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Disruptive innovation in health care: business models, moral orders and electronic records

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Abstract

There is widespread consensus that current healthcare costs are unsustainable, and that efficiencies could be achieved by reorganising care and making greater use of information technology, in particular nationally available electronic health records. Such approaches have, however, been difficult to implement, partly because incentives for uptake are weak. In this article we argue that the difficulties go deeper than calculations of costs and benefits, and include disruptions to the complex moral orders that surround the production and exchange of health information. Using the introduction of national electronic health records in England and Australia as examples, we show how attempts to reshape and transfer distributions of rights and responsibilities developed in the age of paper into the digital world go awry. We suggest that a fundamental rethinking of the role of 'records' in healthcare may be an integral component of the moral re-ordering required to transform health care through such means.

Keywords

orders, electronic, moral, innovation, models, business, care, disruptive, records, health

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Disruptive Innovation in Health Care: Business Models, Moral Orders and Electronic Records

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There is widespread consensus that current healthcare costs are unsustainable, and that efficiencies could be achieved by reorganising care and making greater use of information technology, in particular nationally available electronic health records. Such approaches have, however, been difficult to implement, partly because incentives for uptake are weak. In this article we argue that the difficulties go deeper than calculations of costs and benefits, and include disruptions to the complex moral orders that surround the production and exchange of health information. Using the introduction of national electronic health records in England and Australia as examples, we show how attempts to reshape and transfer distributions of rights and responsibilities developed in the age of paper into the digital world go awry. We suggest that a fundamental rethinking of the role of 'records' in healthcare may be an integral component of the moral re-ordering required to transform health care through such means.

Key words: Disruptive innovation, electronic health records, moral order, positioning theory

Introduction

There is widespread consensus among policy-makers and researchers that current systems of healthcare are unsustainable. In many developed nations, ageing populations and increasing chronic disease, combined with rising expectations, have led to escalating costs. Many commentators claim that deep-seated reforms are necessary, and that healthcare would be cheaper, more efficient and better co-ordinated if more use were made of digital technologies that share information across organisational boundaries (Department of Health, 2008; National Health and Hospitals Reform Commission, 2009a; Christensen *et al.*, 2009). Such technologies, however, have been difficult to implement. In particular, attempts to build information systems that compile and exchange health records on a national scale, such as England's Summary Care Record (SCR) and Australia's Personally Controlled Electronic Health Record (PCEHR), have been plagued by controversies and delays (Timmins, 2011; Townsend, 2012).

In this article we explore why these systems are so challenging. We begin by acknowledging, along with others (Christensen *et al.*, 2009; Westbrook and Braithwaite, 2010), that these technologies potentially enable disruptive innovations in healthcare.

That is, rather than facilitating incremental improvements to current practices, they can support transformations in the way care is delivered. This capacity is the source of both their reforming potential *and* the problems they pose for developers, implementers and users. If the problems can be overcome, their capacity to improve care may be realised. However, this requires a different understanding of what these technologies are implicated in disrupting. To date, researchers working in this area have mostly highlighted disturbances to work routines and business models. In particular, they have focussed on disruptions to traditional workflows that reflect provider-centric models of care (Hendy *et al.*, 2005; Westbrook and Braithwaite, 2010; Currie and Finnegan, 2011).

We argue, however, that the potential for disruption goes far deeper than this. National systems of electronic health records do not just unsettle medical routines and the business models underpinning the provision of care, they also challenge the moral orders through which risks, rights and responsibilities pertaining to health records are distributed and managed. These moral dimensions emerge in debates about privacy and consent, and reveal the paradoxical nature of the 'value' that the digitisation of records putatively adds to healthcare encounters.

