The impact of ICT on health and health care

Royal Society

Draft report on key findings

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working with you
to improve social results

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1. Introduction

OPM was commissioned by the Royal Society to run two workshops and conduct a number of telephone interviews to provide evidence from patients and their representatives and clinicians on:

- Future issues in healthcare from clinician and patient groups' perspectives;
- How scenarios concerning the development of ICT in the next 10 – 15 years will impact on such healthcare.

Two stakeholders groups were involved in the project:

- Healthcare professionals
  - 12 attended the healthcare professional workshop, which was held on 1st November 2005
  - 14 telephone interviews have been carried out with healthcare professionals. Three interviews are yet to be completed.
- Patient support groups
  - 9 attended the patient group workshop, which was held on 4th November 2005
  - 13 telephone interviews have been carried out with patient support professionals. Three interviews are yet to be completed.

This consultation is part of a wider study being undertaken by the Royal Society.

Executive Summary

Challenges facing health services over the next 10 – 15 years

Participants identified a range of general issues facing the NHS over the next 10-15 years. These are not seen as representing a sudden shift or break with existing policy agendas but as continuing a direction of travel whose basic route is already plotted. In general, therefore, participants focus on the future implications of changes already underway.

System-wide

- An ageing population, increasing numbers of people with chronic conditions and a declining birth rate are seen as placing pressure on existing services, generating changing patterns of need and changes in the nature of available provision.
- Continuous change within the NHS, both structural and through technological advancement is felt to be affecting staff motivation. Whilst a period of stability would be welcome, this is not seen as likely. Instead, the pace of change is felt to be accelerating.
- The financial pressures of increased life expectancy and expensive medical interventions are seen as continuing into the future. The current policy of payment by results is seen as having significant implications for data management and for the development of IT packages to support this.
- Changing disease patterns, with the emergence of new diseases and patterns of distribution are thought to be driving changes across the system. Infectious diseases, the possibility of biological or chemical agents being used in terrorist attacks will require a rapid response across organisational boundaries.
- The split between funding and providing healthcare, under the government policy of plurality, will add layers of complexity to information sharing and present challenges to the management of funding flows.

Organisational issues

- Future healthcare should be focused around the patient, rather than structured around organisations. A networked model, with the patient at the centre, will lead to a breakdown of traditional boundaries and a shift from ‘location compartmentalisation’. Care will be available in a range of locations, many of which are not currently associated with healthcare. More care will be provided in people’s homes.
- A networked model will require more collaboration across health and social care. This will present challenges for information sharing, responsibility and accountability. However, it is seen as being more stable across change.

Practitioner issues

- Recruitment and retention is seen as a problem now and one which is likely to impact in the future, on both the organisation and delivery of services and the required skill mix. Different roles will emerge, partly as a response to workforce shortages and partly in response to technological innovation. Changing demographics and models of care are also seen as driving changes to the current roles and skill mixes.

- The number and range of specialists is felt likely increase, though many will also have more general skills. The networked model will drive the need for a 'lead professional 'approach, with one health professional managing care for their patient across different services.

- As the quantity of data increases, the challenges of managing it will grow. New ICT will be needed to support knowledge management and decision-making.

- Training and lifelong learning will be essential to enable practitioners to draw most benefit from new technologies. Integrating learning into a healthcare professional's everyday role is seen as crucial.

Patient and public issues

- The focus on prevention and leading a healthy life will continue. This has implications for how health messages are delivered and for the support needed to encourage communities and individuals to maintain their own health.

- Patients will increasingly be involving in managing their own care and health services will need to consider very carefully what mechanisms are appropriate for extending this involvement and ensuring it is effective.

- Organisational change and the plurality of providers are likely to further extend patient choice. However, choice is not seen as implying a 'consumer health market'. Value is felt to be created in the interaction between patient and provider and the relative contribution a patient is able to make will differ, depending on their condition, the stage of an illness, socio-economic background, age and other factors. Relevant and timely information will need to be in place to support choice.

- Patients are growing increasingly knowledgeable. The internet has provided access to research information and to patient campaigning and support groups which might previously have been out of reach. This is already changing the power relationship between professional and patient. Healthcare professionals will need to adapt to this and accept the benefits and challenges it will bring to their practice.

- Patients' expectations will continue to grow, driven by the choice agenda, increasing patient and public involvement and a focus on self-management. This will give rise to concerns about how professionals will deal with patients' expectations being out of line with what is clinically most beneficial – or financially available.

- Wider public involvement in planning services, governance, and management and building design will present a challenge to services, which will need to consider the extent to which they are willing to embrace participation. It will also present challenges to health care organisations, which will need to have appropriate engagement mechanisms in place.

Potential ICTs and their application

ICT is seen as having a key role to play in addressing all of the above challenges, although in some case the availability of new technologies will bring new challenges. The general consensus is that change over the next 10 – 15 years will not be the result of radical new technological breakthroughs but of the extension and refinement of existing technologies. This means that the future successful use of healthcare technologies will be determined by decisions being made now.

Email and internet

- The internet, email and other 'general' communications have had a considerable impact on healthcare, from both the professional and patient perspective.
- On-line access to doctors surgeries means that repeat prescriptions can be ordered at a time convenient to the patient, without the need to leave the home. Appointments can also be booked. Some programmes may allow patients to self-manage their conditions more effectively.
- The differential access to these technologies may result in the current 'digital divide' exacerbating existing health inequalities.

Other communication technologies

- Web- and video-conferencing are seen as bringing a range of benefits to healthcare professionals, including easier and more timely access to specialist knowledge, the possibility of assessments in non-traditional locations and more efficient use of time.
- Mobile communications technologies, such as PDAs, will allow those working in the community to access electronic patient care records and input data whilst on the move.

Other technologies

- Monitoring technologies for use by patients in their own homes, in nursing homes or hospitals are increasingly being used.
- There is an increasing separation between the capture and analysis or diagnosis of images. Analysis can be done overseas, or by healthcare professionals at home.

System-wide and inter-organisational issues

- ICT allows for more accurate projection and analysis of future healthcare needs across the country. Improved monitoring of individual health status could lead to the development of a picture of public health that could inform the planning, development and provision of future services.
- Electronic patient records (EPR) hold out the promise of effective data sharing which can support improved continuity in patient care. A single record for individuals might be developed, which would include all information relating to their contact with public services, including health, social services, housing and income tax.
- The sharing and promotion of best practice is likely to improve through more rapid communication and increased information sharing.

The relationship between patients and health professionals

- Technology could allow multiple patients with the same condition to consult simultaneously with a single consultant. They will hear the questions and answers of others, so increasing their knowledge of their condition.

- Patients might have electronic consultations, email queries to their healthcare professional. The implications of advice given without examination and wider attitudes towards emails (eg, the tendency towards informality and speed) would need to be considered carefully.

- ICT could support improved care by identifying tasks relating to a specific individual care. Activity prompts might make 'hand over' between different health professionals more efficient, improving the patient journey and continuity of care.

- The roles of pharmaceutical companies and independent healthcare providers need to be considered, in particular in relation to the development of diagnostic tools that lead to the prescription of drugs produced by the company that provides the tool.

Individual patients

- Patients will increasingly use automated monitoring and testing, including mobile technologies to log health status. This might help with earlier diagnosis and hence prevent acute exacerbations of long-term conditions. It might also mean that care can be targeted to those who most need it, on the basis of real information, rather than being given to those who are most vocal. The difference in patients' abilities to take advantage of monitoring technologies needs to be taken into account. Careful and considered design is also crucial.

- Challenges to greater use of in-home monitoring equipment include costs, a need to understand the context in which data is collected (eg, the reason for a raised heart rate) and the potential compromise to patient privacy/

- Increased monitoring of individual health might lead to more targeted health promotion messages. There will be a need to distinguish information from advertising and for the source of the promotion to be evident and trusted.

