MEMORANDUM OF EVIDENCE TO THE ROYAL SOCIETY WORKING GROUP ON INFORMATION AND COMMUNICATION TECHNOLOGIES IN HEALTH CARE

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1. Introduction

1.1. The Royal Society's working group on ICT in health care is an important opportunity to consider the impact and effects of ICTs across the health care sector, and beyond the specific issues that attend particular systems or devices.

1.2. This memorandum of evidence is concerned with the human relations and organisational contexts of emergent ICTs. In particular, it is concerned with the implications of networking between different devices and across domains of information. It is not concerned with specific systems or technologies.

1.3. The memorandum takes the following form. In section 2, it deals with the impact of networked health care ICTs on human relations problems within the health care system. In section 3, it deals with problems of organisation, implementation and integration of new ICTs in relation to chronic illness. In section 4, brief conclusions are offered, with special reference to areas that the working group might wish to consider further. An annex briefly describes the empirical research which has informed this memorandum.

1.4. This memorandum of evidence expands on material presented in written and oral evidence to the Commons Select Committee on Health, *Inquiry into New Medical Technologies in the NHS* (March 2005), at which the author was principal academic witness [1;2].

2. Emerging ICTs and their societal consequences

2.1. At every level, and across multiple domains, emergent telecommunications and information systems promise revolutionary change in the foundation, organisation and delivery of health care. The UK government has consistently argued that information systems are the key to programmes of service modernisation, and that these systems will lead to:

- Improvements in access to services and responsiveness to patients.
- Improvements in accountability and organisational efficiency amongst professionals.
- Improvements in management and accounting information for managers.
- Improved national economic competitiveness.

2.2. Policy in this area is underpinned by programmes of R&D and real service provision with unprecedented levels of contract driven public investment. It is not the place of this memorandum to comment on the likely outcome of some of these programmes.

2.3. The scope of current development in health related ICTs is very wide, and new systems are emerging across a number of apparently fragmented fields. These include:

(i) **Investigation:** Systems using GRID and other advanced computing technologies for fundamental investigations in molecular medicine and population health (e.g. Virtual Biobanks)

(ii) **Visualisation:** Systems using advanced imaging technologies, parallel and supercomputers to visualise data, from the molecular level to that of the whole body (e.g. HYPERBODY, the Visible Human Project).

(iii) **Management:** Systems that organise and make available data about individuals and populations at national and local levels to enable service delivery (e.g. the NHS Information Spine and clinical governance systems).

(iv) **Networked delivery:** Systems that remotely act upon individuals and populations (e.g. implantable devices, haptic and robotics applications, telemedicine systems).

(v) **Assistive technology services:** Systems that permit users to join networked services that survey populations and alert service providers (e.g. nanoscale devices, falls detectors, telecare systems, personal monitors and alarms, smart homes).

(vi) **Information services:** Systems that enable and empower service users by providing health and service information, create virtual user communities, and link them to service providers (e.g. web ehealth applications, on-line dictionaries and libraries, interactive digital television, call centres, direct to patient advertising and pharmaceutical sales).

2.4. These developments are driven in the UK by policy interventions that optimistically run together specific technological innovations, R&D policy and new patterns of service delivery with organisational modernisation and improved national economic competitiveness effectiveness. The recent Department of Health proposal for a National Institute for Health Research [3] is one example of this policy impetus.

2.5. However, these developments cannot be seen in isolation from parallel developments in e-government and e-commerce. Those two sectors demonstrate rapid joining up of different platforms, databases and communications networks. The policy assumption is that rapid networking of new technologies is desirable because of improved efficiency, rapid movement of management and performance data from one sector to another, and improved knowledge management within sectors. These moves have been accomplished by rapid developments within innovation sectors, but without public debate and all have been focused on the assumption that more information improves efficiency and competitiveness.

2.6. In the field of health ICTs, significant public and private investment in R&D, new service provision, and the business re-engineering of existing services, both have been accomplished without active consideration of their wider implications for citizens and of the implications of the rapid processes of interlinking and networking that have consistently occurred in other sectors. The rapid emergence and coalescence of on-line credit referencing services in e-commerce provides a recent example of this loss of control over distributed personal information. In some areas of research personal control over information has been seen as an obstacle to high quality research, and one extreme response has been the suggestion that citizens should automatically ‘opt in’ to clinical and epidemiological studies as a *condition* of NHS care. This

reflects the views of a small group of researchers. Far more important is the more general sense that the public does not *understand* new ICTs, data mining processes, and networked facilities. This leads to a focus on three perceived problems.

