Royal Society Consultation Exercise on the Impact of ICT on Health and Healthcare

Response on Behalf of the Edinburgh University Interdisciplinary eHealth Research Network

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About the Edinburgh eHealth Research Network

We represent a multidisciplinary group of researchers and clinical colleagues, linked to the University of Edinburgh, who share an active interest in the area of ICTs applied to health care systems and services. Our participants include representatives from across the three Faculties of Medicine and Veterinary Medicine (Clinical & Community Health Sciences), Science and Engineering (Informatics) and Humanities and Social Sciences (e.g. Management, Sociology, Psychology, Law), as well as related research institutes and NHS organisations.

Our primary focus is eHealth - an emerging concept relating to the use of networked, digital ICTs to facilitate the organisation & delivery of health care and services (e.g. see below). This encompasses applications for *providers and organisations* (e.g. for storing, exchanging and using clinical or administrative data or aiding evidence-based practice) and for *citizens and patients* (e.g. web-based health information, education, virtual consulting), as well as research applications of eHealth technologies. Given the scope of the field, research in this area is wide-ranging and covers pragmatic issues associated with meeting service needs and demonstrating effectiveness (e.g. acceptability of electronic patient records, impact of clinical decision support tools), technical issues (e.g. standards & interoperability, emerging devices impacting healthcare), sociotechnical issues (e.g. ensuring usability, managing change for effective implementation & workflow integration, effects on clinician-patient relationships), as well as other topics, such as ethics and policy. For this reason eHealth research benefits from an interdisciplinary approach utilising multiple methodologies.

Our response to the Royal Society consultation exercise is based on a broad view of ICTs in healthcare, as covered by the wider eHealth concept. It does not focus on the purely technical issues associated with computer systems or hardware nor on basic science involving ICTs (e.g. genomics) and we assume that other groups may be commenting in more depth on these issues. Nonetheless we believe that it addresses the broad objectives of the consultation exercise. We would be happy to participate further in the project, if so requested.

Pagliari C, Sloan D, Gregor P, Sullivan F, Kahan J, Detmer D, Oortwijn W, MacGillivray S. (2005) What is eHealth (4): a scoping exercise to map the field. *Journal of Medical Internet Research* 7(1):e9 http://www.jmir.org/2005/1/e9/

Pagliari et al (2004) Literature Review & Conceptual Map of the Area of eHealth. London. NHS SDO. http://www.sdo.lshtm.ac.uk/ehealth.htm#pagliari

Identifying relevant future technological developments

1. *What relevant technology trends are likely to impact on health and healthcare in the next ten to fifteen years?*

Core technology developments: Grid computing. New generation Internet. The evolving NHS IT infrastructure & improved data integration. Improvements in data warehousing, data mining and knowledge management. Increasing Internet bandwidth. Digital TV. Increasing quality and transferability of digital images (+ improvements in screen resolution). Advanced mobile applications and wireless infrastructure (including satellite-enabled broadband). International standards. Geographic information systems. Intelligent, adaptive systems. Robotics. Biometrics. Speech recognition. Developments in sensors, pervasive and wearable computing (medium term) and Nanotechnology (longer-term).

Applications of technology: Increasingly sophisticated clinical decision support for evidence-based medicine. Intelligent systems for managing clinical data and knowledge. Improved inter-professional clinical communications systems supported by electronic patient data (e.g. for referral, booking, bed monitoring). Improved e-learning resources for medical education. Greatly increased capacity for the real-time monitoring of public health, and for modelling and predicting demand for healthcare services. Increasingly tailored and personalised decision aids and support tools for patients. Electronic record linkage and integrated patient records, facilitating shared care across professional boundaries and 24-hour access. Increasing patient access to and interactivity of personal health records, supporting self-management and shared decision making (web-based and portable). Growing access to Internet health information and advice by members of the public. 'Smart' and assistive technologies for home-based patient monitoring and management. Mobile applications for chronic disease management. Digital technologies for remote patient care and medical education. Increasingly consistent standards for electronic data and messaging, leading to greater interoperability. Virtual reality simulations to aid diagnosis, treatment (e.g. surgery) or medical training.

