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Making and unmaking telepatients: identity and governance in new health technologies

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The emergence of the field of healthcare-at-a-distance or ‘telehealth’ has been embedded within discourses of high ambition, about health improvement, seamless services, empowerment and independence for patients. In this paper we examine how telehealthcare technologies assume certain forms of patient – or ‘telepatients’ – who can be mobilised and combined with images and artefacts which speak for them in the clinical encounter. Second we make a tentative intervention in these emerging identities in the form of facilitating some alternative discourses around telehealthcare. Our aim is to stimulate debate by presenting and contrasting these different approaches to technology development. Such differences take material and discursive shape in the making and unmaking of telepatients, showing, we argue, important interferences in the shaping of identity and possibilities for governance and participation.

**Keywords:** identity, interference, innovation, governance, patients
Introduction: constructing telehealthcare

In a series of recent policy pronouncements and technological rhetorics we can see how information technology has been placed at the centre of a looked for transformation in healthcare. ‘eHealth’ as it is sometimes called, imagines a global seamless future, yet a future at risk from current failings, asymmetries and interruptions:

Healthcare is the world’s largest industry, accounting for some three trillion US dollars annually….yet this vast and essential industry is plagued by gross inefficiencies, inequities and quality variations. Many of these are directly attributable to poor information flow. (Gorm Kirsch, Vice President, MacQuarie Technology Investment Banking, 2001)

Over almost two decades, health technology policy in Britain has reflected a conflation of medicine with information, and information with modernisation (Dept of Health, 1997; NHS Executive 1998; Dept of Health 2000). This conflation can be seen in assumptions that improvements to the flow of information will unproblematically lead to improvements in patient care within a highly ambitious programme of change:

(The NHS will) create a multi-billion pound information infrastructure, which will improve patient care by increasing the efficiency and effectiveness of clinicians and other NHS staff….creating an electronic highway….a major step towards providing seamless care for patients….provide public access to information and care through online information services and telemedicine…. For all this to happen, major coordinated investment and change must take place……..The process of connecting the delivery of the NHS Plan and the modernisation of services to the information strategy subsequently began… (NHS Information Authority, 2004)

Some have described this conflation as part of a wider ‘informatisation’ of medicine (Webster 2002; Nettleton 2004,) or as ‘technogovernance’ (May et al. 2005b). There is arguably a tension between medicine and information, engendered by the ways in which eHealth and telemedicine services have been framed in just these terms: as flow, transmission, mobility. Patients and clinicians can be mobilised; conditions and skills digitally combined. But this cannot be achieved without ‘major co-ordinated investment and change’. The investment part of this can be seen in the huge English National
Programme for IT, later renamed Connecting for Health, where costs have escalated to £12.4bn and which is claimed to be the ‘largest non military IT project attempted in the world’ (Bowers 2007). The programme involves no less than the creation of a new identity for the English National Health Service in which actors’ roles will also change: ‘patients’ will receive ‘seamless care’ from ‘clinicians and other NHS staff’ whose efficiency and effectiveness will be increased by means of ‘modernisation of services’.

We examine ways in which some of these identities are being proffered and inscribed in the development of particular ICT base telehealthcare systems. We undertake this task in a policy and practice environment where technological innovation continues to be viewed largely uncritically (Edgerton 2006), and like other writers interested in the sociology and social history of technology we wish to ‘problematise innovation as a critical project’ as Suchman & Bishop (2000) have put it. Our starting point from Science and Technology Studies is a view of technologies as cultural products that make social relations visible, and that they shape and are shaped by those relations. To this end, we explore ways that identities promoted for patients discursively and materially interact with patterns of governance, and also with notions of involvement and engagement. If discourses about health technologies assume and frame certain roles for patients, undertake particular kinds of enrolment, we draw from actor network studies linking ideas about technological scripting (Akrich 1992) with developments in social psychology about the sociomaterial framing of identity. This leads us to ask in what ways do telehealthcare technologies both construct identities and privilege certain kinds of citizenship and societal participation (Shotter & Gergen 1989; Rose 1989; Rose & Miller 1992; Michael 1996)? Ostensibly telehealthcare and telemedicine are technologies of deinstituionalisation in that they permit clinical and care encounters away from the traditional settings of hospital or clinic into more diffuse and unpredictable spaces such as the street or the home. It has been argued that e.g. community mental health care and call centre based homecare for older people are exitutional technologies, in that they seek to control (rather than actively discipline) patients and users (Domenech & Tirado 1997; Domenech et al 2006; Tirado & Domenech 2001; Lopez 2006) in these kinds of contexts which are processes and programmes rather than buildings or enclosures. Considering examples of telehealthcare technologies in development and practice, we want to ask
what are the possibilities for intervention in these sociotechnical reshapings of the care encounter, such that their design, implementation and governance might be opened up?

