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Abstract: This paper introduces the special issue on Personal Health Records: Empowering patients through information systems? In addition to introducing the two papers in the special issue, it provides a brief review of the debate and research relevant to Personal Health Records (PHR) to situate the contributions of the special issue papers. The paper reviews major developments in the PHR debate and identifies current challenges facing PHR researchers and developers.

Introduction

Many national governments, healthcare providers, nonprofit organizations, technology firms, and other private businesses spend significant resources to improve healthcare systems, cut costs, reduce medical errors, and improve quality. Deployment of health IT has been viewed increasingly as an essential component to advance healthcare systems (Blumenthal 2009; DesRoches et al. 2008; Jha et al. 2009). The three most recent American presidents starting with Clinton have made it a priority to stimulate adoption and use of electronic health records, health information exchanges and telehealth (Blumenthal 2010). Similarly, we find large investments in many European countries, where, for instance, the UK government has spent more than £12 billion on health IT development (Mathieson 2011). Under this broader umbrella of health information technology, and over the past 10-15 years, the notion of the Personal Health Record (PHR) has emerged. The Institute of Medicine predicted that "current trends in healthcare delivery, management, and research will likely broaden the vision of computer-based patient records in two areas: population-based management of health through computer-based population records and citizen-based management of health through another variant of the computer-based patient record, the computer-based personal health record" (IoM 1997: 5). Since then PHR has become a popular label referring to a wide range of information systems aimed at allowing laypeople (to a varying degree) to access, manage, share, and supplement their medical information; as well as making critical patient data available across healthcare delivery sites (See Davidson, Østerlund and Flaherty (Submitted) for a comprehensive review of the PHR organizing vision).

This special section of IT&P is a result of the first in a series of workshops on "Personal Health Records and Patient-Oriented Infrastructures." This international workshop, jointly organized by the Department of Sociology and Social Research of the University of Trento and the Fondazione Bruno Kessler (Trento, Italy) aimed at providing an arena for discussion on the evolving landscape of personal health information management (http://phrworkshop2014.fbk.eu). Following the first

workshop in 2011 and an open call, 12 papers were submitted to the special issue. The editors checked the papers for suitability and identified appropriate reviewers with each paper being reviewed by two to three reviewers. These were drawn from the advisory team and other academics. Ten papers were rejected after the first round of reviews. The authors of the remaining two papers were asked to revise their papers based on reviewer and editorial feedback. Before we introduce these two papers we provide a brief history of the PHR debate, setting the context for the current research in the field. Our ambition has been to keep the intellectual debate on PHRs open and to stimulate their practical design and implementation in order to find ways for the high expectations to become real.

PHR History
The idea of individuals holding copies of their health-related information is not a new one. Earlier discussions focused on "patient-held records" as opposed to "personal health record." Conducted largely among academic researchers, these studies emphasized the status of the record holder as a patient and ways to bridge the communication gap between patients and physicians, as well as to increase patients' knowledge of their health status and thus their adherence to treatment (Østerlund et al 2010). Discussions highlighted potential uses, such as the patient's self-entry of data and the record's utility when patients carry their records between various healthcare providers (Gearon 2007; Grossman et al. 2009). A patient-held record was generally viewed as time-limited (e.g., pre- or postnatal care; pediatric patients; the terminally ill) or bounded within well-defined domains of care (e.g., diabetes foot care, breast cancer). Early studies of patient-held records going back to the 1960s considered the ideal size and format of paper-based records (Østerlund et al 2010). Rapid deployment of computers in households in the 1990s, followed by the growth of healthcare information sites on the Internet (such as WebMD) resulted in more technology-sophisticated ideas, such as health records on memory sticks or smart cards (Eysenbach 2000), or web-based standalone PHR systems (Halamka et al. 2008).

From these ideas, the notion of personal health records began to gain prominence in the United States around 2000 (Kim and Johnson 2002) followed by several highly cited workshops and reports organized by the Markle Foundation (Markle Foundation 2003), the National Alliance for Health Information Technology (NAHIT), and the American Medical Informatics Association's College of Medical Informatics (Tang et al 2006). Around 2005 the debate gains momentum with a tenfold jump in the number of PHR publications (Kim et al 2011). Launched in the US at the beginning of the new millennium, PHRs are spreading in Europe (especially in the UK and Scandinavia), where one witnesses an increasing number of systems that vary to suit the local healthcare context. In Denmark, for instance, the government introduced sunhed.dk (health.dk) giving citizens free access to general and personal health information based on a personal ID number. Health professionals can access data from the site on patients currently in their care. In the US, one finds a few large systems implemented by, for example, Kaiser Permanente

in California or the US Department of Veterans Affairs healthcare system, but there are also numerous smaller experimental systems (Jones et al 2010).