Assessing the potential positive and negative impacts of relevant future technological developments

2 What areas in the provision of health and healthcare could be positively or negatively affected by these developments?

Positively affected – Shared and patient-accessible electronic health records, and multifaceted interactive health communications tools will encourage patient-centred care and therapeutic concordance and will be of particular benefit for those with long-term disorders such as diabetes, which require considerable self-management. In general, consumer empowerment for health will be increased by access to eHealth resources on the Internet (e.g. information, decision support, social support). Such resources will prove valuable for the management of short-term, self-limiting illnesses, thereby reducing the need for consumers to engage with the health service. Biometric methods for identify verification will improve the security of digital health data, while speech recognition may facilitate the use of eHealth resources. Epidemiological research and health care planning will be facilitated by access to linked electronic records. Disease surveillance and population risk management will be aided by grid technologies and geographic information systems. Grid technologies also have the potential to facilitate multicentre trials and processor-intensive biomedical research (e.g. genomics), as well as translational research. Community-based care of chronically ill, terminally ill, disabled or aged persons will be made easier though developments in assistive and supportive technologies (e.g. 'smart' homes, using pervasive computing for monitoring and task support, backed by central grids and telemedicine). Satellite-enabled Internet technology will facilitate rural medicine by enabling mobile and remote access to electronic databases and knowledge repositories, medical second opinion, and transfer of images and reports. Patient safety will be improved by effective automated clinical decision support and alerting systems (e.g. for prescribing). Shared patient care will be improved by access to integrated patient records. 24-hour access to integrated care records will support continuity of care.

Negatively affected – Such systems may potentially compromise patient confidentiality. Security breaches may undermine public confidence in systems and professionals and/or lead to misuse by third parties. Conversely, an over-rigid security regime may impede the uptake of systems and hinder access to data for clinical or research purposes. The status of clinicians as sole experts may be threatened by greater public access to health information, with impacts on the doctor-patient relationship. Poor-quality, misleading or unethical health information on the Internet may put members of the public at emotional and physical risk. Contrary or misleading Internet information may also confuse patients and generate conflicts with professionals (e.g. by encouraging patients to seek unproven, dangerous or costly therapies). Over-reliance on computerised clinical decision support may give rise to medical errors if algorithms are flawed or records incomplete (although such systems are designed to have opposite effect). Clinicians' sense of professional autonomy may be affected by increasingly protocolised care, and this may create resistance to implementation.

3 What actions should be undertaken now to maximise positive impacts, or to prevent or minimise adverse effects?

Greater consensus on appropriate policies for information governance and data ownership. Pragmatism to avoid over-regulation, which could stifle research and population health surveillance (e.g. could affect response rate for natural disasters, epidemics, bioterrorism). Research to obtain evidence of consumer attitudes surrounding information governance and to engage consumers in the process of developing policies and laws in this area. Testing of new eHealth technologies before release to ensure fitness for purpose (reliability and validity), usability & accessibility, workflow integration and acceptability (end-user engagement critical). Rigorous research to demonstrate the potential cost-effectiveness and safety of new technologies prior to widespread implementation, along with evaluation post-implementation. Appropriate use of change management processes within the organisational context of ICT implementation. General monitoring of technology trajectories, from idea through to final clinical application and anticipatory intervention if indicated.
Widespread training of consumers and health professionals in appropriate eHealth information search and appraisal techniques and in legal and ethical guidelines related to ICTs (e.g. issues for remote consultation and diagnosis where the identity of the patient may be difficult or impossible to establish). Stepping-up efforts to encourage paperless practice and adoption of universal eHealth systems within the NHS. Government funding to speed up access to and adoption of high bandwidth Internet (inclucing Internet2) to facilitate the implementation of data-intensive applications, such as multimedia patient or clinical support tools.

Evaluating the wider implications of relevant future technological developments

4 Do you have any concerns associated with the generation, release and subsequent use of personal data?

Current policies are unclear, are not evidence-based, and are not well known or understood by the majority of researchers, administrators and practitioners working with such data, nor by patients. We need to seek a broader consensus on appropriate custodianship of data, research uses under various levels of anonymisation, and levels of access by alternative stakeholders. This needs to be informed by research on patient and clinician understanding and preferences, as well as ethical and legal considerations. The contrast between the pragmatic approach adopted in Scotland (Committee on Security and Confidentiality) and the more prohibitive approach adopted in England, and their outcomes in terms of risks and benefits, would be worth exploring. The evolving National Programme for IT in England (NPfIT, now NHS Connecting for Health) will require existing policies to be adapted to meet the challenges of greater data access and interactivity that are proposed. Research exploring how public attitudes on personal health data may be affected by the increasingly consumerist culture within the UK (issues of data ‘ownership’ etc.) would be of value.
While availability of NHS treatment is not determined by personal health status or risk profile, increasingly privatised care will generate issues around access to electronic patient records by insurers. The BioBank project and other genomics developments are generating debate over ownership of genetic information. Such information may, in the future become part of the electronic health record. Simulation studies to determine the possible risks of security breaches (e.g. misuse by third parties), and stakeholder responses to these, would be worthwhile.