The article proceeds as follows. First, we review literature on disruptive innovation in healthcare and suggest how it can be extended by taking account of the moral ordering that distributes rights and responsibilities among participants in care. We then describe debates that have occurred over the introduction of national electronic health record systems in England and Australia, and argue that we need to go beyond a focus on business models and bring in a consideration of the moral dimensions of divisions of labour in healthcare. We conclude by arguing that the tensions accompanying the introduction of electronic health records may be due to a basic inability to transfer moral orders that governed medical information in the age of paper into the digital world. A fundamental rethinking of the use of information in healthcare may be required that is more compatible with the dynamic, relational aspects of care that are supported by digitisation.

Disruptive innovation in healthcare – business models and moral orders

The theory of disruptive innovation emerged from the field of business administration to explain how seemingly successful business models and products are challenged and replaced by newer, cheaper, entrants to a market, partly because incumbent firms seem unable to respond before it is too late. The upshot is far-reaching change that either sweeps away or transforms entire industries (Bower and Christensen, 1995). This thesis has recently been applied to public services, such as healthcare and education, in the hope that a better understanding of what inhibits innovation in these sectors can help 'cure' their inefficiencies and high costs (Christensen and Overdorf, 2000; Christensen *et al.*, 2008, 2009). In their seminal application of the theory to healthcare, Christensen and colleagues (2009) argue that many of its problems derive from the fact that hospitals and primary care practices have been allowed to become complex and confused institutions. They require high costs to administer that detract from patient care. In their analysis, these problems are caused by the persistence of a business model which dates from the nineteenth century. That is, hospitals and general practices, albeit with some modification and additions over the years, essentially operate as 'solution shops', where clinical experts 'diagnose and recommend solutions to unstructured problems' as they are presented in situ by patients (2009: 20). Doctors practice 'intuitive medicine' on a fee for service basis,

collecting data from tests, imaging equipment and physical examinations of the patient to develop diagnoses and prescribe treatments.

Over the years a second business model has also emerged. Accumulated evidence concerning what works in healthcare has allowed some procedures to become standardised, repeatable and controllable. Such treatments add value to healthcare outcomes with such certainty that, once a definitive diagnosis has been made, the service can be charged on a fee fixed to the output, which normally comes with a guarantee. These so-called value-adding processes can be highly efficient when organised into specialist hospitals or clinics where the high overheads associated with their mixing with solution shop business models can be reduced. Practitioners who can accumulate appropriate medical data to provide an evidence-base for their value adding processes can, in principle, therefore disrupt the solution shop approach to dealing with such health conditions.

A third, more emergent business model is based around the idea of facilitated networks. This model challenges established models of care by offering, in principle at least, a more patient-centred approach in which providers and patients 'co-produce' healthcare (Dunston *et al.*, 2009). This model is relevant to people with chronic conditions whose treatment involves different medical specialists and behavioural changes that require them to take more responsibility for their own health. Compiling information on such conditions and sharing it among patients and those engaged in their care become a vital part of long-term management. Indeed, patients may be able to learn from each other, thus enhancing mutual well-being.

Christensen *et al.* see a place for all three models in future healthcare, but argue that instead of the current confused mix, the models need to be separated and reorganised. Expensive 'solution shops' should be reserved for complex problems, while well-understood conditions can be treated by less qualified practitioners according to rule-based procedures. Facilitated networks can reduce costs further by helping patients to manage known and chronic conditions themselves (2009: 131). In this reorganised system, no one health professional is responsible for coordinating an individual's care. Instead, electronic records provide the 'connective tissue that draws and holds together the individual elements' of care (2009: 132). According to Christensen *et al.* (2009: 130–43), the fact that such records have been promoted for some time, but have rarely been successfully implemented, is due to the current confused state of medical practice and the lack of a coherent business model that makes their uptake worthwhile.

