Making the distal patient: Systems of practice and the economy of algorithms

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Abstract

Important shifts are taking place in contemporary patient-hood. Many of these seem to be politically led, but others seem to be powerfully affected by the structuring effects of different kinds of technologies. One important domain in which these shaping effects can be found is in the constellation of practices that have coalesced around the application of technologies of health informatics, e-health, telemedicine and telecare that mediate between sick people and health services. This paper explores the reconfiguring effects of these new systems of practice, focusing attention on the ways that they mediate and shape relations between patients, professions, corporations, and the State. The paper points to the ways that such relational reconfigurations not only discipline patients and populations in new ways, but also implicated them in new forms of rule-boundedness, imposing an economy of algorithms in the experience and organization of healthcare.

Introduction

Important shifts are taking place in contemporary patient-hood. Many of these seem to be politically led, but others seem to be powerfully affected by the structuring effects of different kinds of technologies. These mediate and shape relations between patients, professions, corporations, and the State. One important domain in which these shaping effects can be found is in the constellation of practices that have coalesced around the application of technologies of 'health informatics', 'e-health', 'telemedicine' and 'telecare' that mediate between sick people and health services. These technologies are appealing for both governments and professions because they promise to deliver efficiency gains in gate-keeping and demand management; to increase patient throughput and reduce staff inputs; and to provide more robust information about effectiveness and costs. These systems promise the reconfiguration of the delivery of care, and in the process they also promise a new kind of patient, a distal patient (May et al., 2005). This distal patient is separated in time and space from many of the material practices of healthcare, while at the same time being constituted as a particular kind of object of clinical practice and administrative procedures by means of these mediating technologies. As a result, distal patients are being asked to accept new organizational and organizing responsibilities, and the work of patient-hood is being reconfigured around them, and in association with four modes of digital delivery:

- **Digital Gateways:** where people and algorithms interact to form points of access to health (and other) services (Hanlon et al., 2005, Taylor, 2000). Applications include: (a) Teletriage systems that define and allocate citizens to specific clinical service, or (b) Information and advice systems that promote self-care or engagement with service providers beyond formal health services.

- **Digitized Medicine**: where virtual elements of the patient are imaged, manipulated and mediated within and between specific professionals or healthcare settings (Mort et al., 2009, Oudshoorn, 2008). Applications include: (a) the diagnosis and management of medical conditions at a distance (telemedicine), or (b) offering a range of tools that inform and support patients in making decisions about elective treatment choices (decision-support interventions).

- **Remote monitoring**: where populations are subject to digital surveillance (Poland et al., 2005, Percival and Hanson, 2006). Applications include: (a) self-monitoring of symptoms and the circulation of data about these to healthcare providers (mobile devices), or (b) remote monitoring of vulnerable people in their homes or in motion (telecare, GPS tracking).

- **Digital outreach:** where populations and groups can discover their health problems and begin to manage them on their own (Seale, 2005, Webster, 2004). Applications include: (a) web-based tools for behavioural medicine including smoking cessation, alcohol consumption, harm minimization. (b) support groups and online communities that share and mediate knowledge and practice around specific health problems.

The aim of this paper is to explore these reconfigurations. Its principal argument is that technologies that seem to 'make' distal patients do not simply offer mechanisms for improving throughput

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and quality access or efficiency, but that they reconstitute and reorganize political relationships between individuals and institutions in isomorphic ways. They do this by restructuring professional knowledge and practice, and reconfiguring the work of patient-hood. In this context, the autonomous privatized relationship between health professional and patient which has formed a historically and culturally stable routine in social life for more than a century, is being displaced by corporate impulses of control and highly managed processes for service delivery. These depend on organizational not clinical logic, and in subordinate individualizing impulses to systemic ones (May, 2007).

