Drift and shift in the organizing vision career for personal health records: An investigation of innovation discourse dynamics

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ABSTRACT

Organizational information technology innovations develop and diffuse through the efforts of communities of stakeholders working in cooperation and competition to articulate, motivate, and diffuse an innovation. Community members' discourse can reveal competing interests and tensions that influence whether ideas central to the innovation coalesce, drift apart, or dissipate and thus the innovation's trajectory. To investigate these dynamics, we adopted the theoretical lens of the organizing vision framework and historical and discourse analysis methods to study developments with personal health records (PHRs) in the U.S. for over a decade (2003–2013). Our analysis revealed ongoing drift in PHR discourse across the innovation community despite concerted efforts by key stakeholders to promote an overarching vision. Shifts in discourse developed as four competing PHR versions coalesced around different institutional arrangements for health and health data stewardship, health data stores, and innovation community actors. This analysis furthers our understanding of career dynamics of an organizing vision and the implications of these dynamics for innovation diffusion. The study also highlights implications for health IT innovation research and for practice.

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1. Introduction and motivation

Technology innovations develop through the efforts of communities of stakeholders (Van de Ven, Polley, Garud, & Venkataraman, 1999). Firms, entrepreneurs, government agencies, and so on work in networks and partnerships – collaborative and competitive – to build the institutional and market structures necessary to support the development and commercialization of an innovation (Arthur, 2009; Hargrave & Van de Ven, 2006; Lusch & Vargo, 2014; Vargo, Wieland, & Akaka, 2013). For instance, standards are negotiated among industry actors for inter-organizational information systems (Markus, Dutta, Steinfeld, & Wigand, 2008; Markus, Steinfield, Wigand, & Minton, 2006) and market relationships are configured around new technologies and standards (Garud, Jain, & Kumaraswamy, 2002).

The discourse surrounding an organization IT innovation reveals much about how an innovation develops and diffuses through community efforts (Barrett, Heracleous, & Walsham, 2013; Bijker, 1995; Iacono & Kling, 2001; Nielsen, Mathiassen, & Newell, 2014; Prince, Barrett, & Oborn, 2014; Pollock & Williams, 2009, 2011; Swanson & Ramiller, 1997; Wang & Ramiller, 2009). For instance the actions, agreements, and negotiations of industry actors are reported widely in business and trade media (Wang & Swanson, 2007, 2008). Innovation discourse may also reveal how some firms orchestrate innovation networks through dialogical strategies to favor their own interests and strengths (Prince et al., 2014). Their attempts to legitimate their own accounts of an innovation are likely

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to be contested (Garud et al., 2002) as opposing actors "frame issues and construct networks in an attempt to introduce new institutional arrangements" (Hargrave & Van de Ven, 2006, p. 877). In these various ways discourse both reveals and shapes an IT innovation's trajectory.

In this study, we investigated community discourse dynamics related to an intriguing health information technology (HIT) innovation. Personal health records (PHRs) have been defined generally as internet-based, lifelong health records that are controlled by the individual and are meant to promote the individual's engagement in his or her health and healthcare. For more than a decade policy makers, academics, healthcare providers, technology firms and other health industry organizations debated, defined, and advocated the development and widespread use of PHRs (Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus, 2011; Kim, Jung, & Bates, 2011; Nazi, 2013). Leading healthcare providers developed PHR-like systems, as did health insurers. IT firms like Microsoft and Google invested in and promoted PHRs. Despite the volume of discourse dedicated to articulating and promoting PHRs, ongoing interest among notable stakeholders and substantial investments in PHRs, and governmental promotions of PHRs, considerable confusion and disagreement remained about this innovation and little progress was made towards widespread use in over a decade (Nazi, 2013). Competing instantiations of PHRs took shape, while individual consumers' use of PHRs remained low (Archer et al., 2011; Kim et al., 2011; Lewis, 2011; Markle Foundation, 2011), adding to uncertainty about the future of this innovation (Spil & Klein, 2014).

Personal health records present a potentially valuable health IT innovation as well as an interesting and useful context in which to study IT innovation discourse dynamics. Our research goals were to investigate how the PHR discourse influenced the innovation's trajectory, how and why varied interpretations of PHRs developed, and how discourse dynamics contributed to PHR innovation outcomes. To investigate these questions we adopted the theoretical lens of the organizing vision (Ramiller & Swanson, 2003; Swanson & Ramiller, 1997, 2004) in a study of the discourse surrounding PHRs in the U.S. from 2003 through 2013. An organizing vision serves as a discursive resource for an innovation community (Swanson & Ramiller, 1997), and community sensemaking and actions related to an innovation are evident in ongoing organizational visioning (Nielsen et al., 2014).

Situating our study in the institutional environment of the U.S. healthcare industry (Chiasson & Davidson, 2004, 2005) and using historical and discourse analysis methods (Buhl, Müller, Fridgen, & Röglinger, 2012; Phillips & Hardy, 2002; Prince et al., 2014; Williams & Pollock, 2012) we assessed how innovation community members interpreted and acted on PHR innovation concepts. This analysis highlighted implicit assumptions about novel institutional arrangements for and challenges to existing arrangement for stewardship of personal health data. Examining how stakeholders navigated these challenges helped explain why the PHR organizing vision drifted for over a decade without widespread diffusion or market failure of the innovation and also shifted towards four competing versions of the overarching vision, each representing different assemblages of data stewardship arrangements and innovation community participants. Through this analysis we extended the analytical concept of an organizing vision career to consider how drift and shift may arise as liminal states in the career trajectory of an organization vision and the implications for innovation diffusion processes of these states.

In the following section we first review the study's theoretical foundations in the innovation discourse and organizing vision literatures. We then situate the study in the U.S. healthcare institutional field and describe the study's research design and application of historical and discourse analysis methods. In the findings and analysis we consider how the innovation community theorized an overarching PHR organizing vision, the challenges to institutional arrangements for health data stewardship this vision presented, and translations of the overarching vision into four assemblages that navigated around these challenges. This analysis informed our discussion of organizing vision career dynamics and *drift* and *shift* as two liminal states that may develop in an organizational IT innovation diffusion process. We conclude with a discussion of implications for theory and for practice.

2. Theoretical foundations

Acknowledging the importance of community discourse in the early stages of an organizational IT innovation, Swanson and Ramiller (1997, p. 460) define an *organizing vision* as "a focal community idea of the application of information technology in organizations … a vision for organizing in a way that embeds and utilizes information technology in organizational structures and processes." An organizing vision centers on the "business problematic" – well-recognized organizational issues or opportunities for which the innovation is a possible solution – and the core technologies and organizational practices brought together in the innovation; it is often characterized by buzzwords and metaphors that suggest its potential usefulness (p. 463).

The organizing vision concept has been used to study a variety of IT innovations (Currie, 2004; Ellingsen & Monteiro, 2003; Kaganer, Pawlowski, & Wiley-Patton, 2010; Ramiller & Swanson, 2003; Reardon, 2009; Wang & Ramiller, 2009; Wang & Swanson, 2008). These studies draw attention not only to the information technology (IT) components of innovation but also to the organizational practices and structures in which technology components would be embedded. For instance, the organizing vision for enterprise resource planning (ERP) envisions not only how databases and software could be integrated but also how operational practices across functional areas of a firm could be tightly integrated and coordinated (Pollock & Williams, 2009).

Beyond organizational practices, technology innovation and institutional arrangements are interwoven (Lusch & Vargo, 2014). The term *institutional arrangement* refers to the "schema, norms, and regulations" that organize and regulate social life in and between organizations within a socio-economic sector (Hargrave & Van de Ven, 2006, p. 866). Novel institutional arrangements or challenges to existing arrangements may be implicit in an innovation and its organizing vision. For instance, the development and diffusion of smart mobile phones entailed new institutional arrangements as well as technology artifacts between IT firms and wireless carriers to orchestrate data services and between IT firms and consumers for voice services, which have challenged existing arrangements between telecom firms and customers who have abandoned land-line phone services.

Swanson and Ramiller (1997, p. 461) posit an organizing vision serves three critical functions in the early stages of the innovation diffusion process: (i) *interpreting* the expected uses and usefulness of the innovation; (ii) *legitimating* the innovation by linking it to commonly acknowledged and accepted business problems; and (iii) *mobilizing* industry actors to participate in the innovation. Shared understanding among members of an innovation community may foster cooperation and aid diffusion (Wang & Swanson, 2007, 2008). On the other hand, a vision fraught with ambiguity and lacking coherence may stymie innovators' promotional efforts. Ramiller and Swanson (2003) highlighted aspects of the community's reception of an organizing vision that indicate the vision's ability to facilitate the innovation's diffusion: (i) Does the vision suggest a clear *interpretation* of the innovation?; (ii) is the vision overburdened with unrealistic expectations, or are its assumptions *plausible*?; (iii) is the vision *important* enough to garner market interest?; and, (iv) is the *discontinuity* between current socio-technical practices implicit in the vision sufficient to warrant investment but not overwhelming or discouraging?

The organizing vision shapes and is shaped by the innovation community. It emerges through the discourse of diverse stakeholders interested in the innovation, such as technology vendors and professionals, consultants and industry media pundits, and potential customers (Pollock & Williams, 2009, 2011; Swanson & Ramiller, 1997; Wang & Ramiller, 2009). Discourse takes place in many communication channels: industry journals, public and private presentations, conferences, workshops, trade expositions, and so on (Kaganer et al., 2010; Wang & Swanson, 2007, 2008). Ideas and opinions circulate among potential adopters, influencing their decisions whether to adopt and how to implement (Pollock & Williams, 2009; Swanson & Ramiller, 2004). However, these discursive processes usually do not result in full consensus about the innovation or vision (Swanson & Ramiller, 1997).

2.1. Organizational visioning and career dynamics

An organizing vision evolves as adopters gain experience with the innovation and their reports about implementation refine the community's understanding of it (Pollock & Williams, 2011; Wang & Ramiller, 2009; Williams & Pollock, 2012). Nielsen et al. (2014) characterize the interplay of field-level discourse and discourse within organizations as they gain experience with the innovation as an ongoing and dynamic process of *organizational visioning* through *translation* and *theorization*. *Translation* occurs when organizations "filter, tailor, and reformulate the discourse of an organizational field as they transform ideas to local practices," so that "certain elements take center stage while others are pushed to the background" (p. 170). *Theorization* involves making ideas more general and universally applicable, thus enabling ideas about the innovation to "travel" across an institutional field in "a complex interaction process as rival stakeholders with different interests exchange, discuss, and negotiate new ideas about IT usage" (p. 169). Theorization and translation processes entail conflict as well as organizational and field-level learning, because technology innovation involves actors and entrepreneurs with diverse interests and is a contested field (Garud et al., 2002; Hargrave & Van de Ven, 2006; Prince et al., 2014; Swanson & Ramiller, 1997; Williams & Pollock, 2012). Barrett et al. (2013) argue that entrepreneurs may at times draw rhetorical justifications from underlying, competing ideologies to promote alternative organizing visions, engendering power struggles over which vision is more pragmatically or morally legitimate.

Swanson and Ramiller (1997) characterize the innovation community's active interest in and support for an organizing vision as its *career* and theorize that all organizing visions eventually dissipate. A successful vision facilitates widespread innovation diffusion but then fades away as the innovation becomes taken-for-granted. An unsuccessful vision may be overtaken by more popular visions and lose the limited attention of the innovation community (Wang, 2009) or be overcome by competing visions (Barrett et al., 2013) to fade away without widespread adoption. Nielsen et al. (2014, p. 180) posit that theorization and translation are recursive, intertwined and ongoing processes throughout an innovation's diffusion in an organizational field, rather than a distinct phase of institutional change (Greenwood et al., 2002). This suggests that a vision's career dynamics continue well past the early formulation of the organizing vision, as Swanson and Ramiller (1997) originally argued. However, further development of the organizing vision career concept is needed to better understand the implications of career dynamics on IT innovation and diffusion trajectories (Barrett et al., 2013).

