THE ROYAL SOCIETY

Ref:ICT/19(05)

ICT & healthcare science & technology workshop report

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Summary of key points

- It was widely agreed that the major benefits from ICTs in healthcare in the next 10 – 15 years would come from the exploitation of existing technologies, rather than from novel developments.
- The growing importance of evidence-based healthcare could be supported by ICTs with computer aided diagnosis and decision support tools to get the right information in the right place at the right time for the healthcare professional.
- It was agreed that there would be an exponential increase in the amount of data generated. Data quality, information completeness and authority (provenance), presentational consistency, national consistency and standards for coding are all issues that need to be addressed.
- It was widely agreed that the choice of performance indicators for the different sectors of healthcare could be potential drivers or barriers for the successful implementation of new ICTs.
- Views varied amongst attendees on whether ICTs would increase or lower costs. Some felt a more important factor was whether ICTs would improve the quality of care (such as being able to treat more patients, more successfully).
- It was suggested that systems that provide a focus on the individual will tend to be more successful. ICTs could be the vehicle for delivering 'personalised content' and to integrate disparate sources of information to offer more personalised care.
- Both ICT and healthcare should be considered as drivers of innovation.
- Developments in sensor and imaging technologies will lead to benefits in all areas of healthcare, including real-time monitoring and treatment delivery.

This report presents a summary of the key issues and challenges that emerged from the workshop and is not necessarily an expression of the views of the Royal Society or the RS working group.

1 Introduction

This evidence gathering workshop was held at the Royal Society on 24 October 2005. It was part of the Society's study into the potential impacts of information and communication technologies (ICTs) on health and healthcare. The key objectives of the Society's study are:

- To investigate the developments in information and communication technologies relating to health and healthcare in the next ten to fifteen years.
- To identify relevant future technological developments.
- To assess the potential positive and negative impacts of relevant future technological developments.
- To evaluate the wider implications of relevant future technological developments.

22 individuals from academia, industry and funding bodies attended the workshop along with eight members of the Society's ICT and healthcare working group. Full details of the attendees are given in appendix one. The aims of workshop were:

- To inform the RS study through the working group members present and the meeting report.
- To identify potential new information and communication technologies with applications to health and healthcare that are likely to be used in 10 – 15 years.

- To identify the drivers and barriers for the development of relevant new ICTs, along with the strengths and weaknesses of specific ICTs.

The workshop consisted of plenary sessions and three breakout groups, each one looking at different sectors of health and healthcare: home care; primary care; and secondary / tertiary care. As there are overlaps between the different health and healthcare sectors, there was a discussion of cross-cutting issues during the closing plenary session. The timetable of the workshop is given in appendix two. A summary of the presentation giving an overview of expected healthcare drivers and needs is given in appendix three.

This workshop was part of the evidence gathering process for the Society's study. An open call for evidence was issued in June 2005, and nearly 40 responses were received by September. In addition to the science and technology workshop, there have been workshops concentrating on healthcare professionals and patient groups. The working group is also looking to identify a few individuals and organisations to fill in any gaps in the evidence and to get more detail on key areas.

This report summarises the cross cutting issues raised during the workshop, and also those relating to particular health and healthcare sectors. This report presents a summary of the key issues and challenges that emerged from the workshop and is not necessarily an expression of the views of the Royal Society or the RS working group.

2 Cross cutting issues

Exploitation of existing technologies: It was widely agreed that rather than being dependent upon the development of novel technology, there remain many opportunities to derive major benefits from the exploitation of existing ICTs over the next 10 – 15 years. For example, the convergence of personal digital assistants (PDAs), mobile phones, wireless communication and security measures will overcome many of the current difficulties with interconnection of systems and technologies. This will allow much easier transfer of healthcare information. It was noted that internet use has grown rapidly in the past 10-12 years and that this growth would be expected to continue. Looking forward, current technologies, such as broadband internet, that are seen as a special interest service will become more widespread and be seen as a utility. There will be a move from wireless 'hotspots' in homes and offices to wireless 'communities' that will allow easier exchange of information.

Evidence-based medicine: The growing importance of evidence-based healthcare could be supported by ICTs with computer aided diagnosis and decision support tools to get the right information in the right place at the right time for the healthcare professional. Evidence-based medicine currently focuses on text-based sources and expanding this to include images will require appropriate computational infrastructure to be able to handle the increased volumes of data.