Since the mid-2000s, major US insurance companies (e.g., Aetna http://www.aetna.com/showcase/phr), employers, and IT vendors have joined the PHR arena. Dossia, a consortium of US companies, started to engage the notion of PHR through their collaboration with INDIVO, a PHR platform developed at Children's Hospital Informatics Program in Boston. The entrance of Microsoft's HealthVault platform in 2007 and Google Health in 2008 gained significant attention, as did Google's exit from the field a few years later in 2011. Epic, a major health software vendor now also offers a range of PHR products associated with its EHR product suite (http://www.epic.com/software-phr.php). Amongst patient and nursing organizations one also find a few participants. The American Heart Association discusses the benefits of PHRs in some depth on its website (http://www.heart.org/HEARTORG/Conditions/More/MyHeartandStrokeNews/Tracking-Your-Health-Online_UCM_456017_Article.jsp). It also offers its own PHR named Heart360 powered by Microsoft HealthVault. In the nursing literature a number of studies have sprung up around Professor Patty Brennan (e.g., Brennan et al 2010; Rodriguez et al 2007). By 2010 a report by the Medical Library Association/National Library of Medicine Joint Electronic Personal Health Record Task Force (Jones et al 2010) reports that they identified 117 PHRs of which they categorized 91 as viable. More than half were standalone products and less than half were mobile device-enabled. The report found both publicly available PHRs, and services offered only to enrollees of particular health plans or employees at particular institutions. A small number of systems specialized in particular health conditions.

The PHR literature highlights three benefits associated with personal health records, considered crucial for tackling the industry's socio-economic challenges: 1) person-centric integration of a fractured health care system (IoM 1997; Koch 2006), 2) active patient participation and self-management (Holman and Lorig 2004), and 3) personal control over healthcare data (Street et al. 2005). These three themes have dominated much of the PHR debate over the past decade. First, early ideas for patient-held records depicted the patient enacting network linkages between disconnected points of healthcare service delivery by physically carrying his or her health records (Gearon 2007; Grossman et al. 2009). PHR are more recently portrayed as an electronic communication hub between providers and patients across multiple providers and sites in an otherwise fractured healthcare system where information often lives within institutional silos (iHealthBeat 2008). Second, arming people with access to their health information should entice them to become active participants in their own health (e.g., see http://www.dossia.org/about-dossia), hopefully leading to healthier people and more efficient healthcare delivery based on better overall data management (Gearson 2007). Third, personal access to and control of personal health records distinguish PHRs from electronic health records maintained by healthcare providers. The individual or close family members guard information stored and accessible within a PHR (NAHIT 2008: 19).

How far this personal control goes has been debated and a number of scholars have attempted to clarify the complex socio-technical relationship between PHRs and providers' electronic records (e.g., Thielst 2007; Tang et al. 2006).

Despite an abundant literature on the topic and large number of PHR systems, many available for more than a decade, consumer adoption remains low. A national consumer survey conducted by the Markle Foundation in 2011 suggests that 10% of American adults currently use a PHR (Markle Foundation, 2011). That is up from 1-3% in 2008. The majority of these adults used PHRs offered by their doctor or hospital (62%) followed by PHRs offered by their health insurer (36%), pharmacy (11%), their own (10%), internet services (5%), and their employer (5%). One in four reported using multiple systems (cf. Grossman et al. 2009, Markle Foundation 2003, 2008). On the US scene Kaiser Permanente and the US Department of Veterans Affairs (VA) represent exceptions. At the end of 2012, one in four out of Kaiser Permanente's 9 million members have registered to use its patient portal, My Health Manager (Kaiser Permanente. 2012). At the VA one in five report using the VA's PHR, MyHealthyVet (Tsai and Rosenheck, 2012). The Danish sundhed.dk had some 80,000 unique visits per month in 2003. By early 2014 that number had increased to 1.2 million out of a population of 5.6 million. At the same time 64% of the population responded that they knew of the site.

The recent prevalence in health monitoring technologies and consumer applications further bring into stark focus the complex socio-technical questions associated with self-management and personal control of healthcare data. An increasing number of applications and mobile devices have emerged that facilitate not only personal health records but also patient generated health data (PGHD). Large IT vendors such as EPIC, and employer run systems, e.g. Dossia, now offer applications that allow people to store personally generated health data in their PHR. These data can be downloaded from mobile heart monitors and other sensors or simply entered manually into the PHR. Apple has recently announced that its new operating system IOS8 can integrate health and fitness data from a range of health apps and monitors (http://www.apple.com/ios/ios8/health/).