3. Organizing visions and institutional arrangements in healthcare it innovation

There are many organizing visions for HIT innovations, for example electronic health records (EHR), telehealth, and health information exchanges (HIE) (Klenun-Dabrowska and Cornford, 2000). These visions share sweeping assumptions that HIT deployment will address societal issues of rising costs and lack of coordination in health service delivery and will enhance quality and access to healthcare (Tang, Ash, Bates, Overhage, & Sands, 2006). HIT visions are stimulating historic levels of government and industry investments in HIT deployment. For instance, in the United Kingdom the National Health Service funded over £12B for HIT developments (Mathieson, 2011), while in the U.S. the Health Information Technology for Economic and Clinical Health (HITECH) legislation committed over $20 billion to stimulate HIT adoption (Blumenthal, 2009, 2010). Health service organizations are likely to expend even more to implement or upgrade HIT systems in response to incentives and regulations.

The healthcare sector presents significant challenges that influence HIT innovation and diffusion (Davidson & Chismar, 2007; Oborn, Barrett, & Davidson, 2011). HIT innovations are nested in the healthcare industry's complex institutional arrangements of societal values, government regulation, and health industry actors, professional practices and inter-organizational relationships (Scott, Ruef, Mendel, & Caronna, 2000). Each national setting has distinctive regulatory and market structures that influence HIT innovation. This study focused on the U.S. healthcare sector from 2003–2013, where HIT deployment has been viewed as essential to solve quality, safety and cost problems in the U.S. healthcare system (Blumenthal, 2009, 2010; DesRoches et al., 2008; Institute of Medicine, 1999,
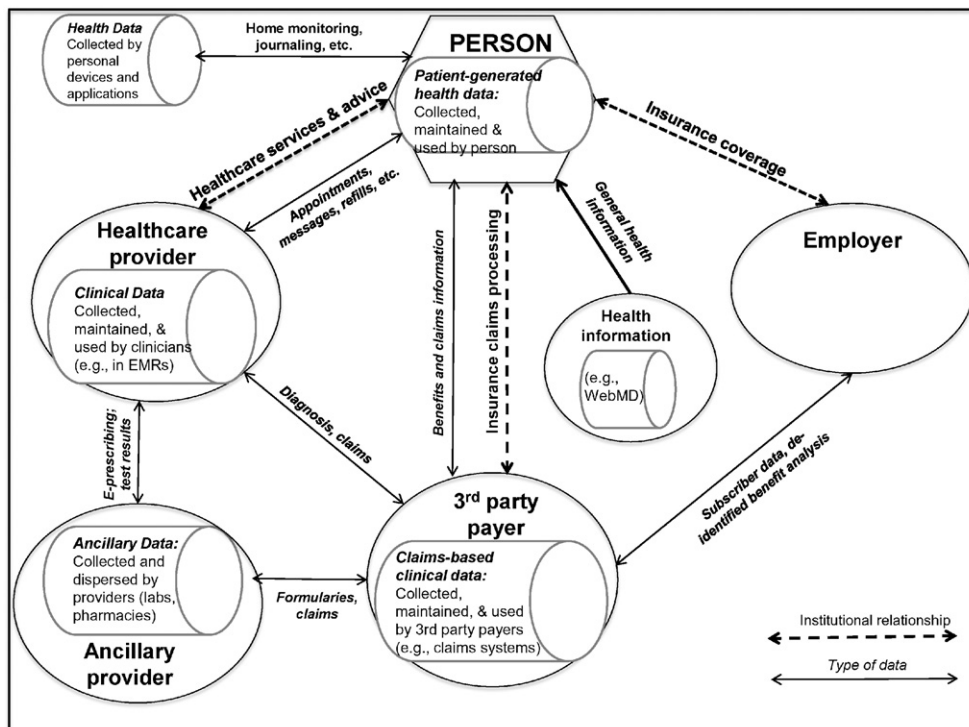
Fig. 1. Institutional arrangements and health data stores in the U.S. healthcare setting.

2001; Jha et al., 2009). Of note, the U.S. Federal Government, through the Center for Medicare and Medicaid Services (CMS)[1] has advocated HIT adoption, including efforts to promote development of personal health records.

Investigating HIT innovation thus requires an appreciation of the key actors in the organizational field, their relationships and practices (Chiasson & Davidson, 2004, 2005). With regard to PHR innovation, how health data will be collected and used are central concerns. Health data management has typically been associated with regulation of retention, privacy and confidentiality of personal health data. A broader concept of *data stewardship*, which we adopt here, considers actors' responsibilities and relationships for data collection (with data integrity, accuracy, timeliness, and completeness), storage, exchange, aggregation, analysis and use as well as coordination of data curating activities, sociotechnical infrastructures, and the responsible dissemination of data products across multiple communities in the field (Baker & Yarmey, 2009). The following discussion gives an overview of data stewardship arrangements in the U.S. healthcare system (Iglehart, 1999) relevant to PHRs. Fig. 1 depicts these arrangements, and Table 1 describes key actors in the PHR innovation community.

The *person* who is the subject of a *personal* health record has relationships with various organizations that accumulate data about the person's health: healthcare services providers[2] maintain clinical data on *patients*; health insurers and other 3rd party payers hold benefit claims data on *subscribers*, including clinical data such as diagnosis and medications; employers who subsidize health insurance for *employees* are not allowed access to identified individual data, but they can receive summary reports of health plan costs and services; and, ancillary providers such as pharmacies and laboratories maintain *customer* data such as prescriptions and test results. A *person* typically holds some data about his or her health on paper or in computerized form, and many use health information websites on the Internet for general health information. With recent popularity of health monitoring devices and applications, some individuals also accumulate patient-generated health data (PGHD) electronically outside of clinical settings (Deering, 2013), such as sleep patterns, diet, and blood pressure.

Health data are maintained in multiple locations under the control of different organizations but are shared in the course of delivering healthcare services and for billing purposes through various institutional arrangements. For instance, ancillary service providers such as laboratories transmit data to and from healthcare providers, and providers exchange individual-level health data with insurers for reimbursement. The privacy and protection of healthcare data are regulated at the federal level by the Health Insurance Portability and Privacy Act (HIPPA), which holds healthcare provider organizations accountable for securing patients' data. Providers are legally obligated to provide patients copies of health records, and recently CMS began promoting electronic exchanges between patients and providers (HHS (Department of Health and Human Services), 2012).

Amid this mangle of health data repositories, practices and arrangements, the PHR vision grew from early discussions of the *patient-held record* (Østerlund, Dosa, & Arnott Smith, 2010). These discussions were conducted largely among academic researchers,

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[1] CMS, the largest government 3rd party payer in the U.S. healthcare sector, wields substantial policy and market power.
[2] The general term *heath care service provider* includes clinical personnel such as physicians and organizations like hospitals.

Table 1
Stakeholders in the PHR innovation community in the U.S. (2003–2013).

Employers:
Large employers pay for health insurance and have goals for promoting employee health such as reducing insurance costs and improving productivity. Employers such as Walmart and Intel have formed consortia to provide employees with PHRs (see: http://dossia.org/about-us).

Health insurers:
National and other large insurers offer some forms of PHR to enrolled members, sometimes in conjunction with employers, provider organizations or IT vendors. Prominent examples include Aetna, US Health, Cigna, and various Blue Cross/Blue Shield plans.

Health IT vendors:
IT vendors specializing in health IT applications provide PHR systems and PHR applications, often through provider organizations. See Epic System (http://www.epic.com/software-phr.php) and Indivo (http://indivohealth.org/).

Healthcare foundations.
Charitable foundations such as the California Foundation for Health, Markle Foundation, and Robert Wood Johnson Foundation provide funding for research, workshops, white papers, and may sponsor pilot projects. (See http://www.projecthealthdesign.org/ for examples). Organizations such as the AHIMA Foundation sponsor PHR technologies (e.g. http://www.myphr.com.)

Industry promotion groups:
Industry consortia and not-for-profit associations, drawing together various industry and collective actors, produce position papers, engage in pilots, and do contracted consulting on health and health IT topics. The now disbanded National Alliance for Health Information Technology is an example of a consortium that helped develop HIT standards and created definitions of PHRs. The Healthcare Information and Management Systems Society (HIMSS) is another group that promotes PHR discourse. The American Health Information Management Association (AHIMA) developed and promoted PHR products and discourse.

Integrated healthcare provider organizations:
These organizations typically have already developed extensive electronic health records and offer patients access through "patient portals." Prominent examples include Kaiser Permanente (https://healthy.kaiserpermanente.org/health/care/consumer/my-health-manager) and the U.S. Veterans Administration (https://www.myhealth.va.gov/index.html).

IT vendors:
Microsoft, Google, IBM and other large IT vendors have entered the health IT market and actively promote their technological platforms for health information exchange. A notable example is Microsofts HealthVault™ (https://www.healthvault.com/us/en), offered as an individual PHR and as a data platform/ecosystem.

Medical Informatics community:
Members of this community are primarily academics, who are associated with integrated healthcare provider organizations (typically university medical centers), with medical schools, or public health schools in universities. These individuals conduct conferences, publish position papers and research reports, and are often involved in foundation- and government-sponsored workshops or pilot projects.

Professional Provider Associations:
Groups such as the Association for Family Practitioners offer interpretations of PHRs to mobilize their members to participate. Nursing associations and other physician associations such as the American Medical Association (AMA) sponsor and participate in projects.

US Government agencies:
Various agencies, operating under the Department of Health and Human Services, e.g., Center for Medicare and Medicaid and Agency for Health Research and Quality (AHQR), participate in pilots, sponsor research, commission policy working groups, and formulate policies and regulations (e.g., see http://www.healthit.gov/providers-professionals/faqs/what-personal-health-record).

emphasized the status of the record holder as a *patient* and highlighted the patient's self-entry of data or the record's utility when patients carry their records between healthcare providers (Gearson, 2007; Grossman, Zayas-Caban, & Kemper, 2009). Rapid deployment of computers in households in the 1990s, followed by the growth of Internet health care information sites (e.g., MedlinePlus.gov, WebMD.com) resulted in more technologically-sophisticated ideas, such as health records on memory sticks or smart cards (Eysenbach, 2000) or web-based standalone PHR systems (Halamka et al., 2008). The transition in discourse from a *patient-held* record to a *personal health* record began to gain prominence in the United States in the early 2000s (Archer et al., 2011; Kim & Johnson, 2002; Kim et al., 2011; Markle Foundation, 2003; Tang et al., 2006). Over the next decade, the PHR organizing vision took root, garnering the attention of many stakeholders (Table 1) as well as significant investments in the innovation.

Drawing on these theoretical foundations and an understanding of the institutional setting relevant to PHRs, we examined PHR discourse in the U.S. from 2003–2013 to investigate PHR innovation processes and dynamics. Our analysis revealed how institutional arrangements for health data stewardship influenced theorization and translation of the PHR organizing vision and how these processes affected the PHR vision's career dynamics.

4. Research design and methods

Swanson and Ramiller (1997, p. 471) suggest that process-oriented, historical studies of specific organizing visions are needed to extend our theoretical understanding of how organizational IT innovations come to be institutionalized; such studies should "probe the larger community terrain" to encompass the many settings in which relevant discourse is produced. Pollock and Williams (2009, 2011) and Williams and Pollock (2012) similarly argue that innovation research should adopt larger-scale historical designs that

extend beyond single-site organizational case studies or cross-sectional analyses to consider how innovation concepts evolve and are shaped over time by innovation stakeholders. Following these recommended approaches, our study examined the PHR discourse in the U.S. healthcare sector, key participants in the PHR innovation community, and institutional arrangements implicit in PHR concepts and claims.

We adopted historical and discourse analysis methods in the study. The term *discourse* has multiple, nuanced meanings in research, ranging from socially acceptable ways of speaking and writing to the body of texts related to a societal phenomenon (Phillips & Hardy, 2002). Here we mean the latter, as our goal was to analyze multiple texts that described and promoted personal health records. To assemble an appropriate set of texts for analysis, we drew from academic, mass media, and trade press publications indexed in electronic databases as well as texts accessible via the Internet. These documents represented the wide variety of discourse channels and participants engaged with PHRs.