There were strong feelings that ICT should be able to facilitate access to up to date information on the patient at any time. It should allow the integration of information from different specialists without them needing to meet. ICT should be used to capture the meta-data such as relevant socio-economic data and information about circumstances under which particular tests were taken (eg during a period of stress) that

are needed by healthcare providers. However, it was noted that up to date access to information is one objective of the NHS Information Authority[1] that has not been met.

ICT can be used to collect and analyse data on efficacy and adverse drug reactions (ADR) to pharmaceutical drugs once they have been approved for widespread use. This will inform future drug development and allow identification of patients likely to suffer from adverse effects. If the information relating to all patients could be captured the analysis of these data could be used to modify clinical experience and practice, to set goals for improved performance and the adoption of best practice. With respect to the individual, such information should improve clinical decision making by ensuring greater consistency, reducing avoidable non-compliance and reducing error rates by doctors.

Governance of information: A number of issues were raised regarding who owns any data generated. It was suggested that there would inevitably be a difference of opinion between the patient and clinician on this issue. It was also noted that a number of other bodies could lay claim to data including the company that produced the equipment and the health trust that purchased or leased the equipment. It was suggested that there would be an increase in the number of healthcare providers and equipment manufacturers (especially in home or self care), which would further complicate this situation. It was suggested that in 10-15 years there will be a culture of personal ownership of health data.

The issue of what can be done with data beyond using it for the initial treatment of the individual was raised, and who would be responsible for making these decisions. This will influence public trust and safeguards for the data. Common principles and lessons about the governance of data could be learnt from the current implementation of the electronic patient record, DNA fingerprinting and databases in the criminal justice and pensions systems. The US Food and Drug Administration is working with healthcare providers to develop an appropriate regulatory system.

There are examples where ICTs are currently being used to store individual healthcare records: eg individual medical records are being stored on radio frequency identification (RFID) implants produced by VERICHIP in Florida, aimed at patients with chronic conditions such as diabetes)[2].

Information management and sharing: It was agreed that there would be an exponential increase in the amount of data generated. Data quality, information completeness and authority (provenance), presentational consistency, national consistency and standards for coding are all issues that need to be addressed.

Increased data volumes have implications for storage and computer architecture. Three medical areas where this will be important are medical imaging, physiological monitoring (such as ECGs) and genotyping. The huge data volumes cannot be analysed by people, so there is a need for systems to analyse and quality assure these data and provide a summary for the patient's record without losing raw data.

E-consent was seen as a key issue: patients will want to be able to control which pieces of information that are held on them are released and to whom. Protocols will need to allow for the fact that the patient may in incapacitated (and unable to give consent) or may be outside the UK. The development of databases to

[1] http://www.nhsia.nhs.uk/def/pages/aboutus.asp
[2] http://www.verimedinfo.com/technology.html

improve clinical practise and monitor adverse drug reactions will require people to consent to their information being stored.

Tagging patients and medications (potentially using bar coding) could be linked to protocols for drug delivery and treatment to avoid the wrong drugs or treatments being given. There has been plenty of research on the public's perception of the trade off between loss of privacy and better care (facilitated by the collection & analysis of patient data).

It was suggested that the key limiting factor to the exploitation of Grid technologies was identity authentication and that insurance and financial service companies are developing appropriate software. It was noted that most methods of authentication will face a challenge to gain public acceptability.

It is essential to have back-up for any electronic systems. However, it was felt that it is unlikely that a single system would be in place, thereby removing the possibility of paralysing health care if anything (deliberate or accidental) happened to it.

Key performance indicators: It was widely agreed that the choice of performance indicators for the different sectors of healthcare could be potential drivers or barriers for the successful implementation of new ICTs. For example, GP's contracts, hospital performance targets and other measures will all have an influence.

Equity and access: These will be key issues for next 10-15 years. An increasingly diverse set of treatment options will be available and there will always be circumstances where demand for particular treatments cannot be met by supply. ICT can inform decisions about which patients should have a particular treatment.

ICT can address some of the barriers to community healthcare. It could facilitate the community approach to healthcare by enabling specialists to access all the information that they need in regional clinics or any community setting, ultimately even the patient's home (a current limiting factor). However there will be other barriers eg travelling time of specialists.

