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Transforming healthcare: policy discourses of ICT and patient-centred care

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TRANSFORMING HEALTHCARE: POLICY DISCOURSES OF IT AND PATIENT-CENTRED CARE

Abstract

Information Technology (IT) is increasingly seen in policy and academic literature as key to the modernization of healthcare provision and to making healthcare patient-centred. However, the concept of Patient-Centred Care (PCC) and the role of IT in the transformation of healthcare are not straightforward. Their meanings need unpacking in order to reveal assumptions behind different visions and their implications for IT-enabled healthcare transformation. To this end, this paper analyses England's health policy between 1989 and 2013 and reviews literature on PCC and IT. English policy has set out to transform healthcare from organization-centric to patient-centred and has placed IT as central to this process. This policy vision is based on contested conceptualizations of PCC. IT implementation is problematic and this is at least partly due to the underpinning goals and visions of healthcare policy. If this misalignment is not addressed then producing technologically superior systems, or better IT implementation strategies, is unlikely to result in widespread and substantial changes to the way healthcare is delivered and experienced. For IT to support a healthcare service that is truly patient-centred, patients' needs and wants should be identified and designed into IT-enabled services rather than simply added on afterwards.

Keywords: information technology, health information systems, patient-centred care, patient-centered model, health policy, organizational transformation, discourse analysis

Introduction

‘An IT-enabled transformation of health care is just beginning, and it cannot happen too fast’ declared Lucas et al. (2013 p. 377).

Transformation of healthcare is often depicted as being necessary and urgent because of the rapidly rising costs of healthcare and changing requirements. This stems from the widely presented view of the challenge of providing care for an aging population in an era of increasing levels of chronic illness. Often such transformation is envisaged as a shift from an organization-centred model of healthcare to a patient-centred or person-centred model (Davis et al., 2005, Krist and Woolf, 2011).

Information technology (IT) is proposed in national policies of a number of countries (e.g., in the United Kingdom (UK), United States (US), Canada, Australia and Singapore) and in academic literature as key to this transformation, not only having direct financial or clinical impacts but also enabling or facilitating new forms of care delivery (Agarwal et al., 2010). The information systems (IS) literature in this area tends to outline macro-level visions of IT-led healthcare transformation, or produce micro-level empirical, often qualitative accounts of implementation and use of particular IS. Such accounts highlight the importance of organizational environment, stakeholders’ interests and work practices for IS implementation efforts and their outcomes (Barrett et al., 2012, Barley, 1986, Oborn et al., 2011).

There is also a significant body of literature that describes particular technologies, concentrating either on their design or on testing pre-defined variables. Articles focusing on policy and its implications for healthcare transformation are less common in IS journals, with some exceptions, including a number of papers in the *Journal of Information of Technology* discussing the UK’s National Programme for IT (NPfIT) (Currie and Guah, 2007, Currie, 2012, Sauer and Willcocks, 2007). Policy analyses appear in journals such as *Health Affairs*, but IT is not seen as central in those publications. Perhaps the relative scarcity of policy analyses within the IS literature arises due to perceptions of policy as a topic on the fringes of, or beyond, our field. However, I would argue that policy is important for understanding the role of IT in healthcare transformation, and thus a legitimate subject for an IS scholar. Policy may open up new possibilities and rules for organizational legitimacy and societal relations (Motion and Leitch, 2009). In the UK, the role of public policy is

particularly strong since the vast majority of healthcare is provided by the National Health Service (NHS). Policies and strategies influence the NHS ethos, priorities and organization, as well as both the organizing vision of IT innovation (Swanson and Ramiller, 1997) and implementation of IT. In doing so, they have a direct impact on people's lives. Similarly, in the US, current health policy initiatives explicitly assign a role for IT in healthcare transformation. The US's Health Information Technology for Economic and Clinical Health (HITECH) Act, a part of a much larger stimulus bill, known as the American Recovery and Reinvestment ACT (ARRA), is described as "an unprecedented effort to reengineer the way the country collects, stores, and uses health information" (Blumenthal, 2011a p. 2323). The HITECH act authorizes the Center for Medicare and Medicaid Services (CMS) to provide health professionals and institutions (e.g., hospitals) with incentives to implement and demonstrate use of electronic health records (EHRs) and other types of IT. The subsequent demonstration of use, known as 'meaningful use', outlines functional IT requirements and IT-related benchmarks required from healthcare providers. Thus, in the UK and the US (and in other countries) policy is shaping both – the healthcare field and the IT field.

Much of the rhetoric in healthcare policy is about re-organizing healthcare around patients and providing Patient-Centred Care (PCC). The aim of this paper is to gain an understanding of how policy interpretations of PCC, as well as visions and specific strategies for IT shape the transformation of healthcare in England. This aim translates into the following research questions:

1. What visions of healthcare and its transformation are constructed in English policy discourse?
2. What roles and meanings are assigned in policy to IT?
3. What are the implications of those visions and meanings for the way IT-enabled transformation of healthcare in England is taking place?

I refer to England because other devolved nations in the UK have their own national NHS organizations and set of relevant policies. This paper analyses English health policy documents between 1989 and 2013. The analyses are informed by concepts of transformation, as developed by institutional scholars (Ashburner et al., 1996, Scott et al., 2000), and the sociotechnical approach to IS (Berg et al., 2003, Coakes et al.,

2000, Kling, 2000). The paper employs the notion of discourse to address the research questions. In taking this approach, this paper aims to avoid two simplifications: (a) a technology-deterministic account of the potential of technology, which underplays the complexities of institutional transformation, and (b) a fixed notion of healthcare, and specifically PCC, as a 'given' rather than as having different, sometimes disputed, meanings.

This paper is structured as follows. The following section outlines theoretical assumptions that have guided this research and develops a conceptual framework that provides a structure for the analysis of policy discourse. This is followed by a description of research methods and an overview of the literature on PCC and IT. The subsequent section introduces the NHS in England, and analyses PCC and IT discourses in policy. Discussion and Conclusion section outlines the implications of this analysis for healthcare transformation and sets out the agenda for healthcare policy and IS research in this area. It closes with an outline of this paper's contributions and limitations.