- Greater use of the internet amongst the general population will allow a growing number of patients to draw on a wider range of information. On-line support groups will grow and their voices will strengthen. There is currently felt to be a need amongst the public for communication and information that falls between complex research findings and populist, often unreliable, media health stories.

- Access to services over extended hours will grow beyond NHS Direct in its current form. As the number of commercially available healthcare products grows, patients will be able to monitor their own health at times most convenient to them.

Potential impact of these technologies

Impact on organisations

- ICT is seen as catalyst for organisational change but should not be the reason. Technology has the potential to improve information sharing, for example, but if a *culture* of information sharing is absent, the potential is unlikely to be fulfilled.

- Resources for implementation and training are essential. If staff need to be released for training, this will have an organisational impact.

- Communicating early and well, ensuring that change is inclusive, learning from both the public and private sector and using available research are essential.

Impact on existing systems

- The primary impact of ICT is likely to be on patient involvement and patient care, including reduced waiting times, more informed and empowered patients and more flexibility and choice.

- Poorly implemented or configured technologies, together with the manner of their introduction and training available, will lead either to a repetition of existing problems or increase resistance to new ICT.

Impact on the patient – professional relationship

- It may be that the impact of ICT will be negligible, if these are introduced appropriately and play a supporting role, enabling healthcare professionals to focus on their core task of caring for their patients.

- Positive impacts could be the development of more open and equal relationships, as patients grow more knowledgeable and influential in directing the course of their care. Anxiety might also be reduced as test results or reports will be more speedily available.

- A major concern is the potential for less face-to-face contact between healthcare professional and patient, leading to a reduction in the emotional support offered by personal physical contact, which is seen as having health benefits.

- Professional resistance to more empowered patients has the potential for impacting negatively on patient-professional relationships.

Impact on healthcare professionals

- The development of new roles, such as a health information specialist, and the better and more focused use of specialist skills are seen as likely. The shift in culture to patient-led services, accelerated by improved ICT, is also seen as driving the emergence of new roles.

- Ensuring that patients understand new roles is crucial to their successful introduction. Many still view healthcare professionals as either doctors or nurses and are unaware of the variety of new roles that have emerged over the past few years. Further changes will need to be communicated carefully so that their role and value is understood.

- Patients having easier and faster access to healthcare professionals might lead to communication overload, with emails to respond to, requests for information from other professionals, self-monitoring data to log or interpret. New roles may need to be developed to support these additional pressures. However, time saving is also a potential benefit, with

'at a glance' information replacing the need to leaf through journals or decipher pages of handwritten information.

- Technical support will need to be in place to ensure malfunctioning technology does not lead to curtailment of services. Technical support staff may need to be trained to understand the context in which technology operates in healthcare.

Impact on patients

- Understanding the impact on patients of having, for example, self-monitoring equipment or therapeutic technology in their homes will be crucial. Aesthetics, size, security, maintenance, insurance costs – all these will be important issues raised by patients.

- The impact on patients will not be consistent. Older patients may have more difficulty in accepting or using technology, though this is likely to change over time, as technical literacy becomes a basic skill. Well-designed technology should minimise difficulties. People with disabilities may gain great benefit from remote technologies that allow them access to services from home, as may people living in rural areas or those with limited local health infrastructure.

- There will be a need to consider the balance of safety and privacy, both in terms of data confidentiality and in establishing protocols for monitoring equipment. Monitoring equipment should not compromise independence.

- Protecting equality of access is paramount. If technology results in reduced face-to-face contact, those who are less willing or able use it may be negatively affected, especially if services are re-configured on the basis of an assumption that people will be able to use, will prefer to use and will have access to technology.

- Questions around the use of data, such as who owns it, who controls it, who can have access to it, who can change it and whether it can be used for purposes other than the direct care of the individual to whom it relates will need to be answered. This is particularly important as an increasing number of independent providers enter the healthcare field.

- Faster patient pathways, more diagnosis and treatment in the community and a more balanced relationship between professional and patient could lead to an improved overall patient experience.

- The impact on carers of more healthcare being delivered in the home was not explored in any detail during this project. However, their views will need to be heard and taken into account, since there may be additional benefits or disadvantages to them which patient groups and professionals would not identify.

Lessons for the future

- Learning from the use of technology in areas other than healthcare will help those responsible for scoping, developing, procuring and implementing new equipment.

- The uptake of new technologies needs to be driven by the health needs of patients and the public overall rather than by what is available and marketed by private companies.

- Ensuring that there is a need for collecting information will help to prevent the accumulation of data which sits unused on a database. A fundamental shift in attitudes to an outcomes approach is seen as one way of preventing the collection of data for no clear purpose. This approach will help to ensure that strategic plans, processes, training and education are determined through reference to the wider outcomes desired. There will be a need to negotiate between the different outcomes required by different people.

- Continuous and improved patient and public involvement is a basic requirement for the successful introduction of new technologies in healthcare, in particular in relation to the ethical issues.

- A more collaborative approach is seen as necessary to realise fully the advantages of ICT development. More broadly, this is related to the development of a culture in which health is seen in the broader context of social, mental and physical wellbeing, with patients being empowered to take responsibility for their own good health.

- Education and training, aimed both at removing the 'scary' factor and at ensuring that the underlying rationale for its use are understood. The concern amongst some healthcare professionals that the growth of technology will get in the way of the relationship with patients that is at the heart of their work needs to be addressed.

- Involving health professionals at every stage in the introduction of new technologies is important. There is some concern that recent continuous structural and organisational changes have led to healthcare professionals being resigned to change, rather than engaged with it.

- The appropriate approach to implementation will depend on the nature of the technology and the changes it will bring. For some, a 'big bang' approach might be most fitting. For others a more incremental method would work. All those involved will need to be aware of the rapidity of technological change and the ease within which systems become obsolescent.

- The government should take a strong and confident lead, providing the necessary investment and regulation and communicating and consulting clearly and well about planned changes. The government's current approach is seen as indecisive and unimpressive.

- The research challenges presented by new technologies will need to be addressed. These include the impossibility of large randomised trials when only a few prototypes of very expensive equipment may be available. The absence of good and reliable research data may have legal implications for health authorities or trusts refusing care to patients, along the lines of the recent herceptin case. The government may need to assume responsibility for funding the evaluative and pilot studies which will form the basis of future ICT developments. Evaluation is at present seen as inadequate and its value under-recognised.

2. Challenges facing health services

Participants identified a range of general issues facing the NHS over the next 10-15 years. These are not seen as representing a sudden shift or break with existing policy agendas but as continuing a direction of travel whose basic route is already plotted. In general, therefore, participants focus on the future implications of changes already underway.

The issues identified can be categorised under four themes:

- System-wide
- Organisational
- Health professionals
- Patients and the public.

System-wide issues

- **Demographic change**

Demographic change is seen as a critical issue facing the future of the NHS and healthcare in the UK. This includes:

- An ageing population, with associated increased health needs and long term conditions;
- A rising incidence of people with long term conditions, both amongst the older and younger population (e.g. increasing incidence of diabetes and heart disease in young people);
- A declining birth rate, with a related fall in the numbers of young people.

These three in combination will create challenges to the public sector in general and to health services around:

- changes in patterns of need around health and social care will necessitate changes to current patterns and models of service provision
- increased need for services to support older people and those with long term conditions – with real challenges to the capacity of services to meet demand;
- A fall in the number of young people entering health and social care professions to meet the increased demand for these services.

- **Continuous change**

The NHS is in the midst of major change and it is clear from some respondents that there is some weariness with this, with staff becoming de-motivated. A more stable future is hoped for and seen as necessary to address recruitment and retention rates in particular. However, the pace of change is instead felt to be accelerating, both in terms of technological and other advancements in treatment and in terms of structural and organisational changes to the NHS and the wider healthcare system.