The 'disruptive innovation' thesis has enhanced our understanding of industrial and business change in the private sector, and can highlight in new ways the problems that afflict healthcare around the world, and possible paths to their solution. It has been taken up by others advocating the development of electronic health records (for example, Westbrook and Braithwaite, 2010; Fasano, 2013). However, in our view these reformers have seriously underestimated the depth of the changes required to support the co-production of healthcare through facilitated networks. As Dunston *et al.* (2009) note, advocates of co-production, in which patients and doctors become partners in care, tend to focus on 'instrumental and technical recommendations', while leaving cultural change issues under-theorised, if they are theorised at all. An important aspect of the cultural changes needed to support the co-production and sharing of electronic records concerns relationships among individuals, their healthcare providers and the governments that regulate care. Shifting the balance of power over medical information

potentially transforms the identities of those participating in care (Dunston *et al.*, 2009). These transformations can be fruitfully explored using ideas from the field of social psychology, and in particular concepts developed by Rom Harré and colleagues (2009). These researchers observed how individuals discursively construct their identities and relationships by positioning themselves and others within 'moral orders'. Moral orders are collectively negotiated systems of 'rights, obligations and duties' that mediate social and professional interactions (Davies and Harré, 1990; Harré and Slocum, 2003; Harré *et al.*, 2009). Thus, in most developed nations, citizens claim a 'right' to healthcare based on their vulnerability to sickness or disability, and see its provision as a state responsibility. Doctors, as part of their professional identities, have rights and responsibilities with respect to medical information and patient care. In the moral orders of healthcare, medical records are more than mere repositories of information. They mediate relationships among the state, healthcare providers and citizens by providing an audit trail that can be used to legitimate actions or allocate blame when care goes awry (Berg and Bowker, 1997).

In the solution shop model, medical records are clinical in nature and controlled by doctors. Their disclosure to patients is largely a medical prerogative and contingent on clinical interpretation to render them meaningful and actionable. In the value-added model, healthcare providers' 'right' to autonomous practice is constrained, but they still retain control over, and responsibility for, medical information about patients. A facilitated network model, supported by electronic records owned and controlled by patients, represents a fundamental shift in these rights and responsibilities. The digitisation of records may make them more accessible, but it also complicates practices that have been established over decades to ensure data quality and privacy. Moral orders that were developed in the age of paper records do not translate easily into the electronic era.

Below, we illustrate how attempts to introduce national systems of electronic health records in England and Australia disrupted the moral orders through which health information is collected and exchanged. Both attempts were inspired by the benefits identified by Christensen *et al.* (2009). That is, the SCR and PCEHR were promoted as facilitators of self-care and connective tissue holding a fragmented health system together (Department of Health, 2002a, 2008; National Health and Hospitals Reform Commission, 2009a, 2009b). However, they soon became mired in controversy, as redistributions of rights and responsibilities among the state, healthcare professionals and citizens were vigorously debated. The controversies played out differently in each nation, influenced by pre-existing moral orders, details of technology design and the configurations of institutions through which healthcare is delivered. In both cases, however, the issues that emerged illustrate the degree to which policymakers who were seduced by visions of 'streamlined' healthcare failed to take account of the moral re-ordering required when entrenched patterns of information management are disrupted by digitisation.

England's Summary Care Record

In England, as in most developed countries, healthcare providers have traditionally been responsible for ensuring that the information they hold about their patients is accurate, confidential and secure, that any disclosures to third parties are for authorised purposes only and that such disclosures have the implicit or explicit consent of patients.

During the 1980s and 1990s, the British government promoted the use of information technology in healthcare, and many hospitals and GP clinics implemented new systems

(Department of Health, 1992; Leaning, 1993). However, increasing digitisation and interconnectedness led to concerns about privacy. While paper records can be lost or stolen, the ease with which electronic data can be copied and distributed, and the potential damage that can be caused by hackers, means that digitisation creates significant new risks (Davies, 1996). The government tried to manage these risks through the Data Protection Acts of 1984 and 1998 and its endorsement of recommendations put forward by the Caldicott Committee (Caldicott, 1997). These measures sought to extend the moral orders that governed information in the paper era into the digital age by creating new positions of data controller, data protection supervisor and Caldicott guardian, with new responsibilities for ensuring that electronic data are handled 'fairly and lawfully'. These attempts to fortify the moral orders surrounding health information shaped the development of England's national system of electronic health records during the late 1990s and into the 2000s. However, enduring controversies over the 'right' of the state to extract data from citizens' medical records complicated the development of electronic 'connective tissue' among providers, and patients have been reluctant to assume the responsibilities for self-management implicated in the 'facilitated network' model of care.

