grandma, who – if she had been given the opportunity – could also have accomplished this.

San Francisco, April 2015

# CURRICULUM VITAE

# Terese Otte-Trojel

Date and place of birth: 30 May 1984, Copenhagen



- Education**
- 2008-2011 M.Sc. in Public Health from Copenhagen University, Denmark
    - Thesis about use of health information technology for health promotion in the EU (graded the equivalent of A+)
  - 2009-2010 Graduate level exchange at the Division of Health Policy & Management at UC Berkeley's School of Public Health
    - Graduated with a GPA of 3.83
    - Awarded a Fulbright Scholarship
  - 2005-2008 B. Sc. in Public Health from Copenhagen University, Denmark
- Professional experience**
- 2015 - Business Consultant at NNIT, Copenhagen
  - 2012-2015 Doctoral Candidate at the Institute of Health Policy & Management (iBMG), Erasmus University Rotterdam; visiting scholar at UC Berkeley's School of Public Health
    - Teaching experiences: "Minor, Integrated Management in Healthcare"; "Internship: 'working in healthcare'"; Co-reader on bachelor theses
    - Teaching credentials: "Feedback & grading module 1"; "Teaching in small groups".
    - Academic courses: "Advanced Theory of Health Care Organizations & Environments"; "Applied Impact Evaluation"; "Business Fundamentals"
    - Competence building: "Academic writing in English", "Scale validation"
    - Conferences and paper presentations: CareTank, Hamburg 2012; VitaValley, Ede 2012; Relational Coordination Workshop, Amsterdam 2014; AcademyHealth, Minneapolis 2015
    - Additional activities:*
      - Assisting on 'CONNECT study' at Kaiser Permanente's Division of Research
      - Wrote awarded proposal for EU project for 'ReAAL'
      - Reviewed for the Journal of Medical Internet Research
  - 2011-2012 Project assistant (freelance) at EuroHealthNet, Brussels
    - Worked on EU project 'Crossing Bridges' aimed at promoting

implementation  
of 'Health in All Policies' in Europe

- 2011-2011 Freelance researcher at the University of Maastricht
- Involved in EU project "Reviewing Public Health Capacity in the EU" as key expert on the Danish public health capacity
- 2010-2011 Intern at EuroHealthNet, Brussels
- Co-authored report: public-private partnerships for obesity prevention
  - Co-authored report: healthy and active ageing in the EU
  - Created compilation of national and regional-level policies and strategies to tackle health inequalities in the EU member states
- 2009-2009 Student Assistant at the Unit of Patient-Perceived Quality, The Capital Region of Denmark
- Validated questionnaires for national patient satisfaction survey
  - Performed quantitative analyses for project on blood donors
  - Set up online questionnaire in Analyzer for project on cancer patients
- 2006-2007 Student Assistant at the Danish Cancer Society
- Performed outbound qualitative interviews for national cancer study

**Voluntary work experience**

- Present Mentor for Master's students at Copenhagen University
- 2012-2013 Board member, Erasmus PhD Association Rotterdam (EPAR)
- 2008-2009 Activity Coordinator for Save the Children Youth, Asylum Centre, Kongelunden
- 2008-2009 Mentored international exchange students at Copenhagen University

**Publications** *Published or in review:*

Otte-Trojel T, de Bont A, Rundall T, van de Klundert J. How outcomes are achieved through patient portals: a realist review. *Journal of the American Medical Informatics Association*, 2014; 21(4): 751-757

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# APPENDIX

# USING REALIST REVIEWS TO UNDERSTAND HOW HEALTH IT WORKS, FOR WHOM, AND IN WHAT CIRCUMSTANCES

Randell R, Greenhalgh J, Dowding D

In a recent JAMIA article, Otte-Trojel et al [1] presents a realist review of patient portals. We commend the authors for using this approach to synthesizing evidence, which is a divergence from traditional systematic review methodology. We believe realist approaches have much to offer the medical informatics community, providing a means to not only determine if health IT interventions provide benefit in terms of outcomes, but to understand why and in what contexts such benefits may occur. However, we feel it is important to address some concerns we have regarding the way in which the authors used realist methods in their review. Our intention is to encourage the authors to expand on this work and to clarify for readers some of the key concepts of realist reviews and how they differ from traditional systematic reviews. In this, we respond to the call of realist evaluators for collective scrutiny of each other's work to drive the method forward.[2]

Realist reviews identify theories of how an intervention works, for whom, and in what circumstances, and then test and refine those theories through consideration of primary studies.[3] For realists, interventions themselves do not produce outcomes. Rather, interventions offer resources; outcomes depend on how recipients respond to those resources, which will vary according to the context. Realist theories, referred to as Context Mechanism Outcome configurations, explain how different contexts trigger particular mechanisms (the reasoning and responses of recipients) which, in turn, give rise to a particular pattern of outcomes.