- **Funding**

  Financial pressure is placed on the current and future funding of health services by the increasing availability and use of expensive medical interventions and increased life expectancy. This is likely to lead to growth in the demand for healthcare services and treatments**.** Investment will also need to be available to ensure that the health service is able to make the most of the new opportunities offered by ICT.

  Under the policy of payment by results, individual health care organisations – both NHS and independent sector – are paid by the NHS for the care that they provide to the individual patient, rather than through block contracts. This already has significant implications for data management about patient activity and accounts management, with associated implications for the development of IT to support this.

- **Changes in disease patterns**

  The emergence or identification of new diseases, changes in the populations suffering these diseases and changes in their patterns of distribution are likely to drive changes to health care across the system. There is also an increased emphasis on infectious disease management and the possibility of terrorist threats involving chemical or biological agents. The potential flu pandemic, widely seen as both imminent and inevitable, is seen as a more immediate challenge. In response health services need to gear up to respond in a unified way at speed across organisational boundaries.

- **Plurality**

  The government policy of plurality means that from December 2005 health care may be *paid for* but not necessarily *provided by* the NHS. This means that individual patients may receive different aspects of their health care from different organisations within the NHS and from independent sector providers in the voluntary and private sectors. The involvement of organisations outside the NHS will add layers of complexity to information sharing – both in terms of patient and management information. It will also present additional challenges to managing funding flows to support care.

Organisational issues

- **Models of care and organisational boundaries**

  At present, health services are structured around organisations. Future health and social care should, participants feel, be structured around the patient and services related to the individual. Existing networks in cancer care, and children's and maternity services are seen as providing models for future developments.

  Shifting the focus to a network model with the patient at the centre is seen as leading to a breakdown of traditional divisions – for example, between community, primary, secondary and tertiary care and the organisational structures built around them. This in turn will lead to a shift from 'location compartmentalisation' and the removal of boundaries, which at present mean that specific types of care are delivered in specific places.

The integration of health care with other services is already having an impact, on processes if not always on structures. The pressures for organisational change and new models of care will come too from the increased number of patients with multiple conditions requiring on-going support, implying the need for more flexible multi-disciplinary and multi-agency services.

In addition, there is a new emphasis on providing services in or close to people's homes. This will receive additional attention when the white paper on healthcare outside hospitals is published (expected in January 2005). This means changing the location and current model of service provision for many health care services that are currently provided on a hospital site.

A networked model brings challenges, in particular around responsibility and accountability – for example, where responsibility lies within the network for clinical and IT processes. At present, health care organisations are not seen as collaborating in ways that provide improved and cost effective care. Increased collaboration and resource sharing in administration, management and infrastructure support are seen as delivering benefit for both patients and services alike. An example of this is patient transport services, where shared scheduling has helped to reduce the number of journeys made. Funding mechanisms will also need to be addressed.

These organisational shifts are also seen as having implications for the current development of technology. If this is focused around organisations rather than being patient-centred, it will not be stable across change.

Practitioner issues

- **Workforce issues**

  Healthcare professionals raise the problem of recruitment and retention, seen as an issue now and likely to impact in the future on both the organisation and delivery of services and on the skill mix needed in the future. Workforce shortages are also likely to drive thinking about how roles can be extended and in some cases how tasks currently provided by health professionals can be provided by others. In some of the more specialised allied health professions, shortage of skilled practitioners is seen as reaching crisis point now and in need of addressing before the pressures mentioned above (demographic change in particular) increase any further.

  In addition to the shortage of clinical practitioners driving changes to the skill mix and role of clinicians, changing demographics and models of care are also likely to drive change in this area.

- **Approaches to 'patient management'**

  Some suggest that there will be an increasing number of specialists, who are also able to perform more general tasks. This may lead to use of a 'lead professional' model, with a single health professional managing care for their patient across different services, which might include social as well as health care. This model is already in place in Great Ormond Street, with a child being assigned a key worker from the specialism required for their main condition.

- **Knowledge management**
  There are huge challenges in knowledge management, as knowledge is continuously extended and the quantity of data relating to individual patients increases. This will require good quality ICT support for knowledge management and decision making. Participants note that greater quantities of data are useful only to the extent that the processes and people are in place to turn this into useful information.

  Robust decision support could also support extending professional roles, helping to address the workforce issues, with limited additional training.

- **Training and lifelong learning**

  This issue links in particular to ICT and the support implications of this for practitioners. Ensuring that training and learning become fully integrated into a healthcare professional's day-to-day role is seen as crucial.

  'Training needs to be continuous and integrated…particularly with the agenda for change and new plans for the workforce. Every member of NHS needs person-specific training.'

Patient and public issues

- **Focus on prevention**

  Patient representatives tended to focus on the renewed emphasis on prevention and on encouraging individuals to live healthier lives. The focus on encouraging people to take greater responsibility for maintaining their own health is seen as driven by some of the changes identified earlier in this section. The ageing population is seen as having higher expectations of the quality and availability of services; there are a growing number of people with long-term chronic conditions and an assumption that good health will be maintained until the point of death.

  The new focus on prevention has implications for health and other services in how health messages and support to communities and individuals to maintain their own health are best delivered.

- **Involving patients in their own care**

'Patients [want] to be fully involved in their care… They [want] to know about how to become healthy and they [want] sufficient information about options for treatment and to be able to follow treatment accurately and liaise with medical centres appropriately.'
(Healthcare professional)

Increasingly, patients want to be involved in their own care and initiatives such as the expert patient programme are designed to support them in that wish. Health services will need to think about more mechanisms for extending patient involvement in their own care.

- **Supporting patients to make choices**

Giving patients more choice about how, when and where they receive treatment is one cornerstone of the Government's health strategy.[1]

Under the government's policy of patient choice, patients will have the opportunity to choose where they go for elective care, and there is already discussion about extending choice to people with long term conditions and mental health needs and into primary care services.

The introduction and extension of choice in health services is, in general, viewed positively. However, some urge caution in drawing an equivalence between 'the patient who chooses' and 'the consumer health services'. Both practitioners and patient representatives emphasised the importance of creating value in health services through the interaction between healthcare professional and patient, which is seen as displacing a straightforward provider/producer – consumer model.

Some participants in the patient support workshop emphasised the need to recognise that there will be occasions on which patients are not able to make choices, other occasions on which they are not willing to make choices, that some patients will not want choice under any circumstances and that some groups of patients will not be able to exercise the choices available to them at all. The value of choice is not seen as constant for either a single patient or across all patients.

'Choice can be stressful when you're very ill.'

'Choice is the remit of the middle class – we could end up with a schism, with choice available to those who can ask for it.'

Variability amongst patients in their use of available choice will be accompanied by different information needs. Health services will need to provide different types of

[1] http://www.dh.gov.uk/PolicyAndGuidance/PatientChoice/fs/en

information in different formats for different patients making different choices. There will also need to be support in place to ensure information and the implications of choice are understood by people with different capacities and capabilities.

- **Increasing patient knowledge**

  The internet has given many patients access to information that would previously have been out of their reach. Health practitioners remark on the increasing number of patients arriving in their surgery armed with information on their condition or symptoms. This is seen as changing the power relationship between health practitioners and patients, with one participant describing it as becoming more 'adult'. Some feel this will present a challenge for practitioners, who will need to be more open, more able to acknowledge uncertainty or lack of knowledge and more able to say no to patients asking for treatments learned about on the internet.

  'Already I wouldn't dream of going to see my GP without having looked up on the internet first what might be wrong with me.' (Patient support workshop)

- **Rising patient expectations about access to services and technologies**

  The choice agenda, greater attention to patient involvement in healthcare and the growing knowledge – and power – of patients have contributed to rising patient expectations. As the use of technology grows and mobile technologies provide a greater range of services, the expectation that health technologies will offer new treatment options to patients also rises.