We analyzed texts using qualitative content coding methods (Creswell, 2012; Miles, Huberman, & Saldana, 2013) and drawing conceptual categories from the literature discussed in Section 2. Through this analysis we identified institutional arrangements implicit in PHR discourses, particularly in relation to health data stewardship, influential stakeholders in the innovation community, their actions to develop or implement PHRs, and changes in the innovation community's response to PHRs during the study period (2003–2013). Finally, we developed an analytical generalization of PHR organizing vision career dynamics based on this comprehensive understanding of the case.

4.1. Data collection procedures

Table 2 summarizes the types of sources and Appendix A lists individual texts we utilized in this study. We used iteratively a combination of systematic search, snowball sampling, and theoretic sampling to assemble documents for analysis. Our research goal was not to present a statistically representative sample of every text related to PHRs or of the discourse conducted in particular outlets. (See Kim et al., 2011 for the latter type of study.) Instead, our goal was to bring to the foreground texts that contributed in substantial ways to the PHR organizing vision in the U.S., that revealed assumptions and claims implicated in the vision, or that documented notable stakeholders and their actions in regards to PHR developments.

We began with a systematic literature review using the comprehensive electronic database of medical publications, MEDLINE, via PubMed through the National Library of Medicine. After reading a selection of publications, we narrowed our search using the term "personal health record" to select documents that specifically addressed PHRs and to differentiate between publications addressing "electronic health records" or HIT innovations generally. Influential sources of PHR publications in the U.S. medical informatics field include the *Journal of the American Medical Association* (JAMIA) and the American Medical Informatics Association (AMIA) conference proceedings. We searched other online database sources, which index academic and trade press articles (through EBSCOHost and Web of Science) using the same terms. We reviewed abstracts to select articles for in-depth review that discussed PHRs substantively or that documented PHR activities by community members.

We utilized the Google search engine as a first step to search the Internet for white papers, blogs, and online news reports related to PHRs. We expanded searches by following relevant links and searching specific sites mentioned in relevant websites. These searches surfaced white papers and studies commissioned by government agencies and charitable foundations. Some reports and

Table 2
Types of sources for PHR texts used in the study.

Sources for PHR texts[*]	Examples	Number
Published research reports and papers • Papers published in academic journals and indexed in electronic databases • These typically represent the medical informatics community	Articles published in JAMIA, New England Journal of Medicine	64
Conference proceedings and PHR workshop presentations, proceedings, and reports • General medical informatics conferences with PHR sessions • Specialized conferences focusing on PHR • Meetings among leaders and spokespersons in the Health IT movement or PHR innovation (published on the Internet as white papers or publications)	American Medical Informatics Association (AMIA) conferences	43
Commissioned white papers and workshop reports • Public reports from government or foundation sponsored task forces focused on PHR	Markle Foundation Reports, U.S. DHHS Reports on PHR	26
Web sites • Description of policies, platforms, marketing material, and so on from IT vendors, professional associations, foundations • Blogs and pundit commentaries on PHR	U.S. Health and Human Services government site Microsoft Health Vault site	27
Trade press and mainstream media publication • Press reports on events or announcements of vendor initiatives, e.g., brief reports of events, assessment of PHR activities, adoption or policies distributed in online health or health IT-focused media	Wall Street Journal articles on Microsoft or Google PHR announcements	73

[*] See Appendix A for a list of all texts reviewed for this study.

Table 3
Organizing vision concepts used to analyze PHR discourse.

Analytic category	Examples of discourse statements
Innovation community stakeholders (Hargrave & Van de Ven, 2006; Swanson & Ramiller, 1997) • Actors identified as participants in PHR innovation or contributors to discourse	• "*Multiple stakeholders—patients, providers, employers, payers, governments, and research institutions—must play key roles in developing PHR technology more fully and to overcome the barriers to widespread adoption.*" (Tang et al., 2006, p. 126) • "*The digital health start-up was early in the race to build a lifelong and portable personal health record … But unlike Google, Dossia is still very much in the game.*" (Nosta, 2013, *np*)
Societal/business problems that IT innovation addresses (Swanson & Ramiller, 1997) • Widely agreed-upon social or organization problems • Articulated ways in which innovation addresses problems	• "*PHRs have the potential not only to improve personal and family health but also to support national objectives for health care quality, safety, efficiency and ultimately, health outcomes.*" (CMS, 2005, p. 31) • *Your first step in taking control of your healthcare is to own your health data. Data is power. It empowers you to be your own healthcare advocate.* (http://zweenahealth.com/free-personal-health-record/#U1McAVye2kQ)
Institutional arrangements related to the innovation (Hargrave & Van de Ven, 2006; Phillips, Lawrence, & Hardy, 2004; Swanson & Ramiller, 1997) • Assumptions about or challenges to legitimated practices in PHR-related stakeholder interactions	• "*It is possible that PHRs will threaten the control, autonomy, and authority of some health care providers, based on traditional provider–patient roles.*" (Tang et al., 2006, p. 125) • *Since both the patient and physician use the data in My Health Manager, consumers are actively using their Kaiser Permanente PHR to communicate with their physician and support their health goals.* (Kaiser Permanente, 2007; *see Appendix #I-13.*)
Core technologies implicated in innovation (Ramiller & Swanson, 2003; Swanson & Ramiller, 1997) • Data sources, algorithms, hardware and software, standards entailed in the IT innovation	• "*This paper summarizes the College Symposium discussions on PHR systems and provides definitions, system characteristics, technical architectures, benefits, barriers to adoption, and strategies for increasing adoption.*" (Tang et al., 2006, p. 121) • "*Get Real Health's InstantPHR™ platform is a robust, secure, and flexible platform for a wide range of patient engagement and care management solutions. The InstantPHR™ platform includes a patient portal, provider dashboard, administrative console, and an extensive widget-based feature set that can be used to create effective connected care solutions.*" (http://www.getrealhealth.com/differentiators/)
Community reception of the organizing vision and innovation (Ramiller & Swanson, 2003; Swanson & Ramiller, 2004) • Innovation community's response to interpretation, plausibility, importance, and discontinuity of innovation evident in the organizing vision	• "'*PHR*' *means different things to different people — there is no universally accepted definition.*" (Gearson, 2007, p. 2). • "*The immaturity and slow diffusion of standards for interoperability and data portability are key barriers.*" (Detmer, Bloomrosen, Raymond, & Tang, 2008 *p.6*) • *Not everyone is sold on the merits of PHRs. Security and privacy issues stop some patients from jumping on the PHR bandwagon.* (Vecchione, 2012; *see Appendix #M-69*) • *PHRs are boring to the outside world and too insular within the established medical community.* (Krasner, 2011; *see Appendix #M-36*) • *Although shared access to PHRs could improve communication among patients, their caregivers, and their dispersed health care team, few PHRs currently offer this feature.* (Zulman et al., 2011; *see Appendix #J-64*)

white papers reported on activities of taskforce workshops or conferences. Internet searches also led us to IT vendor websites on which vendors presented their approaches to PHRs for potential adopters in videos and narrative texts, websites of employers and insurers who sponsored PHRs, and online trade press reports of PHR developments.

We extended the database of PHR discourse materials with backward and forward snowballing to examine references cited in documents already identified as well as citations of key documents. For example, a 2003 white paper by the Markle Foundation was routinely cited as an authoritative source for PHR definitions. We assessed the influence of key academic texts with citation analysis in the Web of Science (http://isiwebofknowledge.com). Notably, Tang et al. (2006) was cited widely as an authoritative source in a range of PHR publications. Together, these methods ensured we had a broad spectrum of texts to analyze as well as influential policy documents, published papers, white papers and workshop reports.

Throughout this process we used theoretic sampling to supplement data sources as needed. We constructed an analytic table of innovation community stakeholders (Table 1), determined whether each stakeholder group's views were sufficiently represented, and gathered additional data as needed. Interestingly, the "person" or "consumer" who is the central subject of a PHR was evident only through other participants' discourse, for example, in PHR vendors' use of vignettes or in surveys of consumer's PHR expectations and use.

4.2. Data analysis procedures

Table 3 summarizes key organizing vision concepts (Ramiller & Swanson, 2003; Swanson & Ramiller, 1997) utilized in our analysis and provides illustrative quotations from the data. There is no uniform measure of "text" in our study, thus counts of documents, statements or codes have little analytical significance. Instead we developed the analysis interpretively and qualitatively using the conceptual categories of the organizing vision framework holistically to assess the body of discourse (Klein & Myers, 1999; Walsham, 1993). Each author read, summarized and analyzed texts using relevant concepts, and we clarified collectively the emerging analysis.

Table 4
Notable activities and events in the PHR organizing vision discourse (2003–2013).

Year	PHR activities, announcements, and publications
2003	• Markle Foundation Workshop held and seminal white-paper published (Connecting for Health: the Personal Health Working Group Final Report). • MyHealtheVet launched by the US Veterans Administration. • AHIMA promotes the MyPHR online health record.
2004	• Medical informatics scholars and practitioners promote PHR concepts by developing and publishing more technical frameworks. • Government sponsored research (e.g., Markle Foundation Connecting for Health) indicates there is no "one path" for PHR development.
2005	• U.S. Health and Human Services solicits contributions and comments on PHR policy. • AHIMA e-HIM Personal Health Record Work Group publish and promote PHR definitions. • My HealtheVet extends features to include patient portal features such as prescription refills.
2006	• Seminal article is published in JAMIA outlining broad view of PHRs (see Tang et al., 2006). • Markel Foundation publishes follow up report: Connecting Americans to their Healthcare: A Common Framework for Networked Personal Health Information. • National Committee on Vital and Health Statistics publishes policy statement on PHRs: Personal Health Records and Personal Health Record Systems: A report recommendation. • Dossia Consortium formed to offer employees a personally controlled health record. • Aetna Insurance makes claims-based PHR available to subscribers.
2007	• Robert Wood Johnson Foundation's Project Health Design initiated. • Dossia selects Indivo as a platform for personal health record. • Microsoft® HealthVault launched. • Agency for Research on Health Quality (ARHQ) reports results of funded research to study PHRs among elderly. • Multiple health insurance plans announce PHRs for subscribers.
2008	• Multiple pilots of PHR-type systems, including Dossia pilot at Walmart to 1.2 million employees, US Department of Defense, Aetna Insurance; My HealtheVet expanded. • Google Health announced and launched. • Multiple partnerships between Microsoft or Google with healthcare providers or insurers announced. • Markle Foundation publishes follow-up report and survey on PHRs; survey indicates broad interest but low levels of adoption among individuals and healthcare providers.
2009	• Conference dedicated to PHRs held in Washington, DC (Personal Electronic Health Records: From Biomedical Research to People's Health Conference). • Additional partnerships and pilots announced for HealthVault or Google Health. • Google Health and Microsoft HealthVault™ increasingly compared in trade press. • State of Florida announces a multi-year demonstration project for Medicaid PHR. • Robert Wood Johnson Foundation's Project Health Design final report issued on pilot projects.
2010	• HITECH Act Meaningful Use regulations specify EMR electronic communication capabilities. • California HealthCare Foundation survey indicates limited adoption of PHRs. • Dossia expands PHR platform to other employers via cloud services. • MyHealtheVet adds "blue button" feature to download/share health data. • Study identifies 117 PHR systems, mostly standalone products (Jones, Shipman, Plaut, & Selden, 2010).
2011	• Published literature reviews indicate continued attention and interest to PHRs but differences in interpretations and PHR models persist (Archer et al., 2011; Kim et al., 2011) • Google announces retirement/shutdown of Google Health. • Dossia reportedly has 6 founding firms using the PHR for employees, as it upgrades interface. • Standards group (HL7) publishes implementation guide to facilitate transfers of data across PHRs. • Survey of consumers indicates only 7% have ever used a PHR, less than half continue to use.
2012	• HITECH Act Meaningful Use Stage 2 criteria requires physicians and hospitals to begin electronic interchange of health data with patients. • Kaiser Permanente announces 4 million subscriber/patients use the patient portal PHR. • Dossia promotes integration of patient generated health data for patient engagement via PHR. • Government-sponsored report on patient-generated health data policy released.
2013	• Google Health formally shuts down. • Microsoft announces multiple mobile apps for personal health data monitoring, along with provider-based record portals and improvements to HealthVault. • Dossia expands personal health record system as health and wellness platform. • Kaiser Permanente studies indicate improved health outcomes from patient portal use.