Cost implications: Views varied amongst attendees on whether ICTs would increase or lower costs. Some felt a more important factor was whether ICTs would improve the quality of care (such as being able to treat more patients, more successfully). It was suggested that improving primary care would reduce the cost of more specialist treatment (typically undertaken in secondary or tertiary care at the moment). However, any investment in ICT will need evidence to justify it.

It is possible that patients receive money vouchers to spend on their care as they choose which could then shift towards personal payment for technologies and care.

Trust: Individuals are becoming consumers of healthcare technologies – but it was suggested that individuals are more likely to follow a certain course of action if that action has been endorsed by a trusted healthcare professional. Although new healthcare technologies might be available in shops and pharmacies, a healthcare professional will need to explain the technology to the patient and relate it to them. It was suggested that patient groups are taking on new roles in providing support – and so could provide the support needed when using new technologies.

Personalisation: It was suggested that systems that provide a focus on the individual will tend to be more successful. ICTs could be the vehicle for delivering 'personalised content' and to integrate disparate sources

of information to offer more personalised care. For example, when treating a tumour information from DNA and RNA profiles of tumour could be combined with symptoms collected at home (by phone or other techniques) to produce a personalised treatment that can be monitored and altered as necessary.

It was suggested that healthcare needs to find a balance between codifying the clinical process (to allow efficiencies and development/implementation of best practise) and recognising the individual experience or factors that will influence effectiveness of treatment regime.

Drivers of innovation: Both ICT and healthcare should be considered as drivers of innovation. ICT may transform treatment technologies in the same way as the internet and mobile phones have transformed the way people work and interact. Changes in healthcare needs and development technologies may alter how ICT is deployed to support healthcare delivery.

Move away from secondary care: There was a general consensus that the move from secondary care into either the home or primary care would be facilitated by ICTs. For example, near patient diagnostics and monitoring would become cheaper and easier to use, allowing them to be used in home care or primary care rather than secondary care. Another example is in drug delivery systems (such as sprays, slow release implants and smart patches) facilitating a move away from hospital based treatment as they get easier to use and cheaper.

Sensor Technologies: Developments in sensor technologies will lead to benefits in all areas of healthcare, including real-time monitoring and treatment delivery. ICT is improving treatments by facilitating minimum invasiveness (reducing the amount of direct vision required) during surgery.

Sensors combined with neural networks could be used to monitor patients by integrating information from a variety of signals and samples (eg advances in proteomics allowing diagnosis from a urine sample). Once trained and linked into appropriate sensors, neural nets could be as efficient as humans in monitoring (including drug levels) and diagnosis (eg identifying signs of imminent heart attack).

Ubiquitous sensor networks could be used to monitor the health and wellbeing of older people to allow them greater freedom by alerting carers when their assistance is required. Smart clothing including sensors (such as monitoring to identify when an individual has fallen) is already being developed, such as the University of New South Wales work using existing Bluetooth technology to link sensors.

3 Home care

Good patient-technology interfaces required: Past projects on the use of digital TV in homecare have shown that people really value being able to talk to someone face to face at moments of stress. NHS Direct is looking to utilise digital TV. The service provided needs to be looked at before the technology. In the 1970s and 1980s, much work was done around human- computer interaction which demonstrated the importance of good interface units. A study of diabetics showed that only 10-15% have consulted the internet about their condition. This will grow, but is never expected to be 100% - it should be noted that this might reflect the inclination of people to discover information to support themselves as opposed to anything related to the user interface. Mobile phones are much more pervasive.

Another study of diabetics showed that 30% are managing their care well, 30% do not care or are in denial, and 40% would like to do more, but are not sure what to do. Therefore an everyday tool is needed to tap into this motivation and change behaviour.

Changes in health conditions: A substantial amount of healthcare is directed to treating people in the last years of their lives. Health technologies need to take into account age and levels of understanding and education. Also some people want to be very active in their care, whilst others would prefer to have a much more passive role.

Forty years ago, type II diabetes was not a problem, but the WHO predicts that it will be the biggest threat to health in 2020.

In future the mental and social side of health will be at the forefront of health issues. ICT could be used to treat the physical or psychological side of depression.