First in this paper we explore prominent identities promoted for patients in the policy and practice discourse. Initiatives such as eHealth and telehealthcare are said to promote the goal of ‘patient centred care’ (NHSIA 2004) but we ask whether as currently figured, they may act as other ‘innovations’ have done, more to recreate existing (conservative) power relations (Suchman 2000). Second, we consider roles and identities which may be said to be inscribed in particular forms of telehealthcare. Thirdly we consider the relationship between identity and governance in the shaping of telemedicine and telecare. Telehealthcare may facilitate meetings between professionals but in so doing, do these systems also end up leaving patients ‘out of the loop’? If so how can patients re-emerge into the consultation in any meaningful way? As certain roles are inscribed and prescribed for patients, so the opportunities for opening up the governance of this sociotechnical reshaping of healthcare provision, are we argue, constricted. Here, we go on to consider how involving groups of citizens in the design, development and evaluation of new care technologies might start to offer different identities, roles and consequently, effect more indigenous forms of telehealthcare networks.

This paper draws on a series of studies which have run continuously since 1998 and which have examined the development, implementation, evaluation and experience of telemedicine systems in a range of clinical settings in the UK. They have ranged across a number of applications including internal medicine, psychiatry and dermatology (Finch et al. 2003, Finch et al. 2005, May et al. 2001, May et al. 2003a, May et al. 2003b, Mort et al. 2003, May et al. 2005a). These studies have generated a mass of ethnographic, interview, and other data – derived from several hundred data collection episodes - we draw on this material extensively in this paper. Taken together, these studies represent data collected in the form of interviews (123), web responses (39), and observation of public meetings (13) that represent the views and experiences of a range of stakeholders including policy makers, academic researchers, health professionals (general practitioners, nurses, consultants), administrators, technology developers/IT technicians, and patient advocates. These respondents were drawn from a diverse range of applications in telehealthcare including dermatology; minor injuries; telecare and
telemonitoring; NHS Direct; cancer services; mental health; diabetic services; community care and general medicine. Interviews were conducted either in person or over the telephone, and were audio-recorded with participants’ consent and transcribed.

However, the utility of this data for developing our arguments about identity and governance are limited because they are focused so intensively on clinical settings. A wider analysis of citizens’ views on what and how services should be provided is also needed. To begin to address this shortcoming, we conducted a specific sub-study, which took the form of a pilot citizens’ panel (10 participants). Participants were shown specific examples from tele-dermatology, tele-cardiology and tele-diabetes, using developers’ web links and video footage of telecare in action with clinicians and patients (the interactions showed were inevitably somewhat stylised for the camera and promotion of the system). A facilitated discussion ensued from which participants then developed a set of principles for the development of telehealthcare services.

Inscribing Patients

The practice of medicine assumes the existence of patients - and each form of practice assumes a certain form of patient. Patients are defined as those whose assessed needs fall into certain categories and whose bodies (or minds) can be expected (or sometimes coerced) to be present at particular times in particular settings. New medical technologies engender new forms of patient and have the potential to transform the ‘medical repertoire’, to re-define health, medicine and the body (Webster 2002). However, defining the ‘patient’ has long been at the centre of ideological and economic contests in state funded healthcare systems. The marketisation of healthcare during the 1980s in the UK led to an uneasy settlement of citizen-as-consumer, one whose responsibilities for self-care are emphasised alongside accompanying rights. In both cases however, the shift in patienthood – from a role traditionally characterised as passive, to one ascribed active identities such as ‘informed’, ‘expert’, ‘self-managing’, and as ‘having responsibilities’, pervades official discourse and also responses from a range of informants in our work – the ‘resourceful’ or ‘future’ patient (Coulter 2001, Kendall
2001) who can be wirelessly linked to services (May et al. 2005a) and who is understood to have a greater role in their care:

…..new home monitoring and diagnostic equipment and telemedicine could all increase the potential for patients to take on more responsibility for their healthcare in future years. Yet the benefits from these developments will be lost if patients are unwilling or unable to take on a greater role. (Kendall 2001:56)

The ‘greater role’ here is exemplified in a report, The Future Patient, from the UK Institute for Public Policy Research ‘centre-left think tank’. It implies a form of patient who assumes active participation in their health and medical care. Yet this projection is at odds with what we found in our studies, for example in the process of setting up home monitoring where the user is not configured as the patient, but configured as the clinician, (often a nurse delegated by doctors), who operates the system. Rather than assuming a greater role, the patients (in the case above frail elderly) are cast very much as passive players being monitored, yet with the ostensibly enhanced autonomy of being ‘at home’.

Policy discourse reveals multiple and often contradictory conceptualisations of ‘the patient’ in projections about the potential of telehealthcare. Early telemedicine projects included developments in the specialities of dermatology, cardiology, radiology and psychiatry. While there are many interesting sociotechnical specificities within each, one commonality we find lies in the assumption of passive patient roles. Our studies showed how patients have been ‘silent’ in design and development of systems, in the production of knowledge about their effectiveness and in policy development about telehealthcare services. Because of this silence, we attempted an intervention which might ‘indigenise’ telehealthcare, extending our work to construct a deliberative citizen’s panel, inviting participants to construct their own principles to underpin developments. Not surprisingly, the interests of patients and their informal carers, issues about equity of access, and preserving the option to ‘see’ the doctor face to face, figured prominently in the panel's principles.