We organized our analysis of events chronologically to develop an understanding of innovation community members involved in activities and events, changes in the organizing vision discourse, community reception of PHRs, and innovation community actions over time. Key actions and events occurring in 2003–2013 are summarized in Table 4 and discussed below. We also assessed how key participants aligned around different versions of the PHR organizing vision and compared our analysis with those published in the medical informatics literature. This analysis highlighted institutional arrangements implicit in the PHR vision in two general categories: assumptions about health data stewardship and about guiding individuals' engagement in their health. Table 5 provides a summary of this analysis and is discussed below.

In the second order analytical generalization of organizing vision career dynamics (Swanson & Ramiller, 1997) and theorization and translation (Nielsen et al., 2014), we identified and explicated *drift* as a PHR organizing vision career state associated with ambiguous theorizing the overarching PHR vision. We identified *shift* as a career state that developed when variations of the PHR vision formed around different institutional arrangements for health data stewardship. In the final stage of analysis we integrated these findings with this existing theory.

Table 5
Translations in the PHR organizing vision.

Translations of the overarching PHR Vision	Implications for institutional arrangements	
	Stewardship of Health Data	Guiding engagement in health
(1) Tethered-to-EMR PHR	*Person*:	*Person*:
Key technologies	Activate EMR-portal account	Become engaged in health by using data
Stores of clinical data in EMR	Port PHR data if desired to stand-alone system	
Patient-accessible "portal" interface for health data and other communications	Control/share PHR access with others	*PHR/IT vendor*:
		Provide standard health information
Software to port data from tethered system to stand-alone or platform	*PHR/IT vendor*:	Present customized health data advice
Connectivity via mobile devices	Provide storage and access to data for patients	
	Maintain security	*Healthcare provider*:
	Share data as authorized by person	Provide healthcare services and advise using clinical data
Key proponents and participants	Sell or market data (potential)	
(Integrated) healthcare provider organizations		Engage patients in portal/PHR through electronic exchange (in "meaningful use 2" criteria)
Health IT vendors	*Healthcare provider*:	
Medical informatics community	Maintain patient clinical data	
IT vendors	Allow access to selected data and interactions	
	Comply with HIPPA regulations	
(2) Tethered-to-insurer PHR	*Person*:	*Person*:
Key technologies	Use insurer-portal account to access data and add data (e.g., immunizations)	Become engaged in health by using data
Health insurance claims databases	Control/share PHR access with others	*Health insurer/PHR provider*:
"Rules engines" for analyzing and giving medical advice		Provide access to general health information
PHR portal interface to insurer claims data	*Health insurer/PHR provider*:	Present customized health data advice and general health advice based on health data
Connectivity via mobile devices	Provide data storage and access to subscribers	
	Maintain security	
Key proponents and participants	Sell or market data (potential)	
Large national health insurers	Comply with HIPPA regulations	
(3) Stand-alone PHR/PHR as app	*Person*:	*Person*:
Key technologies	Collect and manage self-generated data	Become engaged in health by using data
PHR database on Internet with web access	Aggregate data from other sources	
Mobile & health monitoring devices	Control/share PHR access with others	*PHR vendor*:
Rules-based advisory systems		Provide general health information
Connectivity via mobile devices	*PHR/IT Vendor*:	Present customized health data advice from general sources
Disease or health-state monitoring applications	Provide life-long health data storage and access	
	Maintain security	
Key proponents and participants	Share data as authorized by person	*Healthcare provider*:
PHR vendors & health information associations	Sell or market data (potential)	Utilize patient generated data as part of healthcare service and advice
IT vendors with health apps		
Healthcare foundations	*Healthcare provider*:	
Medical informatics community	Provide access to clinical data files to aggregator	
Healthcare providers		
US Government/CMS		
(4) PHR platform/ecosystem	*Person*:	*Person*:
Key technologies	Activate EMR-portal account	Become engaged in health by using data
PHR database on Internet with web access	Port data from patient portal to PHR system	
Health data acquisition and translation software	Control/share PHR access with others	*PHR/IT vendor*:
Connectivity via mobile devices		Provide standard health information
Rules-based advisory systems	*PHR/IT vendor*:	Present customized health data advice and general health advice based on health data
Disease or health-state monitoring applications	Provide life-long health data storage and access	
	Maintain security	Develop and conduct engagement programs (e.g. Dossia with employers)
Key proponents and participants	Provide service to aggregate data	
General IT/HIT vendors	Share data as authorized by person	
Not-for-profit consortium (e.g., Dossia)	Sell or market data (potential)	
Medical informatics community	Follow HIPPA regulations (varied)	
NfP healthcare foundations		

5. Findings and analysis

5.1. Theorizing the PHR organizing vision

Evident throughout the study period were public discussions and commissioned workshops that *interpreted* what a PHR is conceptually and technically and how it should be developed and implemented. Research foundations such as the Markle

Foundation, the National Alliance for Health Information Technology's (NAHIT) and the American Medical Informatics Association's College of Medical Informatics conducted workshops with prominent medical informatics and clinical experts and published detailed specifications for personal health records. A highly cited workshop report presented a precise depiction of PHR characteristics, users, and uses:

> The Personal Health Record (PHR) is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results, and information from their pharmacies and insurance companies. Individuals access their PHRs via the Internet, using state-of-the-art security and privacy controls, at any time and from any location. (Markle Foundation, 2003, p. 3–4).

These core concepts of a person-centered and controlled lifelong health record, accumulated from the various data sources depicted in Fig. 1, appeared in many publications such as a highly cited paper by Tang et al. (2006) that reported a similar PHR workshop event.

PHRs were depicted as a way to span health data stores (Fig. 1) so as to facilitate healthcare delivery. Seeking to explain PHRs to family practice doctors, a text authored by medical practitioners used a vignette of an elderly female patient's imagined experience in an emergency room to illustrate the value of a PHR to span healthcare settings:

> "That evening, Mrs. Johnson woke with severe chest pain and shortness of breath … The emergency department physician diagnosed an acute coronary … He asked what medications she was taking. She could not remember all of them but told him that her entire medical record was available on the Internet … There he found her medication list and her medication allergies, which included an aspirin allergy. He canceled the aspirin order he had just written and switched it to clopidogrel, signing, "a potential adverse drug event avoided, thanks to patient's PHR." (Endsley et al., 2006, p. 58).

Also evident in the discourse were stakeholders' efforts to highlight the *distinctiveness* of PHRs from electronic medical records (EMRs). The National Alliance for Health Information Technology (NAHIT), in alignment with the U.S. Federal Government's view, stated:

> "The most salient feature of the PHR, and the one that distinguishes it from the EMR and EHR, is that the information it contains is under the control of the individual … The individual is distinctively the guardian of information stored or accessible within a PHR." (NAHIT, 2008 p. 19).

IT firms and vendors in the PHR market also encouraged individuals to demand their health data from providers and to manage data in (the firm's) PHR repositories. For instance:

> "Google believes that you own your medical records and should have easy access to them. The way we see it, it's your information; why shouldn't you control it? … You choose what you want to share and what you want to keep private." (www.google.com/intl/en-US/health/about/index.html).

> "Your first step in taking control of your healthcare is to own your health data. Data is power. It empowers you to be your own healthcare advocate…get in the habit of requesting your medical documents or pages every time you leave the doctors."(http://zweenahealth.com/free-personal-health-record/#U1McAVye2kQ).

Along with assumptions about the individuals' access to and control of health data were assumptions that PHRs would extend beyond clinical data to include health-related information (such as diet and exercise). The term "patient generated health data" (PGHD) was later coined to describe data to be included in the individuals PHR through his or her own actions:

> PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways. First, patients, not providers, are primarily responsible for capturing or recording these data. Second, patients direct the sharing or distributing of these data to health care providers and other stakeholders. (Deering, 2013, p. 3).

Underlying *interpretations* of the core technologies and user practices in the PHR organizing vision were powerful *legitimizing claims* about societal and organizational issues that would be addressed if individuals could be engaged in their health and healthcare by giving them access to and control over health-related data. The *engaged consumer* – alternatively termed a person, patient, or consumer – could take action to monitor and improve their own (or family members') health by creating a PHR, as this healthcare foundation encouraged individuals:

> "By creating a PHR, you take control of your overall health and help ensure that you and your family get the most appropriate, individualized care possible …The better you understand the full picture of your health, the more empowered you will be to partner with your healthcare provider in determining your best treatment options." (http://americanheart.org/presenter.jhtml?identifier=3056156).

For example, to illustrate engagement, Microsoft used a website vignette depicting a mother using the firm's HealthVault™ PHR to keep records of her children's immunizations, encourage her husband to track his high blood pressure, and track her own weight loss (www.healthvault.com/personal/websites-overview.aspx). Representing the perspective of U.S. employers, who established the Dossia Consortium, this PHR vendor asserted that "arming" engaged consumers with PHRs would also make them more effective heath care consumers:

> "*Arming individuals with access to and control over their health information and providing them with personalized health tools enables individuals to become more engaged partners in their care and facilitates competition in the field of healthcare, which, in turn, improves quality of care while reducing cost.*" (http://www.dossia.org/about-dossia).

To *mobilize* adoption, the *importance* of PHRs was promoted at two levels. To individual consumers who might adopt a PHR, arguments were framed in terms of having access to health data while traveling, moving to a new location or in an emergency, or to manage a family member's health, often with vignettes or video clips on web sites of health provider organizations, insurers, or PHR vendors. For instance, health insurance Aetna used a website vignette to promote the value of the firm's PHR system to subscribers if an individual relocates:

> "*My company transferred me to three different locations in five years, which has meant changing doctors three times. Having Aetna's PHR made it easer to share my health history.*" (http://www.aetna.com/showcase/phr/).

For organizations in the healthcare sector, PHRs were linked to addressing urgent problems with quality and cost in the healthcare sector, promising these types of stakeholders organizational cost reductions as well as beneficial health sector outcomes:

> "*The opportunity costs for PHR deployment are measured in medical errors, dollars, and lives. If we are to realize the potential benefits for both routine health care and for responding to catastrophic disasters like Hurricane Katrina, these important PHR-related issues must be addressed.*" (Tang et al., 2006, p. 126).

> "*Shared, ubiquitous, consent-modulated access to medical information promises reduced medical errors, improved efficiency and safety of medical care, and lower health care costs, as well as activated patients who take responsibility and become partners in managing their own healthcare.*" (Bourgeois et al., 2008, p. 737).

5.2. Challenges to institutional arrangements in the PHR vision

Beneath these interpretations and legitimating claims, the PHR organizing vision implied significant challenges to relationships and practices among the various actors depicted in Fig. 1. In 2003, no information systems existed that would meet the specifications of the comprehensive PHR. Moreover, many participants in the innovation community acknowledged that there were significant technological barriers to realizing this idealized PHR:

> "*The full potential of PHR systems will not be realized until they are capable of widespread exchange of information with EHRs and other sources of personal and other health data.*" (National Committee on Vital and Health Statistics, 2006, p. 25).

> "*The immaturity and slow diffusion of standards for interoperability and data portability are key barriers to the integration and exchange of structured data among PHRs and the range of relevant entities that provide and finance health care.*" (Detmer et al., 2008, p.6).

Technological barriers reflected the absence of institutional arrangements for health data exchange among the various actors depicted in Fig. 1 and the need for new arrangements to be negotiated and enacted among them. New or altered arrangements depended on some organizational actors relinquishing some of their control over health data stores to allow data exchange with new actors. For instance, IT firms and PHR vendors proposed to act as a 3rd party to accumulate health data across data stores for individuals, but these firms found many provider organizations uncooperative. Members of the medical informatics community acknowledged that healthcare providers were hesitant to share clinical data with 3rd parties, particularly as some PHR vendors claimed not to be subject to the HIPPA data privacy legislation that providers themselves faced. This legal analysis highlighted concerns about 3rd parties' use of PHR data:

> "*Using the data in PHRs for marketing or public heath surveillance might lead patients to worry about privacy, for example, while physicians might balk at having PHR data used for monitoring quality of care if PHRs are not perceived as reliable or complete or if they were not run by trustworthy institutions.*" (Wynia and Dunn, 2010, p. 68).

