



Telemedicine and the 'Future Patient'? Risk, Governance and Innovation

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RESEARCH FINDINGS

KEY FINDINGS

Telemedicine is disappearing, being displaced by more routine telehealthcare and telecare applications

Innovation is risky in the new IT environment of the NHS, because of NPfIT.

Technological advances are being reframed as tools for effective management control over patients.

Risk

Key findings in relation to risk are that:

- Conceptualisations of risk have shifted from prevention (or avoidance) to *manageability*;
- The location of risk has shifted away from *clinical* risk to *social/organisational* risk;
- A perspective is emerging in which 'telemedicine' is seen as 'no different' to other clinical practices; and
- Risk has become diluted and more diffuse as new applications of technology have permitted greater flexibility in practice

Governance and Accountability

In relation to governance our key findings are:

- There exists no specific formal structure for governance in this context;
- Patients remain absent from decisions about service configuration; and
- Clinicians and managers believe that the shift of telemedicine away from 'innovative' practices to more routine care suggests that no special forms of governance or accountability are required. The citizen's panel disagreed.

RESEARCH TEAM

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Our study reveals that telemedicine as an innovation is 'disappearing', and that telehealthcare and telecare – and 'ehealth' – have almost completely displaced it. This configures a shift from *clinically focused innovation to organisational change* in service delivery. Equipment designers have followed this move, shifting from developmental 'hybrid' systems designed to mediate between the doctor and patient in specific clinical situations, to generic ICTs that can be widely distributed (telecare systems), while service developers have shifted attention to larger scale organisational changes in service delivery utilizing call centres (e.g. NHS Direct). In this study, clinical champions of telemedicine focused on it leading to change in service delivery, and downplayed the previously 'innovative' qualities of systems themselves. Consistent with this view, 'champions' of technology developments within the NHS are now often identified as senior managers seeking to control costs of chronic illness, rather than clinicians seeking to innovate around diagnosis and management.

Telemedicine and Risk

The perception and management of risk has been an important issue in the development of telemedicine. Archived data demonstrates significant concerns about the clinical safety and accuracy of telemedicine as a substitute for face-to-face medical consultation, and the potential medico-legal ramifications of using telemedicine. The concerted research and evaluation effort that accompanied early telemedicine development was itself a response to concern about risk. At the same time, the individuals' concern about the risk of using telemedicine impacted on whether specific developments were seen to 'work' and the extent to which they could be evaluated. 'Risk' at this time was very much constructed as 'clinical risk', and strategies

for managing risk were based in clinical service protocols. With the emergence of telehealthcare, telecare and ehealth, the concept of risk in relation to technologically mediated health care provision has become much more diffuse. Our research participants discussed an array of 'risks', including clinical (misdiagnosis); social/interpersonal (interactional); personal/professional (liability/role change); technical (failure); and organisational (poor integration). This highlights the multifaceted nature of risk in this context.

For telemedicine, clinical risk remains important but is viewed by those engaged in it as manageable in practice. An important theme in our data is that ideas about risk are framed in relation to the question 'what is different about telemedicine?' This reflected a view that medicine always involves risk and uncertainty and that the health professionals need to judge whether any system of practice technologically mediated or otherwise permits a sufficient clinical assessment of a patient. It also reflected concerns about potential organisational 'risks', such as security of data and confidentiality of records, issues that were often raised by respondents as potential risks but at the same time dismissed by them on the grounds that paper-based records and data storage procedures are equally (perhaps more so) prone to security lapses and loss of records.

Our study data indicates two key ways in which perceived risks are resolved through evaluation (or 'audit') of services, and by clinical judgement. Evaluation and audit are perceived as important conditions of the introduction of telehealthcare, as with any new service, though many feel that over-emphasis on formal approaches to research and evaluation by the medical community have impeded progress in telehealthcare

developments. Those using telehealthcare state that they are less concerned about clinical risk because clinical judgement emphasises caution. Likewise, professionals concerned about threats to interpersonal interaction posed by the telehealthcare system draw on their professional expertise to accommodate the perceived limitations of the technical system. It is important to emphasise that where telehealthcare systems are seen by their users to 'work', they are characterised as alternatives rather than substitutes for conventional services thus concerns about risk can be accommodated if the health care professional can choose between the use of telehealthcare and the traditional service. The value of this as a principle for telehealthcare development was identified independently by members of the Citizen's Panel.

