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National electronic health records and the digital disruption of moral orders

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ABSTRACT

The digitalisation of patient health data to provide national electronic health record systems (NEHRS) is a major objective of many governments. Proponents claim that NEHRS will streamline care, reduce mistakes and cut costs. However, building these systems has proved highly problematic. Using recent developments in Australia as an example, we argue that a hitherto unexamined source of difficulty concerns the way NEHRS disrupt the moral orders governing the production, ownership, use of and responsibility for health records. Policies that pursue digitalisation as a self-evident 'solution' to problems in healthcare without due regard to these disruptions risk alienating key stakeholders. We propose a more emergent approach to the development and implementation of NEHRS that supports moral re-ordering around rights and responsibilities appropriate to the intentions of those involved in healthcare relationships.

Introduction

Many governments are investing in nation-wide information systems that will collate individual health records and make them available across organisational and geographic boundaries (Brennan, 2007; Morrison, Robertson, Cresswell, Crowe, & Sheikh, 2011; Stroetmann et al., 2011). These systems, which for the purposes of this paper we call NEHRS (National Electronic Health Record System/s) are often integral components of broader attempts to reform healthcare. Policymakers, politicians and some researchers claim that digitising health information will help eliminate inefficient paper-based systems and cut costs, while facilitating the development of new, better coordinated models of 'paperless' care (Christensen, Grossman, & Hwang, 2009; Hunt, 2013). Making electronic records available to citizens, proponents claim, will also encourage them to take more responsibility for their own health (Ball, Smith, & Bakalar, 2007; National Health and Hospitals Reform Commission, 2009a).

However, existing research suggests that although these visions are compelling, translating them into workable systems is highly problematic (Deutsch, Duftschmid, & Dorda, 2010; Greenhalgh, Russell, Ashcroft, & Parsons, 2011). As well as the technical challenges of replacing or connecting diverse legacy systems, new forms of governance are needed to manage the potential risks associated with the wider distribution of potentially sensitive information. In many nations, including England, Australia and the Netherlands, attempts to formulate new rules at a national level around patient consent, privacy, data quality and access in relation to NEHRS became mired in controversy. In England a 'big opt out' campaign forced changes to policy and contributed to significant delays in the roll out of a national 'summary care record' (Carvel, 2006; Cross, 2008). The Dutch Senate abandoned plans for a NEHRS in 2012 amid concerns about privacy (Smits, 2013). Australia's NEHRS has also encountered opposition from privacy groups and doctors who are concerned about its security, safety and utility (Coiera, Kidd, & Haikerwal, 2012; Dearne, 2012a).

In this article we argue that one reason NEHRS have been so difficult to implement is that policymakers have seriously underestimated the degree to which digitalisation disrupts existing social, moral and medico-legal orders through which healthcare is governed and delivered. Too often, these disturbances are pushed into the background while the technical capabilities of NEHRS are foregrounded as '*the solution*' to the challenges facing healthcare systems. Centralised authorities attempt to resolve the resulting disruptions by trying to impose new rules that seemingly fail to satisfy interested parties. We suggest that a more holistic, flexible

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and emergent approach that prioritises and supports the intentions of those involved in care relationships may help address some of the difficulties encountered by nations attempting to introduce NEHRS. Governments need to demonstrate more commitment to providing adequate opportunities for those engaged in healthcare to explore anticipated and unexpected shifts in their identities, practices and relationships, and to consider modes of governance that support the intentions of those involved in care as it evolves in the digital age.

Our argument is structured as follows. In the next section we develop the idea of healthcare as a cluster of intersecting and negotiated moral orders that, while stable enough to facilitate care most of the time, are also subject to change and disruption. These orders emerge out of and shape interactions across many sites, from private, situated healthcare encounters to public debates about national health policy. Our focus in this article is on the latter, as it is in the policy arena that governments have tried, without much success so far, to manage the disruptions generated by the introduction of NEHRS. We place these debates within a broader context of shifting power relationships among doctors, patients and the state, and outline the pivotal role that medical records play in mediating these relationships. Debates surrounding the introduction of a NEHRS in Australia are then presented to illustrate how the innovation disrupted established patterns of formalised rights and responsibilities. While these disruptions open up possibilities for more connected, person-centred care, they also create ambiguities that may hinder implementation if, as occurred in Australia, parties who perceive the innovation as threatening attempt to fortify their positions within pre-existing orders. We conclude by considering approaches that may facilitate a more productive way of reaping the potential benefits of NEHRS while working through the governance challenges they pose.