The PHR organizing vision also questioned institutionalized relations between patients and physicians. PHR advocates in medical informatics acknowledged that physicians might resist PHRs if their professional dominance was challenged by *engaged consumers* "armed" with health data and advice from a PHR system:

> "*It is possible that PHRs will threaten the control, autonomy, and authority of some health care providers, based on traditional provider–patient roles.*" (Tang et al., 2006, p. 125).

A HIT industry pundit predicted that healthcare providers would also be skeptical about the accuracy and usefulness of patient-provided data in PHRs and patients' expectations that clinicians would utilize these data, given the need for extensive new practices to do so:

> *The inclusion of PGHD brings with it an avalanche of procedural and programmatic preparation*: *data review and quality assurance, governance models and new workflows, the prickly issue of data ownership, staff time and training, liability concerns, HIPAA extension of coverage, ever-increasing insurer coordination, clinician accountability, and of course, patient consent, onboarding, and marketing.* (http://www.chilmarkresearch.com/2014/01/17/pghd-staged-progress-on-patient-engagement/).

Among individual consumers/adopters, the PHR organizing vision relied on individuals developing everyday practices for and expectations about accumulating and managing their health data that were not commonplace, as this former Google Health employee opined:

> "*… you only care about your medical data when you get sick, show up in the ER, or start taking care of someone who is sick … At the end of the day, people want their lives to be made easier and to save time on everyday healthcare tasks. They are not as interested in archiving medical data at large.*" (http://thehealthcareblog.com/blog/2011/06/29/the-phr-school-of-hard-knocks/comment-page-1/).

In these ways the PHR discourse highlighted significant challenges to institutional arrangements for health data stewardship that raised questions about the *plausibility* and *discontinuity* of the innovation. Nonetheless, the PHR organizing vision did *mobilize* notable organizational stakeholders to invest in the innovation during the study period (See Tables 1, 4 and 5.). A tenfold jump in the number of PHR journal publications by 2005 indicated growing interest and attention to this innovation, particularly in the medical informatics community (Kim et al., 2011). Intense market interest was also evident in a 2010 commissioned report (Jones et al., 2010), which identified 117 different PHRs. Numerous cooperative agreements and partnerships announced between 2008–2010 among healthcare providers, insurers, government agencies and IT/PHR vendors indicated ongoing *mobilization* and *market importance* of PHRs among these stakeholders. The *market importance* of the PHR vision among consumers was less clear. Surveys indicated that consumers would value electronic access to health records, but their actual adoption and use of PHRs ranged from 1%–10% of consumers (Fortin & Drazen, 2011; Kahn, Aulakh, & Bosworth, 2009; Markle Foundation, 2011; Noblin, Wan, & Fottler, 2012; Undem, 2010).
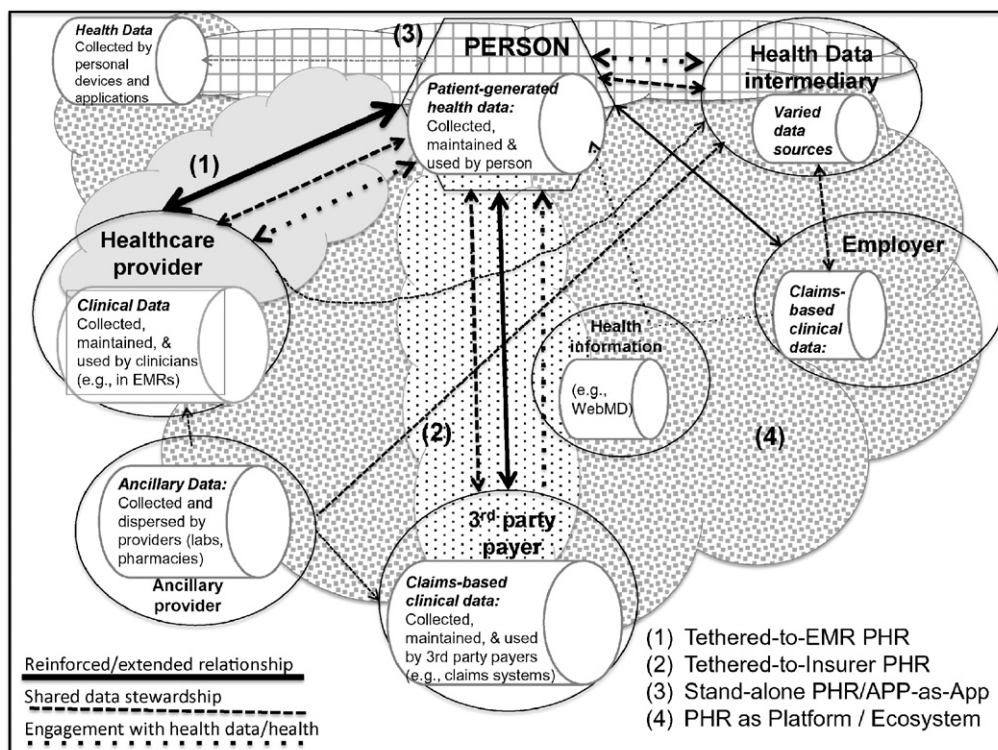

Fig. 2. Translations of PHR vision around institutional arrangements.

5.3. Navigating institutional arrangements in translation

Theorization of the PHR innovation assumed new or significantly altered institutional arrangements for health data stewardship. Between 2003 and 2013, these field-level ideas were translated as different instantiations of PHRs, as the organizing vision discourse coalesced around four versions of the theorized PHR, each with different assumptions about personal health data management, control, and use. Table 5 summarizes the analysis of translations and Fig. 2 depicts the four versions superimposed on the data stores and relationships of Fig. 1.

5.3.1. Reinforcing existing arrangements: the tethered-to-EMR PHR

The tethered-to-EMR PHR (Detmer et al., 2008; Tang & Lee, 2009; Tang et al., 2006) reinforced long-established institutional arrangements between healthcare providers and individual persons (patients) for caregiving and clinical data stewardship. (See Fig. 2, cloud [1].) For instance, the widely reported "My HealtheVet" program, sponsored by the U.S. Veterans Administration, was introduced in 2003 and developed over the decade. Another well-publicized example, Kaiser Permanente's "My health manager", allowed patient access to data in the provider's electronic medical record system (http://www.epic.com/). The following website scenario outlined patients' expected uses of this type of PHR system:

> "*My health manager provides critical time-saving features, including online appointment scheduling and prescription refills. In addition, users have 24/7 online access to lab test results, eligibility and benefits information, and even their children's immunization records. With secure e-mail messaging, members can also communicate with their doctors at anytime, from anywhere… By providing consumers with access to the same clinical record their doctors see and unique tools to interact with both their providers and health plan, My health manager goes well beyond the standard PHRs powered solely by claims data.*" (http://ckp.kp.org/newsroom/national/archive/nat_071106_myhealthmanager.html).

In this translation of the overarching PHR vision, institutional arrangements for health data sharing between clinicians and patients were purportedly strengthened by providing patients "*access to the same clinical record*" that clinicians use and by offering patients an electronic communication channel for routine communications such as appointments. Collecting and maintaining patient data arises naturally from clinicians' healthcare practices, so that the provider's data stewardship role would extend naturally to offering patients a "portal" to look into the providers' health data store. Limiting health data housed in the *tethered-to-EMR PHR* to data created by providers (in the EMR) reduced challenges to physicians' professional authority over valid health data. Patients could be *engaged* in their own healthcare via enhanced clinician-to-patient exchanges in the PHR as well as through automated advice-giving features such as follow-up or preventative service reminders and links to relevant general health information.

Many medical informatics academics were proponents of this approach (Collins et al., 2011; Detmer et al., 2008; Endsley et al., 2006; Tang & Lee, 2009; Tang et al., 2006) as were IT vendors with electronic medical record (EMR) systems. For instance Tang and Lee (2009) advocated for the *tethered-to-EMR PHR* over other approaches by appealing to legitimating claims of the theorized PHR vision:

> "*… the "integrated PHR" that is an extension of physicians' electronic health records (EHRs) will go further in facilitating the type of physician–patient relationship that will improve health and health care, at a lower cost.*" (Tang and Lee, 2009, p. 1276).

With these convenient and practical features, instantiations of this version of the PHR vision achieved some adoption among patients of large, integrated healthcare providers such as Kaiser Permanente (McCann, 2012) and the U.S. Veterans Health system. However, the *tethered-to-EMR PHR* could more aptly be termed a "*patient portal*", since this translation of the PHR vision violated core assumptions that a *patient-controlled*, *life-long* record would also house a variety of *patient-generated health data* and would not be limited to one organization (here, the healthcare provider). Thus, the legitimizing claims that patients should act as stewards of their own health data in a PHR were diminished. In response some provider organizations partnered with IT firms to give patients a means to extract some EMR-tethered data and to create an independently controlled PHR record (e.g., in the Microsoft HealthVault™).

5.3.2. Extending existing arrangements: tethered-to-insurer PHR

A second translation of the PHR organizing vision extended institutional arrangements between health insurers (3rd party payers) and persons/subscribers and depended on insurers' ownership and control of vast electronic data stores of health benefit claims data (Fig. 2, cloud [2]). Insurers' repositories included clinical and ancillary data such as diagnostic codes, prescriptions and laboratory tests, which the insurer could utilize to compile a subscriber's PHR record. A health insurer's website vignette illustrated for subscribers what this version of a PHR could do:

> "*What is a PHR? Typically offered by health insurers, a PHR contains a snapshot of the health information that matters most, such as insurance claims, doctors' visits and prescribed medications. Some information is automatically added by your health benefits provider. In some cases you can also personalize your PHR by adding your own details — everything from immunizations to your family medical history and current diet and exercise regimens. Some PHRs also allow you to provide electronic access to your physicians.*" (http://www.planforyourhealth.com/family/phr3/).

This scenario highlighted how the insurer's role as claims processor (with associated data stores) would be extended to that of health data steward to aggregate and maintain as much health data as possible on behalf of the individual subscriber. Data

stewardship would be partially shared with the subscriber by allowing subscribers to access their records, to curate some health data in the PHR and grant access to their record to others. The subscriber was also offered an online channel for routine inquires such as status of insurance claims, potentially strengthening existing insurer/subscriber relationships through PHR-related features.

Beyond health data stewardship, the *tethered-to-insurer PHR* implied the 3rd party insurer's roles of authorizing and paying benefit claims and providing general health information to subscribers would expand to offering "personalized" health care advice to subscribers. For example, insurer Aetna's self-acclaimed cutting-edge technology, termed the CareEngine™, could access the individual's PHR and utilize the firm's vast storehouse of subscribers' claims data to generate personalized "alerts" and suggest healthcare actions:

> "*The CareEngine looks at information in your Aetna Personal Health record such as medications you are taking, lab test results and any health conditions. The CareEngine then compares your information to today's medical standards for care … If the analysis reveals an opportunity for better care or a potential medical concern … the CareEngine issues an alert.*" (http://www.aetna.com/showcase/phr/).

Proponents of this approach (large U.S. insurance companies) relied on legitimating claims of the PHR vision to engage individuals to better manage their health, and in this way to address healthcare costs. Some also claimed this form of PHR might provide continuity of health data access across providers and care settings. However, like the *tethered-to-EMR* version, the *tethered-to-insurer PHR* violated the core assumption that a PHR would be independent of any one organization (the insurer) and would be fully under the control of the individual (rather than a "portal" into the insurer's databases) as a lifelong health record (rather than during the subscriber's tenure with the insurer). Like providers, some insurers partnered with IT vendors to interface with an independent PHR platform. Unlike with the *tethered-to-EMR*, PHR discourse suggested that clinicians were wary of using claims data for clinical decision-making and subscribers would question how insurers could utilize health data, for instance to deny a benefit claim. Thus this PHR version gained little traction with individuals/subscribers despite the market power and financial resources of 3rd party insurers to promote their PHR system, beyond serving as an online customer service channel for established insurance claims subscriber/insurer relationships.