Theoretical perspective: transformation, technology and policy discourse

This paper follows Scott et al. (2000) in defining transformation as a radical (i.e., substantial) change in the institutional environment that gives rise to new governance systems, logics, actors, meanings and relations all of which lead to shifts in the ecology of organizations. Transformation can be spurred by social upheaval, technological disruption or regulatory change (Greenwood et al., 2002). Ashburner et al. (1996) propose potential key indicators of transformational change; multiple and multi-related change agenda, rise of new organizational forms, development of new roles, reconfiguration of power relations, new ideologies and systems of meaning. Most institutional theorists study transformation at a macro level and see it as discontinuous and episodic. Others, however, point out that patterns of transformation might arise from the cumulative influence and interaction of institutionally triggered and technology-triggered change processes (Davidson and Chismar, 2007).

Whilst aiming to contribute to the understanding of the process of IT-enabled transformation of healthcare, this paper adopts a focus on IT and PCC discourses

constructed in policy. These discourses are seen as a part of a wider organizing vision of IT for healthcare (Davidson and Reardon, 2005, Klecun-Dabrowska and Cornford, 2002, Swanson and Ramiller, 1997).

There are many definitions of discourse, but this paper refers to discourse as meaning-making resources having capacity to constitute social reality, forms of knowledge and identity within specific social contexts and power relations (Hall, 1997 p 220). Discourse is taken here not as purely linguistic or textual device but as being multi-modal (Iedema, 2007 p. 937) and “institutionalized and reproduced in social and material practices” (Doolin, 2003 p 755). Discourse is historically situated (Iedema, 2007 p. 931) and constructed in a particular context (Fairclough and Wodak, 1997 p. 277). Thus, the way IT in health are debated and adopted depends on country-specific regulatory structures, their respective values, actors’ organized interests, the status of health professionals (Mathar, 2011) and other resources they can draw on, as well as user practices (as depicted in Figure 1). Actors can include organizations, groups and individuals. Their resources may be financial, institutional (e.g., as afforded by British Medical Association), cultural (e.g., the status of medical profession) and material (e.g., journals). Moreover, discourses are always interlinked (Fairclough and Wodak, 1997 p. 277). PCC and IT discourses are not only interlinked with each other but also with other discourses, including New Public Management (NPM), e-Government, Evidence-Based Medicine (EBM) and health economics. ‘Meta’ discourses are deployed locally in organizational discourse and become reconstituted in the process (Jian, 2011). Discourse, delineating what is legitimate and what is not, may be perceived as a strategic resource that governments and other types of organizations can draw on to bring about and legitimize change (Motion and Leitch, 2009). For example, Bloomfield and Hayes (2009) have shown how the major modernization programme for local government in the UK was legitimized through the appeal to the importance and centrality of the citizen/customer.

Such a conceptualization of discourse informing this research envisages technology as constructed in discourses (e.g., of organizational transformation and PCC) and in turn as influencing those discourses. It does not, however, deny the materiality of technology. Doolin (2003) suggests that discursive analysis tends to relegate technology to an element of context, or treat it as independent of human mediation

and that this should be avoided. I see IT as implicated in and co-constitutive of social practices and linked to systems of politics and power relations (Berg et al., 2003, Kling, 2000). Viewing IT a socio-technical network or ensemble suggests that its implementation is an ongoing social process influenced by stakeholders' needs, interests, norms and ways of doing things. The design of IT involves interrelated decisions about technology and the organization of work (Kling, 2000). In conceptualizing the IT role in transformation, I follow Davidson and Chismar (2007) in treating technology analytically as an integral component in the change process not as a static, external change trigger. Technology both shapes and is shaped by processes of change.

The framework in Figure 1 presents a discourse view on healthcare transformation. On this framework, the areas that this paper concentrates on are highlighted in bold. The arrows depict flows that are considered important for the construction of this paper's arguments. For clarity other flows have been omitted (e.g., it could be argued that policy is not only influenced by other discourses but it influences them as well).