What remains unclear in this current push for self-monitoring and PGHD is what role these data will play in the larger healthcare system. Some scholars hope to invigorate the original promises of the PHR vision including increased consumer engagement in the monitoring and improvement of their own or family members' health, and patient empowerment when it comes to the management of health data (Deering 2013). In parallel with these positive expectations, critical voices have been raised. For instance, Dedding et al. (2011) warn that such services may "disturb" patient-clinician relations and lead to more "sick work" for the patients. Huh and Pratt (2014) remind us that patient expertise as compared to clinicians' expertise becomes an important issue. Clinicians may also feel that their professional practice is threatened or undermined by the new technologies (Chen et al., 2013). Further, some providers are questioning if they will become responsible for this volume of patient generated data.

Papers in the Special Issue
The two papers in this special issue provide important insights into this emerging topic by exploring patient generated health data in diabetes PHRs. This context provides a particularly valuable opportunity for understanding PHR use as diabetes has long been an area involving patients' active self-monitoring and recording of personal health data.

The paper by Cristiano Storni applies an ethnomethodological approach to study the design implications associated with a Type 1 diabetes PHR. The system enables what Storni calls self-care "in the wild," which involves a number of care practices associated with chronic disease that are carried out by lay people outside clinically controlled settings. However, the evaluation of the system suggests that we re-think the current medical model and traditional patient sick-role that is often unreflectively reproduced in the design of information systems for patients. If we don't, Storni suggests, PHRs supporting self-monitoring and PGHD are likely to foster conflicts between patients and medical staff.

Enrico Piras and Alberto Zanutto focus on the "P, " the "personal" in PHR. Studying pediatric diabetes management they explore the role and meanings attributed to patient generated health data when a PHR enables new forms of communication in the healthcare management network. The patients saw the PHR as supporting their personal diabetes management and confirming their competence and right to manage their own information and disease. The possibility that doctors at any moment could access the data in the PHR is perceived as an intrusion into their personal sphere, a lack of trust in their capacity for self-management.

Comparing these two studies on PGHD and PHR systems in the same domain – diabetes care – raises a number of larger questions about the enabling role of ICT within and beyond healthcare. The 'migration' of medical information and technology from traditional expert users and clinical settings (clinics, hospitals, laboratories, and universities) to lay user and domestic environments (mobile-care, home-care) parallels movements associated with open source software development (Wasko and Faraj 2005) and citizen science (Bonney et al 2014; Wiggins and Crowston 2012) . In all three cases, information work traditionally carried out by highly skilled professionals within specialized organizations (e.g., hospitals, software companies, and universities) have been reallocated to lay people, whether they are diabetics monitoring their own blood sugar levels, volunteers contributing to Mozilla, or citizens gathering and analyzing scientific data to assist astronomers or biologists (e.g., see Zooniverse.org). With this emerging division of labor we might also witness a movement from centralized to more decentralized information management structures. In the diabetes case medical information used to be stored in central health records managed by larger healthcare organizations. As depicted in these two studies, part of that information management is now handled in the patient's home, away from healthcare organizations' reach.

As illustrated in the two articles the new work arrangements associated with PGHD and PHR systems question existing relations among key stakeholders, and build on the belief that healthcare practitioners, patients, and caregivers are interested and willing to form new socio-technical and collaborative arrangements. The two articles render visible gaps between expectations and actual applications, and the need to deal with some of the emerging problems in diabetes care and beyond. In particular, there is a need to understand: 1) the disease not only as a biomedical condition but also as a complex lifestyle where the patient has to compromise between different logics and needs; 2) the intra- and inter-variability of individual patients (of their actual health status, of their lay expertise, and of their attitude toward the disease); and 3) the potential conflicts and separations that can emerge when a clinical perspective is imposed on affected individuals. As self-care practices and technology become more ubiquitous, especially in relation to the explosion in chronic disease, the current medical models and their related technologies of care might become problematic and fail to really empower patients, support everyday self-care practices, and, ultimately, improve health outcomes.

In conclusion, PGHD and PHR systems have become a point of convergence among different visions concerning the future of healthcare systems, characterized by the (desired) emergence of 'new patients' willing to share the burden of care and reshape their relationships with doctors and institutions. Accordingly, PHR can be considered an interesting lens through which social informatics researchers, computers scientist, healthcare professionals, and managers can examine tentative transformations in the healthcare sector. It allows us to bring the actors, their daily practices, technologies and the meanings attached to them into focus within an industry with great societal consequences.

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