5.3.3. Building new arrangements: stand-alone PHR/PHR-as-app

This version of the PHR organizing vision (Fig. 2, cloud [3]) relied on the assumptions that *individual consumers* should be the primary stewards of their personal health data and that these data would exist independently of health industry organizations like providers or insurers. In simple instantiations, a stand-alone PHR would simply be an online data file, sponsored by a PHR vendor or an organization such as a healthcare foundation, into which an individual would type, scan or otherwise enter his or her health data. The PHR system sponsor could also provide links to general health information for the individual's education or self-assessment.

A more expansive approach to the *stand-alone PHR* entailed a 3rd party organization accumulating health data on behalf of individuals rather than the individual entering all data. A 2008 Markle Foundation Report specified the requirements for *consumer access services* to act on behalf of the consumer to aggregate health records from the multiple data sources depicted in Fig. 1. This analogy suggested doing so would be (or should be) easy and automated:

> "*Just as an individual can use Quicken™ to aggregate information from financial institutions, an individual can use the PCHR to 'subscribe' to data from electronic health record systems, pharmacies, and laboratories.*" (Bourgeois et al., 2008, p. 737).

The viability of this new-to-the-field actor depended on the aggregator establishing institutional arrangements with individuals as well as with owners of existing health data stores and on field-level technological solutions for secure, standardized health data exchange. The experiences of Google Health illustrated the substantial challenges building new arrangements entailed. In 2008 Google announced its PHR offering Google Health with this bold claim:

> "*It's what we do. Our corporate mission is to organize the world's information and make it universally accessible and useful. Health information is very fragmented today, and we think we can help … we have a lot of experience storing and managing large amounts of data and developing consumer products that offer a positive and simple user experience.*" (http://www.google.com/intl/en-US/health/faq.html).[3]

Google's entry into the PHR marketplace was premised on the firm's ability to gather, curate and present information via the Internet. However, the IT firm lacked institutional arrangements for accumulating and storing personal health data, such as pre-existing relationships with individuals as patients, subscribers, or (for employer-provided insurance) employees and controlled no health data stores. Despite partnering with several large provider organizations in pilot projects, Google Health found that the technical and organizational barriers to building a health data aggregator service were onerous, as a former Google Health manager described in an interview on the demise of Google Health:

> "*The reason it was tough to do an untethered PHR, is because you have to go out and build all of these point-to-point integrations with the data, and that's very hard to scale. I have to hit all of the insurance companies. Once I integrate with their claims systems, then I*

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[3] URL links to Google Health were collected in 2009–2011. These webpages were removed after Google Health disbanded.

have to go talk to all of the EHR vendors." (http://medcitynews.com/2013/09/3-qualities-that-define-personal-health-records-version-2-0-cloud-social-and-mobile/).

The PHR innovation community debated widely Google's withdrawal from the PHR marketplace in 2011 and the health data stewardship barriers a stand-alone PHR vendor would face to build these relationships. For instance: Were consumers really interested in the ability to build and curate their own comprehensive stand-along PHR? Would consumers trust independent PHR or IT firms (such as Google) to keep their health data private and confidential rather than use data for marketing or advertising revenues? Would healthcare providers agree to transmit and share patient data via Google Health, which had declared itself exempt from HIPPA regulation that providers had to abide by?

A scaled-back version of the *standalone PHR*, the *PHR-as-app* approach, avoided many of these data stewardship challenges by zooming in on the individual's actions to record and act on the most relevant health data through mobile IT devices and trackers (i.e. PGHD) rather than to accumulate and curate a comprehensive historical healthcare record. Proponents of the *PHR-as-app* approach included some members of the medical informatics community (Brennan, 2009; Brennan et al., 2007), IT vendors such as Apple Corporation, and myriad health-and-wellness IT startup firms. Some *PHR-as-app* instantiations assumed individuals would build new relationships with IT firms through personal health recording "apps" whereas others built on the patient/provider bond for disease or chronic care management. For instance through pilot projects funded by charitable healthcare foundations (see http://www.projecthealthdesign.org/projects) medical informatics researchers developed prototypes to link care providers and patients between office visits through mobile devices used for patients' entry of daily life event data. The following description argued for this targeted, personalize health recording (versus historical records):

> "[*The application*] *captures information about daily living that is important for diabetes management and gives action-oriented advice for self-care … that consumers can access on the Web via a computer or Internet-enabled mobile device … It will also enable consumers to conduct "what if" analyses that can predict the health results of choices they might be considering, such as the effects of a particular meal on blood glucose levels.*" (http://www.projecthealthdesign.org/media/file/TRUE.pdf).

To summarize, translating the general PHR organizing vision as a *standalone PHR/PHR-as-app* assumed that new institutional arrangements for health data stewardship would develop around the individual's interests and needs, rather than growing from existing arrangements for stockpiling comprehensive health records. Thus, legitimating claims about the empowered consumer were heightened, while the purported value of life-long, comprehensive personal health records as a means to coordinate the fractured healthcare was devalued.

5.3.4. Reconfiguring arrangements: the PHR platform/ecosystem

The *PHR Platform/Ecosystem* (Fig. 2, cloud [4]) was the most comprehensive translation of the theorized PHR organizing vision, incorporating many assumptions about an all-encompassing PHR (Markle Foundation, 2003, 2008; Tang et al., 2006). Medical informatics specialists associated with Boston Children's Hospital had developed the Indivo Personally Controlled Health Record Platform Model in the 1990s (Bourgeois et al., 2008; Halamka et al., 2008; Mandl & Kohane, 2009). This open-source PHR infrastructure was incorporated in the My HealtheVet PHR of the U.S. Veterans' Administration, the Dossia Foundation's employer-sponsored PHR, and Google Health and proposed as a general resource for PHR development:

> "*The Indivo model has inspired a number of commercial efforts throughout its evolution. Most recently, we have advocated a move towards a platform model, so that other application can connect to the PCHR and extend its core functionality.*" (http://indivohealth.org/research).

Overlapping with the expanded *stand-alone PHR*, the translation to *PHR platform/ecosystem* would purportedly "untether" the comprehensive PHR from both providers and insurers and give consumers control of their health records even if they changed employer, insurer, provider or location, a position the U.S. Federal Government has long advocated:

> "*This requirement for portability excludes models in which sponsors such as health insurers or health care providers give individuals access to health-related information that is dependent on the individual remaining with that sponsor.*" (http://healthit.hhs.gov/portal/server.pt?open=512&mode=2&cached=true&objID=1221).

By "untethering" from established data stores and existing institutional arrangements for health data stewardship, the *PHR platform/ecosystem* also encompassed the challenges to institutional arrangements noted in Section 5.2 and encountered barriers like the extended stand-alone PHR did (e.g. Google Health). However two instantiations of this PHR translation illustrated how organizations attempted to orchestrate networks to navigate around these barriers.

A consortium of six large U.S. employers formed the Dossia Foundation in 2006 to build a personally controlled health record for employees. By aligning Dossia's PHR platform with employers that self-insure their health benefit plans, healthcare claims data could be directed to the Dossia PHR platform more readily (Nosta, 2013). This allowed Dossia to develop a claims-data based PHR similar to a *tethered-to-insurer* PHR but arguably "portable". In this way the Dossia model relied on health data stewardship arrangements already established between employees and employers but also required Dossia establish new institutional arrangements with individual employees to set up and use the PHR services. Reports about Dossia indicated that few employees established a PHR record, and only two additional firms joined the consortium. In later years Dossia refocused its PHR platform from health data stewardship

towards consumer engagement techniques with personalized healthcare advice and engagement programs. In an interview with a Dossia executive (Goldsmith), this commentator described how Dossia's PHR would "nudge" individuals towards better self-care health practices:

> *Dossia is rolling out a suite of population health management tools that aggregate its members' PHR data and utilize evidence-based health rules to drive personalized interventions. These are tied to specific* "*triggers*" *that are known to motivate people at times when they are much more likely to act on their health.*" (http://www.forbes.com/sites/johnnosta/2013/11/27/for-dossia-digital-health-isnt-just-personal-anymore/).

This translation of the PHR vision entailed Dossia reconfiguring institutional arrangements with employers to manage population-level health outcomes and health-related incentives (or penalties) with a firm's employees in order to reduce the firm's health-related costs. Dossia also needed to establish new relationships with individual employees to serve as their health advisor and coach, in order to act as the employers' agent to intervene in employees' health behaviors.

In 2007, Microsoft Corporation launched HealthVault™ (http://www.healthvault.com/), a PHR for individuals and a platform for aggregating and exchanging health data. HealthVault™ shared many technological features of the Indivo-based Dossia PHR platform. With the slogan, "*Together we can create a connected health community*" (http://www.healthvault.com/industry/index.aspx), Microsoft depicted the consumer at the center of its PHR platform with all other health industry actors (providers, insurers, employers, application developers, and so on) and with health monitoring devices as spokes connected to the consumer through the HealthVault™ platform and the IT firm's data translation and storage capabilities. In contrast to Dossia's alignment with employers, Microsoft's HealthVault™ aligned (but not exclusively) with healthcare providers to interface providers' patient portal with the patient-controlled HealthVault™ PHR. In these ways Microsoft's *PHR platform/ecosystem* could build on clinicians' relationships with individuals and clinical health data stores.

6. Discussion: drift and shift in the PHR organizing vision career

The findings and analysis of our study of a decade of PHR innovation community discourse in the U.S. are consistent with the process views of discourse and organizational IT innovation diffusion articulated by Swanson and Ramiller (1997, 2004) and Nielsen et al.
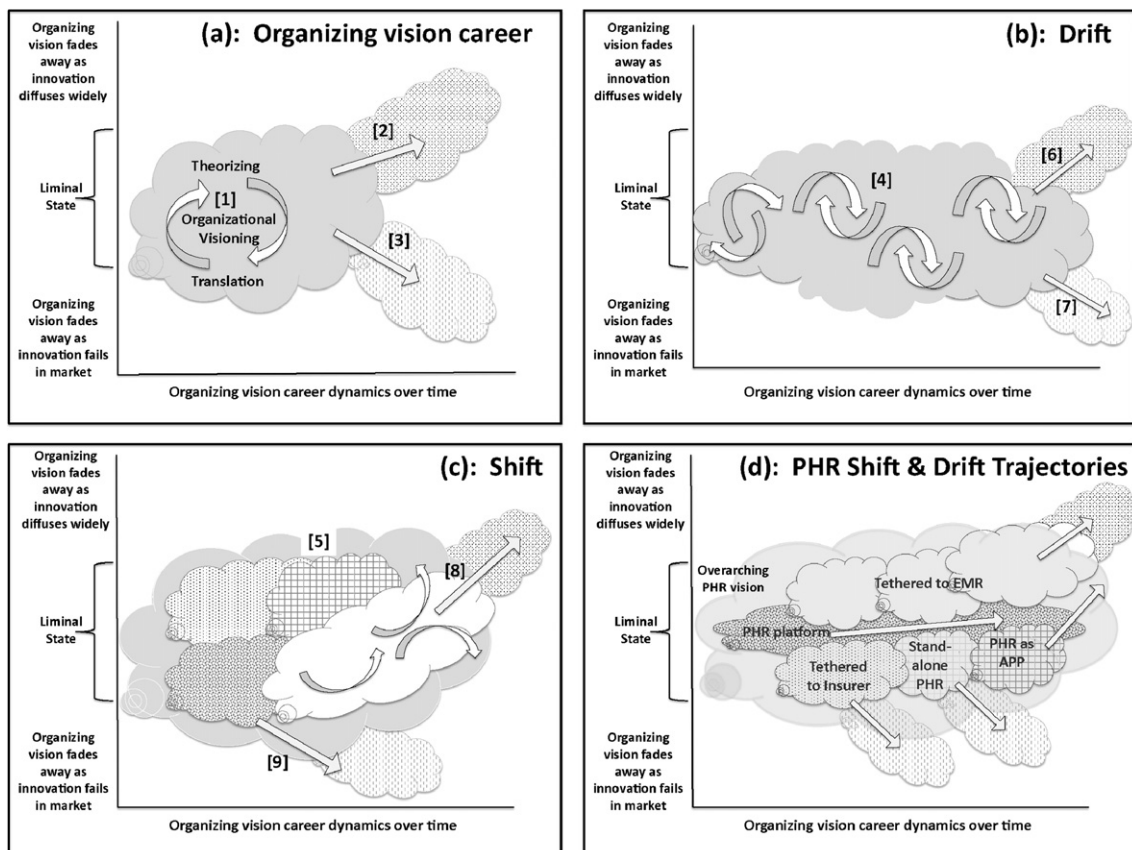

Fig. 3. Organizing Vision Career Dynamics.