Homecare technologies: The technologies used in self care can be categorised as follows:

- **Home security**: sensors to help with safety issues such as leaving the gas on, switching the heat on when it gets too cold, sensing before the bath has overflowed. It was suggested that currently 1.5 million people already have some of these (including simple community alarms such as a panic button or pull cord).
- **Vital signs**: sensors to detect vital signs and manage chronic diseases such as diabetes. The technology for this is largely available although it has not necessarily been taken up.
- **Activities of daily living (ADL):** detecting individuals moving about in their house and performing routine tasks to detect early onset of conditions such as Alzheimer's. This technology is under development as there are still issues around how you use data to detect problems. The difficulty is in reliably inferring high level human behaviour from socially acceptable low level sensor data, such as movement or vibration.
- **Information** – interactive healthcare applications such as NHS Direct and digital TV services. Also information used for education and for information related to health (eg weather forecasts – pollen, pollution levels – which may affect certain conditions).

Some of these technologies are developed, but not all. There remain issues around what is done with these data and how this feeds back. This is particularly true of ADL technologies – it is unclear how you model or detect onset of conditions from the data you receive from the sensors – especially if there are added complications such as two people living in the house. Many sensors are available now, but more robust, reliable and smaller ones will be developed in coming years. There has been much work on smart homes for Telecare[3].

It was agreed that in the next 10-15 years healthcare will mainly utilise existing technologies in new ways and in new settings, rather than brand new technologies. Convergence and improved interoperability would improve healthcare – and would involve all people involved in healthcare. However, it was suggested that nanotechnologies and robotics would have an impact: robotic pets could monitor and provide company for elderly people, cognitive prosthetics could be used to enhance memory.

[3] Eg see http://technology.guardian.co.uk/online/insideit/story/0,13270,1546344,00.html

Much work has been done on SMART homes, particularly in relation to chronic disease management and dementia. One specific example was the 'Smart toilet' that constantly monitors excretions[4].

4 Primary care

Changing role for General Practitioner: It was widely agreed that GPs would be seen as 'triage brokers', directing patients towards more specialised treatment elsewhere. NHS Direct and walk-in health centres provide a different form of triage to the GP: this illustrates the proliferation of primary care providers. However, it was suggested that people would still go to their GPs for more complex conditions.

Making better use of patients' and GP's time: It was suggested that better use could be made of GP's and patients' time. For example automated tests could be undertaken in GP's waiting rooms whilst patients waited for their appointments. For GPs, smart paper and voice recognition could be used to reduce the time required to input data to electronic systems.

Enabling better drug compliance: It was suggested that ICTs could help improve drug compliance, which was recognised as a major problem (for example 80% patients with high blood pressure do not take their prescribed medicines correctly). However, it was also noted that there are many non-medical reasons why patients might not take their medicines, so ICTs would not solve all of the issues relating to drug compliance.

Blurring the leisure / medical boundary: It was suggested that the border between leisure and medical treatments would become increasingly blurred, with examples being energy patches, Viagra and neutracueticals.

Education / training for both patients & professionals. It was suggested that the general public only look at health issues when they're unwell. It was also noted that information needs to get to the key users – putting details on a website does not mean that the desired audience will read it. It was noted that knowledge does not always lead to changes in behaviour (the example of the harmful effects of smoking was given).

Unintended negative consequences of new ICTs: It was noted that some cancer treatment drugs are potentially degraded to toxic by-products by high frequencies used in some ICTs and that studies are being undertaken in Finland, Israel and US on this.

5 Secondary / tertiary care

Computer aided diagnosis, treatment and decision support tools:

ICT is being used for Cognitive Behavioural Therapy allowing patients to access their data independently. It can address the bottleneck caused by the lack of therapists and may increase compliance as patient can have a session at a time that suits them.

[4] http://news.bbc.co.uk/1/hi/health/1433904.stm

ICT can also empower patients through supporting decision-making eg it can be used to support women during genetic counselling for breast cancer. Patients can be shown timelines for possible treatments and decide when to have particular treatments.

ICT can support evidence-based decision making through decision-support aids eg ISABEL project (http://www.isabelhealthcare.com/), a web-based clinical decision support system for paediatric medicine. ICT can help avoid mistakes and alert physicians to possibility of rare conditions/complications. Similar systems can be used to improve compliance and communicate best practice.