  Some health practitioners raise concerns about the difficulties this might present. As more sophisticated technologies become available and patients become more informed through their own research, their expectations may increasingly be that they should have access to these technologies. A recent example of this issue is the national publicity about prescribing herceptin through the NHS.

  This creates two challenges for health professionals, one around managing patient expectations when the treatment they have identified may not be appropriate to them; and one around the danger that health professionals are expected to act in a rationing role.

  - Rising expectations about people's own health

    Improvements in the general health of the population, in the range of health services available and in access to health services have contributed to an increased expectation amongst many people that they will live long and healthy lives. This in turn contributes to a rising expectation of what health services should deliver to support this.

  - Acting in a rationing role

    The government has sought to address such issues through the NIHCE, creating national guidance on what support should be available through publicly funded

health services. Again, the deficiency of a 'pure' consumer model operating in health care is raised.

'I've just heard of a colleague with a patient thumping the table and demanding technology, saying they shouldn't be denied it – even if his judgement is that it's not the most appropriate for that patient. Patients are more informed and knowledgeable about what's out there, but not necessarily about what's appropriate for them. Some could be a waste of money.'

(Healthcare professional)

- **Public involvement**

Government policy across public services has placed an increased emphasis on involving not only users of services but the wider public in service planning, building design, service development and governance. Within health services, mechanisms for achieving this include Section 11 of the Health & Social Care Act and the introduction of Overview & Scrutiny Committees based in local authorities.

This is seen as presenting a challenge to the services themselves and the extent to which they are willing to embrace the active participation of the wider public in planning health services. It presents too a practical challenge to health care organisations to ensure that all sectors of their local population are appropriately engaged and / or represented in planning and decision-making processes.

'You need the right information at the right time which is accessible to the people who need to have access to it and accessible to the service user.' (Healthcare professional)

'Patients should know what care they should expect. Patients can be involved in governance and help to drive the health service.' (Healthcare professional)

3. Potential ICTs and their application

ICT is seen as having a key role to play in addressing all of the above challenges, although in some case the availability of new technologies will bring new challenges. Just as the issues facing health care over the next 10-15 years are seen as continuing trends already in motion, the general consensus is that change over the next 10 – 15 years will not be the result of radical new technological breakthroughs but of the extension and refinement of existing technologies. This means that the future successful use of healthcare technologies will be determined by decisions being made now, making it particularly important that the right range of skills and experience contributes to those decisions. It is important too that information being transferred into an electronic format is clear and well-organised, since computerisation will not cure existing chaos, but simply transfer it to a different medium.

'I'm quite sure, as we go on, that ICT ought to play a role in keeping people in their own homes; and the monitoring technologies that we know are coming. It ought to be possible for ICT to improve NHS responsiveness and communications. For example, with call centres, websites, faster interactions with people and not forgetting who people are.'
(Healthcare professional)

'If you computerise a mess, you get a mess.
(Healthcare professional)

This section looks briefly at how familiar 'everyday' technologies are used in the context of health and healthcare. It looks then in more detail at how ICT might address the issues raised in the previous section, the potential impact of doing so, and the potential challenges at 3 levels:

- System-wide and inter-organisational
- Health professionals and the impact on their relationship with patients
- Individual patients

'Everyday' technology used in healthcare

Email and internet

All participants mentioned use of internet, email and other 'general' communications technology. Participants from patient representative groups tended to refer primarily to how these have helped to support communication or information gathering. Some from groups representing patients with specific conditions or from groups whose access to healthcare is currently limited referred to particular technologies designed to meet the needs of these groups.

Amongst patient groups, the internet in particular is seen as a means of empowering patients and carers. This might be through access to research information or treatment

options for particular conditions. An increasing number of patient support groups are also moving on-line, offering opportunities for sharing experiences, solutions to specific difficulties (which might be on the wider impact of health problems) and limiting isolation. Young people in hospital or at home can keep in contact with friends, make new contacts with children elsewhere suffering from the same condition or keep up with their education. People with physical disabilities can receive particular benefits from these technologies and wider use of speech-synthesised technologies will help to spread these benefits more widely.

For patient support groups, email and the internet have become increasingly important. A participant from a patient support group noted that, over the last six-seven years, the number of telephone enquiries on their helpline had reduced from approximately 26,000 to 20,000 per annum and that callers were more informed than previously, frequently ringing after having researched the queries on the internet.

> '*I champion the website as a method for people to contact us. We've seen that our discussion boards, in particular, have been really popular.'*
>
> (Patient support group)

A further benefit of communications technology identified by patient support groups is being able to order repeat prescriptions on-line, at whatever time suits you.

In the area of mental health, on-line services such as Cognitive Behaviour Therapy may help patients to self-manage their condition, so reducing the call on services and providing them with more independence and self-esteem.

Other communication technologies

Web- and video-conferencing technologies are seen as bringing a range of general benefits to practitioners, including:

- Easier access to specialist knowledge for general practitioners
- Possibility of assessments being done in 'non-traditional' locations – eg, from police stations and prisons
- More efficient use of time (no travel time needed)
- Better use of limited specialist resources
- More flexible professional development opportunities

> '[Telemedicine] w*ould provide a link between forensic client services and the local community. Consultant Psychiatrists could provide an assessment from hospital to the custody room and/or prison.'*
>
> (Healthcare professional)

As these technologies become more widely used, however, it will be important for healthcare professionals to understand the perspective of patients, who may not see the same benefits. In discussing video-consultations, one patient support group participant noted:

'I have my reservations. There might be [some clinicians] *who use it as an excuse to avoid proper consultation. Clinicians could see it as an easy option. From a user's perspective they could veil issues more easily by ducking out of providing all the information they have.'*
(Patient support group)

Mobile communication technologies are seen as particularly useful for professionals working in the community. PDAs, for example, can give access to electronic patient records or allow data input in areas where access to PCs or laptops is limited. These might be of particular use in rural areas where people might travel some distance between patients. However, some raise a note of caution about signal strength in some areas of the country.

System wide and inter-organisational issues

- **Public health monitoring**

From the planning perspective, ICT allows for more accurate projection and analysis of future healthcare needs across the country. Data gathered from monitoring of individual health status could be aggregated to inform a more detailed picture of public health that could be used to support the planning, development and provision of services in the future.

If individual data is to be aggregated to support public health monitoring, this secondary use needs to be considered in the design phase, both in order to generate useful public health information and in practical terms. For example, the system will need to work through complex information to generate meaningful data – e.g. clinical outcomes (such as standardised mortality ratios) need to include severity and lifestyle.

- **Data sharing**

Managing patient data is seen as a critical challenge. Electronic patient records (EPR) hold out the promise of shared information across different regions and health care professionals and this is generally welcomed.

Data sharing, for example, of individual's health records is important in bringing about an improved experience of health services from a patient perspective. Effective data sharing can support improved continuity in patient care. At present many patients feel that they have to co-ordinate the various healthcare professionals themselves by telling them what treatment, advice etc other healthcare professionals have given them.

Effective sharing of health records will be increasingly important as:

- Different aspects of a single patient's care are provided by different organisations both within and outside the NHS (particularly under the government's policy of plurality)

- There is increased emphasis on joined up working (e.g. between health and social services).
- Effective data sharing across organisational boundaries is vital to avoiding risk and supporting patient safety.

There may also be a move towards the creation of a single record for individuals that includes information relating to all their contact with public sector provision – e.g. health, social services, housing, income tax.