(2014). However, these views do not explain fully one of the more puzzling aspects of the PHR diffusion process. Despite much interest and investment from important and powerful innovation community stakeholders, the PHR innovation failed to thrive and diffuse widely. At the same time, despite persistent questions about plausibility of the PHR vision and lack of consumer interest in the innovation, these stakeholders continued discussing, debating and investing in PHR-like pilot programs and systems for over a decade and investing in PHR-like pilot programs and systems. We might characterize the PHR innovation process and its organizing vision as being "stuck in neutral gear with the engine racing," such that diffusion did not gain traction but the vision continued to consume stakeholders' attention and investments.

To better understand this innovation process outcome, we return to the idea of an organizing vision career and draw on the metaphor of liminality in technology innovation (Henfridsson & Yoo, 2014; Wagner, Newell, & Kay, 2012) to explicate career dynamics. Swanson and Ramiller (1997) conceived of the career of an organizing vision in terms of the innovation community's waxing or waning interest in the vision. They theorized all visions dissipate eventually as the innovation is either widely adopted or abandoned by the market. The metaphor of *liminality* further illuminates key aspects of these dynamics. Originally defined by anthropologists to explain individuals' experiences of ambiguity in the midst of rituals of "becoming" (Turner, 1969), the liminality metaphor has been used to explain technology innovation processes. For instance, Henfridsson and Yoo (2014) used the metaphor to describe the experiences of institutional entrepreneurs, defining liminality as "*the state of ambiguity faced by institutional entrepreneurs when their new possible innovation trajectory is not yet fully formed but coexists side-by-side with established trajectories*" (p. 946). Wagner et al. (2012) characterized an IS implementation team's experience as transitory and ambiguous, commenting: "*Liminality describes the transition experiences involved in the process of separating from one* (*the old*) *state of being and incorporating into another* (*the new*) … [*it*] *provides opportunity for reflection and experimentation free from the constraints of the established or new norms but also creates a barrier that complicates incorporation*" (p. 260). We also draw on the notion of liminality metaphorically to consider the innovation community's reception of an organizing vision and hence its career dynamics. Fig. 3 depicts these processes.

During the early uncertain and ambiguous stages of an innovation process, an organizing vision functions as a discursive resource within an innovation community to guide innovators and mobilize their development and diffusion of the innovation (Ramiller & Swanson, 2003; Swanson & Ramiller, 1997, 2004). Through ongoing organizational visioning (Fig. 3a, point 1), innovation ideas are theorized across the organizational field to interpret and legitimate the innovation and envision its future. Ideas are also translated in organizational instantiations of the vision (Nielsen et al., 2014) as innovators engage with and attempt to reconcile future envisioned practices with past, realized ones. Our analysis of PHR discourse explicated these dynamics by demonstrating how the organizing vision was theorized as a life-long, comprehensive healthcare record controlled by individuals engaging proactively in their own healthcare. The legitimating claims of the PHR vision entailed novel institutional arrangements for health data stewardship and changes to existing arrangements. PHR systems were developed and piloted as organizational actors translated the theorized vision into four co-existing and competing assemblages of organizational actors, health data stores, and health data stewardship and health advising arrangements (Fig. 2 & Table 5).

Swanson and Ramiller (1997) theorized that if an innovation diffuses widely, an organizing vision fades away (Fig. 3a, point 2). That is, the innovation community collectively transitions from the liminal processes of envisioning and experimenting into assimilation and institutionalization processes. Nielsen et al. (2014) argue that organizational visioning continues throughout community-wide assimilation. While we concur, we posit that theorization and translation become less open and more incremental as organizational practices related to the innovation becomes routinized and taken-for-granted. We note, however, that PHRs did not reach that level of diffusion in the U.S. during our study period.

The organizing vision also fades way if the innovation fails to maintain the community's attention (Fig. 3a, point 3), for instance if a more compelling vision subsumes its legitimating claims (Swanson & Ramiller, 1997; Wang, 2009) or the vision lacks plausibility or entails too much discontinuity from current sociotechnical practices (Ramiller & Swanson, 2003). Problems with the core technologies may undermine diffusion, though sociotechnical issues such the failure to develop supporting standards (Lusch & Vargo, 2014; Markus et al., 2006; Vargo et al., 2013) can reflect contestation over institutional arrangements. This was evident with Google Health: lack of industry-wide standards for data exchange inhibited the IT firm's ability to build a personal health data aggregation service, but this technical limitation arose from existing institutional arrangements and practices for health data management (depicted in Fig. 1).

Beyond these career dynamics, our analysis of PHR discourse highlighted two intermediate liminal states an organizing vision career might exhibit, which we characterized as *drift* and *shift*. An organizing vision experiences *drift* when currents in the innovation discourse maintain the active interest of the innovation community around the theorized organizing vision but also create eddies so that the vision does not gain sufficient momentum to mobilize widespread adoption (Fig. 3b, point 4). *Drift* in the organizing vision suggests that the innovation community collectively remains in a liminal state, caught between past practices and the potential future of the innovation (Henfridsson & Yoo, 2014). Discourse currents can be examined using the analytical categories outlined in Table 3 to reveal tensions between past practices and the envisioned future of the innovation that sustain drift. If these currents remain counterbalanced, the organizing vision can be carried along somewhat aimlessly in the innovation community discourse for an extended time.

The theorized PHR organizing vision exhibited drift for most of our observation period. Government- and foundation-sponsored workshops and publications specified broad ambitious goals for an infrastructure of PHR technology and standards (cf. Markle Foundation, 2003; Tang et al., 2006), which presented a detailed *interpretation* of what a PHR should be and the societal benefits that would result. These *legitimating claims* were widely shared, particularly assumptions about engaging consumers in their health via PHRs and the urgency of addressing pressing healthcare sector issues via PHRs. Stakeholders' actions and reports of them signaled

the *market importance* of PHRs and stakeholders' *mobilization* (e.g., entry of Google Health and Microsoft with PHRs). This was notable because there was significant competition for innovators' attention (Wang, 2009) from burgeoning activity around electronic medical records at the time. Despite these propelling currents, questions of "what a PHR actually is" continued to be asked and answered differently by various stakeholders (Section 5.3). Government policy documents and commentators pointed to the lack of consensus, for example:

> "*It is not possible or even desirable, to attempt a unitary definition (of PHR) at this time.*" (National Committee on Vital and Health Statistics, 2006, p. 15–16).

> "[*The term*] '*PHR*' *means different things to different people – there is no universally accepted definition.*" (Gearson, 2007, p. 2).

Interpretations of PHRs entailed broad *discontinuities* in technology infrastructure and data interchange standards and importantly in organizational and inter-organizational practices for health data stewardship. Google's announcement in 2011 that it was shutting down its Google Health project raised questions about the feasibility of "untethered" PHR systems generally, though IT firms like Microsoft and PHR organizations like Dossia remained committed to a PHR strategy. Moreover, consumers' lack of understanding of and interest in PHRs was evident in surveys that indicated very low adoption rates. In a commissioned report on PHRs, Fortin and Drazen (2011, p1) described the implications of this ongoing organizing vision drift for the PHR innovation:

> "*Unfortunately, despite continued buzz and some well-publicized initiatives, the reality is that we are still no closer to a true personal health record than we were 5 or 10 years ago. Fundamental barriers still exist, and without major changes in behavior and dramatic increases in adoption of technology, a true PHR – and the benefits associated with it – will not be possible.*"

We characterized *shift* as an organizing vision career state (Fig. 3c, point 5) that reveals community members' attempts to translate the theorized vision into a distinct assemblage of stakeholders, institutional arrangements, organizational practices, and core technologies. Nielsen et al. (2014) argue that translation entails suppressing some aspects of the field-level vision in organizational instantiations of it. We posit that shift may develop as the innovation community struggles to translate key elements of the theorized vision into viable organizational practices or to theorize organizational practices as field-wide concepts in compelling ways. Shift might also indicate some innovators' attempts to propel a vision caught in drift forward by suppressing aspects of the vision that sustain drift. Alternatively, shift may simply indicate community members' self-interest, if some actors employ discursive strategies and actions to orchestrate the innovation network in favor of their own interests and market strengths (Prince et al., 2014; Swanson & Ramiller, 1997).

Four significant shifts in the PHR organizing vision developed during the study period. (See Section 5.3). The self-interests of organizational actors (healthcare providers, insurers, employers, IT firms) were apparent in the discourse surrounding each of these PHR versions. These shifts also reflected the significant challenges of translating the theorized vision of a life-long, comprehensive personal health record into workable institutional arrangements for health data stewardship, despite compelling societal arguments for promoting the innovation. Thus, translation of the overarching organizing vision along the lines of existing *institutional arrangements* for health data stewardship (e.g., tethered-to-EMR PHR) was predictable.

Finally we theorize that drift and shift are liminal states. In these states, the innovation's transition from early formation to institutionalization or market failure is incomplete. The innovation community continues to experience ambiguity and uncertainty about future trajectories as the innovation remains suspended between past practices and the envisioned future. The innovation community may remain "stuck" in drift or shift for some time (as we have seen with PHRs), but these states are nonetheless temporary and transitory, because the interest and attention of the innovation community will eventually move on to other innovations (Wang, 2009). Drift can resolve if the counterbalances of currents that maintain drift in the vision are disrupted, for instance if innovation community members' doubts about plausibility or market interest diminish. As drift resolves, the vision will fade away, either as the innovation moves towards institutionalization (Fig. 3b, point 6) or loses innovators' interest and fails in the market (Fig. 3b, point 7). Shift in the organizing vision may resolve in various ways. If a translation of the organizing vision subsumes the legitimating claims of the overarching vision or appears to be more plausible, the shifted vision may come to dominate the community discourse and to mobilize broader diffusion (Fig. 3c, point 8). In this instance some core ideas of the theorized overarching vision will likely fall away (Nielsen et al., 2014). On the other hand, by suppressing aspects of the organizing vision, a shift may weaken the legitimating claims and appeal of the vision, such that the community's interest in the innovation or in the translation of it diminishes, and the organizing vision fades without widespread diffusion (Fig. 3c, point 9).

Our analysis revealed how the PHR organizing vision experienced the liminal states of drift and shift simultaneously during the decade studied. (See Fig. 3d). How and when these liminal states would resolve was uncertain, although developments in the U.S. healthcare field pointed to likely trajectories. Kaiser Permanente, the largest health maintenance organization in the U.S., reported over four million of its nine million patient/subscribers had registered to use its PHR patient portal (McCann, 2012) and claimed beneficial health outcomes from patients using the system. Similarly one in five VA clients reportedly was using the MyHealtheVet PHR (Tsai & Rosenheck, 2012). Along with federal government regulations,[4] these developments suggested the *tethered-to-EMR PHR* translation of the overarching vision (Section 5.3.1) could come to dominate the innovation's future trajectory and dispel broad community interest in the theorized overarching PHR vision.

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[4] The 2009 HITECH Act regulations for "meaningful use" of EMRs required providers to actively engage their patients in electronic data exchange. This regulation spurred healthcare providers' interest in patient portals, a scaled-down version of the tethered-to-EMR PHR.

The growing popularity of health monitoring devices and applications indicated that consumer interest in personal health data, notably lacking with regard to the theorized PHR vision, might finally develop in the market. Organizational actors such as Dossia, healthcare insurers, healthcare providers and even IT firms like Apple began adapting their PHR strategies to include health advising to individual consumers as well as health data stewardship via health-monitoring devices to capitalize on consumers' interest. Thus, the *PHR-as-app* translation appeared to be gaining strength in the discourse and the market. Whether health providers would incorporate data from patients' monitoring devices into their clinical practices and tethered EHRs remained doubtful, suggesting these two translations would co-exist rather than merge in the near-term to maintain a state of shift. Finally, the failure of *tethered-to-insurer PHRs* and of *stand-alone PHRs* to attract individual subscribers suggested these translations of the overarching PHR vision would dissipate through market failure (as we saw with Google Health), while the *PHR-as-platform/ecosystem* translation continued to drift along with the theorized PHR vision, as stakeholders such as Microsoft HealthVault persisted in the market.