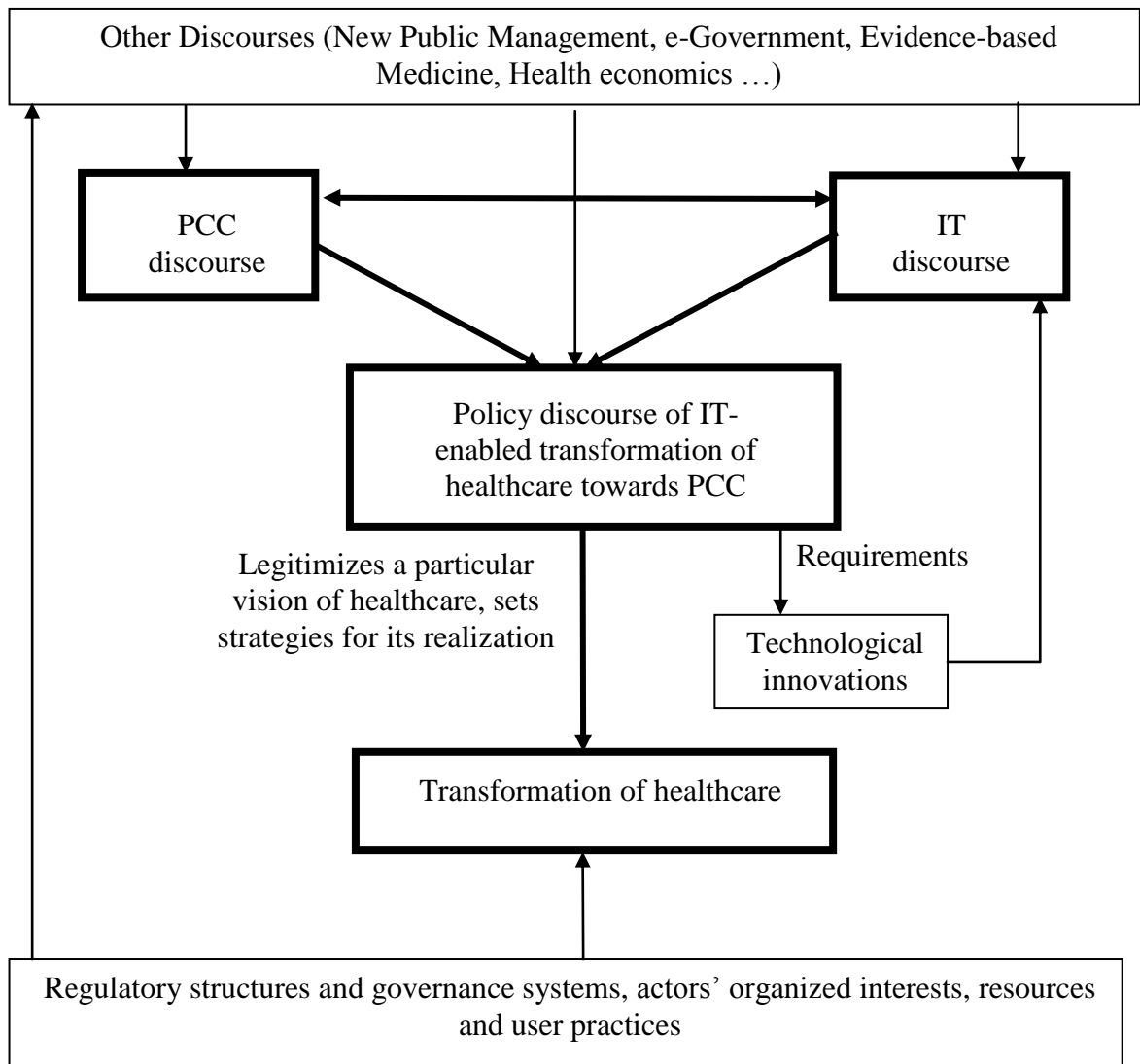


Figure 1 A discourse view on healthcare transformation

Research Methods

The analysis described in this paper is confined to a study of meanings through ‘formal arrangements’ and ‘vocabularies-in-use’ (Hasselbladh and Bejerot, 2007 p. 178) constructed in policy. I studied texts (i.e., policy statements) and the context in which they were developed and might have been interpreted. *Texts* can be defined as a manifestation of discourse and the discursive ‘unit’ on which the researcher focuses (Chalaby (1996) referenced in Grant and Hardy (2004)). Hence, *discourse analysis* is the systematic study of texts. I placed detailed analysis of meanings produced by actors and their situated actions outside the scope of this research. Following Hasselbladh and Bejerot (2007 p. 178), I see it as a deliberate research strategy that

seeks to focus on ‘what cuts across and shapes different contexts of action’, i.e., what conditions transformation of healthcare.

I analysed health policy and information strategy papers for England between 1989 and 2013, focusing on the 2 recent documents (DOH, 2010, DOH, 2012). My starting point is the 1989 policy paper because it introduces major reforms of the NHS and themes that are of relevance to PCC discourse (although this term was not explicitly used there). The 1992 policy paper (DOH, 1992), as far as I am aware, is the first health policy paper that discusses to any extent the role of IT in healthcare. My analysis of policy papers focused on visions of healthcare transformation, meanings of PCC and the roles ascribed to IT. These were placed in the context of history of reforms in the English NHS, in particular changes to regulatory structures and governance systems.

I also conducted a review of literature related to the role of IT in PCC. Publications from IS, organization studies and health informatics fields were examined. The search was conducted using multiple databases and terms including ‘patient centred healthcare and information and systems’ (and their different combinations and spellings). The search returned 166 articles with all of those search terms appearing in papers’ abstracts. After reading all their abstracts, I selected 57 articles for further reading, based on article’s scope and approach. Articles describing technologies, rather than their application, were disregarded. In addition, papers that were most referenced by the selected articles were read. As with the policy analysis, the literature review was concerned with visions of healthcare transformation, meanings of PCC and the roles ascribed to IT.

Patient Centred Care and IT discourses in the literature

PCC discourse

A patient-centred approach to medical care, often referred to as Patient-Centred Care (PCC), has been advocated in the medical literature for at least four decades. However, there is no one definition of PCC. Research has shown that different healthcare groups tended to focus on different aspects of PCC, reflecting their professional interests and norms (Kitson et al., 2013). PCC discourse can be generally divided into two strands; labelled by Vikkelsø (2010) as philosophical and

managerial. The philosophical strand advocates a whole person approach to care and focuses on understanding patients' needs, preferences and experiences, while providing care that is closely congruent with these. Decisions about treatment, for example, are negotiated between healthcare professionals and patients (Mead and Bower, 2000). PCC advocates suggest that it would help patients to access appropriate and preferred medical care when and where it is needed, potentially leading to positive health outcomes.

The managerial strand conceptualizes PCC as reorganization of services around patients' care plans requiring changes to the entire organization of work and relationships related to patient trajectory (Lutz and Bowers, 2000) and as a transformation of healthcare towards optimal care (Davis et al., 2005). It is underpinned by a belief that PCC not only leads to better patient satisfaction and health outcomes but also to economic gains. Patients are seen as a 'resource' that can be utilized to contain costs and improve quality, e.g., through assessment of service quality, partaking in management of hospitals and taking increased responsibility for their own health and healthcare. The managerial PCC discourse is linked to an IT discourse. Vikkelsø (2010 p. 341) suggests that "[t]he managerial version of PCC aims to integrate information technology in every link of the care chain in the belief that web-portals, distributed records, and online access facilitate relationships between professionals and patients by providing, for example, sufficient information, patient engagement and mutual feedback".

IT discourse

The IT discourse expounding transformational potential and benefits of health IT takes place in journals belonging to different disciplines, including IS (Agarwal et al., 2010, Fichman et al., 2011, Gianchandani, 2011), health informatics literature, organisation and public sector management (Ranerup, 2010, Vikkelsø, 2010), and social science, health and medical fields (Hillestad et al., 2005, Kerr and Hayward, 2013, Krist and Woolf, 2011, May et al., 2005).

The literature identifies a number of different technologies that are transforming healthcare. For example, electronic infrastructures and applications, such as EHR and e-prescribing systems, and decision support tools are seen as altering the way healthcare professionals coordinate care and collaborate. Data warehouses and data

analytics tools are described as facilitating medical research, planning and management of healthcare (Hayes, 2010). Health related sites and social networking applications, personal electronic patient records and disease management systems are promoted as enabling the transformation of passive patients into informed and empowered consumers of healthcare services, giving patients control over the management of and responsibility for their health (Hogarth et al., 2010, Murray et al., 2008). Telecare applications (such as monitoring systems) are seen as enabling self-care. Emails, texts, instant messages or video chats are proposed as means of improving access to healthcare professionals, and allowing for richer engagement and deeper doctor-patient relationships resulting in better care for patients (Hawn, 2009). Developments in genetics and informatics are seen as opening a new dawn of personalized medicine that is tailored to the needs of individuals (Gianchandani, 2011, Lucas et al., 2013). These developments have given rise to different technological terms, such as Health 2.0 (Murray et al., 2008) and more recently Health 3.0 (Gagnon and Chartier, 2012) with its implied claims of a paradigm-like shift in the way healthcare is delivered and experienced. Success stories, such as those from the Veterans Health Administration (VHA) and Kaiser-Permanente's, have acquired almost mythical status in the academic and practitioner literature (Chen et al., 2009, Perlin et al., 2004), and play an important role in the discourse on IT-enabled transformation of healthcare.