- *Dystopian* concerns about the direction of fundamental or basic technologies (see 2.3 (i) and (ii) above) are answered by programmes to encourage 'public engagement with science' that celebrate advances and the possibilities that they offer in solving specific health care problems (e.g. in genetic studies of disease).

- Concerns about *privacy, security and safety* of management and networked delivery systems (see 2.3 (iii) and (iv) above) are answered by effectiveness studies and promises of technological fixes that relate to specific systems.

- Concerns about *relevance and workability* of assistive and information focused systems (see 2.3. (v) and (vi) above) tend to be answered by 'patient satisfaction surveys' that rarely suggest that users are dissatisfied, but which most importantly are brought into being after the system concerned has been developed and at least partially implemented.

2.7. Users of new technologies – either direct or indirect – are rarely involved in choices about their design, evaluation, and implementation in meaningful ways. Instead, efforts are often made *after the fact* to persuade them that the right technological choice has been made. Moreover, the focus on technological aspects of these choices means that debates about their wider implications are excluded from both R&D and policy processes.

2.8. Most importantly, new technologies are not socially or politically neutral, nor are decisions about their development and definitions of whose knowledge counts in making decisions about their design, evaluation and employment. They reconfigure relationships between citizens, service providers in the public and private sectors, and the state. The rapid development of new systems and services means that they seem to outrun both public debates and emerging regulatory frameworks.

3. Chronic illness and technogovernance

3.1. Innovations in healthcare ICTs have important effects for the public more widely – as noted in section 2 of this memorandum of evidence – but they also impact on individuals and their experiences of health care. Work by my research group[*] reveals one of these, which we have called technogovernance [4]. In this section I will briefly discuss this with reference to the epidemiological transition from acute to chronic illness experienced by health care systems across the advanced economies.

3.2. Chronic illness (e.g. asthma, diabetes, heart disease, chronic back pain) are major problems for health services in the developed world. There has been a massive *epidemiological transition* to these diseases, partly as a result of major medical successes in preventing and curing other diseases (especially infectious diseases) that would, until recently, have been lethal (e.g. Tuberculosis). This has resulted in an older population run through with multiple co-morbidities for whom *care* rather than *cure* is the issue.

[*] In collaboration with Professor Frances Mair (University of Glasgow), and Dr Maggie Mort (University of Lancaster).

3.3 The epidemiological transition to chronic illness as the major health problem for the 21st century means that new kinds of work increasingly demand the re-engineering of health services.

(i) Chronic illness demands routine surveillance of the stability and trajectory of symptoms. This impacts on the gross workload of health professionals.

(ii) Chronic illness produces routine and highly determined patterns of professional work – focused on symptom management – that extend over lifetime illness careers.

(iii) Chronic illness engenders forms of professional work that are more amenable to external regulation and governance.

3.4. The increasing focus on routine symptom management work that has measurable progress and outcomes indicators means that this kind of work is the focus of attention in the development of health care ICTs that enable at least some elements of this work from the health centre or hospital into the home of the chronically ill person. We can define three of these as follows:

(i) Information systems that make possible management decisions about treatment (e.g. web based information resources, treatment guidelines).

(ii) Devices that define objective criteria for medical assistance or hospital admission (e.g. home monitoring, blood chemistry and vital signs tests).

(iii) Systems that disperse agency and accountability beyond the 'traditional' encounter between doctor and patient (e.g. telehealthcare services)

3.5. These new systems encompass the range of problems outlined above in section 2. Our work has pointed to the absence of meaningful user participation in the design of specific technologies or services [5]. This is one reason why their proponents have encountered real difficulties in implementing and stabilising these technologies in practice. These new systems radically reconfigure the relationship between patients and health care providers, moving from traditional doctor or nurse-patient encounters, to ones in which a *distal* patient accepts a new burden of clinical self-care (and their costs), and is necessarily reconstituted as a particular kind of data-set [6] rather than a whole person. This new kind of clinical encounter brings with it a range of problems around inclusiveness, information, knowledge and trust [4].

3.6. In addition, we have seen how failures to include clinical users of new technologies in debates about their design have added to problems of implementation, stabilisation and normalisation of new health care ICTs [7]. Central to this has been the frequent and wrong assumption that such technologies can be incorporated in existing clinical services without re-engineering their business processes, and considering wider effects on service provision. The National Programme for Information Technology in the NHS, and the development of a national electronic health record (the 'Information Spine') is currently playing out these problems on a grand scale.