In its theoretical concerns, this paper links to the ways that research in Science and Technology Studies that has sought to 'follow the actors' as they form networks and seek to stabilise the relationships between human and non-human participants in socio-technical change (Halford et al., 2009). These interests have been played out in several important research programmes, in particular through the work of Marc Berg and colleagues (Berg, 1998, Berg, 1997, Timmermans, 1998, Timmermans and Berg, 1997, Timmermans and Berg, 2003). Important contributions to understanding the dynamics of distance have also drawn attention to the stabilisation and operationalization of the distantiating and calculating regimes that underpin them (Milligan et al., 2011, Mort and Smith, 2009, Oudshoorn, 2008, Oudshoorn et al., 2004, McLaughlin et al., 1999, Webster, 2006, Greenhalgh and Stones, 2010, Swinglehurst et al., 2010, Greenhalgh et al., 2010).

This paper takes a slightly different tack to much recent STS work on informatics and telecommunications in healthcare. In particular, it integrates into that framework a Foucauldian line of analysis on discipline and governmentality (Foucault, 2003, Deacon, 2002, Osborne, 1992), and a Weberian perspective on rationality and rationalization in newly forming bureaucratic systems (Olsen, 2006, Gajduschek, 2003, Flynn, 2002). In relation to these, the paper is not simply concerned with the ways that reconfigurations take place, but also with the interests that are served by these technologies and their associated ensembles of social practices. Further, it rests on the notion that there is nothing about these systems that is inherently about health, whatever their uses, they rest on the logic of the rationalization of their users (both patient and professional), according to rules and algorithms that effect both social distance and affective neutrality.

It is important to be clear that the purpose of the paper – betraying its origins in a series of conference plenary addresses intended to provoke debate – is not to review empirical work or present results from empirical studies. My work since the mid-1990s has included studies of the development, implementation, and integration of telemedicine, telecare, ehealth systems and electronic healthcare records. It has also reflected on wider aspects of policy and practice around technological innovations in healthcare. This is not the place to review fully that programme of research or its outcomes, which have focused on micro (interactional) and meso (organizational) level analyses of practice, and on the development of a middle-range theory of implementation, embedding, and integration of social practices (May, 2009, May and Finch, 2009). It is, however, the place to theorize some of the macro-social or societal consequences of the processes by which distal patients are produced, managed, and organized – and of the ensembles of actors, objects, and contexts that interact to make these processes and to frame what it is that must be embedded. The question that follows from this is how to express that theorization, which links my own research with a wider body of theory acknowledged above. My method of choice here is to crystallise these processes and their shaping effects in a series of propositions. There are ten of these. The paper proceeds in four main sections. First, it defines the domains of digital delivery. Second, it points to the ways that digital delivery both rests upon, and effects, practices of differentiation. Third, the problem (and problematization) of distance itself is discussed. Fourth, the paper points to the ways in which differentiation and distance are configured around impulses of the intensification of labour in healthcare systems.

Healthcare provision and digital delivery

The policy justification for interposing electronic space between professionals and patients has been that distantiating technologies are innovations that will solve important micro-level problems of professional practice, specialist service delivery, and the production of evidence. This solution is accomplished by separating patient and professional in time and space, thus reducing the possibilities for *individual negotiation* between them that are at the core of the clinical encounter (Heritage and Maynard, 2006). At the level of micro-social organization, modes of digital delivery define the transaction spaces in which routes into healthcare are governed. The implication of this is the topic of the first proposition.

1. The aggregation of healthcare ICTs makes possible the reconfiguration of interpersonal relationships and interaction processes within the corporate ecologies of healthcare. They map on to impersonal and rule-bound pathways in an economy of algorithms.

Analysis at the micro-level, whether of specific actor-networks (Latour, 2005), or of strategic action fields (Fligstein and McAdam, 2011), means that we can understand the *operational* aspects of relational ensembles of social practices as these define identity, eligibility, and opportunity for care. However, although we know a good deal about the contingency and instability of actor-networks in relation to healthcare-related information and communications technologies, the proliferation of small scale case studies in STS means that we know more about the instability of localized and localizing networks and much less about the meso-level social orders in which they are set and their macro-level consequences.