We first turn to examining specific ways in which identities get configured for patients, through both the design of particular telehealthcare systems and through their evaluation. In telemedicine, patients are represented and mobilised through different
telemedical specialties and systems of observation; particular types and forms of knowledge/data patient come to speak for the patient. Some examples of these representations from teleradiology, teledermatology, telecardiology and telepsychiatry are described in the table below. This table is however an heuristic, a particular way of representing human entanglement with technology, used here as a way of opening an avenue of investigation.
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<tr>
<th><strong>Teleradiology</strong>: The patient is represented by an image of the interior</th>
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<td>Digitally formed images reprocessed as email attachments in concert with other clinical data. Asynchronous (extended dyadic) communication between clinical specialists permits distributed expertise (e.g. between local physicians and tertiary experts) for remote diagnosis and clinical discussion.</td>
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<th><strong>Teledermatology</strong>: The patient represented by a fragment of a map of the surface</th>
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<tr>
<td>Digitally formed images of cutaneous lesions, transmitted as email attachments with other clinical data. Asynchronous (extended triadic) communication between patient and dermatologist, nurse or medical photographer acts as a proxy to permit remote diagnosis and management.</td>
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<th><strong>Telecardiology</strong>: The patient represented by a set of graphs and a sound in the distance</th>
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<tr>
<td>Vital signs e.g. BP, pulse, temp and echocardiograph transmitted as real time data with textual and other clinical material and parallel conversation using web or telecast. Synchronous (concurrent triadic) communication between patient, local clinician and remote expert. Local clinician undertakes physical examination, to facilitate diagnostic and management.</td>
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<th><strong>Telepsychiatry</strong>: The patient is apparent yet disembodied</th>
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<tr>
<td>Psychiatric interview undertaken in real time using videophone or web cam. Synchronous (concurrent dyadic) communication between patient and clinician for diagnosis or management.</td>
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**Representations of the patient in Telehealthcare**
Patients are configured (or reconfigured) at different levels, through the design and use of telehealth systems, and the practices that these technologies assume. For example, the introduction of telecare monitoring technologies in patients’ homes assumes a form of patient who is frail (or if they suffer from dementia, may be restless or wandering), and who requires greater physical surveillance than was previously necessary; but also who can be discharged earlier from hospital. In teledermatology, where a consultant may diagnose on the basis of digital images and an online history (rather than consulting face to face) a form of patient is assumed in which the visual image is privileged and personal accounts of symptoms and experiences are relegated in the gathering of evidence. Here, the (tele) image-plus-online-history package appeared to tell the structuring narrative, to speak for the patient in this context; except that, as we have discussed elsewhere, in practice it doesn’t entirelyii.

The user’s relationship with the machine is a configured one (Woolgar 1991). Classic studies in STS reveal ways in which assumptions about users are built into the design of technologies in ways that afford particular kinds of agency, e.g. Prout’s 1996 work on the Metered Dose Inhaler (1996); Bates on the External Fixator in orthopaedics (2002). However, in the case of telemedicine/healthcare, the users of these remote and real-time systems are largely seen to be healthcare professionals; here user does not mean service user. In a system designed to gather remote diagnosis using store-and-forward technology as in teledermatology, the patient is collapsed into a visual image and an online proforma history. The camera operator and online history taker is typically a nurse, and the conditions of use which get worried about, such as lighting, image quality, manoeuvrability, transferability can be adjusted with very little reference to the patient. In the case of homecare tele-monitoring (often in real time), a spectrum from passive to active patient is observed within the definition of goals and design/re-design of systems. But critically, the user is the nurse or medical team at the hospital, watching the patient, at home.

We observe then that the identities for patients (and indeed professional users) get inscribed in the design process of systems of telehealthcare. The concept of inscription/scripting, elaborated by Rose (1989) and Akrich (1992), is helpful in the analysis of the design and practice of e.g. teledermatology, where the visual image and
pro-forma re-construction of the patient had to be accommodated and manipulated by intermediaries in order that some kind of ‘workability’ be achieved (Mort et al 2003). Rose’s reflections on the development of systems of translation of human subjectivity into calculable and transferable forms offers insights here. He calls these systems ‘techniques for the disciplining of human difference’ where people ‘are gathered together en masse, but by this very fact they may be observed as entities both similar to and different from one another’...through a ‘regime of visibility......’. While Rose is discussing the development of intelligence tests, his comments have relevance for tele-patients in that ‘traces’ must be created which can be worked on and must ‘...be neither too large or too tiny, but of proportions that can be rapidly scanned, read and recalled.’ Constructing such systems or schema is part of a dual process of objectifying and subjectifying (and governing) individuals, characteristic of modernity. It is not that these systems crush subjectivity, but that they act to produce it, to shape it.