The multiple negotiated orders of healthcare

The idea that healthcare is delivered through a series of negotiated orders grew out of ethnographic observations of work in hospitals in the 1960s. Strauss, Schatzman, Ehrlich, Bucher, and Sabshin (1963), Strauss, Fagerhaugh, Suczek, and Wiener (1985) observed how the work of caring for patients was not determined by rules or procedures, but achieved through ongoing actions and interactions carried out in response to contingencies as well as formal and informal rules and expectations. Negotiated orders are not just evident within single organisations, however. They also emerge out of and shape relationships among organisations and entities in their environment, such as client groups and government agencies (Strauss, 1982). Following this line of analysis, we can view healthcare as occurring within arenas populated by different social worlds – lay people, medical professionals, policymakers and bureaucrats – who collectively negotiate the formal and informal 'rules' that shape the delivery of care (Clarke, 2005).

An important aspect of these negotiations concerns the moral orders of healthcare, that is, systems of 'rights, obligations and duties' that mediate relationships among actors in the arena (Langenhove & Harré, 1994). Moral orders are multi-layered and often contested. They can be found at different levels of generality – from the policies and regulations that allocate rights and responsibilities to institutions, to the implicit 'rules' that shape interactions in single healthcare encounters (Harré, Moghaddam, Cairnie, Rothbart, & Sabat, 2009; Thévenot, 2001). Moral orders are also integral to the discursive production of identities, as individuals and institutions position themselves and others in relation to these orders. Positions, in this view, are 'clusters' of rights and responsibilities that 'belong' to individuals as members of collectives, or that individuals claim and contest as they create themselves and their institutions as competent, moral entities. Positions are adopted, negotiated and challenged with regard to people's capacities, training, vulnerabilities and social and institutional locations (Harré et al., 2009; Langenhove & Harré, 1994). Thus, in most developed nations, people position themselves as having 'rights' to healthcare based on their vulnerability to sickness or disability, and see its provision as a state 'responsibility'. There are many, often contestable, moral orders within this broad pattern, especially around controversial issues such as vaccination, contraception, end-of-life care and abortion (Blume, 2006; Simonds & Ellertson, 2004).

Since the middle of last century, doctors have wielded considerable power in healthcare arenas. Based on their training and expertise, they have claimed and exercised rights to control the content and conditions of their work. As Hughes noted, these rights are linked to doctors' assumption of major responsibilities for healthcare outcomes. In common with other occupations in which mistakes can be fatal, they 'build up collective defenses against the lay world' (Hughes, 1971: 318). They claim rights to police the boundaries of their profession – who is allowed in, processes for managing accidents and mistakes, the circumstances in which colleagues are called to account, and the criteria according to which they are judged competent or otherwise (Hughes, 1971; Willis, 1983). As we discuss below, medical records are crucial for policing and legitimating medical work.

In recent decades, rising costs and expectations of improvements in the quality of care and health outcomes, have prompted policymakers to negotiate new orders that erode some of these rights. Providers are now often obliged to follow standardised evidence-based protocols with payments linked to compliance (Bury & Taylor, 2008; Christensen et al., 2009). Policymakers are also attempting to reduce costs by 'empowering' people to take more responsibility for their own health. Proponents of NEHRS claim that the technology has the potential to facilitate this empowerment by providing citizens with access to their own records and electronic connections to multiple carers when illnesses are chronic and complex (Christensen et al., 2009). However, merely implementing NEHRS without paying attention to and managing disruptions to entrenched distributions of rights and responsibilities can lead to frustration and waste (Westbrook & Braithwaite, 2010). The benefits of NEHRS, we suggest, are unlikely to be realised until we understand their implications, not only for models of care, but also for the moral orders that govern medical practice and the interactions we all have with our healthcare systems.

Records in the moral orders of healthcare

The medical (or health) record is a 'mundane yet surprisingly multi-layered technology' (Berg & Harterink, 2004: 15) that has evolved as healthcare practices have changed. Initially records were 'owned' by practitioners, as they chronicled symptoms and illness trajectories for teaching and research (Reiser, 1991a). These often idiosyncratic accounts helped develop the expert knowledge that legitimates doctors' rights to practice. From the 19th century onwards such narratives were supplemented by more organised records designed to facilitate additional modes of ordering linked to new positions within the healthcare arena. With the introduction of managers in hospitals, separate records were used for billing and administration (Siegler, 2010).

As the influence of scientific management spread, initially in the United States then elsewhere, attempts were made to enhance the efficiency and effectiveness of hospitals through more reliable, standardised record keeping (Reiser, 1991b; Berg & Harterink, 2004). Reformers in the early 20th century proposed using