That said, there is almost nothing new about the technologies involved in digital delivery. Email, picture transmission and video-conferencing, remote data-linkages, and call centres, are all established and normalized means of mediating between participants in different kinds of membership and service transactions. There is convergence between the utilization of these technologies across different sectors of the economy in the financial services, logistics, and telecommunications sectors (Robins and Webster, 1999); and State through the production of large relational databases for managing government records, the application of

web-interfaces for calculating benefits and taxes, the collection of intelligence and the management of criminal justice (Henman and Adler, 2003). Against the background of the complexity of contemporary healthcare knowledge, and the multiplicity of possibilities that are raised by its digital mediation, some clinicians and health policy-makers have optimistically pointed to unbounded information as a basis for medical practice (Mort and Smith, 2009). Here, the informational potential of new technologies, (and thus of the institutional contexts in which they sit), can be contextualized in relation to *political* shifts in which the citizen's strict obligations to the State have come to include not only the observance of laws and the payment of taxes, but also the disclosure and transfer of accurate personal information. So, our relations with the State are coming to be framed by the same informational obligations as our relations with Capital. Both are coming to be structured by an algorithmic economy founded on personal information and that relies on the production and reproduction of particular kinds of rule-boundedness. We can express this through a pair of connected propositions.

2. Digital delivery of healthcare is rule-bound in that it relies on structured decision-tools, protocols, algorithms, and relational databases. These define possible relationships between citizens and services.

3. The rule-boundedness of digital delivery both assumes and enforces the standardized differentiation of healthcare problems and segmentation of populations. These define possible relationships between services and citizens.

Rule-boundedness helps to solve a troubling problem for healthcare, which is the power of individual narratives of need and creditable standing. For both the financial services and the healthcare sectors, eliminating the subjectivity of both client and practitioner has been a priority. Digital delivery disciplines the persuasive character of patients' accounts by mechanizing them. Standardized and structured records and decision support systems eliminate some professional and patient choices and preferences, and prioritize others (Rogers et al., 2011). These rules are not only technical standards (Timmermans and Epstein, 2010), but they are also normative constraints on knowledge and practice. In fact, they constitute modes of 'technogovernance' (May et al., 2006), that reconstitute the patient as a minimum data set in which narratives of the self are distilled into synopses of images, personal memoranda, and preferences. Invariably, these can be reproduced in a standard quantitative form. Now, there is no sense that these shifts are in any way complete. But models for all of the restructuring and reconfiguring services described here exist. In the UK National Health Service they were a key element of the New Labour *modernization* project for healthcare (Harrison, 2002) throuth the 2000s, and are now deeply embedded in subsequent health policy as policy makers and managers push for 'remote control' of future patients (Confederation, 2011). These models and policy impulses reframe interaction within healthcare settings, and we can express these through two further propositions.

4. Rule-boundedness redefines subjective autonomy – in both 'patients' and 'professionals' – with regulatory governance according to corporate objectives. These define limits of interactions between participants in the clinical encounter.

5. Regulatory governance replaces negotiable institutional asymmetries of power and knowledge between persons with non-negotiable, rationally structured, bureaucratic constraints. These define limits of interactions between participants within the organizational contexts of healthcare.

Just as rule bound systems discipline the patient's subjective narrative, they also break the link between individual professional authority and autonomy. Collective accountabilities arrive with systems that record professional actions and compare them with peer groups. In turn, these rely on taxonomies of measurable competencies rather than judgments of individual knowledge expertise. This forms the focus of another proposition.

6. Healthcare ICTs are media that do more than collate and distribute information because they have embedded within them political purposes as well as assumptions about use. These are shaped and reshaped in interaction with the corporate goals of organizations.

At the meso-level, we can build a strong picture of the way in which executive functions of different kinds thus effect the organization and direction of practice. We can also go on to explore the plasticity of institutional and organizational roles and practices, and their underlying political rationalities as they are enacted and acted upon.