Scripting within the design process also figures prominently in the study of ‘Babywatch’ by Oudshoorn et al (2005). The authors unravel the development of a video-communication system that enables parents of premature babies to visit virtually the neonatology ward of a hospital to watch their baby. The researchers observe the asymmetrical distribution and redistribution of agency within the development stages of this technology, uncovering the political and theoretical importance of those actors silenced downstream of technological developments. A key feature of this work is to track and trace who and where are the users of these technologies – showing empirically how close or how far the configured user is from where the patient is, in any stage of the development (often they are very far apart). This tracing offers us a tool in making occluded patients and their carers visible.

In telehealthcare, the political implications of technology and system design are frequently overlooked or misunderstood by the developers of such systems (Lehoux & Blume, 2000). If the user is assumed to be a healthcare professional, then professionals’ ways of working and operational needs will figure uppermost in design practice. How both user and patient are configured/reconfigured can be traced by following the many design changes apparent when actors try to slot technical systems into clinical trials or
service pilot projects. Such changes are often accompanied by shifts in agency and responsibility:

…. the equipment that the nurses have used to date (pilot project) is going to be different from the equipment they’re going to use in the (clinical) trial. Because one of the things that we noticed for the pilot, we used just plain video phones and the patients had none of the peripheral attachments, they had like a blood pressure monitoring device. So they had all these other contraptions and they just did it themselves and told the nurse ‘my pulse reading is this’, and what we’re (now) getting is equipment that can do that and send it down the line automatically to the nurse. So it will be much more advanced and they haven’t actually had experience of using it, they’ve been using quite primitive equipment and the picture quality of the thing we’ve got is not very good. (Clinician/academic researcher)

Here the automation of the transmission of vital signs is a feature of the ‘more advanced’ equipment which has been developed in the short time between a pilot telemedicine project and the full-blown research trial. That automation carries a reconfiguration in which patient agency and control are downsized. Here, automation of another function was rejected:

The other funny thing that they were talking about was whether when you set the system up so that after the fourth ring everything comes on, an automated reply. But then they were thinking, ‘what if patients have just got out of the bath or something, and automatically the thing comes on!’ So they decided not to have that automatic.

Interviewer: Was the idea behind that (automation) that it would make it easier for the patient?

Yeah, yeah. But then they thought what if they were in a compromising position and all of a sudden the phone goes and the television comes on…(Researcher involved in telemedicine trial)

But it’s important to recognise that agency and control can be seen in different ways and might shift in use. Below, a nurse describes the telecare project as something which is about ‘managing patients’ but which also might help determine the nature of agency which patients might want to assume:

I think the purpose of the project will hopefully ultimately answer the question as to what is the best way of managing patients with a diagnosis of heart failure ………. is it that they need some assistance with helping to manage their disease in the community, such as taking their own blood pressure, measuring their weight daily, so that they can also perhaps be more involved in their care as well, so that I think the ultimate answer is to try and find and answer to that. (Research nurse)
Inscribing patients through the production of evaluative knowledge

Research in telehealthcare also plays an important role in configuring patients, for identities are assumed in the ways in which telehealthcare systems have been evaluated and in how research findings are used in service development decisions. Despite some evidence of increasing patient involvement through organised participation, engagement in the process of knowledge production is completely absent in the case of telehealthcare, where patients have been largely ghettoised within the legitimising device of the Patient Satisfaction Survey. In the proliferating literature on patient satisfaction, clinical and managerial proponents of telehealthcare systems have stressed that patients are supportive of telemedicine. However, systematic reviews (Mair & Whitten 2000; Roine et al. 2001; Whitten et al. 2002 and Williams et al. 2002) have demonstrated the limits of this literature, pointing to the poor methodological quality of many studies. Harsher critics challenge the very concept of patient satisfaction on the basis that patients have been largely excluded from the process of concept formation, and have potentially been misrepresented by it (Williams 1994; Fitzpatrick & Hopkins 1983) and that patients’ views of clinical practice in telemedicine suggest these are highly context dependent (Williams et al. 2001). Both telemedicine systems and the highly structured forms of evaluation applied to them may be construed as intervening technologies. Both act to specify and construct particular versions of adequate knowledge.

So how are patients reconfigured through the process of telehealthcare evaluation? In the context of Evidence-based Medicine (EBM) telemedicine has been seen as changed medical practice, no different from any other new medical practice or health technology and must therefore be subject to rigorous evaluation. The need for evidence was particularly problematic for telemedicine development; critics of telehealthcare research pointed to an overemphasis on evaluating hardware, and to an uncritical assumption that if telehealthcare systems could be shown to be 'safe' they would therefore be beneficial to patients. This provided an agenda for evidence production that prioritised certain types of knowledge and set up criteria against which
methods of producing this were judged. Therefore, the production of a defensible evidence base that supported the further development and implementation of telehealthcare could be viewed as an activity not only scientific and technical, but also political (Harrison, 1999).

Prioritising particular forms of knowledge and expertise over others served to marginalize actors not adequately represented in the preferred knowledge production framework. Research protocols then assign abstract identities to actors, eliminating their specific identity and reifying them as objects of externally imposed procedures. Professionals and patients are both reconstituted in these procedures: for the normative resources of knowledge production in evaluation are quite different from those typically applied in clinical practice. Patient identities are also assumed in the types of ‘evidence’ produced, and which are subsequently taken to represent the patient.