England's Summary Care Record (SCR) grew out of an ambitious attempt to replace and connect existing fragmented information systems across the National Health Service (NHS) through a 'National Program for Information Technology (NPfIT)' (Department of Health, 2002a). The intention was to provide 'a seamless continuum of care for an individual patient or service user across all care settings' (Department of Health, 2002b: 19). From the outset, the Department of Health (DH) assured citizens that, apart from exceptions such as emergencies, their consent would be required before information about them could be shared (2002b: 23). However, in the initial plans this consent would only be elicited on a 'one-off' basis *after* records had been uploaded into the system (National Health Service, 2003: 72). In other words, the DH assumed a right to extract records from GPs' computers without the involvement of providers or the explicit consent of citizens. While people could exercise some control over who could see their information once it was uploaded, they did not have the right to opt out of the system altogether. They were, however, granted an additional right to access their own records through a portal titled HealthSpace (National Health Service, 2005).

The assumed 'right' of the state to upload records was hotly contested and eroded over time. At first, anyone who objected had to prove that they would suffer 'significant distress or damage' if their information were included (Anonymous, 2005; National Health Service, 2005: 6). Connecting for Health, the body responsible for delivering NPfIT, issued a 'Care Record Guarantee' that tried to reassure people that their records would be secure (National Health Service, 2005), but this did not placate critics. Public campaigns were mounted. Opponents pointed out that the Data Protection Act gave citizens the right to refuse to have their information copied from one database to another. They were not required to prove 'distress' (Collins, 2006; Leigh and Evans, 2006; Carvel, 2006a; TheBigOptOut, ND).

Initially the DH held its ground, claiming that privacy considerations were less important than the benefits that would follow implementation (Carvel, 2006a, 2006b). However in 2006, it backed down. Citizens would now be informed about impending uploads, and given the option of opting out (Carvel, 2006c). Changes to the consent model were made after trials of the system, in which healthcare workers expressed unease about accessing the records of people who had not opted out. In their view, the assumption

of 'implied consent' for these individuals was not substantial enough (Greenhalgh *et al.*, 2008). Since 2008, unless they are unconscious or otherwise lacking capacity, patients need to give consent for their SCR to be viewed at each clinical encounter (Carlisle, 2008).

Despite this moral reordering, many doctors still opposed the system (Anonymous, 2007, 2008). During the development stages, they lobbied successfully to have the information in the SCR reduced to allergies, prescriptions and adverse reactions. This was a response to concerns about data quality as well as patient privacy (Anonymous, 2006). Doctors have consistently positioned themselves as protectors of their patients' privacy. According to surveys conducted in 2006 and 2007, 50 to 60 per cent of doctors would not upload data without explicit patient consent (Carvel, 2006d, 2007). The British Medical Association favoured an opt-in approach (House of Commons Health Committee, 2007: 32), and in some regions doctors have encouraged patients to opt out (Nowotny, 2009; Anonymous, 2010).

