

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

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### SUMMARY OF FINAL REPORT

Telemedicine systems offer clinicians a means to interact remotely with patients in real time, or to review and evaluate patients (often using digital images or digitised vital signs data) asynchronously. In our previous work, we had explored the local development, implementation and evaluation of telemedicine systems in NHS settings. We were struck by the strong claims made about the *promise* of telemedicine as a field of new technological developments supported by policy; active clinical champions; and through a very large technical and clinical evaluation literature. These different bodies of discourse stand in contrast with the apparent failure of most of these systems to enter clinical practice and service delivery in any routine way. Our approach to this study stemmed from the recognition that questions about why telemedicine systems 'work' or 'fail' had become tightly focused on the specific qualities of particular services and systems. The complex networks between policy and practice that we saw emerging around telemedicine when this study began in 2002 have become more complex and diffuse as the study has continued. Our starting point in this study was that previous research had elided questions about the links between these services and their points of public and private accountability, and about the reconfiguration of patient-hood that they seem to promise. The study was therefore informed by three questions.

**(i) How is telemedicine constructed and enacted as an innovative health technology?** How do different constituencies of actors within policy/practice networks define and understand telemedicine as an 'innovation'? How do their interventions shape not only the production, but also the *experience* of health care?

**(ii) How is telemedicine constituted as a field where risk is experienced and resolved?** How are the risks that attend this new technology defined and understood? How are these risks managed and resolved? How do patients, and users' groups conceptualise and respond to potential risks in using these systems?

**(iii) How is telemedicine organised in relation to ideas about governance and accountability?** As clinical expertise becomes dispersed, what implications does this have for assuring quality and accountability? How does the development of telemedicine shape ideas about what patients *are* and what services should be provided for them?

**Methods:** This was a qualitative study. We primarily used semi-structured interviews and observation to collect data. Respondents for the study were selected on the basis of known experience in telemedicine (as policy makers, clinicians, NHS managers, and as representatives of industry) or patient advocacy. We supplemented data collection through interview and observation in three ways. First, we utilised a large body of data collected in our earlier work. Second, we used a web-based questionnaire based on our interview schedule to identify further respondents for the study, and to collect additional free text data from a wider community of practitioners and managers. For NHS staff providing contact details for interview, formal approval was first obtained by the employing NHS Trust. Thirdly, as it became apparent during the life of the project that local and national service providers were doing little to engage people from outside of a narrow clinical and managerial community in thinking about telemedicine and its configuration of patient-hood, we used a Citizens' Panel to explore the views of patients' advocates and carers. Interviews and panel meetings were audio-recorded and transcribed. Anonymised transcripts were used as formal data for analysis. This was conducted independently using QSR NVivo to support coding and interpretation of the data, and collectively in 'data clinics' where we met to develop further analyses.

Across the terrain of our study we found that 'telemedicine' as it has been conventionally understood by its clinical and policy champions is *disappearing*. Electronically mediated doctor-patient

interactions, are being rapidly displaced by applications that involve a wider range of staff (mainly nurses) utilising systems explicitly intended to manage the routine trajectories of chronic diseases. Diagnostic services in dermatology have tended to provide advice between clinicians and to cope with a low volume of patients. The exception to this was a private sector supplier, which has recently gone into liquidation. The ‘disappearance’ of telemedicine stems from several factors. In the last decade, the struggle for its champions has been to try to channel longstanding policy commitments to modernising informatics into resources for specific telemedicine services. Telemedicine’s champions have therefore sought to co-opt and harness a discourse of more effective *management control* over health care delivery.

## **Innovation**

Our key findings around innovation are that:

- 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.

## **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. 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 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.

## Publications from the study

In addition to contemporaneous data collection, this study has drawn on archived data collected in previous projects. Where publications 'share' data with these studies we have indicated this with an asterisk.

1. May C, Mort M, Mair FS, Williams TL. 'Factors affecting the adoption of telehealthcare in the United Kingdom: the policy context and the problem of evidence. *Health Informatics Journal*. 2002; 7(3/4):131-134.\*
2. May C, Mort M, Williams T, Mair FS, Gask L. Health technology assessment in its local contexts: studies of telehealthcare. *Social Science and Medicine*. 2003; 57: 697-710 \*
3. May C, Harrison R, Macfarlane A, Williams, T, Mair FS, Wallace P. Why do telemedicine systems fail to normalise as stable models of service delivery? *Journal of Telemedicine and Telecare*. 2003;9(1):25-26.\*
4. May C, Harrison R, Finch T, Macfarlane A, Mair FS, Wallace P. Understanding the normalization of telemedicine services through qualitative evaluation. *Journal of the American Medical Informatics Association*. 2003; 10(6): 596-604\*
5. Finch, T, May C, Mair FS, Mort M, Gask L. Integrating service development with evaluation in telehealthcare: an ethnographic study. *British Medical Journal*. 2003; 327 (7425): 1205-1208\*.
6. Mort M, May C, Finch T, Mair FS. Telemedicine and clinical governance: controlling technology, containing knowledge. In Gray A & Harrison S (Eds). *Governing Medicine: Theory and Practice*. Buckingham, Open University Press (2004)\*
7. May C, Mort M, Finch T, Mair FS. The anatomy of failure? Teledermatology in an English city. In: Whitten PS, Cook D. eds. *Understanding Health Communications Technologies: A Case Study Approach* San Francisco, Jossey-Bass Inc (2004).
8. Finch T, Mort M, May C, Mair FS. Telehealthcare: perspectives on the changing role of patients and citizens. *Journal of Telemedicine and Telecare* (in press)
9. Mort M, Finch T. Generating principles for telehealthcare: a citizens' panel perspective. *Journal of Telemedicine and Telecare* (in press)
10. May C, Finch T, Mair FS, Mort M. Towards the wireless patient: chronic illness, scarce care, and technological innovation in the NHS. *Soc Sci Med* 2005. In press.