So the process of constructing a study design and identifying questions and research objectives is based on assumptions about what counts as valuable knowledge. Here a consultant researcher is asked whether they were examining how the telemedicine service might affect patients:

I don’t think so, no I think we’re looking at how quick the management of patients can be achieved. We have to assume that if we can make the right decision either with the best information, the best images then the patient is [going to be happy].

(Oncology Consultant)

This absence of patients from knowledge production is not specific to telehealthcare research. However, the possible implications of this exclusion are paramount, since telehealth systems have the potential radically to alter service provision in ways that directly affect the patient, e.g. by removing the opportunity for face-to-face consultation with the specialist. The absence of the patient from the process of producing knowledge about the patient who receives telehealthcare, at least restricts the possibility of achieving workability in practice (arguably at most it runs the risk of being viewed as unethical) and legitimacy in policy.

Where new systems are being evaluated, the patient ‘appears’ in multiple roles. From the clinical perspective, they are still ‘patients’, but in the research study context they also become ‘research subjects’. Those involved in operating and evaluating systems
take various positions on how patients are perceived, ranging from ‘guinea pigs’ to being ‘obliging’ in the spirit of medical research:

[the patients] are aware it’s a pilot project that we’re doing and that they’re helping with research and I suspect that’s why they don’t mind going to the teledermatology clinic because they see it being helpful. (Manager of nursing team, teledermatology)

From the perspective of the randomised clinical trial, it is quite possible for some patients to be ‘good research subjects’ or ‘bad research subjects’.

I think it does work a little bit the other way round, they are looking for people who might be quite good in it, because I have overheard once a comment ‘he’d be good for the trial’, if they think somebody is quite good and would be quite keen, 'let's do this patient', so this is an interesting learning point that we need to get past fairly quickly (Consultant specialist attached to telecare trial).

In another study, an appointments manager recounts a series of ‘types’ of patients (of particular ages, and with particular problems) that turned out to be inappropriate for a telemedicine services such that:

[…] by the time you’ve finished the process of elimination there’s only a small percentage left. (Appointments manager - teledermatology)

The ‘telepatient’ therefore reflects only a small proportion of patients who attend for diagnosis and treatment of any given health problem. These evaluations are intended to produce knowledge about the effectiveness of new telehealth systems, but who is the patient about whom this knowledge is being produced? The knowledge produced is limited not least by the restricted view of the patient on which it is based. This creates a problem for researchers themselves, as they struggle to interpret their research findings in light of the question, ‘Who is the patient?’

[…] from my mind it raises a very big issue of whether the studies, including ours, are in any way representative of what would happen in real life any way. If somebody said the service is going to be telemedicine you don’t have the option of using it or not as a GP, it’s just part of the service that has to be used for certain types of patients then you’d have different GPs using it who are obviously less enthusiastic than the ones we are recruiting from and they’d be recruiting doubtless different sorts of patients because I suspect there are all sorts of biases going on. (Clinical Academic – teledermatology)
So in summary, particular technological forms afford spatial and temporal mobilisation of the patient identities and particular forms of evaluation afford particular versions of knowledge about the patient. In drawing on the concept of affordances as explored by Hutchby (2001), we offer neither a deterministic view of these technologies nor a wholly interpretivist one; more simply we seek to make ascribing and inscribing processes visible in a field of practice where they are largely occluded. Telehealthcare assumes that at some point patients will take on particular roles and functions with varying degrees of agency. So it's not that telehealthcare makes patients redundant; more that their agency is distanced and mediated; they are distant agents or ‘absent intermediaries’.iv

**Governance and telepatients**

We have shown how the identities of patients get inscribed in policy, practice and research about telehealthcare. Patients get surveyed, the limitations of which we have discussed elsewhere (Williams et al 2002), and a small amount of undeliberative research has been carried out with consumers (Turner et al 2001). But citizens (who may or may not be patients) remain absent from debates about how this new field of telehealthcare is shaped and implemented. To involve citizens implies an explicit association with governance, and by implication, politics. This is an association which is not made by proponents of telecare technologies. We argue this lack of association has come about for two main reasons. First, is the point made above, that the users of telehealthcare technologies are almost exclusively configured as health professionals. Patients are seen as users of the service, not its technical systems or platforms or intervention vehicles. Second, that technological development is often wrongly considered to be a neutral, value free process which takes place apart from normative or political influence and therefore is not a matter for social investigation (MacKenzie & Wacjman 1999). This disassociation with the ‘social’ (class, gender, race, affect) coupled with the rather esoteric and elite
nature of many telehealthcare systems, contributes to this ‘black-boxing’ of telehealthcare.