5 What medico-legal and ethical issues merit consideration when introducing new technologies, such as the responsibilities, processes and liabilities for decision making?

Concepts of ‘the public interest' and how this can and should impact on individual rights to confidentiality and privacy. How the legal concept of 'patient autonomy' may be facilitated or compromised by ICT advances. The changing nature of the doctor-patient relationship (are new obligations created by the generation of new knowledge?) as well as the shifting relationship of researchers to research subjects (what is the nature of their duty of care?) Ownership of databases, access provisions and appropriate monitoring and vetting of third parties. Issues for the potential commercialisation of products or databases created from ICTs, particularly those derived within the NHS. Whether certain ICTs should be made freely available in the public interest. The impact of human rights arguments and the growing influence of European Union legislation.
The need for appropriate international regulations and standards to maximise the benefits of ICTs for managing global threats to public health. Issues relating to extrapolation from consented data (e.g. using patients’ CD4 count as a surrogate for an HIV test or research results to predict future mortality). Research is required to explore what patients understand by consent and how far their implied consent extends in terms of data use. Liability issues for internet websites (e.g. kitemarking improves quality but puts the kitemarking organisation at legal risk). Liability for decisions informed by computerised CDSS algorithms (where does it lie – with the technology developers or with clinical users who should be judging the output based on medical expertise?)

6 What regulations or other mechanisms (including standards) would facilitate the responsible development of relevant technologies?

Standardising electronic data and messaging protocols would help to ensure interoperable systems. Standardized policies for ensuring data security, commissioning software, hardware acquisition, and so on, would also help to reduce inconsistencies in IM&T activity and thereby improve cost-effectiveness. Agreement on legislation covering data ownership, access and use has the potential to facilitate research, patient care and public health. International agreements and standards would enhance the ability of new ICTs to impact on global health care.

7 What infrastructure would be required to allow any new technologies to be used effectively?

Within healthcare – broadband Internet, as currently implemented under NPfIT, and new generation Internet for data-intensive transactions. Wireless networks (mindful of security risks). In society, broadband or new generation Internet, with enhanced functionality of Digital TV.

8 What are the most likely promoters and barriers to the take up of new ICT devices and systems?

Promoters – User engagement in design and implementation planning. Demonstration of clinical utility and effectiveness. Time savings/efficiency gains. Whether systems meet patient/consumer needs. Reliable systems and infrastructures (e.g. NHS-Net). Procurement and budgetary strategies that take account of technology cycles and anticipate changing needs across phases of development and implementation and their implications for suppliers and purchasers.
Barriers – For professionals: resistance to change caused by failure to engage end-users, time demands (e.g. for completing protocolised clinical communications), fear of 'cookbook' medicine, mistrust of CDSS algorithms. Difficulties reconciling the needs of different stakeholder groups (e.g. clinical and administrative). Bureaucratic barriers and lack of integration between technology acquisition cycles and institutional reform in the health service. System or infrastructure unreliability (e.g. NHS net down time). Lack of access to mobile and wireless technologies. For the public: out-dated or poor quality websites.

9 What education and training would need to accompany the introduction of any technologies, and who would need to be involved?

For any new technology, training is required to demonstrate both how to use it and to take account of its potential impact on professional practice (e.g. impact on workflow processes, effects on processes of patient care). Training should be tailored to the appropriate user group (e.g. laboratory staff versus GPs) and should ideally be carried out by a trained peer.

10 How are professional roles and responsibilities likely to be affected by the increasing use of ICT?

Decreasing needs for paper-based administration and duplication of data entry will affect the dynamics of work practice. On the one hand, increasing willingness of doctors to enter data electronically during and between consultations will release clerical time for transcribing voice or paper notes. At the same time, increasing electronic mail communication with patients may generate additional clerical needs (e.g. for processing appointment requests or relaying clinical enquiries). Likewise electronic clinical communication of patient information and integrated care records will increase the availability of data and save time in paper transfer. Questions remain over whether increasing clinical decision support linked to evidence on effectiveness, will threaten clinician autonomy for decision making and how this will affect experienced professionalism and quality and safety of care. On the other hand, such systems (and records) will make it easier for nurses and allied health professionals to fulfil many of the roles previously only offered by doctors (see NHS-Direct as an example). Professionals may also have to deal with ethical and legal issues, as they strive to deal with patient confidentiality issues and as the health insurance market increasingly takes hold in the UK.

11 How can the development of technologies that meet patients' and informal carers' needs and are practically useable be best facilitated?