As is well documented, the NPfIT as a whole (dubbed 'the largest computer project in the world') ran into significant problems and was eventually terminated (House of Commons Committee of Public Accounts, 2011; Cross, 2011). However, reviews of the SCR recommended it be retained, along with other elements of the system which had worked in practice (Keogh and Saddler, 2010). Roll out escalated during 2010 and by February 2013, 23 million SCRs had been created (Davies, 2013). Despite continued pockets of scepticism (Anderson, 2010; Davies, 2013), a new moral order has settled around the SCR, which at the time of writing, consists of a minimal amount of information that can be accessed in emergencies. Additional information can be added, but only with the explicit consent of patients (National Health Service, 2011a, 2011b, 2012). The fifth version of the NHS's Care Record Guarantee assures people that they 'will have control' over their records (National Health Service, 2011b: 1). There is some evidence that SCRs are being accessed by providers delivering care after hours (Praities, 2012), but it is some way from supplying the 'connective tissue' that ensures continuity of care across time and space, or a 'facilitated network' that encourages self-care. The HealthSpace portal that enabled people to view their SCR and maintain their own records online did not prove popular and was scrapped in 2012 (Crispin, 2011; Whitfield, 2012a). The Department of Health has promised that by 2015 patients will be able to access their electronic records by other means (Raywood, 2012; Whitfield, 2012b), although a recent Parliamentary Committee review expressed scepticism that such benefits, along with a new vision of a 'paperless NHS', would ever be realised (House of Commons Committee of Public Accounts, 2013).

If moral ordering around the SCR seems to have stabilised, controversies over the 'right' of the state to collect, distribute and even sell citizens' health details continue (Carlisle, 2011; Ramesh, 2013). Recent policies to reform the NHS include moves to combine disparate data sets across health and social services so that information can be shared more easily. In a process separate to the SCR, a new Health and Social Care Information Centre receives information 'extracted' from GP computers for research, auditing and planning, which is available to private companies and external researchers (Department of Health, 2012; Department of Health and National Health Service, 2012; Todd, 2013). A second Caldicott Commission was convened in 2013 to provide guidance on information governance (Caldicott, 2013), that is, to assist with moral re-ordering. However, government assurances that identifiable data will be kept secure and confidential have not prevented criticism of the reforms. In early 2013, several of the

groups that challenged the Department of Health's assumed right to upload patients' records into the SCR reconvened to oppose what they see as new and serious threats to medical confidentiality (Evenstad, 2013; medConfidential, ND).

The digitisation and sharing of health data are clearly controversial. Although policymakers, along with analysts such as Christensen and his colleagues, often frame the issues in terms of costs and benefits, moral conundrums relating to risks, rights and responsibilities run deep and cannot easily be resolved, at least in England, by 'Care Guarantees' and other government assurances. The history of the SCR shows how digitisation generates disruptions that seriously complicate technically inspired visions of self-management and seamless care (Tsoukas, 1997). Battles over the moral reordering of information management in the digital age in England are shaped by relationships in that nation among the state, citizens and healthcare providers. To see how they played out in different circumstances, we now turn to an account of the introduction of national electronic health records in Australia.

Australia's Personally Controlled Electronic Health Record (PCEHR)

The controversies generated by Australia's PCEHR are different to those surrounding the SCR in England, largely because the Australian government has not assumed a right to upload data from doctors' information systems without patients' explicit consent. Ever since the failed attempt to introduce a compulsory national identity card ('Australia Card') during the 1980s (Clarke, 1988), similar endeavours have encountered resistance and been abandoned (Greenleaf, 2007; Dearne, 2007). As a result, plans to introduce national electronic health records in Australia have required citizens to explicitly opt in. As the name of the current system attests, the government has emphasised the 'personal control' that people will putatively exercise over their electronic data. Battles over moral orders in Australia have largely revolved around the meanings of 'personal control' and its impacts on medical practice, rather than the 'right' of the state to extract information.

Although there were attempts to introduce national electronic health records before 2009 (Robinson *et al.*, 2007), moves towards the current PCEHR only began to coalesce in that year as part of a broader attempt to reform healthcare (National Health and Hospitals Reform Commission, 2009a, 2009b). As in England, the technology was presented as vital connective tissue enhancing the continuity of care, and a means of encouraging responsibility among patients. The reform body that advocated the PCEHR claimed it would shift the 'locus of control' over information away from providers towards citizens (National Health and Hospitals Reform Commission, 2009b: 11–12). Citizens can decide whether to have a PCEHR and, if so, what information is included. They can determine which providers and other people (carers, family members) can see it. They can access their record and audit trails to see who else has viewed it and what they have done with it (Department of Health and Ageing, 2011).