However, in a distinctive intervention in this field, the General Medical Council President, Graeme Catto called for a ‘public debate’ around telemedicine and telehealthcare to ensure that decisions about development and implementation could be made with the support of citizens. He did this in his keynote address at the annual Royal Society of Medicine telehealthcare conference ‘TeleMed ’03’ in London. When questioned from the floor (by us) about how this could be done, he proposed meetings or assemblies where the public might debate emerging issues and concerns about new care technologies. Catto was, highly unusually for this kind of forum, advocating for a politics of telehealthcare, an acknowledgement that developments in this field might lack legitimacy if they ignored the public, or citizen, perspective. We therefore undertook to find a way to pilot Catto’s idea, convening a panel of citizens to debate and offer direction for the development of telehealthcare. We believe this is the only such forum to have taken place in this field, and that the findings show how a future series of informed debates held regionally would provide important insights and guidance for both practitioners, developers and policymakers. The panel’s deliberations show, we argue, that far from being an esoteric and elite domain, telehealthcare development is infused with social relations, and illustrates the intimate relationship between identity and governance.

The participants of the citizen panel were not configured here as patients, or as individuals with a particular experience of or interest in telehealthcare, but as lay policy actors. After a brief introduction to the concept of telehealthcare and demonstration of some available examples, we considered five pre-circulated questions:

1. **What do you think about moving to new systems of practice for receiving health care at a distance using:**
   a. Remote monitoring of a patient’s clinical condition/data, such as blood pressure, or blood sugar (e.g. diabetic patients)?
   b. When expert opinion/diagnosis is made from a store and forwarded image of a patient supplemented by online clinical history?
   c. Video-based consultations?
   d. Telephone-based advice services or consultations?
2. **What benefits and risks do you think telehealthcare poses for:**
   a. Patients?
   b. Carers?
   c. Healthcare providers?

3. **Are there certain circumstances in which telehealthcare is particularly appropriate? (or inappropriate?)**

4. **Are there certain locations in which telehealthcare is particularly appropriate? (or inappropriate?)**

5. **What principles would you wish to see underpinning telehealthcare developments?**

Participants moved quickly beyond the specificities and technicalities of particular forms of telehealthcare to questioning assumptions underlying these developments and discussing their possible effects and outcomes for patients, carers and for public policy. They were particularly interested in the contexts in which telemedicine would be practiced and in possible exclusionary and inclusionary practices which might (re)occur. Interestingly they did not call for more trial based research to address these issues, opting rather for human-centred design approaches with continuous evaluation and feedback, which they called ‘design flexibility’. Below are some of the themes we have drawn out from the debate.

a) **Hybridity**

CPP2: Are we not looking at this sort of, all or nothing, y’know it’s a case of yes, we use this at times and this sort of system, telemedicine, … but I mean it cannot take the place of the personal, the face to face consultation or treatment or whatever … it’s a bit of both. You could never, it could never take the place of that…..personal interaction.

This participant, speaking at the opening of the discussion, is concerned to question any notion that telecare might be ‘all or nothing’. She advocates for a situated, contextual approach and emphasises that a form of telemedicine where patient and doctor do not meet is qualitatively different from co-located practice. We might say that she wants to
see telemedicine as something hybrid, heterogeneous, ‘a bit of both’. Interestingly this kind of language: ‘all or nothing’; ‘bit of both’ and the call for hybridity it implies, is not a feature of ‘official talk’ where the discourse reflects more certainty, speaks of transformation and greater efficiency. The latter conceptualisation has emerged out of policy and research discourse that characterises telehealthcare as an alternative rather than an additional or ‘complementary’ form of practice, to be compared with the existing health care practice in terms of efficacy and efficiency (and thus adopted if proven to be more efficacious and/or efficient). Other work shows that the notion of hybridity expressed by the citizen participants is actually more workable in practice and increases the chances of telemedicine services becoming ‘normalised’ (Finch, Mair & May, 2006).

Another respondent points to the problem of the ‘closed question’ in relation to producing knowledge about telehealthcare and to seeing new technologies in context, rather as the ‘be-all and end-all’. He argues for a view that telemedicine is a ‘technique’, is part of wider practice:

CPP1: Well this is the same as your open and closed question isn’t it, and y’know you get to the point where you say well if it’s a closed question then this technology is not useful, it doesn’t get to the nitty gritty of what you actually want, and that I think that goes across the whole (of) this isn’t it? It’s whether the technology is useful and I, and I think if it’s there, and it’s useful then we’ve got to find a way of using it, but it’s not the be-all and end-all, that it must be technology driven. We mustn’t always have this telemedicine that is the be-all and end-all, we’ve got to sort of look at the combination between the one to one, the telemedicine and other techniques that we use.

b) Counting and targets

CPP7: No but it, but knowing that that’s how the NHS Direct has gone and erm I think it was the American video that talked about the number of consultations that were done in a day; now the NHS is so target driven that are we going to get a target for how many consultations that telemedicine’s supposed to achieve within a (…)?

MM: Well fifteen to twenty consultations they want [refers to a service previously studied] didn’t they and that, I suppose if you got, if they’re all dermatology that’s quite a lot of consultations in a day…

CPP3: Can I just say I think the closed questions are likely to (pause) well I just wonder if they’re more likely to appeal to medics because they’re more likely to be
quantitative, you’re going to be able to count them, they’re going to be easier to theoretically analyse even though they may not be telling you things you want to know.