These visionary accounts range from thoughtful and measured to technologically-deterministic visions of the (near) future. In many of those accounts technology is seen as more or less unproblematic, and the difficulties of modelling healthcare work in a computerized information system remain unaddressed or are merely mentioned in passing.

To date evidence for the benefits of IT-based interventions is inconclusive (Black et al., 2011, Buntin et al., 2011, Wootton, 2012), although some argue that it is simply too early to see the benefits (Jones et al., 2012). The IS literature points to difficulties of implementing large-scale IT systems in healthcare and highlights challenges of translating policy into practice. It notes diverse interests, norms and values of different stakeholders, highly institutionalized, often politicized environment characterized by conflicting instructional logics, as well as complexity of healthcare work and technical challenges (Aanestad and Jensen, 2011, Currie and Guah, 2007,

Currie, 2012, Klöcker et al., 2014, Rivard et al., 2011, Ure et al., 2009).

Adoption and use of IT may potentially influence formal structures and authority (e.g., changing locus of decision-making), stakeholders' power and identity, division of labour and distribution of tasks (Barley, 1986, Cho et al., 2008, Petrakaki et al., 2014), but the same IT used in different organizations may have diverse, even contradictory, outcomes (Aarts and Berg, 2006, Robey and Boudreau, 1999). Major IT-enabled programmes of change, such as an EHR implementation, do not automatically lead to transformation (Greenhalgh et al., 2009). Technological effects are indirect and vary over time (Kling, 2000).

In summary, the literature delivers diverse accounts of transformational potential of IT that are underpinned by different conceptualizations of PCC and IT. There is tension between visions of a paradigm-like shift in healthcare facilitated or brought about by IT, and the evidence that IT is neither easy to implement, nor, even if implemented, that it leads to expected outcomes. Few IS scholars conduct longitudinal studies at the level of the institutional field linking policy and practice, although there are some notable exceptions (Currie and Finnegan, 2011, Currie, 2012). It is to this type of studies that this paper aims to contribute.

The UK's National Health Service (NHS): IT and PCC Discourses in Policy

This section begins with a brief historical overview of regulatory structures and governance systems in the NHS. This is followed by critical analysis of PCC and IT discourses in England's health policy.

Regulatory structures and governance systems in the NHS: Historical overview of reforms

In the UK, the majority of healthcare is provided by the NHS free at the point of delivery (with some exceptions). The NHS represents a series of organizations that are publicly funded through general taxation. It is divided into primary and secondary care. Primary care is the first point of contact for most people and is delivered by a wide range of independent contractors, including general practitioners (GPs), dentists, pharmacists and optometrists. Secondary, or acute healthcare, includes elective care and emergency care. The NHS organizations such as primary care practices, hospitals, mental health and ambulance services are grouped into Trusts.

The Trusts enjoy varying levels of financial and operational autonomy. The overall responsibility for funding, directing and organizational transformation of the NHS and social care rests with the Department of Health. The Department publishes strategies and policies on wide ranging issues that are relevant to the NHS. In this study I am interested in the papers that set the overall health policy and information strategies for the NHS in England.

Since the inception of the NHS in 1948 it has been subject to countless initiatives to transform it from a succession of UK governments (Ashburner et al., 1996, Oliver, 2005). One of the most fundamental administrative reforms was the establishment of an 'internal market' (DOH, 1989). This involved the separation of the service into purchasers (primary care practitioners) and providers of care (secondary care). GPs were given an option to become fund holders, i.e., to control allocated budgets for purchasing part of the secondary care for their patients.

The Labour government that was brought in office in 1997 re-organized the NHS and promised the replacement of the internal market with integrated care (DOH, 1997). In 1998 the GP fundholding scheme was abolished, but from 2002 a new wave of market-based reforms was introduced. Overall, the period of Labour government (1997-2010) saw the emergence of a new model for the NHS based on choice, competition, payment by results and a plurality of providers (including the increasing involvement of private providers). Trusts were encouraged to apply for fundholder status giving them semi-autonomy from the central management of the NHS.

In 2010, under the new Coalition Government, another major re-organization of the NHS was announced. The vision for this is set out in the policy paper 'Equity and excellence: Liberating the NHS' (DOH, 2010). The policy sets objectives to bring more power to local organizations, closer to patient needs. Newly established GP led commissioning consortiums are made responsible for buying in patient care. This policy can be viewed as a continuation of the market reforms that began in the early 1990s, opening the door for more involvement from private companies by forcing commissioners of care to tender contracts to any willing provider, including voluntary sector organizations and commercial companies.

Overall, the last 25 years can be described as a period of transforming the NHS, characterized by multi-related change agendas, establishment of new organizations

and roles in addition to emergence of new ideologies (such as PCC, NPM and EBM).

PCC discourse

PCC discourse in policy can be traced to the early 1990s. A health policy paper from this period (DOH, 1992) stresses the importance of people taking responsibility for their health and promised individual opportunities and wider choices. The paper states the need for comprehensive health monitoring and for the measurement of health outcomes.

In a later paper, the choice agenda is taken a step further with the promise of more rights and more choices for patients, such as participation in decision making about care received and in management of the NHS Trusts (DOH, 1997). The NHS is to be ‘built around the needs of people, not of institutions’, e.g., by becoming more flexible and supporting local ways of delivering healthcare, as well as integrating health and social care services. The ambition is to change the whole system to create a patient-led NHS (DOH, 2005).