The problem of differentiation

The field of digital delivery has always been marked out by practices of differentiation. The most obvious of these is the division between 'traditional' patterns of healthcare delivery that rely on traditional notions of *synchrony* (the interaction, in real-time, of health professionals and patients), and 'modernized' interactions organized around ideas about the desirability of *asynchrony* (where participants are separated in time and space). This basic difference has been celebrated in accounts that promised the arrival of a global clinic, in which professions could offer the best care without restriction across borders (Cartwright, 2000). In fact, there have been few such services, and borders – or rather the problems of licensure, reimbursement and accreditation that are contained within them – have continued to retard their utilization (Whitten and Mackert, 2005).

While the promised 'virtual gaze' (Sinha, 2000) of medicine has not extended globally, the distinction between synchronous presence in real time, and asynchronous distal relations out of it, have become more important as a new pattern of policy differentiation between (acute) medicine and (chronic) care has formed around the crises of healthcare spending. Chronic illness (Diabetes, Chronic Obstructive Pulmonary Disease, Chronic Heart Failure), and chronic vulnerability (physical frailty and cognitive impairment amongst older people), are formulated as key *policy* problems related to a new crisis in health care expenditure and delivery that required the reform of professional knowledge and practice, the modernization of services, and the reconfiguration of patients (Health, 2006). In this context, care and management of people with chronic illnesses, especially by nurses and professionals allied to medicine, has become a central interest of proponents of telemedicine and telecare (May, 2006). Key processes of differentiation are at work here: between

traditional and modern; global and local; acute and chronic; treatment and care. Related to this we see a shift in who is to do the work, moving from a small number of expensive physicians, to a larger number of nurses and para-professionals, to the population of chronic sick people. And as this process of linking technological change to the differentiation of professions and populations continues, then telecare applications, and other technological tools, can be linked to elements of 'self-care' and expert patient-hood that have become central to policy formation around the chronic sick (Gately et al., 2007, May et al., 2010).

Against the background of general differentiation and segmentation of populations, policies, and practices (Klecun-Dabrowska and Cornford, 2000), and the general shift towards seeing informatics applications as a core part of the management of health care services and their users (Mathar, 2010), the idea of telemedicine and telecare has become embedded in the rhetoric of policy about the 'future patient' and 'future services' in the NHS (Kendall, 2001, Finch et al., 2007). Here, standardizing patterns of governance and regulation across clinical contexts form a set of common constraints, experienced equally by all, and ultimately a common vocabulary of practice. The relationship between general practice information systems and the Quality Outcomes Framework in the UK suggests precisely such a process (McDonald et al., 2007). Epidemiological objectives have been transformed into standards of practice, then into components of a relational database (patient records), and finally into something approaching firm rules of practice implemented and enforced by local healthcare providers such as Primary Care Trusts in the UK or Health Maintenance Organizations in the US. Finally, they become the routine typifications of practice for the doctor's day. Rules for practice are intimately linked, therefore with contracts and service level agreements, job descriptions and performance targets. At the same time, systems of practice become steadily less amenable to reconfiguration. The subjectivity of the autonomous professional is steadily constrained by standardizing routines (Harrison, 2002, Kuhlmann and Burau, 2008). The systems of practice that have been the focus of interest in this paper are, of course, only a very small part of a transformation of the ways in which public corporations, relatively autonomous agencies of the State, and the State itself, interact with citizen consumers. In this context, discipline is the product of practices of differentiation, and this is crystalized in a seventh proposition.

7. The reconfigurations that are mediated through Healthcare ICTs are not bounded off from other social changes in relations between people and corporations, both public and private. They make politically determined patterns of eligibility and standing real at a population level.

Here, we can develop an understanding of their contribution of differentiation practices to economic organization and political co-ordination at a societal level. ICTs make possible *politically imagined* communities of clearly defined healthcare problems and processes – linked to processes of policy formation and implementation – but they do this by drawing down interpretive flexibility and personal autonomy.

How far away is the distal patient?