The exchange above relates to one of the video sequences shown about a trial in the US and indicates a concern that telemedicine systems with their explicit recording of throughput, may lend themselves to the application of targets for tele-consultations.

CPP7: Yeah and it just, it’s just about thinking about the safety factors isn’t it, in terms of the benefits of it and the risks, and making sure that those who choose to use, it use it with, in an informed way erm, and that the staff that are being trained to provide it aren’t being put under undue pressure to achieve *(inaudible - all talking at once)*

CPP5: But *are* they being trained?

This then relates to the possibility of staff being placed under pressure to meet targets which then might compromise safety. New systems should be used in an ‘informed way’ where risks and benefits are understood. There should be ‘training’, and here the implication was training beyond achieving competence with the ‘technical’ to include how risks and benefits and tacit skills are accommodated.

c) Tacit skills

Here the possibility of missing important signs and cues from the patient or client is raised in the context of safety.

CPP6: There would be nothing for a gut feeling either
CPP2: Yeah well this is why it’s so important to see someone face to face or
CPP6: Cos you know, you know when you’re talking to particularly an older person, you know when they’re not giving you the information that you’re wanting because you can see that that they’re actually holding it back *(pause)* on the face to face consultation at this y’know, conversation with them

d) Compensation for a poor service

In spite of these concerns about the loss of face to face contact, there were few illusions about the existing quality of continuity of care, particularly in general practice. The erosion of personal relationships and the pressure on resources was seen as part of the context in which telehealthcare would be introduced and evaluated:
CPP1: Many, many of the GP’s are mourning that sort of situation in a sense … I mean I mean the fact of the matter is in XXX and XXX that you in fact you hardly ever see your own GP in that sense that appointments are given with a whole series of GP’s; they can be locum GP’s or erm new GP’s coming into the practice and so on

CPP5: It’s part of a fragmentation if you like, though that’s a rather negative way of putting it, that’s happening anyway

CPP9: …..I think there will be a combination of pressure on resources and as you say, this fragmentation y’know, like in the move towards a side by side approach where y’know … all the, what we’ve got and what will still be there it’ll just be harder to access and it maybe that this secondary way (telecare) allows some kind of contact…

e) Acceptability

Rather than promoting hostility to the idea of telehealthcare, the concerns expressed here made participants keen to see parameters and ‘boundaries’ established for new technologies, boundaries which were shaped in accordance with public concerns:

CPP8: If it’s inevitable as you believe, and and I think you’re probably right, then maybe we don’t want to be thinking so much about whether it’s going to happen but how far it should go if it does happen and what boundaries the public will find acceptable

This notion of consulting the public about what has been seen as an elite and ‘technical’ domain, is largely missing from professional discourse, which constructs consultation as a matter for individual patients (later aggregated in patient satisfaction surveys), rather than collective deliberation.

f) Complexity of care

There was anxiety that the ‘users’ of e.g. home telecare systems might not be seen to include informal carers; that new systems might not be able to do justice to the very complex role which informal carers often performed in practice:

CPP7 That American video, actually you could read it differently couldn’t you from what that lady was saying. She was saying that, that the service made it that her children didn’t need to worry, but you could also read it that the service meant that the children didn’t need to visit anymore, cos y’know they can take an angle on it can’t they?

CPP5: We’ve found a huge number of carers go to the the GP appointments with the person they care for because they don’t, the person they care for tends to present themselves in a better light than maybe they are, but the carer in fact knows a huge
amount about their condition and is likely to be a lot more honest about how bad things really are […]

CPP7: Quite often carers get very frustrated when health professionals won’t share information with them and become very er... protective

The participants thus clearly had concerns about the possible implications of telehealthcare for the role of the carer. Although acknowledging potential benefits where telehealthcare could be used as a support, they also raised concerns about the potential exclusion of carers in how services get organised and were wary of over-reliance on technology. These views are in contrast to the more optimistic policy discourse outlined earlier in this paper concerning the possibilities of self-management and empowerment for individuals with chronic disease.