The choice agenda presented in the earlier papers of the Labour Government era is expanded in the Coalition Government policy. Patients are given rights to choose a provider organization, consultant-led team, or GP practice and take part in decision making about care received. This is coupled with a promise that patients will have control over their health records, initially envisaged as ability to access the record, see any amendments to it and determine who else is allowed to access it. The foreword to the 2010 policy paper (DOH, 2010) proclaims that “patients will be at the heart of everything we do. So they will have more choice and control, helped by easy access to the information they need about the best GPs and hospitals. Patients will be in charge of making decisions about their care.” Overall, the following proposals relevant to PCC discourse can be identified in the recent policy (DOH, 2010):

Patient perspective

- More convenient care (easy access to services, new services and new modes of their delivery)
- More choice (e.g., of care provider) and control over their care
- Shared decision making regarding care (negotiation of care plans)

- Taking responsibility for one's health (self-care)
- Taking a stake in managing healthcare organizations (e.g., hospital Trusts) and planning of services

Provider perspective

- Providing better care for a particular patient (e.g., through access to relevant data and sharing of data across organizational boundaries and professions)
- Efficient and effective service delivery for all (e.g., better planning, monitoring and use of resources)
- Using data for medical research and planning of future services.

These proposals can be seen as different conceptualizations of PCC:

- PCC as care of patients provided by healthcare professionals.* This focuses on care of individual patients in an organizational setting (e.g., a hospital, doctor's practice or community care) and across organizational and professional boundaries. It emphasizes the need for information to co-ordinate care, collaborate and to provide support for decision making (e.g., undertaken primarily by healthcare professionals but also with patients).
- PCC as efficient and effective service.* This conceptualization reflects the aim of making the best use of limited resources for the good of the population. Central to this is the underlying belief that competition, information and IT-based services will lead to better management.
- PCC as self-care.* This focuses on the well-informed individual (in the context of the information society) taking responsibilities for his/her healthcare and well-being.
- PCC as patient-led service.* This entails re-organization of services according to patient/citizen preferences. In policy this is primarily interpreted as the right to choose and is linked to the idea of patients as consumers, designers and managers of services. It suggests that patients require access to information that can help them to make decisions.
- PCC as face-to-face care.* This invokes most strongly traditional concept of 'care', based on face-to-face encounters between patients and healthcare

professionals.

The above conceptualizations of PCC have different focuses, namely, on organizations (a, b) individual (c, e), or on both (d). They are based on different notions of patients, as (to a lesser or greater extent passive) receivers of care (a, b, e) or active and rational decision makers, shaping their care and healthcare provision in general (c, d). Although they are not mutually exclusive, they are in tension for the following reasons. First, they reflect different ethical principles, deontological (based on patients' rights and doctors' duties) and utilitarian ('doing good for the majority').

Second, underlying those conceptualizations are competing visions of healthcare: as a public good or as a (quasi) market. The former emphasises collectivist principles of the NHS. The latter is influenced by New Public Management (NPM) discourse exemplified by a belief in market forces and in individuals as rational decision makers (Hasselbladh and Bejerot, 2007). Thus competition between healthcare organizations is seen as leading to more effective and efficient services (and overall better quality and value for patients). Recent UK policy favours a market model. However, placing organizations in competition can counter the logic of PCC based on different services collaborating to provide the best care for a patient and meeting patients' needs across care plans, resulting instead, in just delivering a specific part of plans more efficiently and effectively.

Third, the new conceptualization of patients re-defines the notion of patienthood and threatens the status of healthcare professionals (Hasselbladh and Bejerot, 2007). Patients are reinvented as 'empowered' or at least informed, responsible citizens and consumers, who are capable (and expected) to describe experiences, express preferences, make informed rational decisions, negotiate care plans with health professionals, and to evaluate care received (Adams and Bont, 2007). Patients as consumers exert influence and share power through choice (Ranerup, 2010), actively shaping healthcare provision (e.g., by choosing certain providers over others they influence their funding and future viability).

See for example, the following passage from the strategy paper (DOH, 2012 p. 13):

Today's information world is fast, flexible and portable, revolutionising how we can interact with each other and with the services we use. The social networking generation demands and expects a more interactive, personalised relationship with

health and care services.

Greater transparency and information availability is shifting the relationship between patient and clinician, service user and care professional, towards one of shared decision-making. *Information is an essential service in its own right*, allowing us to understand our own health, choose healthier lifestyles, and choose the treatment and support that is right for us. (My emphasis)

This appears to be uncontroversial, but such vision of patients excludes people with different life histories, problems, attitudes and abilities. There is also an expectation that patients/citizens are savvy technology users, who are able to access, understand and evaluate online information, but such skills are not possessed by many (Henwood et al., 2003, Hirji, 2004, Theofanos and Mulligan, 2004).

Fourth, due to the elevated status of information in the policy, the role of *PCC as face-to-face care* is downplayed. A personal relationship is re-defined in the above quote as ‘personalised relationship’ that is conveniently conducted online and tailored to the lives of busy patients/consumers. Information and information processing acquire almost ‘mythical’ meaning (Bowker, 1994). Information is equated with power and intelligence (Boland, 1987), and transmission of information is equated with communication. The primacy given to information in visions of PCC hints that the NHS (as an organization) and healthcare (as practice) are seen through information and thus are defined as such (Mort and Smith, 2009).

Fifth, tensions may arise during IS use. IS obstruct the notion of *PCC as face-to-face care*, because they tend to shift administrative tasks to healthcare staff. Computers can introduce physical barriers between health professionals and patients (Sheikh et al., 2011). They might also obstruct *PCC as care of patients provided by healthcare professionals* when they are designed to collect and process managerial-focused data needed for *PCC as efficient and effective service*. Research has indicated that even if IS (such as EHR) make secondary work, such as audit or research, more efficient, they may make primary clinical work less efficient (Greenhalgh et al., 2009).

Understanding those tensions is important as they come into play when initiatives, such as the NPfIT, are envisaged and realized (or not), and specific IS are designed, implemented and used (or not used).

IT discourse

“The NHS cannot be the last man standing as the rest of the economy embraces the technology revolution. Only with world class information systems will the NHS deliver world class care.” Jeremy Hunt, the Secretary of State for Health, January 2013 (<http://digitalchallenge.dh.gov.uk/2013/01/16/paperless/>).