Despite the creation of these new rights for citizens, healthcare providers still carry significant responsibilities with respect to medical information. People opting into the PCEHR must nominate a provider to enter their details (allergies, medications, adverse reactions and immunisation status) into a shared health summary. Additional documents (for example, discharge letters, X-rays, pathology results) can also be added by professionals, if patients request. In effect, the PCEHR is a data repository accessible

to patients and authorised others that exists in parallel with providers' own records. Although doctors generally support technologies that improve information flows, they have expressed opposition to the PCEHR. There were heated discussions up to the launch date regarding remuneration, risks and responsibilities (Dunlevy, 2012; Dearne, 2012). Shifting the locus of control over medical data away from clinicians and into a grey area where it is shared with patients disrupts long-standing moral orders in which professional responsibilities for the production and use of patient information are integral components of competent care.

Health records are not just repositories of information that can be detached from the contexts and the moral orders through which care is delivered (Brown and Duguid, 2002), they contain traces of past medical judgments that providers are obliged to consult and augment as part of their professional practice. They can be subjected to scrutiny under medico-legal processes that exonerate doctors or allocate blame when adverse patient outcomes are questioned. Relinquishing control over records contains risks for doctors, as it is they, not patients, who are held accountable when records are inaccurate, incomplete or out of date. Concerns over data quality spurred English doctors to restrict information in the SCR to prescriptions, allergies and adverse reactions. Along with computer experts, they have warned of possible mishaps as the SCR expands and responsibilities for data quality remain diffuse (British Medical Association, 2008; Anderson, 2010). In Australia, the broader scope of the PCEHR, combined with personal control, has brought the issue of diffuse and unclear responsibilities to the surface. The Australian Medical Association (AMA) advises doctors to take a defensive position with respect to the PCEHR. Its guidelines for providers using the PCEHR recommend they record all details of their interactions with it, and all conversations with patients about it (Australian Medical Association, 2012). While the norms associated with 'reasonable care' in the age of paper records are fairly well established, defensible standards using shared electronic records are yet to be developed. As the AMA warns, 'the medico-legal risks [of the PCEHR] for medical practitioners and medical practices are unknown until case law develops' (Australian Medical Association, 2012: 22).

As in England, doctors in Australia generally support patients' rights to privacy. However, while English doctors formed alliances with privacy advocates, there has been some tension between the groups in Australia. Bodies representing doctors have argued that the 'personal controls' built into the PCEHR compromise its reliability and utility (Australian Medical Association, 2011; Royal Australian College of General Practitioners, 2011). According to the President of the AMA, the PCEHR has 'unacceptable complexities' due to the 'disproportionate emphasis given to the concerns of an extreme minority who wish to mask details of their health record' (Australian Medical Association, 2011: 2). In contrast to its British counterpart, the AMA claims that an opt-out approach would be more clinically useful and equitable, as it would make the details of disadvantaged groups (the aged, infirm, technologically deprived) more available (O'Rourke, 2011). The AMA has been successful in convincing at least one non-medical lobby group to support its cause. In 2012, the Consumers' Health Forum, Australia's peak consumer group, announced that it had reversed its previous position in favour of people opting-in to support an opt-out policy (Consumers' Health Forum, 2012). Perhaps memories of the Australia Card are fading, and, in an age of social media, younger generations are more comfortable with publishing their private information online.