6.1. Implications for theory

Our study suggests several implications for theory-building around health IT innovation diffusion and the organizing vision framework generally. First, discourse dynamics surrounding the PHR innovation revealed two liminal organizing vision career states, which we characterized as *drift* and *shift*. We identified how counterbalancing currents in the organizing vision contributed to drift, and how substantial barriers to translation of theorized institutional arrangements for health data stewardship contributed to shift in the overarching vision. We theorize these states as liminal and thus transitory, yet drift in the PHR organizing vision persisted for over a decade, and shifts developed and persisted for much of that time. Identifying and explaining shift and drift is of theoretical interest in order to better understand how IT innovators experience and resolve liminality (Henfridsson & Yoo, 2014; Wagner et al., 2012) and to assess how the organizing vision career influences an innovation's trajectory.

Second, our study suggests that organizing visions that span the practices of individual consumers, organizations, and field-level actors require theorization by and for these various actors in ways that are most plausible and compelling to each type of actor. The organizing vision for personal health records depended on more than organizational actors developing new health data stewardship arrangements. If the legitimating claims of the vision (such as reducing health system costs) were to be realized, consumers would need to incorporate stewardship of their own health data into their self-care practices. In contrast to its mobilization of many organizational actors, the PHR organizing vision proved to be much less compelling to consumers, who failed to adopt even free PHRs widely. Some commentators attribute American consumers' lack of interest in PHRs to a lack of interest in their own health. Beyond this possible cultural explanation, we suggest that the *interpretations* and *legitimating claims* of the vision held more appeal to organizational actors than to individual consumers. All of the actors depicted in Fig. 1 arguably value *engaged consumers* improving their health, but for individuals, improved health is the end goal, whereas for organizational actors improved health is a critical means to reduce healthcare spending and contain health insurance costs. Only in the *PHR-as-App* and *tethered-to-EMR PHR* translations were the individuals' practices for and plausible benefits of using PHR *to improve their own health* more apparent.

Third, personal health records are indicative of an expanding category of IT innovations that entail institutional arrangements for data stewardship. Assumptions about access to and control over health data shaped theorization and translation of the PHR vision. Other health IT innovations and organizing visions similarly entail challenges to existing health data stewardship arrangements. Data privacy and security are critical to health data management, but we suggest that the broader concept of data stewardship including aspects such as curating and responsible dissemination of data products (Baker & Yarmey, 2009; Kanaan and Carr, 2009; Rosenbaum, 2010) is needed in health IT studies. More generally, organizational IT innovations are rapidly developing around the accumulation of personal data stores that arise from individuals' everyday use of social media, e-commerce, mobile phones and other information and communication technologies. As these "big data" are increasingly collected, aggregated, shared, curated, sold and resold, or appropriated by governments, novel and contested institutional arrangements for individual-organizational and interorganizational data stewardship will become increasingly important, contentious and central to organizing vision dynamics and thus to IT innovation scholarship.[5]

Finally, Nielsen et al. (2014, p. 181) argue the importance of looking at the common institutional field and institutional structures as well as specific organizations and institutional pressures simultaneously to understand theorization and translation of organizing visions. We identified the broad cast of actors involved in health IT innovations (Table 1) including actors such as charitable foundations and regulatory agencies. Accounting for the influence of such actors, who generally do not play a role in the industries typically studied in the IS field, will be important to understanding health IT innovation as well as IT innovation in institutional fields such as education, law and economic development (Chiasson & Davidson, 2004, 2005).

6.2. Implications for practice

In this analysis we found that assumptions about stewardship of health data were central to understanding how innovation community participants attempted to shape the PHR vision and by so doing to promote advantageous institutional arrangements for themselves. At first it seems counterintuitive that an organizing vision with the core tenet of empowering consumers to manage

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[5] Current debates range from business firms and IT vendors' accountability for data security given massive security breaches and privacy controversies (cf. Sanger & Savage, 2013) to newly developing cultural expectations that social media firms like Facebook should act as data stewards for subscribers' personal data archive after their death (McCallig, 2014) or that IT firms that develop archives should allow individuals to curate personal data, for instance, "the right to be forgotten" in Internet data searches (Rosen, 2012; Schechner, 2014).

their own personal health data evolved as industry actors jockeyed for control of or access to those very health data in order to play the roles of data source, aggregator or steward and even health advisor. Yet, when we consider that information has been called the life-blood of modern medicine and HIT its circulatory system (Blumenthal, 2010), and that healthcare spending accounts for over 17% of GNP in the U.S. (Truffer et al., 2010), it is unsurprising that many stakeholders would seek control of personal health data.

In this regard, the broad *interpretation* of PHRs as an all-encompassing, lifelong health record that would span health data stores across the healthcare field (Fig. 1) implied significant challenges to existing institutional arrangements for health data stewardship between individuals and organizations and among organizational actors. Yet inter-organizational, regulatory, organizational and individual practices take time to develop and some proved to be implausible. Innovation community members' struggles to understand and resolve these issues sustained the prolonged periods of drift and shift we observed with PHRs. For instance, a few consumers were willing to rely on IT vendors for health data stewardship, while many others apparently found that entrusting their health data to advertising-funded IT vendors too novel and risky. Questions about the longevity of a private company's commitment to data stewardship were also acknowledged, following Google's exit from the PHR innovation community. Considering the cumulative effects of challenges to institutional arrangements it is not surprising that institutionally conservative translations of the PHR organizing vision (*tethered-to EMR PHR*, *PHR-as-app*) exhibited more organizational and individual-level adoption, while institutionally challenging translations (*stand-alone PHR*, *PHR platform*/*ecosystem*) struggled.

The translations of the overarching PHR vision as a *tethered-to-EMR* PHR or standalone *PHR-as-app* represent incremental steps that may nonetheless be beneficial to address some societal concerns in the healthcare sector. On the other hand, these incremental steps could inhibit progress towards realizing the legitimating claims of the comprehensive PHR vision. Without widespread adoption of the self-care practices of empowered consumers implied by the theorized PHR vision, societal benefit of health improvement and reduced costs across the healthcare system will not be realized or will be limited to privileged populations. For instance if PHR diffusion results primarily in a disconnected array of tethered-to-EMR patient portals, underserved populations – the poor, uninsured, and unemployed – will be left un-served by PHRs tethered to large, integrated healthcare providers (Horan, Botts, & Burkhard, 2010; Miller, D'Amato, Ovira, West, & Adelson, 2009).

Innovation community members may need to assess PHR developments and redirect policies and incentives to achieve these greater societal goals. Explicitly examining PHR community discourse to understand what factors contribute to ongoing drift or shifts could help health field leaders to understand these dynamics and to actively curate the vision to direct the future trajectory of PHRs more effectively. The leadership and capacity to do so rests jointly with policy makers, government agencies, medical informatics professional, the IT vendors that seek a profitable business in HIT and the individual citizens for whom PHRs are intended.

7. Conclusion

Innovation community discourse not only reflects but also shapes the trajectory and outcomes of organizational IT innovations. Our longitudinal analysis of personal health record discourse helped explain why, despite a decade of technical specification, community-wide investment and early systems implementation, the lofty legitimating claims for the PHR innovation remain largely unfulfilled. Many PHR proponents identified significant technology-related issues such as lack of standards for health data interchange, system interoperability, security, privacy and controlled access that inhibited development and diffusion of PHRs. Industry analysts pointed to the complexity of the U.S. healthcare system as a drag on HIT innovation. Some focused on lackluster interest among consumers — those "persons" who are the subject of a PHR. As one pundit stated succinctly, "*As even Google learned in its fleeting romance with PHRs, if the vicissitudes of a hugely complex $2.7 trillion health care industry don't snuff you out, an anemic consumer market will almost assuredly will*" (Nosta, 2013).

Our analysis complements these assessments of *what* contributed to the innovation trajectory of PHRs with a theoretically-informed analysis of community discourse dynamics that help explain *why* challenges to institutional arrangements contributed to and sustained the vision's drift and shift for over a decade without resulting in widespread adoption of the PHR innovation yet also not leading to its failure in the market. Situating discourse analysis in the healthcare industry and acknowledging its complexity (Chiasson & Davidson, 2004; Davidson & Chismar, 2007; Oborn et al., 2011), our study demonstrated that while one organization may sponsor an innovation such as a PHR, the organizing practices implicated in an organizing vision exist in a complex network of relationships with other field actors and of societal expectations and regulations. This required we acknowledge *institutional arrangements* (Hargrave & Van de Ven, 2006) as well as organizational practices to encompass the complexity and interrelatedness of an institutional field in which such innovations develop. Our study highlighted the importance of health data stewardship in health IT innovations and demonstrated how contestation around institutional arrangements may place the innovation community in a liminal state contributing to ongoing drift in an organizing vision as well as sustained episodes of shift.

As with all research our study has limitations. We restricted the study scope to PHR-discourse in the U.S. due to the country-specific market structures and institutional actors that influence HIT innovation. Additional studies in other national healthcare sectors and cross-national comparative studies will be useful to assess whether the dynamics we observed occur in other settings. To develop a comprehensive accounting of the PHR organizing vision, we searched broadly through Internet web-based resources as well as traditional sources of indexed publications. Nonetheless we may have overlooked less well-known but promising perspectives on PHRs. Supplementing interpretive and qualitative analysis such as ours with text-mining and linguistic analysis could help researchers to assess the networks of relationships among innovators, visions, and technologies more precisely (Tsui, Wang, Fleischmann, Oard, & Sayeed, 2009). Developing technological tools such as web content aggregators to systematically search and accumulate relevant Internet content to supplement indexed publication databases would be useful for future discourse studies such as ours. Mixed-method studies could more precisely assess networks among members of an innovation community and the influence of

community events such as sponsored workshops on an organizing vision and on the innovation's trajectory. Combining web data aggregation and linguistic methods would also be useful to precisely map liminal states of shift and drift and to assess aspects of the organizing vision discourse that sustain these states.

Finally, although our study considered more than a decade of PHR developments, the body of PHR discourse continues to grow and the "end of the story" of the PHR organizing vision has yet to be written. We hope that our study may be of value to innovators as they continue this important innovation journey.

Appendix A. PHR texts reviewed in this study

A.1. Journal (J): published academic research reports and papers

J-1. Ahsan, M., Seldon, H.L., & Sayeed, S. (2012). Personal health records: Retrieving contextual information with Google Custom search. Studies in Health Technology and Informatics, 182, 10–18.

J-2. American Health Information Management Association, American Medical Informatics Association. (2008). The value of personal health records. A joint position statement for consumers of health care. Studies in Health Technology and Informatics 137, 402–405.

J-3. Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K.A., & Straus S.E. (2011). Personal health records: A scoping review. Journal of the American Medical Informatics Association, 18(4), 515–522.

J-4. Ball, M., Smith, C., & Bakalar, R. (2006). Personal health records: Empowering consumers. Journal of Healthcare Information Management, 21(1), 76–86.

J-5. Blumenthal, D. (2009). Stimulating the adoption of health information technology. New England Journal of Medicine, 360(15), 1477–1479.

J-6. Blumenthal, D. (2010). Launching HITECH. New England Journal of Medicine, 362(5), 382–385.

J-7. Botts, N.E., Horan, T.A., & Thoms, B.P. (2011). HealthATM: Personal health cyberinfrastructure for underserved populations. American Journal of Preventive Medicine, 40(5 Suppl 2), S115-122.

J-8. Bourgeois, F.C., Taylor, P.T., Emans, S.J., Nigrin, D.J., & Mandl, K.D. (2008). Whose personal control? Creating private, personally controlled health records for pediatric and adolescent patients. Journal of the American Medical Informatics Association, 15(6), 737–743.

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