This data sharing could support:

- Care planning for the individual across organisational boundaries and services.
- A reduction in face-to-face appointments between the patient and specialists, with contact being mediated through, for example, their GP. I.e. patients would not, for example, need an appointment with the specialist to be given results from their test and a package of healthcare. The results and recommended package of healthcare could be uploaded onto their record and the face-to-face discussion held with their GP. This approach could also lead to an increased role for specialist nurse practitioners. It was felt that GPs and consultants would potentially welcome this approach.

The Office for Science and Technology is currently looking at issues around increased sharing of personal datasets across public sector bodies, including for the purposes of health research. This includes looking at public attitudes towards, for example, the use of pseudonymised data for longitudinal studies which could provide valuable data on environmental health issues. Findings from this work are scheduled for launch towards the end of November.

Challenges in implementing data sharing potentially include:

- **Ensuring access:** providing alternative means of access for people in rural areas where mobile signals are weak or non-existent.
- **Agreed clinical protocols:** ensuring that the protocols are adequate to capture the necessary specialist information and in a sufficiently consistent format.
- **Confidentiality and data protection:** Patient groups and professionals alike raise the question of confidentiality. Some suggest that this is not a new issue, simply one that the shift to EPR has made stark and pressing. Advice from professional bodies is at present seen as ‘ambiguous’ and leadership and information are both seen as essential, for both patients and professionals. Harry Cayton, Director at the Department of Health, is currently leading work to explore issues relating to patient confidentiality.

- **Sharing and promoting best practice**

The time lag between the development of good practice and its general adoption is significant. Participants saw exploration of technological solutions to reducing the time between the identification and broader adoption of best practice as crucial. The implementation of computer-aided diagnosis and decision-making systems was seen as one method of doing this (see below).

The relationship between patients and health professionals

Some of the potential changes to the current health professional and patient interaction as a result of increased use of ICT are described below:

- **Computer-aided diagnosis and decision support**

As described above, there are huge challenges in knowledge management, as knowledge is continuously extended. In addition, there is likely to be increased data relating to the individual patient. This implies the need for ICT support for knowledge management and decision making. Robust decision support could support extending professional roles, helping to address the workforce issues, with limited additional training.

- **Multi-patient appointments**

The technology could enable multiple patients with the same condition to have a consultation with a single consultant at the same time. In this way, patients would hear each others questions and the answers. This has been trialled and has reportedly been effective.

- **Electronic consultations**

Patients could have 'electronic consultations', where they might, for example, email queries or concerns to their health professional, who will respond by email. Some healthcare professionals raised concerns about the legal liability of responding to emailed concerns without examining the patients and of the tendency to write quick, informal replies to emails that in fact should be given more weighty consideration with carefully worded replies.

'I think we need more in here about a potential move away from face to face consultations to phone / tele-conferencing.' (Healthcare professionals)

- **Activity prompts for health professionals**

There is an issue of 'hand over' between different health professionals. This is particularly important in areas where patients require intensive input – e.g. handover from one ward team to the next for in-patients. It has associated issues of continuity of care and safety management. At the moment this is done most commonly through ward meetings and patient notes.

ICT could support improved care by identifying tasks relating to individual's care. The system would identify tasks that need doing for different patients in the order in which they

need doing and at the times they should be done – weighting them red, amber and green. This would simply be the adoption and application of customer relations management software already in use in the commercial environment.

- **The role of pharmaceutical companies**

In addition to the role of independent health service providers, that of pharmaceutical companies also needs to be considered, in particular in relation to the development of diagnostic tools that lead to the prescription of drugs produced by the company also responsible for the tool. Healthcare professionals ask if they will be faced with a choice of different tools developed by different companies, rather than generic ones.

Individual patients

- **Health status monitoring of the individual**

It was felt that testing and monitoring activities are likely to become more automated, with an increasing number of these being carried out by patients themselves, rather than health professionals.

The kinds of technologies envisaged included:

- The use of mobile technologies such as mobile phones that patients can use to log their health status (e.g. diabetes blood tests).
- Sensor technologies that monitor automatically without human intervention – e.g. heart rate monitoring.

More widespread self monitoring is seen as having a range of potential benefits, including:

- The prevention of acute exacerbations of long-terms conditions through earlier diagnosis and self management. For example, at Central Middlesex Hospital it is estimated that approximately 40% of A&E attendances are by people with long term conditions.
- Improved equity through increased monitoring of the individual health of patients already receiving care. At present, people self-identify need, which means it is often targeted to those who are most vociferous, rather than on the basis of clinical need. Monitoring can help to ensure that resources are targeted at those who have genuine need.
- Support for new ways of working and new models of care as automated monitoring could link into a disease management system not constrained by organisational boundaries. Combining the benefits of self-monitoring with improved data-sharing may help with the development of patient-centred, rather than organisation-centred care.

Patients were reported to feel better able to take responsibility for the management of their own good health through self-monitoring technologies. This confidence was seen as central to the paradigm shift needed to move towards a culture of health as something stretching wider than simply the boundaries of the hospital or the doctor's surgery. However, it is seen as crucial that differences in patients' ability to take advantage of

monitoring technologies are taken into account. The design element is seen as an important element in the acceptability – and hence success – of these technologies.

'It's a new paradigm of not having to be face-to-face with the patient…we've made a joint portal to enable people to make themselves positively healthy…it's a cultural thing… it's about the broader issues.' (Healthcare professional)

Key challenges in this area include:

- If individuals and their homes are to be equipped with additional monitoring equipment, this will have an investment implication. (Equipment 'libraries' could be established for short term equipment needs, as currently with, for example, wheelchair services.)
- The need to understand the context in which data is collected – e.g. raised heart rate because someone has been running – which automated collection may not necessarily provide
- The increased availability of health monitoring data has implications around the need for increased analysis of the data available
- The need to codify data collected from the individual, so that it can be aggregated to form a local and national picture of public health that would support public health monitoring and service planning and development in the future. However, this secondary use of the data would need to be planned in the design stage (see below)
- There is confidentiality issues associated with codifying and aggregating data that need to be clarified
- The increase in monitoring outside traditional health care environments has implications for the healthcare estate in the future, including the design and development of healthcare sites
- Ensuring that patient privacy is protected is also important.

Self-monitoring may also help to keep people in their own homes, through the use of, for example, smart clothes or self-administered drugs.

A potential downside of the general population having access to commercially available self-monitoring equipment is that more people might present to healthcare services with worries generated by these technologies. Whilst this might help to identify problems before they become severe, there might also be additional pressure placed on practitioners needing to reassure the 'worried well'. This issue of the difference between having information and understanding its value and implications is one that is raised in a range of different contexts.

- **Health promotion**

Increased monitoring of individual health could be used to develop targeted health promotion advertising, e.g. on-line or embedded in other media, for example, computer games. There are likely to be liability issues associated with automated health advice,

however, including differentiating advice from advertising or promotion of particular products. Participants feel that advice should be authorised by a health professional or agency or opted into by the patient (e.g. people could sign up to having advice on healthy eating or advice tailored to people of a particular age group).

- **Access to health information and support**

As the number of people with access to the internet grows, patients will draw on a wider range of information, relevant to both their own healthcare and to the wider, service level debates. The number of on-line support groups will grow and their voice will strengthen. Research data and new opportunities for remote care will also emerge. Some of those involved in patient support groups suggest there is a need for communication that falls between the two options currently felt to be available. These are high-level complex research findings, often inaccessible to ordinary members of the public and more populist and sometimes unreliable information delivered through the media.

- **Activity prompts for patients**

Existing technologies such as text and email can be used to provide activity prompts to patients, for example to take their drugs or attend health appointments.

- **Access to services over extended hours**

NHS Direct already gives access to health advice on a 24-hour basis. As internet access increases – for example, through television – and as mobile technologies grow in sophistication, a greater range of services are seen as likely to become available. The greater role of the private sector will add momentum to this.