Telemedicine, Governance and Accountability

Applied to health care, ICTs are increasingly enabling shifts in the form and scale of governance and accountability within the National Health Service. As developments have shifted from *telemedicine* towards *telehealthcare* and *ehealth*, different forms of governance have been evident.

As applications of ICT to health care provision in the NHS have moved away from telemedicine, new forms of governance have emerged. The use of ICTs is now being directed more towards systems of 'decision support' (for example, NHS Direct and many telecare applications) that draw on evidence-based medical knowledge to facilitate *consistency* of practice. In such systems, *collective knowledge* is emphasised over *individual experience*. Views about increased governance of practice in this way are likely to be mixed, however several interview respondents

report that it is seen in a positive light. For example, NHS Direct requires staff to demonstrate *accountability* by explicitly justifying professional judgements and decisions, and this can also be understood as protection in the event of allegations of negligence or malpractice.

The study also demonstrated that telehealthcare has important public implications, *yet wider accountability to citizens remains absent*. Telehealthcare and telecare are increasingly advocated as new ('modernised') forms of service *delivery*, but emphasis is on change in the *location* of services and the *mode* of accessing services, whilst the services themselves are presented as essentially the same. Although patients receiving telehealthcare services are often invited to comment about their experience (formally or otherwise), our data reveals an ongoing lack of consultation between the public and providers about the configuration of services. In many instances of telemedicine, telehealthcare and telecare, our interview respondents argue that such services are alternatives rather than replacement services and that patient choice is (or should be) retained.

Questions around accountability and telehealthcare are important, because although such services are reported to *increase* access to health care, they are also a means of *controlling* access for example, as a triaging device at the point of referral or initial contact. The majority of respondents also express the view that telehealthcare and ehealth, by shifting health care provision away from secondary care, is enabling more patients to 'self-manage' and take on greater responsibility for their healthcare. Although this shift is viewed positively (even as necessary) by many, others are sceptical about its desirability and workability.

Future patients?

Across the breadth of data collected for this study, several constructions of the patient are evident. The notion of the changing patient from a role traditionally characterised as passive to one ascribed labels such as 'informed', 'expert', 'self-managing', and as 'having responsibilities', pervades responses from interviewees and public speakers. This shapes local policy and managerial decision-making about how new technologies can be used to modernise health care. Telemedicine and telehealthcare are justified by the presumed preferences of patients for faster access to local services, and that offer greater 'choice' about modes of access. Telehealthcare is seen to offer ways to achieve these priorities, and on this basis is presumed to be welcomed by patients and citizens. In a keynote address, one of telehealthcare's policy champions (32) drew these preferences and solutions together to present an account of 'modern' telemedicine as 'patient-centric'. However, telemedicine and telehealthcare have implications for patients, and for their relationships with health professionals and the NHS, that go beyond issues of access, and the trade-offs that patients are willing to make against various aspects of health care services are assumed rather than known. Data provided by the Citizen's Panel (33) conducted for this study illustrates the complexity of the preferences and values that citizens hold for the ways in which services are developed and delivered.

About the Project

Telemedicine and Telehealthcare are systems of clinical practice that seek to

deliver health care across time and space by using information and communications technologies. The project has examined the following three key questions: (i) How is telemedicine constructed and enacted as an innovative health technology? (ii) How is telemedicine constituted as a field where risk is experienced and resolved? (iii) How is telemedicine organised in relation to ideas about governance and accountability? Using a combination of interviews, observation and the analysis of archived data, we sought to understand how these systems of clinical practice were being deployed in the NHS, and how they were framed across policy and practice networks. We found that electronically mediated doctor-patient interactions around diagnosis and management were disappearing and being replaced by patterns of remote monitoring suitable for chronic disease management. Importantly, service users of different kinds play little part in defining and developing these new services, and patterns of accountability are organised in relation to notions of improving management control over services. Our significant achievements are twofold. First, we have developed a model of health technology normalisation that is demonstrably useful to non-academic users and which can be applied more widely than telemedicine systems. Second, we have developed a strong theoretical analysis within the social sciences that frames telemedicine in ways that let us understand better how it is developed and modified in practice to deliver locally useful services. A key policy recommendation from our work, however, is that it is important to find more effective ways to include service users in decision-making about the shape and direction of new services.

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