Consultation with patients and carers is required to assess which technologies are most likely to meet their needs. This will require creative research designs, to ensure that answers are well informed and generalisable. Prototypes should be piloted with end-users to ensure their functionality, usability, and accessibility, and iterated as appropriate. The accuracy and validity of algorithms underlying electronic decision aids should be established in appropriate simulations. Ideally trials should be mounted in order to gather evidence on potential impact before new systems are rolled out. Government policies and funding should be directed at closing the 'digital divide' by supporting access to internet-linked computers and training for the public in eHealth search and appraisal skills. The development of eLearning technologies to deliver quality-assured patient information on a national and global scale should be encouraged. NPfIT aims to improve infrastructure and standardisation

and to facilitate patient management and self care through the provision of electronic health records, as well as supporting developments in NHS Direct. Ongoing engagement of academics and participative evaluation will help to progress the programme and limit difficulties. Evidence-based and consistent policies on access, confidentiality, security are required to ensure that data is used most appropriately and effectively. More ecologically valid studies of assistive home care technologies (including teleconsultation facilities) are required to demonstrate the potential cost-effectiveness of such innovations.

12 What are the potential impacts or the costs of any of these new technologies?

Potential impacts - New technologies for the storage, mining, communication and interpretation of electronic data within the NHS (including decision support) have the potential to improve the transparency, accountability and management of health service transactions and clinical care pathways. They may also improve the quality of clinical transactions (e.g. by increasing legibility), decrease risk (e.g. by flagging-up contraindications to medication), promote evidence-based practice (e.g. by prompting screening or suggesting treatments) and enhance patient care by sharing information across all appropriate providers, thereby optimising clinical outcomes. Aggregated and person-specific electronic data may also facilitate the surveillance of health trends or drug effects; thereby informing both evidence-based intervention and the development of new innovations (e-genetic data has the potential to impact on diagnosis and disease management in the longer term).

Potential costs - Financial costs include capital expenditure on systems, infrastructure and hardware, and revenue costs in terms of ongoing maintenance and upgrading (there have been problems in the past with respect to budgeting for the latter, leading to the eventual demise of expensively-implemented state-of-the-art systems). Potential costs to the patient include risks of poor quality clinical algorithms, unauthorised access to or misuse of personal health data (including genetic information), risks associated with poor quality eHealth information on the internet. Infringement of patient privacy may have financial risks in terms of lawsuits; likewise reliance on electronic data and decision support may lead to litigation if errors damage patients.

13 What are the implications of the international use of future technological developments, such as global use of health data, variability of ICT-enabled support, and interoperability?

National health care IT plans are emerging across the world and most are united by a wish to develop comprehensive, patient-centred electronic records and support interoperability via common eHealth standards. Facilitating uniformity across nations in terms of infrastructures, policies, standards and systems has the potential to improve global health and drive down costs. However differences in culture and health service provision (e.g. nationalised or privatised) will act as a barrier to integration. Global policies are needed to address this. While developing nations are at a disadvantage and are much behind in terms of eHealth, their relative lack of legacy systems means that there is potential for a huge leap in eHealth, provided that governments make a commitment to implementing national architectures and such work is appropriately sponsored.

The potential for geographical information systems supported by grid technologies to improve population health surveillance and thereby assist coordination of global health interventions has begun to be demonstrated (e.g. in the case of the SARS epidemic). International agreements on electronically-supported remote care and consulting, as well as diagnostics (i.e. telemedicine) also have the potential to create efficiency savings in the UK and create employment elsewhere (e.g. protocolised advice lines, remote screening using high quality digital images).

Are there any other important issues that have not been addressed by the questions above and that you think the working group should address?

The working group should focus on the need for research and evaluation in this area, and address the historical under-evaluation of new computerised electronic health systems prior to their rollout (development has always been prioritised over research in terms of funding). This is often driven by a poor understanding on the part of purchasers on the value of evaluation and user engagement, and by political and funding imperatives. A rigorous evidence-base that has credibility with technology end-users, including health professionals trained in evidence-based medicine, is essential for ensuring effective implementation.

Greater communication and collaboration between public sector agencies, academia and industry, as well as consumers, is required to maximise the potential benefits of eHealth technologies. The opportunities and risks of e-technologies for inter-agency working across the health, welfare and justice systems, would be worthy of attention, particularly in relation to the sharing of person-specific data.

Resolving many of the issues identified in this paper rests upon bringing together different areas of expertise (e.g. social, political, management and health sciences, and clinical practice). For this reason, an exploration of potential funding streams for supporting interdisciplinary groups, such as our own, would be valuable.