In addition, the use of technology, for example in transmitting images to be read remotely, could potentially extend hours of access – as for example, specialists might practice from home or from countries in different time zones.

A further issue is the ability that patients now have to manage their own care, either with the support of health services or through commercially available mechanisms and tools – for example blood tests for people with diabetes.

4. Potential impact of these technologies

Impact on organisations

ICT is seen as a catalyst for organisational change. Some respondents caution against seeing it as the *reason* for change. Whilst the changes wrought by ICT can be significant, with the greater availability of information having the potential to impact on roles and competencies, these need to be seen within the context of the health care system as a whole and, in particular, in terms of their impact on patient care. A *culture* of information sharing is seen as just as important as the technology, if not more so.

Resources are a major concern. One respondent noted that the percentage of their budget spent on ICT was supposed to increase from 1.5% to 4%, but was not clear where this additional investment was going to come from and what impact it would have on existing services. Resources for the training – including releasing staff for training purposes – are also seen as having organisational implications.

A range of advice was given to those responsible for managing organisational change arising as a consequence of ICT. This included communicating well, ensuring the change process is inclusive, doing a lot of research prior to taking decisions, learning from a range of sources, including the private sector and healthcare services in other countries.

One respondent suggested that looking at the use of new technologies through an organisational eye can thwart progress and impede innovation.

'From a knowledge management point of view the culture of sharing information would be more important than having the best tools. You can have the best tools but if there isn't a culture to use and share information they won't work. If you're designing a system, you have to involve the people who are using it right at the beginning. The thing that should come from the top is rewarding or recognising people who use and share information. There's an assumption that people do it automatically but that's not the case because people feel competitive and also feel a sense of value by being the only person to have knowledge about a particular area.'

(Patient support group)

'Technology has the potential to improve things but actually just implementing it isn't actually improving it. A lot of these initiatives and policies tend to be driven by technology…it's a technological determinant, if you like… but that would be a major concern to me – its not the technology but the way people use it.'

(Patient support group)

'Do a lot of research. It's such a technological age - there are so many things being thrown at you it would be possible to follow something that ends up being completely useless.'

'People need to think cost-effectively. Most people think they are being cost-effective but actually they're not being realistic.'

'Communicate x3; try and involve as many people as possible in the planning so that the ownership feels wide within the organisation; and try to reassure people about their anxieties and provide necessary training in a liveable way.'

'I think it's important that all roles are involved as early as possible in assessing the consequence of systems upon their jobs. You can often find that effort is focused at the bottom end of the spectrum or it's focused at the top end of the spectrum and no-one bothers to talk to the people who use the system. Those who use it and those who consume the information.'

'We didn't invite any managers, IT people, government agencies in on the planning. We did it through innovation rather than implementation…. If I'd gone down the traditional route of coming up with an idea, asking for funding, getting permission….it wouldn't have been so successful.'

(Healthcare professionals)

Impact on existing systems

The impact of ICT on existing systems was identified primarily in the context of patient involvement and patient care. Reduced waiting times, more empowered patients with a better sense of their overall care pathway, more knowledge of healthcare and the choices available to them and more flexibility are all identified.

'I think it will reduce waiting times. The journey will be quicker. Sometimes patients find it difficult when they engage with healthcare to see the future or end of treatment.'

(Healthcare professional)

'ICT can increase awareness among patients about their health service or their conditions.'

(Patient support group)

Again, the configuration of new technologies and the mechanisms by which they are introduced are seen as having an effect on their specific impact. Duplication, systems which are not joined up and poorly-trained staff are seen as leading either to a repetition of existing problems or resistance to new ICT.

'If not done right, it could have negative impact, if systems are not joined up and all we do is proliferate a number of separate systems …there'll be more duplication not less...individuals will have to re-key the same information for different patient groups….people just won't do it and you'll get left with incomplete data…which is what we have now.'

(Healthcare professional)

Impact on the patient/ professional relationship

No impact?

Some participants feel that if new technologies are appropriate and appropriately introduced, they will have little direct impact on the relationship between professional and patient. Good technology is seen as playing a supporting role, helping professionals to do their job better by providing clear and accurate information more quickly.

For this to be the case, two things are seen as crucial. The first is design of the technologies themselves. Several participants noted that people have a tendency to blame themselves for being technologically inept, unfamiliar with or just scared of new developments. However, if the focus is shifted onto the adequacy of the technologies themselves and of the user interface in particular, the importance of good design – and of user involvement in the design process – becomes clear. Many participants commented on the difficulty older people can have in using technologies and one pointed out that it is the older generation that is likely to be making the decisions now about technologies and suggested that they are perhaps least equipped to be doing this.

The second crucial element in ensuring that technology supports, rather than interferes with the patient-professional relationship is education and training. These were seen as separate issues, with education providing a general understanding of how technology may be used for the most benefit and what it can do, in the widest sense. Training was seen as a more technical issue – understanding which buttons to push and patient safety issues.

> *'It's a fantasy about more technology decreasing the physical time that needs to be spent with patients.'*
>
> (Healthcare professional)

Positive impacts

- A more open relationship

Many point to the potential for a more transparent relationship between patients and practitioners. As patients have access to their own records, discussions will need to be more open and decisions will be more transparent. Patients will have greater influence over their own care and the relationship between them and their health care provider will in turn become more equal.

Speedier access to information might also help to alleviate some of the anxiety caused to patients who currently have to wait for test results or reports to be delivered by post or by hand.

> *'Overall, where we're up to at the moment is realising that we feel the medical profession has misappropriated people's health.'* (Patient support)

> *'It will break down the historical boundaries between certain specialties and also between doctor and nurse.'* (Healthcare professional)

'From what I have noticed myself, the patients go back much more satisfied that something's happening that they're able to see. The impact factor of an image, both static and dynamic, is much more for a patient than a few lines of text. Also, what happens is that healthcare professionals feel a bit more empowered because they're looking at live data and it's a complete integrated care record rather than a piecemeal one. It gives the patient a lot of satisfaction knowing that the doctor has got the whole picture.' (Healthcare professional)

For children, ICT is seen as having a range of benefits. Foremost amongst these is the opportunity for communication. Children may be able to share experiences with others elsewhere in the country and possibly elsewhere in the world, helping them to feel less isolated. ICT may also be used to support education services within hospital.

Negative Impacts

- Reduction in face-to-face contact

The possibility of the increased used of technology leading to a reduction in face-to-face consultation is of major concern to patient support groups in particular, but raised too by other healthcare professionals, notably GPs. The emotional support provided by personal physical contact – which can extend to a hug – is seen as a vital element in healthcare. In addition, some patient groups suggest that personal contact makes it more difficult for healthcare professionals to dismiss people's concerns.

- Professional resistance

Some participants raise concerns about healthcare professionals not responding well to more empowered patients. Challenges to professional authority made on the basis of internet research or the use of self-testing equipment at home may become more common and healthcare professionals will need to be equipped to understand and deal with the changed relationship implied by these challenges.

Impact on healthcare professionals

Views were mixed over the impact of ICT on the roles and responsibilities of healthcare professionals. Some felt there would be little change, with ICT playing a supporting role which would enable them to play their role more effectively. Others thought there would inevitably be changes. New roles might also be developed, for example, that of a health information specialist who would provide support to patients in accessing and understanding health information. This would ensure that the more specialised skills of clinicians could remain dedicated to patient care in much the same way as is currently understood. Some changes in role were seen as an inevitable consequence of the shift in culture to patient-led services, which will be accelerated through the use of improved ICT. Some professionals sound a note of caution, however. Existing technologies are felt, in principle, to allow these things to happen at present: *'but it's not happening and you have to ask why?'* An alternative view is provided by those who make no separation between technology and medicine: *'to me, medicine to day is techno-medicine'.*

If roles do change – and the majority view appears to be that they will – it will be important to ensure that patients understand the new professions and how they fit into healthcare overall. There is some concern that the recent changes have already left patients behind and that this will be exacerbated if good communication does not accompany the introduction of yet more specialist or new professions.