Thus far, this paper has considered the restructuring effects of technologies on the systems of practice employed in health services, and suggested some of the ways that these have affected the constitution of relations between citizens and services. They form vehicles for discipline, and their constituent technologies—the alternatives to face to face care, the electronic mediation of tasks within care, and relational databases and records within which patient's experiences and professional's practice are recorded as minimum data-sets—all involve the separation of actors in time and space. Organizational distances, breaks, and ruptures, are already routinely experienced in the delivery of healthcare, but the digital mediation of services equalizes them. So, political, technological, and organizational distances begin to appear in the modification of practices that are consequences of this technocratic vision for healthcare. The interactional work of the clinical encounter in such circumstances then becomes that of taking these distances for granted, and smoothing out their consequences. In these contexts, digital delivery is not the same as geospatial distance. Far from it. A caller working through a clinical algorithm is no less distal if they live next door to the call centre than if they live on the other side of the world. Digital delivery equalises distance because whatever geospatial distances lie between them, callers and call-handlers are always the same *social* distance from each other. In fact, processes of equalization - both spatial and temporal – appear precisely as rule-boundedness and distal relations are added to each other. A further proposition makes this clear.

8. Mechanisms for regulatory governance define the limits of interactions between participants within the policy contexts of healthcare. As they do so, they lead to expectations of greater prudence on the part of patients, evidenced by their willingness to minimize the load that they place on formal healthcare provision.

Prudence on the part of patients and professionals notwithstanding, whether these new equalities are desirable is another matter. Of course, contests and conflicts appear around them. Here, social distance and rule-boundedness become significant not just because these new technologies bring fluidity of practices, contingency of meanings, and instability of networks in their wake, but because they aim to operationalize the very opposite of these. Even as they reveal their own contingencies, they invoke the protective shell of bureaucracy (Gane, 1989). So, the distances invoked by technogovernance are not geospatial, but algorithmic. They are measured in the delegation and the transfer of work between classes of human and non-human actors. The distances that are invoked as their consequences are those of the transaction spaces between them. The increasing permeability of boundaries between home and healthcare, and the penetration of the domestic sphere by corporate impulses of surveillance and organization as healthcare (and other agencies) seek to define, possess authority over, manage, and organize aspects of behaviour and relationships in the public sphere. Here, the potential for efficiency savings within health services that is found in the transfer of illness management and its associated work from within formal healthcare organizations to informal settings – especially

the home – and from professionals to patients is central to these (Gately et al., 2008). The next proposition sets out the implications and significance of the use of digital media to secure the separation of patients from services in time and space.

9. Possible relationships between services and citizens become defined by the resourcefulness of the patient. This resourcefulness is made clear by the capacity to operationalize knowledge about health and healthcare and maximize the value of their interactions with existing patterns of service provision.

The journey of the distal patient, then, is along invisible pathways mapped by algorithms – between home and clinic, between decisions and outcomes, between practitioners and practices, and between times and places – and these algorithms discipline the real face-to-face encounters that patients and professionals by calling them to account for their decisions. They drive, too, a set of constitutional expectations of patients. Just as informaticization in the financial services sector means that we have all become our own account managers, in healthcare some kinds of work also get moved to the patient. The transfer of work and the *delegation* of responsibility from formal hierarchies and divisions of labour within healthcare organizations, to patients and their social networks (May et al., 2009). Rule-bounded mechanisms of digital delivery both assume and enforce the standardized differentiation of healthcare problems and segmentation of populations – for example in the ways that care pathways algorithms frame healthcare problems as self-care problems.

Citizens, services, and intensification

A core problem for health policy makers in the United Kingdom and elsewhere is to develop and implement new forms of healthcare that offer the potential efficiencies of digital delivery but do not sacrifice public expectations of high quality face to face interactions. The same is true of health services across the world. Although the UK's National Programme to develop a ubiquitous electronic health record for the National Health Service (NHS) has collapsed under the weight of a £20bn budget, other systems that mediate digital relationships between patients and healthcare providers have been widely implemented (Boddy et al., 2009). These have, and continue to be, unevenly distributed across policy time; the fragmentary organizational geography of the National Health Service; and the multiple actual and potential practical transaction spaces between citizens and services. Underpinning them are fundamental policy problems about defining who, or what, a *patient* is and what patients can reasonably expect from health services; about the configuration of professional knowledge and practice in the digital age; and about the complex institutional boundaries between clinical practice and customer services. In this context, the development of digital delivery links to some important underlying impulses that are driving 'demand' for innovation—both technological and organizational—in practice.