The PCEHR opened for registration in July 2012. Uptake was initially slow but escalated after a publicity campaign and the deployment of 'sign-up squads' to hospitals and aged care facilities (Dunlevy, 2013). By July 2013, 2.7 per cent of a population of 22 million people had registered, and 4,585 shared health summaries had been uploaded (National e-Health Transition Authority, 2013). Debates about its utility continue and its fate after the 2013 change of government in Australia is uncertain, especially as e-health does not seem to be a priority for the new government (Foo, 2013). Controversies during the introduction of the PCEHR revealed its disruptive potential, but its consequences are yet to be realised and may never be.

Discussion

In introducing national systems of electronic health records, governments in England and Australia are venturing into uncharted territory. Although they have taken different routes, both nations have experienced controversies and delays as the systems have proved more difficult to implement than initially envisaged. England's attempt to build a comprehensive system by extracting data from GP computers was challenged, and citizens now have a right to opt out of the SCR. Australian policymakers adopted a different strategy, implementing a system that at the time of writing only includes those who explicitly opt in. This, combined with citizen control over content and access, has raised a different set of concerns around data quality and the utility of records that cover only a segment of the population. Clearly, there is no 'one best way' to build a national electronic health record system, as the perceived benefits of making information more readily available are inevitably accompanied by fears that data will be misused.

Christensen and his colleagues attribute the patchy uptake of sharable electronic health records to the lack of a business model that makes their creation and adoption worthwhile. As they note, 'it's hard to build a practice around activities for which you're not paid' (Christensen *et al.*, 2009: 134). We agree that 'value-adding' is an important consideration in the adoption of new technologies. However, providing incentives for doctors to create and use sharable electronic health records is unlikely to solve the issues that have proved contentious in England and Australia. There is more than remuneration at stake, as even Christensen and colleagues now realise, since such disruptive innovations threaten to strike at the heart of the personal and professional identities of all those involved from consumers to clinicians. To make the point in Christensen *et al.*'s (2013) revised terms, it is not just the 'utility function' of new services, such as electronic records, that determines their adoption, but also the 'identity function' through which such evaluations of value are made by potential adopters. No matter how cost-effective, productive or beneficial an e-enabled service can, in principle, be predicted or shown to be, if it threatens the self-perceptions of those who are meant to use it, it may be rejected. 'Identity' is 'a formidable variable in predicting the success and scalability in disruptive innovations' (2013: 6). Or, as we have illustrated through the above accounts, the moral orders that governed the use of medical information in the age of paper records are not easily transferred to the facilitated networks of the digital era.

One possible way of getting beyond the confusion may be to reconceptualise the status and use of information in healthcare. The current emphasis on electronic *records*, as compilations of data located on servers somewhere, may be an unsustainable hangover

from the days when the solution shop model of healthcare reigned supreme, supported by paper records owned and controlled by doctors, even if they were not always assiduous in their upkeep or willing to admit their centrality to medical practice (see Weed, ND). In this situation, a moral order in which doctors hold rights over, and responsibilities for, their content, quality and accessibility makes sense. As facilitated networks and co-production become possible, this order breaks down as 'records' now exist in multiple locations, are easily reproduced, can be accessed and possibly changed by unknown others and, of course, can be authored by patients as well as doctors. The notion of records that we are accustomed to, as repositories of 'stuff' owned exclusively by doctors, and whose quality and utility holds steady over time regardless of context, may not be compatible with facilitated networks. We may need new ways of thinking about information in healthcare that are more attuned to the dynamic, relational nature of networks and the 'democratisation' of who can publish to them. The value of digitisation may lie in its capacity to infrastructuralise the means of sharing information in ways that are becoming evident through the creation and use of sites such as Cancer Voices NSW¹ and RenalPatientView.² Healthcare is delivered through a series of relationships, and information that is valuable for one interaction may be irrelevant for another. Rather than trying to fix problems of fragmentation by integrating static records, it may be more productive to develop technologies that support flows of information through the ongoing situated contexts in which care is delivered over time.

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Notes

- 1 http://www.cancervoices.org.au/index.php?title=Cancer_Voices_NSW.
- 2 <https://www.renalpatientview.org/>.

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