'I don't think the roles will change in essence. It will improve the relationship with patients and within professionals themselves. A lot of people are scared that district nurses, for example, will have reduced roles. ICT will support people's roles not take them over. Because of the lack of information, people think that their roles will change.'

(Healthcare professional)

'It's bound to change the role. Healthcare professionals will be more exposed to scrutiny from patients.'

(Healthcare professional)

'The NHS is changing very fast, including how and what people do. We haven't been particularly successful in communicating some of these changes generally. People understand doctors and nurses, not emergency care practitioner, nurse practitioners, etc etc – all the new roles that have emerged.'

(Healthcare professional)

- **Communication overload?**

Some GPs raised concerns about communication overload resulting from patients having easier and faster access to them. They suggested there might, for example, be large numbers of emails from patients requiring or expecting prompt responses. The amount of information, including test results and self-monitoring data will also place pressures on practitioners' time. Since the number of GPs coming into the system is unlikely to increase, there is a question over whether new roles are needed to cope with this information, such as that of the health information specialist mentioned above.

However, time savings are also seen as a potential benefit of electronic records, providing 'at a glance' information, with no need to leaf back through and decipher pages of chronological handwritten information.

- **Changing professional boundaries**

It has been noted above that the distribution of skills across professions is likely to be affected by new technologies and that new roles are likely to emerge. This will continue a shift that is already taking place, with some nurses having prescribing authority and this being extended now to physiotherapists, radiographers, podiatrists, optometrists and pharmacists. With the shifting professional boundaries will come an increased need for information sharing – which will, as has also been noted, bring with it questions around patient confidentiality and access to information.

- **Technical support**

Practical concerns are raised about the capacity of GPs to cope with the technical demands that might be placed on them by new technologies. The extent to which technical

support staff understand the healthcare environment is also seen as an issue; an example was given of technical specialists imposing standards on systems that get in the way of their usefulness for the purpose at hand. This highlights the need for early involvement by practitioners in the design and implementation of new technologies.

> *'Because of the lack of information, people* think *that their roles will change…'*
> (Healthcare professional)

Impact on patients

The general impact of technology on patients has already been mentioned, including rising patient knowledge and expectations, 24-hour access to information, the increasing availability of self-monitoring technologies and of healthcare services being accessible in a range of different settings.

Some groups of patient are seen as benefiting more than others, however, though the specific impact may depend in part on how well new technologies are designed and how easily they can be integrated into daily life. For example, if more and more healthcare can be delivered to patients in their own homes, a range of issues arise, including:

- Aesthetics – what do these things *look* like?
- Security – if equipment is expensive, will it be of interest to burglars – and what are the insurance implications of this – for example, who will cover the cost of insurance?
- Maintenance – this includes cleaning and general upkeep; who will be responsible for this?
- How many people will end up having to visit people in their homes to clean equipment, ensure it is working as it should, etc?

A general concern is raised about homes becoming private quasi-hospitals.

Older patients are seen as having the most difficulty in using and, possibly, accepting new technologies. This is seen as a problem that will disappear over time as technical literacy becomes a basic skill across the population as a whole. The design issue arises again here, with some participants suggesting that well-designed technology should not present a problem for even the most technologically nervous patients. It is pointed out that telephones are used as a matter of course, without being seen as 'technology' and that good design should carry this invisibility of the interface into new technologies.

People with disabilities are seen as gaining potentially great benefits from remote technologies which allow them to access healthcare from their homes. At present, appointments with a GP or hospital consultants may involve arranging transport and volunteer support and may need to be made a month in advance for more routine visits, to ensure the necessary support is in place. If consultations can take place remotely and monitoring equipment is in people's homes, some patient support participants feel that existing inequalities in access to healthcare may be reduced for disabled people.

- **Protecting privacy**

It will be necessary to strike a balance between ensuring safety and maintaining privacy, not just in terms of data confidentiality but also in establishing protocols for monitoring equipment. This issue was raised by participants from patient support groups in both the workshop and telephone interviews. It may be difficult for someone monitoring at a distance to interpret the significance of information. For example, if someone is lying on the floor for an hour, are they in distress or just looking at the world from a different angle?

> *'A person may be at risk to outsiders if, for example, they are 'wandering', but it is important not to limit someone's right to walk about and be independent.'*
>
> (Patient support group)

- **Protecting equality**

Some participants suggest that current health inequalities may be exacerbated by the increasing use of technology. If a reduction in face-to-face contact with clinicians is a consequence of greater use of technology and systems such as choose and book depend on access to technology, those whose access or capacity to use it is limited will be negatively affected. Penetration of technologies in high need groups may be low and people of different ages will adopt new technologies at different rates. This implies that diverse modes of delivery will still be necessary.

In addition to some patient groups being more able and willing to use new technologies, there will be differences amongst healthcare professionals. Some will be more pro-technology, which may mean that their patients will benefit more. Some patients will also be sufficiently confident to decipher and use information gathered from the internet to challenge the healthcare system and gain access to technologies that may not be offered as a matter of course. Some participants raise the question of the cost of broadband or WiFi, suggesting that, even if it is provided to all homes in the same way as other utilities, ability to pay will differ and cutting off access as a result of non-payment could have profound and possibility dangerous implications if healthcare is increasingly reliant on these technologies.

For some patients, specific technologies offer the potential for greatly improved communications, leading to greater equity in their access to healthcare. For example, the SIGNHEALTH translation tool can be used by doctors and deaf patients during consultations, in the absence of a Sign Language Interpreter.

The government is felt to have a role in ensuring that the public can and does trust technologies related to health. This might be through the development of a robust regulatory framework.

- **Data use and confidentiality**

Patient and patient support groups raise a number of issues relating to the impact of technology on the ethical issues surrounding the increase in electronic records and health information. These include:

- Who owns the data collected – e.g. the patient, the organisation collecting the data, the end user e.g. the health professional?
- Who controls the criteria under which data is released and what data is released to whom?
- What are the assumptions about who can access what data – e.g. can a health professional access all of a patient's data, or only the data relevant to the aspect of the person's care that they are involved in?
- Who controls the release of data?
- Can a patient ask for things to be changed or deleted if they don't agree with them or don't want people to know about them? Can patients amend the records themselves?

Data use and confidentiality may be less of an issue in a managed network – i.e. where there is a single provider organisation. Where there is a participative network, it will need to be governed by robust protocols. There are commercial questions about how an organisation doing, for example, diagnostics and assessment can use the information it may have on a patient. Will it be able to market to that patient any other services it offers? Will it be able to sell on contact details to other healthcare providers or providers of other services? There are also questions about how access will be controlled. If an organisation is providing, for example, physiotherapy following a hip replacement done by a different provider, to what information will they have access?

- **Easier access to services**

For some patients, not having to visit a surgery for consultation will be of particular benefit. This includes those living in rural areas, people with disabilities affecting ease of mobility and carers. General practitioners and patient support groups emphasise that remote consultation will need to play a support role and not replace personal contact. A GP or nurse's experience in deciphering contextual clues, which may not be visual, and the trust that develops over time between practitioner and patient are seen as having both immediate and longer term health benefits.

"Rather than just ring NHS Direct will you be able to hold up your baby so the nurse can see the rash and tell you whether its just eczema and stop worrying or whether you should go down to A&E"

(Healthcare professional)

- **Improved patient experience**

The increased use of ICT in healthcare should improve the patient experience in a number of ways including faster patient pathways; more diagnosis and treatment in the community and a more balanced relationship between patients and healthcare professionals.

'As service users have more access to their health records, and also health information in general, we will have much more potential for a real partnership between healthcare professionals and patients.'