In all policy documents IT is seen as key to achieving transformation of healthcare or ‘modernization’. The 1992 health policy paper (DOH, 1992) emphasizes the need for reliable and diverse sources of information about health, so people can make choices and take care of their health. It envisages that IS would focus on the individual patient and that details of all interventions, treatments and outcomes over time and across all service providers and agencies would become available (subject to confidentiality rules). Thus, from early on the IT discourse becomes intertwined with the PCC discourse (at first implicitly and in later publications explicitly). Successive papers define the role of IT as supporting front line staff in delivering benefits to patients and bringing new services to communities and into individual homes (DOH, 1997, DOH, 1998, DOH, 1999). The 1998 paper makes a commitment to creating life-long electronic records for NHS patients. Hence, policy papers assign highly transformative meaning to IT, as enablers of new services or new ways of delivering existing services, e.g., they identify telemedicine and telecare as being able to deliver healthcare remotely instead of person-to-person, in home rather than in hospitals, to groups rather than to individuals, and across traditional institutional boundaries (DOH, 1997, DOH, 1999, DOH, 2000, Klecun-Dabrowska and Cornford, 2000). However, progress to implement and embed those services in day-to-day use has been slow (Klecun-Dabrowska and Cornford, 2002).

Subsequent publications support the strategic goals of improving NHS IS and of developing more patient-centred service organization and care delivery (DOH, 2000, DOH, 2001, DOH, 2002). The NHS strategic plan (DOH, 2000) identifies three patient-centred technologies: video and telelinks to hospital specialists enabling e-consultations, telecare and electronic patient records.

In the 1990s, IT strategy was the responsibility of local health providers and commissioner organizations (Cornford and Klecun-Dabrowska, 2003). However, by the end of the decade resulting change was seen as being too slow and too

fragmented, with different organizations having too limited resources and too little incentives to work together. To overcome those problems, a centralized model of IT procurement and implementation was chosen when, in 2002, the Labour Government launched the National Programme for Information Technology (NPfIT) for England (DOH, 2002). The NPfIT amounted to a top-down plan for a major technology-based transformation of healthcare, promising that IS would give patients more choice and health professionals more efficient access to information and thereby delivering better patient care. Core to this vision was an EHR (called NHS Care Record Service (NCRS)) shared across NHS organizations in order to support cross-organizational and cross-professional provision of care. Other main applications included electronic prescribing, the Choose and Book system for booking hospital appointments and offering patient choice among a range of hospitals, and electronic transfer of digital images via PACS (Picture Archiving and Communication System). The Choose and Book system was picked ahead of other applications (such as discharged summaries) preferred by healthcare professionals. This is an example how policy (i.e., its choice agenda) influenced both the healthcare and the IT industry.

The implementation of the NPfIT encountered numerous and well publicized problems (Clegg and Shepherd, 2007, Currie and Guah, 2007, Currie, 2012, Eason, 2007, Randell, 2007, Robertson et al., 2010, Sauer and Willcocks, 2007). The critique of the programme came from different quarters, including the National Audit Office, the Parliament, media and the academic community. The top-down, centralized model of implementation, ‘one-size fits all’ system, and the technocentric vision of the programme (evident at least in its earlier stages) were identified as particularly problematic. At times the entire vision of IT-enabled transformation of healthcare was challenged and any investments in IT were questioned. The NCRS proved to be particularly difficult to implement and progress was very slow (Greenhalgh et al., 2010b, Robertson et al., 2010). Problems were caused by unrealistic expectations about the capabilities of IT and the time needed to build, customize and embed the software in practice (Sheikh et al., 2011). According to Currie (2012 p. 243) “[a]s vehicle to change the doctor-patient relationship, the NCRS was resisted by clinically driven institutionalized agendas where doctors acted as gatekeepers to patient data”. Patients’ groups were concerned about data confidentiality and unhappy with the way the information about consent to share information was

communicated to the public (Currie, 2012).

As a further blow to PCC agenda, an Internet-based personal electronic health record (HealthSpace) was not taken up in any significant numbers, partly because of its limited functionality and lack of integration with wider care package but also due to lack of interest on the part of citizens (Greenhalgh et al., 2010a). Its anticipated benefits of personalization of care, patient empowerment, reduced NHS costs, patient driven improvements in data quality, and improved health literacy were not realized (at least not on any scale). The NPfIT was dismantled in 2011 by the new coalition government. The commitment to NCRS and HealthSpace was ended. Nevertheless, NPfIT closure was not as complete as presented by the press. Many of its applications and programmes, as well as contracts with IT suppliers continued.

In subsequent statements and documents the new government re-states the commitment to IT-enabled transformation of healthcare. The relevant strategy paper ‘Power of Information: Putting us all in control of the health and social care information we need’ (DOH, 2012) sets out a ten-year framework (or rather a vision) for transforming the use of information for health and social care and for providing person-centred care. It states that patients need access to their own records and other electronic data, so that they can choose services, manage their care, and correct inaccurate data. It commits the NHS to offering all primary care patients online access to their health records by 2015 and the ability to book appointments and obtain repeat prescriptions online. The strategy also proposes a new ‘single, trusted health and care portal’ through which patients can see information, investigate their own conditions and choose an appropriate course of action with a support of decision aids.

The strategy paper makes local bodies responsible for funding and implementing IT and proclaims that innovation at a local level will be encouraged. Thus, implementation strategies over the last two decades have come full circle, from local, to centralized and back to local (Takian and Cornford, 2012).

However, the strategy offers little details on how this vision might be taken forward and how it relates to the NPfIT legacy. This is elaborated on in another paper ‘Safer hospitals, safer wards’ (NHS England, 2013) that outlines a plan for an Integrated Digital Care Record (IDCR). IDCR is to become one of the mechanisms for PCC,

with patients given the right to access their own IDCR and to add to it their preferences and insights.

Despite problems that demanding deadlines have created in the past, in January 2013, the UK health secretary Jeremy Hunt announced that he wanted the NHS to become the “most digital health service in the world” with all records and communications in the NHS to become electronic by 2018. This is a very techno-centric and ambitious vision, in terms of its scope and deadlines. It is put forward in times of austerity and uncertainty in the NHS. Many of the deadlines are unlikely to be met. For example, a care.data programme which aims to link information on GP records to secondary care data and make it accessible to researchers and private companies had to be postponed. Echoing earlier misgivings about HealthSpace, professional bodies, some of the patient support groups and press objected to the programme because of its poor communication with patients, the ‘opt out’ clause and worries about data confidentiality (Matthews-King, 2014). It appears that even when challenges related to utilizing IT by healthcare professionals, or the wider population are acknowledged in policy statements, they are then put aside when new projects are envisaged and idealized visions of IT-led transformation are presented.