Participants of the citizens panel agreed that, although technology shapes practice and care relations in particular ways and situations, telehealthcare services should be developed according to some general principles that should always apply, for example the presence of informed choice and consent; protection of confidentiality; free of charge at the point of delivery; clarity of ‘service language’. An overarching principle developed by the panel was that telemedicine shouldn’t distract attention from basic needs and resources in personal care. Another principle was that face to face contact between patient and clinician should underpin any subsequent move to telemedicine or care. The need for longitudinal practical outcomes research was stressed, again an approach which we found lacking in the policy and practice discourse (Williams et al. 2003). Below are the principles drafted by the panel, later agreed and confirmed in correspondence.
<table>
<thead>
<tr>
<th>Patients/users/carers</th>
<th>Approach to service provision</th>
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<tbody>
<tr>
<td>Treatment/interventions must be based on respect for and the dignity of the individual</td>
<td>Face to face forms of service must be maintained - vital to retain human interaction underpinning diagnosis and treatment</td>
</tr>
<tr>
<td>Users, carers and health professionals should be involved in the design of new technologies, to promote design in context</td>
<td>Outcomes should be assessed over time - longitudinal evaluations</td>
</tr>
<tr>
<td>Training in adaptation and use of telemedicine essential for professionals, but also users and carers where e.g. systems installed in the home. Professional training must cover not only the technical system operation, but additional communication skills required when interacting with patients over these new media.</td>
<td>Implementation must be needs-driven not service/industry driven, so that clear benefits for patients are visible.</td>
</tr>
<tr>
<td><strong>Research/knowledge</strong></td>
<td><strong>Context of use</strong></td>
</tr>
<tr>
<td>Ongoing learning and knowledge sharing as technology develops</td>
<td>Access for marginalised groups must be maintained</td>
</tr>
<tr>
<td>Experience to be shared from piloting systems, ‘trying out’ rather than ‘research’</td>
<td>Protection against reinforcing inequalities</td>
</tr>
<tr>
<td><strong>Principles for Telehealthcare Development</strong></td>
<td>Meaningful informed choice and consent for patients/carers - not substitute service</td>
</tr>
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<td></td>
<td>Face-to-face contact in the specialty/discipline should already have taken place</td>
</tr>
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<td></td>
<td>Free at the point of delivery</td>
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<td></td>
<td>Language used in practice to be clear, plain English/ethnic group rather than medical terminology or NHS jargon; systems should accommodate a range of communicative needs of users, patients and carers.</td>
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</table>
Conclusion

In examining rhetoric and practices in telehealthcare we have shown how the introduction of these systems is be accompanied by particular assumed roles and identities for patients. Operating within a culture of innovation (where this term is unproblematically framed), the positioning of patients and citizens at the margins of design and development yet discursively placing them at the centre of the transformation services (patient-centred care’) ironically serves to recreate healthcare as a conservative (exititunal) project.

But of course, it could be otherwise; we might re-imagine telehealthcare. We argue that the development of ‘e-Health’ is not separate from the world of practice, itself complex, messy and infused with local specificities, power relations and inequalities. For this reason it is appropriate to intervene, to attempt to create the conditions for interference between official and indigenous versions of technology development (Moser 2006). This is because power relations are made through the very materials and practices and reorderings which constitute innovation. And in healthcare, if the aim is to promote health, prevent illness and treat disease free at the point of access within an equitable and just framework, then citizens’ knowledge and experience counts towards any critical examination of how this is accomplished. Along with others from technology and society studies (Suchman & Bishop 2000; Webster 2002), we argue that innovation itself should be seen as a critical project.

The deliberations of the citizens’ panel showed that ethical, social, clinical and technical considerations should be balanced together in decisions about new systems. While our intervention was merely a pilot study, we argue that such panels, if further developed, could provide an important and hitherto missing contribution to the development of telehealthcare design and practice. We suggest that a programme of citizens’ panels should be formally developed using one of a number of well-established robust recruitment methods, so that an informed debate can take place about telehealthcare development to underpin policy and practice.
Additionally if recognition could be made of the interpretive flexibility and the ‘repair work’ done at the level of practice (Mort et al 2003); ‘local improvisations’ and ‘artful integrations’ (Suchman 2002a, 2002b) of technology-in-use, then experiential knowledge co-produced by the patient and the clinician could influence the design, practice and evaluation of the system. The possibility of co-construction, taking for example knowledge generated in the clinic back into the domains of evidence and design, draws out an important link between technology as innovation and technology as governance. Recognising the invisible work practitioners and patients do around new health technologies, would we argue, lead to design and use characterised by ‘located accountability’ (Suchman 2000), rather than the marginalisation of constituents. In all these ways citizens, users (clinicians), partial or non-users (patients), designers and developers can all be seen as technologists, as co-constructors (Oudshoorn & Pinch 2003), with creative implications for our experience of healthcare.
A working definition of telemedicine/telehealthcare is offered for this paper: ‘doing medicine at a distance’, and employing technical artefacts, usually ICTs, to mobilise representations of and information about patients. The difference, if any, between telemedicine and telehealthcare and telecare is problematic. We could say that telemedicine is a subset of telehealthcare, that the latter is a term which can cover all the ‘distance’ developments we are observing. But as we have noted elsewhere (Mort et al 2004), how the field is defined is part of the debate about its effectiveness; is it about medicine or is it about delivery?

We have written about the work done to ‘repair’ these structures e.g. how nurses use interpretive flexibility in operating a teledermatology clinic, finding ways to build localised, experiential knowledge into a system constructed to accept algorithmic data (Mort et al 2003).

For example the UK National Institute for Clinical Excellence consumer panel and the Health Technology Assessment Programme’s consumer involvement panel.

Mort & Michael (1998), drawing on the work of Callon and Leigh Star, developed the concept of absent or phantom intermediaries as a way of trying to understand the role of workers and machines made redundant (i.e. jobless) in the production of a new large defence system.

Recruitment for the panel was carried out opportunistically during a conference of voluntary sector organizations held at Lancaster University in May 2003).
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