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Appendix one: workshop attendees

1 Professor James Barlow, Chair in Technology and Innovation Management, Imperial College
2 Mr Bahadar Bhatia, Healthcare Informatics & Computing Special Interest Group, Institute of Physics & Engineering in Medicine
3 Dr Jerome Declerck, Chief Scientist, Siemens Medical Imaging
4 Mr Gilbert Devey, US National Science Foundation
5 Dr Stephen Elsby, EPSRC
6 Dr Jonathan Flint, CEO, Oxford Instruments
7 Professor John Fox, Cancer Research UK
8 Mr Stephen Harbon, Programme Manager, NHS PASA Centre for Evidence-based Purchasing
9 Dr Peter Harrop, Chairman, IDTechEx
10 Professor Derek Hill, CEO, Ixico
11 Professor David Ingram, Director, Centre for Health informatics and Multiprofessional Education, UCL
12 Dr Rob Lang, Corporate Resources Director, MRC Technology
13 Professor Paul Matthews, Professor of Clinical Neurology Director, Centre for Functional Magnetic Resonance Imaging, University of Oxford
14 Mr Mark Outhwaite, Independent healthcare policy consultant
15 Dr Ferdinand Peer, Senior Manager Application Field Mobile Health, Vodafone Group Research & Development
16 Dr Paula Procter, Reader in Informatics and Telematics in Nursing, University of Sheffield
17 Dr Jem Rashbass, Cambridge MIT Institute
18 Professor David De Roure, Head of Grid and Pervasive Computing, University of Southampton
19 Mr Martin Sadler, Director, Hewlett Packard
20 Mr Bill Sharpe, CEO, The Appliance Studio Ltd
21 Professor Lionel Tarassenko, Professor of Electrical Engineering, University of Oxford
22 Professor Paul Wallace, Professor of Primary Health Care, UCL

RS working group members:
1 Sir Michael Brady FRS, University of Oxford
2 Dame June Clark, University of Swansea
3 Professor Brian Collins, Cranfield University
4 Mr Paul Garner, BT
5 Professor Richard Kitney, Imperial College
6 Professor Frances Mair, University of Glasgow
7 Professor Peter Wells FRS, Cardiff University (working group chair)
8 Dr Damon Wischik, University College London

Facilitators: Diane Beddoes, Jude Cummins, Julie Fenner, OPM
RS staff: Nick Green, Kate O'Shea, Rachel Quinn

Appendix two: workshop timetable

9:00 Coffee and registration (Marble Hall)

9:30 Welcome and introduction - Professor Peter Wells FRS, Chair of RS working group (Kohn Centre)

9:35 Overview of expected healthcare drivers and needs – Julie Fenner, OPM

9:45 Breakout groups

A *Home care breakout group* (Kohn Centre)
Group remit: Technologies to be used in people's homes for treating known medical conditions, self-care, detecting and identifying new conditions and / or monitoring / maintaining health. These technologies could be used by the patient, their carers or healthcare professionals (such as health visitors or community nurses).

B *Primary care breakout group* (Conference Room)
Group remit: Technologies to be utilised in primary care by general practitioners, public health specialists and staff in health centres and community hospitals These could relate to education concerning prevailing health problems and the methods of preventing and controlling them, diagnosis and treatment of common diseases/injuries and provision of essential medicines.

C *Secondary and tertiary care breakout group* (City of London Room 3)
Group remit: Technologies to be used in hospitals, for the diagnosis and treatment of both in and out patients with medical conditions that cannot be managed in the community or at home.

12:00 Plenary session, with feedback from break out groups (Kohn Centre)

1:00 Closing comments - Professor Peter Wells

1:05 Lunch (Marble Hall)

Appendix three: Overview of expected healthcare drivers and needs

This will outline what the issues facing the NHS in the next 10-15 years and the wider healthcare context.

Patient-led healthcare: Increasingly knowledgeable patients taking more active role in managing their own healthcare.
Implications of choice: May expose inconsistencies, regional differences and inefficiencies. Will require improved communication between service providers.
Service-user involvement: In planning services, governance, and building design.
Planning future services: Ensuring that services meet future health needs of the population.
Property integrated services: In particular, management of chronic conditions across healthcare boundaries.
Ageing population: Ensuring appropriate care patterns, providers and locations.
Changes in disease patterns: Increased focus on prevention and treatment of chronic conditions (eg diabetes, obesity).
Training / lifelong learning: Crucial with increased use of ICT. Needs to be fully integrated day-to-day role. More tailored ICT support required.
Development and implementation of ICT: The development of 'e-health'. Electronic patient records, e-referrals. Privacy and data security.
Funding: Ensuring resources are there to support new technologies, including training.
Wider context - practical changes: workforce contracts & issues; financial pressures, national targets & standards; organisational changes.
Wider context - philosophical changes: accountability; responsiveness; choice.