Discussion and Conclusion

Implications for IT-enabled transformation of healthcare

My analysis suggest that English policies have deliberately set out to transform healthcare from paternalistic and organization-centric to patient-centred and placed information and IT as central to this process. They have appropriated the wider PCC discourse for a number of ends, including legitimizing reforms of organizational structures and budgetary regulations (e.g., GP commissioning), changing medical practices, such as allowing patients to choose healthcare providers and to negotiate treatments, as well as legitimizing investments in IT. In doing so they have linked PCC discourse to IT-led transformation agenda. Thus, I propose that *PCC discourse legitimizes IT discourse* in the healthcare context. The discourse also *shapes* the context, as different conceptualizations of PCC require different IS. In turn, IT *affords* (makes potentially possible) transformation of healthcare in some directions but less so in others. I suggest that by highlighting the transformational potential of

IT and through idealization of information, *IT discourse amplifies (make more visible and seemingly more achievable) PCC discourse*. Through this process particular conceptualizations of PCC are emphasized, prioritizing information centric view of PCC, focusing on choice agenda and redefining patients as empowered customers and decision makers. Hence, *IT discourse both amplifies and (re)-focuses PCC discourse*. Through the interweaving of IT and PCC discourses a particular vision of IT-enabled transformation is constructed in policy.

Policies influence IT-enabled transformation directly (through incentives, funding of different programmes, guidelines and standards) and indirectly (through legitimizing some ways of thinking and delegitimizing others). But their effects are not automatic or leaner. Policy realization requires transforming of practices (e.g., making them standardized), changing organizational structures, blurring of boundaries (between professions, institutions and patients/citizens) and re-defining relationships, thus effecting professional power and identity. Policies are interpreted, translated in local discourses, and enacted or opposed (Currie, 2012, Morrison et al., 2013, Sheikh et al., 2011).

For example, this paper has shown that ambition to create a patient-led NHS and to integrate health and social care was set out in 2005, but presently, in 2014, it is still far from being realized. Shared EHR was promised in 1998, but its implementation is still in progress and the vision of how it is to be achieved has substantially evolved in subsequent policy papers. Contrary to hopes, many EHR projects have not lead to the transformation of healthcare organizations (e.g., through supporting new ways of collaborative working) or to the realizations of expected benefits (Greenhalgh et al., 2009). Moreover, the choice agenda promoted in policy has been highly controversial with GPs. Forcing its implementation by means of the Choose and Book system resulted in clinician opposition and ultimately patchy take up (Swinglehurst, et al., 2014).

Such an outcome is not surprising, as studies have shown that IS that does not fit with the organizational culture, professional values and practices are likely to be resisted. This is particularly true in healthcare, which is characterized by professional autonomy and a strong set of norms and values (Currie, 2012, Petrakaki et al., 2014, Rivard et al., 2011). The HealthSpace and care.data programmes illustrate that data confidentiality is a major point of contention, evoked by clinicians and patient groups

alike. The example of HealthSpace also suggests that citizens' interest in some of the patient-centred applications might not meet policy expectations, and that patient's needs and wants need to be better understood.

Yet, despite many setbacks and challenges successive policies continue to reaffirm the commitment to transforming healthcare with IT. Although many IT-driven change initiatives have been abandoned, new ones are introduced. Furthermore, abandoned initiatives, such as the NPfIT, do not disappear without a trace. They influence public and organizational discourses, contribute to organizational learning and change (Sheikh et al., 2011) and sometimes leave already implemented IT systems in place. This suggests that organizational transformation, and more so, transformation of a whole complex and diverse sector such as healthcare, takes time. It is a messy process characterized by many detours and setbacks, with the 'old' and the 'new' coexisting, rather than the 'new' simply replacing the 'old' (Bloomfield and Hayes, 2009).

Figure 2 below elaborates Figure 1 to include main points arising from the analysis of England's health policy discussed in this section.