3.7. New ICTs for chronic disease management are being developed without serious consideration of how they may be integrated into (a) the daily lives of their users, and (b) the organisational systems of the NHS. This will lead to poor take up and compliance.

4. Conclusion

4.1. New ICTs and related technologies are rapidly emerging across a range of fields. They promise much. They can connect different levels of activity and domains of knowledge in the health sector, and new platforms for the organisation and delivery of information also promise interconnectivity with other domains of intervention by the state and other agencies.

4.1.1. There are tremendous social, political and technological risks attached to this. The emergence of a *surveillance society* has been posited by some, and while the dystopian elements of this are often framed as being in the realm of science fiction these new technologies do mean that individual citizens have steadily reduced opportunities to *choose* what is known about them, or to contribute to debates about control over this knowledge or the form of regulatory agencies.

4.1.2. New technologies in this field are developed in ways that act to isolate them from each other and from their potential users. Users are rarely meaningfully involved in debates about their development and evaluation. Indeed, R&D programmes in this field rarely have mechanisms through which users' interests can even be acknowledged because the interests and aspirations of the State, service providers, new technology developers, and citizens are presumed to be the same.

4.1.3. Mechanisms for including citizens in debates about the form and direction of new technology developments are often not meaningful. Users untapped potential for focusing attention on important problems, adding value to design processes, and securing technological developments that effect socially desirable and valuable innovations.

4.1.4. New technologies for the management of chronic illness in the community form a vehicle for seeing these problems at work. They enact new mechanisms for social and clinical surveillance without engaging their users in a debate about whether these systems are desirable or useful, while assuming that the societal impact of potential efficiency gains means that the interests of service users and service providers are the same, when there is no evidence that this is so.

4.1.5. New systems of technogovernance shift agency and accountability in healthcare into diffuse networks, threatening the traditional trust relationships between patients and practitioners that are known to be highly valued by patients.

4.2. This memorandum of evidence has focused on the societal implications of patterns of R&D, technology evaluation, and technology implementation. Beyond this, the Royal Society Working Party might usefully consider the following:

- The importance of developing meaningful mechanisms for including citizens in wider debates about the societal implications of the shift to a networked knowledge economy in health care.

- The importance of developing meaningful methods for participatory problem definition, technology design, evaluation and implementation, and the incorporation of users of new technologies into these processes.

- The impact of R&D processes on citizens' experiences of the organisation and delivery of health care.

It is important to note that these matters are not technical problems of practice, but are necessary conditions of a modern deliberative democracy. In technological debates there is a tendency to delegate these matters to social scientists, ethicists, or other expert panels *after the fact*, and to assume that technologies and their development are politically and socially neutral. This is a wrong assumption.

CR May

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ANNEX: Research contributing to this memorandum

This memorandum is informed by four related programmes of work led by the author and undertaken since 1990.

(i) *Studies of doctor-patient interaction in chronic disease management:* These have investigated the processes of relationship-building and management employed by doctors in primary care, genetic counselling and hospital nursing, and have related these to specific clinical problems including: depression, irritable bowel syndrome, chronic musculo-skeletal pain, diabetes, and menorrhagia. This work has led to a model of interaction processes in the primary care consultation [8].

(ii) *Studies of the organisation of clinical work in chronic disease management:* These have examined patterns of clinical reasoning, and organisation aspects of the transformation of clinical work in the face of policy interventions intended to reform the delivery of primary care in the NHS. This work has led to analysis of the changing division of labour in primary care [9] and the impact of chronic disease on changing patterns of clinical work [10].

(iii) *Studies of the production of clinical evidence:* These include studies of the development and distribution of evidence to inform clinical practice around chronic health problems. They include observational evaluations of randomised controlled clinical trials, shared decision-making tools in primary care, and the operation of clinical guidelines development groups. Cumulative analysis from these studies has contributed to the development of a model of the interaction of human and non-human actors in the regulation of knowledge within health care systems [4].

(iv) *Studies of the design, evaluation and implementation of ICTs in health care:* These have included work on telemedicine, telehealthcare, and computer support tools. Work on telemedicine includes a unique programme of observational research that has tracked the development of services over time and shown how R&D processes have themselves contributed to difficulties in implementation and service delivery [7], and how new technologies have acted to reconfigure a shifting political understanding of the nature of patient-hood [6].

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