The intensification of activity within the formal spaces of healthcare organizations – as service providers seek to do more work, in less time, with fewer resources – and the increasing prominence of corporate regulation of previously autonomous professionals (Davies, 1995, Johnstone, 2005). In this context, regulatory governance replaces negotiable institutional asymmetries of power and knowledge between persons, with rationally structured constraints—for example in the ways that the presence of telecare affects the availability of out of hours services (May et al., 2010) and this leads to a final proposition.

10. Corporate impulses define the limits of interactions between participants in the clinical encounter, but in doing so they call for greater expertise from patients who now need to be in possession of the knowledge and skills for appraising management advice and self-management outcomes.

Similarly, a new body of work now appears in organizing participation in healthcare practices and this work stresses the *agentic* component of participation. I have already noted that the escalation of attempts to eliminate subjectivity from the organization of care and the operationalization of professional knowledge and practice (May et al., 2006) is accomplished through the substitution of algorithms for expertise, of protocols for autonomous practice, and of less qualified for more qualified staff (May, 2005). Digital delivery of healthcare is rule-bound in that it relies on mechanisms for technogovernance: structured decision-tools, protocols, algorithms, and relational databases. Finally, the transfer of work between professions and patients relies on the increasing *permeability* of boundaries between home and healthcare, and the penetration of the domestic sphere by corporate impulses of surveillance and organization (May, 2010). This can be characterized as uncompleted institutional projects that form the background for changes in the delivery of healthcare. Uncompleted as it is, it is nevertheless also very real for many of those who work in healthcare organizations and for those who experience healthcare.

Conclusion

Some of the earliest systematic sociological accounts of medical practice pointed to *affective neutrality* as a central component of professional identity, and they emphasized the value of impersonality and social distance in dealing with the complex personal crises that stem from disease and distress (Henderson, 1935, Parsons, 1951). Subsequently, the cultural shifts of the 1960s, and the rise of new kinds of clinical practice that have sought to interrogate and make plastic the subjectivity of patients have undermined the principle of affective neutrality. Instead, they have emphasized the extent to which health professionals ought themselves to engage their subjectivities (and emotions) empathetically (May, 1992). The rise of rule bounded and disciplining technologies may well have effected the transfer of affective neutrality from the person of the clinician to the system of practice in which they are embedded.

This paper has explored the role of healthcare ICTs in mediating and normalizing certain reconfigurations in socio-political relations in and beyond the clinic that stem from this transfer of affective neutrality. It has pointed to some general tendencies of impulses in the organization and delivery of healthcare in the advanced economies, and related these to problems of governmentality in neo-liberal economies of practice. These tendencies have included the intensification and escalation of healthcare work,

and its transfer and delegation across institutional boundaries, (between services and citizens, the clinic and the home) characterized by greatly increased permeability. Second, it has pointed to the ways that different ensembles of practices formed around technologies of digital delivery are able to mediate not only between citizens and services, but between different functional components of very large healthcare organizations like the United Kingdom's NHS or the Veteran's Administration in the United States. They offer these potentials – I have argued – because they replace spatial distances with algorithmic ones, and because they limit the discretion of participants by routinely incorporating patterns of rule-boundedness that structure narrative choices as well as action and its outcomes. These systems of practice thus represent rationalizing processes that have commercial analogues, most obviously those found in the financial services sector. Finally, it has pointed to the ways that the combination of new organizing impulses in healthcare and technologies of digital delivery have led to the patient being defined as a distal co-worker in the healthcare system. By such means patients and professionals are themselves rationalized. What *is* being normalized here is the steady contraction of personal authority and the standardization of practices. Personal autonomy is everywhere being reconfigured.

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