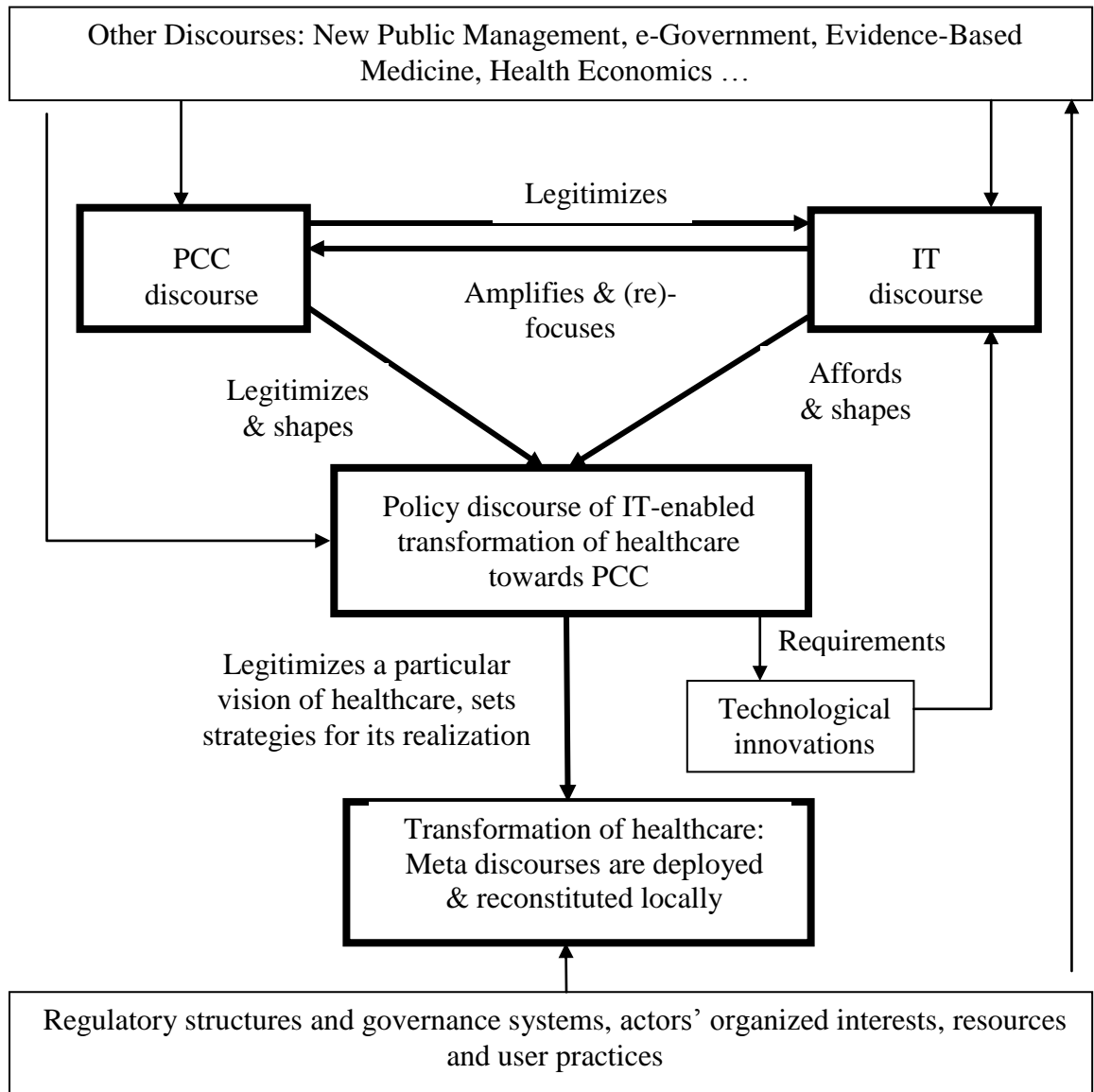


Figure 2 Discourse view on healthcare transformation (revised)

In conclusion, based on analysis presented in this paper and the literature reviewed, I make the following observations:

- The policy vision of the transformation of healthcare is based on different, and at times contested conceptualizations of PCC; making some policies particularly controversial.
- It is difficult to implement controversial policies by means of IT; problems, disappointing outcomes, or even outright refusal to use IT are to be expected.
- Opposition to information systems is at least partly due to their goals and visions of healthcare that underpin them, rather than to problems with their

design. Nevertheless, unrealistic deadlines exacerbate implementation problems.

- If the underlying causes of opposition are not addressed, producing technologically superior systems or better IT implementation strategies is unlikely to result in widespread and substantial changes to the way healthcare is delivered and experienced.
- For IT to support a healthcare service that is truly patient-centred, patients' needs and wants should be identified rather than assumed, and designed into IT-enabled services rather than simply added on afterwards.

Agenda for healthcare policy and IS research

The analyses presented in this paper have a number of implications for policy and IT strategy. First, they indicate that the problems experienced with IT-enabled transformation of healthcare are not solely or perhaps even mainly, due to the design of particular IT, or specific implementation strategies but are caused by underlying tensions in the vision of healthcare presented in policy, and the challenges to identities, values and practices of healthcare professionals and citizens/patients. This suggests that controversial policies and goals that IT aim to serve should be revisited, and decisions made about which are worth pursuing (even when faced with opposition) and which are not. Second, policies need to be mindful of organizational realities and eschew unrealistic deadlines attached to grand and abstract visions of IT-enabled healthcare transformation. When the gap between aspirations and organizational reality is too great, it leads to policy failure (Fotaki, 2010).

My third point relates to strategies for implementing IT. The move to a greater autonomy for NHS organizations in terms of what systems they purchase or develop is welcomed. It opens a space for more local innovation and tailoring of systems, and facilitates building on what is already in existence, an approach advocated in IS and health informatics literature (Aanestad and Jensen, 2011, Atkinson and Peel, 1998, Hanseth and Aanestad, 2003). An ambition communicated in the recent policy (NHS England, 2013 p. 8) to 'meaningfully' engage patients in the design and delivery of the technology that the NHS uses requires a bottom-up approach linking the design and implementation of both, services and IT, and reflecting the spirit of inclusiveness

and sensitivity to cultural and educational differences of the intended service users (Payton and Kiwanuka-Tondo, 2009).

We should not forget, however, that the centralized approach was adopted in response to failures of decentralized strategies of the 1990s. Policies need to provide direction, incentives and support to encourage innovation and collaboration involving different stakeholders, including patients. It is worth exploring what can be learned from the US HITECH Act and in particular its ‘meaningful use’ provisions (Blumenthal, 2011b).

For the IS community there are significant opportunities. We can engage with policy development processes and aim to influence it from the onset, reshaping not only the features and functionality of IT, but also expectations and deadlines articulated in policy. In this way the IS community can help to positively shape the way healthcare is organized, delivered and consumed.

To gain a better understanding of processes and outcomes of transformation and the role IT might play, IS scholars need to move away from a confinement to a single organization or short frame of time (Currie and Finnegan, 2011), and examine phenomena from a system perspective (Agarwal et al., 2010 p 11). By this I do not mean abandoning in-depth case study-based research, but rather building on it to gain a picture over time and spanning organizations. Such research might be conducted by multi-professional research teams, allowing for appreciation of different perspectives. More research conducted *with* patients, not just *about* patients is needed. Some work has already been done in this area (Davies et al., 2011, Darking et al., 2014, Hogarth et al., 2010), but the challenge for the IS community is to consider how such local experiences can inform national initiatives.

Contributions and Limitations

This paper contributes to the IS literature on large-scale, IT-enabled change in healthcare, and responds to calls to conduct longitudinal studies at the organizational field level (Currie and Finnegan, 2011). Despite the narrow focus on English policy, key contributions should be of relevance to IS and policy researchers as well as policy makers in the UK and other countries interested in or planning for IT-enabled transformation of the healthcare provision. The contributions include, (a) the development of the discourse view on healthcare transformation as depicted in

Figures 1 and 2 and elaborated in discussion, (b) the analysis and critique of policy delivering conceptualization of different models of PCC and the roles envisaged for IT, (c) a discussion of *how* interweaving and mutual shaping of IT and PCC discourses takes place in policy and *in what way* this influences the process of transforming healthcare.

However, by concentrating on policy (as represented in official publications) much was omitted or underrepresented (for example analysis of stakeholder interests). Little has been said on how IT-led change is taking place in practice, for instance in particular healthcare organizations and beyond them, in the space inhabited by private providers, entrepreneurs, real-world and online communities. The conceptual frameworks outlined in Figure 2 could be taken as a starting point for a much more ambitious study of the transformation of healthcare.

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