An important initial stage in a realist review is "theory elicitation," where reviewers explore the literature with the explicit purpose of identifying theories.[4] Otte-Trojel et al [1] undertook an exploratory review to "identify ways in which patient portals may contribute to health service delivery and patient outcomes." In reporting the results of this initial review, the authors describe what could be considered a mixture of resources that patient portals might offer (patient access to information and services, patient decision-support) and possible outcomes (coordination of care around the patient; interpersonal continuity of care; health services efficiency; and service convenience to patients and caregivers). However, nothing has been reported about how patients might respond to those resources or how their responses might vary according to the context. Looking at the reference list, it seems the authors drew primarily on journal articles. We suggest that a broader search might have assisted in identifying

theories; while journal articles can provide some insight, stakeholders' theories about how patient portals work are likely to be found in editorials, websites of healthcare providers and patient portal vendors, medical informatics mailing lists, and patient information websites.

In a realist review, it is only once the theories have been identified that identification of primary studies takes place. Searching should be purposive and iterative, driven not by the intervention but by the theories.[4] For example, if one of the theories suggests that giving patients access to their health record will increase their understanding of their condition and thereby enable them to take a more active role in their care, a relevant search would not only look for primary studies on patient portals but also other interventions that seek to engage patients in their care by increasing their knowledge of their condition. Rather than taking this approach, the search strategy employed by Otte-Trojel et al [1] is closer to that of a traditional systematic review, with search terms that describe the intervention. Similarly, the choice of outcomes to focus on should be driven where possible by the theories, rather than being based on an existing review as Otte-Trojel et al [1] have done.

In the results section of the paper, the authors describe four mechanisms. We would suggest that the authors' descriptions of mechanisms focus on resources that the intervention provides, rather than the response of recipients. For example, the mechanism "interpersonal continuity of care" describes how patient portals allow patients to communicate asynchronously with a preferred provider but does not explain what would motivate a patient to do so. In describing context, the authors refer only to organisational context, stating that context at the service unit level and patient-provider level was rarely described in detail. We appreciate that studies do vary in the extent to which context is described. However, an important aspect of context is at the individual level in terms of nature and severity of the patient's condition. While not identified as a context by the authors, they implicitly acknowledge this as a context when discussing outcomes, pointing to the emphasis in the studies on chronic disease patients and the modest outcomes for patients whose condition is already well controlled.

Finally, we feel it is important to acknowledge that different study designs make different contributions to theory testing. From our reading of the paper, Otte-Trojel et al [1] appear to have treated all studies as potentially providing evidence on contexts, mechanisms, and outcomes. Randomized controlled trials (RCTs) provide information on outcome patterns and, by examining differences in, for example, intervention delivery or patient population, some pointers to likely contextual differences might also be identified. However, RCTs seldom provide information about mechanisms as RCTs are concerned with identifying regularity between a particular intervention and a particular outcome, not with understanding how the

intervention changed the reasoning and behavior of recipients. To understand how recipients respond to an intervention, it is necessary to look at qualitative studies, which explore these responses in detail. Realist reviewers would not typically look to qualitative studies for evidence on outcome patterns because such studies rarely explore outcomes and, where they do, small numbers and lack of standardised measurement make it difficult to draw reliable conclusions. We feel that Otte-Trojel et al's [1] findings would have produced more sharply defined Context Mechanism Outcome configurations if they had engaged in a process of knitting together different forms of evidence from different study types as we describe above. Contexts, mechanisms, and outcomes do not just fall out of the primary studies so the realist reviewer has to shuttle between theory and data, integrating the data in imaginative rather than mechanistic ways.[5]

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## RESPONSE TO RANDELL ET AL. "USING REALIST REVIEWS TO UNDERSTAND HOW HEALTH IT WORKS, FOR WHOM, AND IN WHAT CIRCUMSTANCES"

Otte-Trojel T, de Bont A, Rundall T, van de Klundert J.

We appreciate the interest Randell et al. have taken in our realist review, their careful reading and analysis, and their methodological considerations. Similar to Randell et al., we recognize the usefulness of the realist review method to explaining how interventions work, for whom, and in what circumstances, and welcome their efforts to 'drive the method forward' by reviewing and

commenting on how the method is being applied in different fields of research. Randell et al. identify various valuable directions in which the research presented in the review can be extended. In particular, we agree that further exploration of patient related mechanisms and contexts, which address how patients (populations) respond to patient portal related resources, are worthy of further research. Likewise, we agree that an iterative process of 'knitting' the evidence found in quantitative studies with qualitative studies and other sources is likely to produce 'more sharply defined CMO configurations' and provide additional understanding of the mechanisms by which patient portals influence outcomes. We acknowledge that our review has primarily focused on mechanisms and contexts in the domain of service-providers organizations and health systems, and have paid less attention to other domains such as technology or patients.

Our review generates the first systematic scientific understanding of how contexts and mechanisms influence the impact patient portals have on (mainly) patient outcomes. We have adhered closely to the recently published RAMESES protocol [1] to examine evidence and develop this understanding. In addition to developing this scientific understanding of patient portals, our review serves to stimulate further research, because, as we have pointed out, there were (and are) many important questions in this domain that are presently unanswered. We have pointed to a deficiency of descriptions in published studies about how patient portal outcomes are generated and how context may impact these outcomes. Such descriptions are important, since our findings indicate that health system and organizational characteristics may largely impact the outcomes achievable by patient portals. In view of the possible value of patient portals to address the health needs of patients in a variety of healthcare systems (see e.g. [2]), the review adds to an important, but yet small, evidence base. This review and future research it may stimulate contributes to advancing this evidence base. The reflections of Randell et al. are of value in this process.

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