(Healthcare professional)

'You can move expertise through the healthcare system more easily.'

(Healthcare professional)

- **More accurate information**

In the area of prosthetics, smart materials are seen as offering an opportunity for more accurate information on the interface between patient and prosthesis. This may be helpful not only in fitting artificial limbs but also in assessing the extent to which these are used by patients and hence in identifying problems.

Impact on carers

The impact of technology on carers is something which was not explored in detail in this work. However, as more healthcare is delivered in the home and the population ages, the role of carers needs to be considered. Some of the issues facing health professionals will also face them – for example, will there be any training requirements for carers supporting patients using monitoring or other equipments in their homes? Since many carers are themselves likely to be older, issues around fear of technology and the importance of design in helping to address these will also need to be addressed. Will pressure be placed on carers to become quasi-medically trained so that treatment can be administered at home?

5. Lessons for the future

'There are no clinical champions saying "come on, I've got an idea, let's do it…".'
(Healthcare professional)

Learn from elsewhere

Some participants see the need for fundamental changes in the way that the NHS procures technologies. At present, it is seen as insufficiently focused on what it is asking from technology, what problems are being addressed and what outcomes are required. This leads to the procurement of technologies that don't address the specific needs of the health service and its patients. One approach to solving this problem is felt to be learning from other large organisations.

"If you're in the military, you come up with what you want then go out and ask for it…In aviation, you couldn't dream of buying an airplane before going through the design process."
(Healthcare professional)

Ensuring that the uptake of new technologies is driven by the health needs of patients and the public overall is also a crucial issue. For example in the knowledge that obesity is on the increase there could be a focus on designing technologies to combat this. This will ensure that technologies are developed to provide solutions to problems identified, rather than being adopted simply because they are there. There is some concern that, rather than patient and public need being the guiding principles, developments will instead be driven by pharmaceutical companies and designers or developers.

Focus on outcomes

Technology will allow the NHS to collect more and more information. Some participants argue that this tends to be done at present with little thought to the use to which this information will be put. They suggest that there is a need for a fundamental shift in attitude and the adoption of an outcome focused approach, with the direction of specific strategic plans, processes, training and education being determined through reference to these wider outcomes. This issue connects with the question raised above, of ensuring that the driver for new technologies is patient need rather than private profit.

Different people are likely to have different desired outcomes. Negotiation and consultation will therefore play a key role in developing outcomes to which everyone – from patients and carers to healthcare professionals and policy makers – can subscribe. The diversity of interests is seen as greatest in children's services and mental health services.

Patient and public involvement

Continuous and improved patient and public involvement is a basic requirement for the successful introduction of new technologies in healthcare. This is particularly important when looking at the ethical issues surrounding the increased capacity for information storing and sharing, in relation both to individual health records and the use of health data for research purposes as well as considering the impact of ICT on models of care.

Collaborative working

A more collaborative approach is seen as necessary to realise fully the advantages of ICT developments. More broadly, this is related to the development of a culture in which health is seen in the broader context of social, mental and physical wellbeing, with patients being empowered to take responsibility for their own good health. A number of different groups were felt to have responsibility for delivering this agenda including, for example, the media. It was thought that this message needed to be coherent and powerful enough to help promote the perceived culture change required in this respect.

'One important thing is to teach NHS professionals to work together, doing multi-disciplinary work.'

(Healthcare professional)

Education and training

There appears to be a need to increase education around ICT generally, so patients and professionals alike are not *'scared of technology'.* As noted earlier, some patients are thought to be concerned about losing the face-to-face interaction with healthcare professionals. Some professionals are seen as fearful of ICT because of their concern that it will get in the way of their relationship with patients, or even replace some healthcare workers altogether.

To reassure professionals, it might be useful to highlight that ICT is a tool to support their work, rather than to replace the skill they can bring to the role. Helping them to see ICT as part of their caring role, rather than as a substitute for it, is also seen as important.

'There is a concern, especially from nurses, that ICT is going to get in the way of the personal relationship … I think it does reflect a concern from patients that sometimes people talk over the top of their head instead of to them.'

'I think that the roles of healthcare professionals should be governed by their healthcare duties and ICT should be a tool with which to perform those duties. You use medical equipment to examine the patient in the same way as you use a PC, or other ICT equipment, to record the information.'

'There needs to be a culture change. If any Healthcare Professional is doing anything other than caring, they're seen to be not serving as they should be…'

"In relation to using the technology, we've got a workforce who is not particularly skilled…We need to train the workforce to use ICT. There are profound implications when we move from paper to ICT.'

(Healthcare professionals)

Involvement of healthcare professionals

A majority of participants see the need for healthcare professionals to be involved in the scoping, development and implementation of ICT from the earliest stages. Their involvement in procurement was also seen as crucial.

'You need involvement at the very beginning. Technicians do not have a clue about what clinicians do. They [ICT professionals] *think in a straight line, but healthcare is biological.'*

(Healthcare professional)

Amongst a few, however, there was a feeling that healthcare professionals are '*change weary*' and thus resigned to change rather than engaged with it. A possible solution to this is identifying enthusiasts and innovators and enabling them to work with others who are '*prepared to take risks and try things out… you need to use the diffusion of innovative principles.'*

It was seen as necessary to exercise caution in this respect, to maximise the likelihood that people will *'think from an outcomes perspective'* rather than simply '*repeating their current practice within IT'* and thinking less innovatively.

'It depends on skills of professionals. If you have healthcare professionals that are ICT savvy, then [involvement should be] *as early as possible. If they don't have any IT background then they should be involved second.'*

(Healthcare professional)

Implementation

The appropriate approach to implementation is felt to depend on the nature of the change. In the case of infrastructure – notably, *Connecting for Health*, a '*big bang*' approach is seen as required. However, some are more cautious, preferring a stepwise approach. This not only helps to ensure that problems are caught before they can spread more widely but also acknowledges the wider cultural context into which new technologies are being introduced.

Awareness of the rapidity of change and the ease with which systems become obsolescent is seen as critical, especially in a resource-stretched service.

'Schemes that are too ambitious fall flat on their face…. We can't do big bang in ICT, it doesn't work.'

(Healthcare professional)

Caution was also urged with respect to the pressure from both private sector technology providers and civil servants who might be anxious to sell equipment or push through its

implementation before their utility or appropriate applications are properly understood or before healthcare professionals are in a position to use them effectively.

'[There needs to be] *more realistic, less overarching…more emphasising of realistic step change.'*

'I worry about very pushy vendors, very pushy DoH people pushing their ideas and efforts through.'

'It's important to be aware of the speed of change… Most projects need quite big investment and if there's something that's not going to be compatible with systems in a few years time, it's a waste of money.'

'The NHS is very insular. Lots of lessons could be learned from the way industry has implemented IT and we're at least 15 years behind on most of it. They should pick up good ideas from outside and use them.'

(Healthcare professionals)

Role of government

The government is seen as having a number of roles, including taking a strong and confident lead, providing the necessary investment and regulation and communicating clearly about their planned changes.

Some are not currently impressed by the role the government is playing in current changes; it is seen as indecisive, which increases uncertainty in what is already an uncertain field. Some diagnose the lack of investment as a consequence of the lack of leadership. Government communications are also seen as inadequate at present.

'… [There is a need] *to persuade someone to take some risks to start funding and do less talking about it. The government and civil service talk but don't invest because they can't make up their minds… we need confidence and funding and strategic direction from the centre.'*

(Healthcare professional)

'Some of the stuff that's come out from the centre has been very, very glossy propaganda which our staff don't believe. What's coming out is counterproductive…'

(Healthcare professional)

Research issues

New technologies, many of which will be expensive, are seen as introducing challenges to medical research. Randomised trails become impossible if only a few prototypes of a new technology are available. In some fields, the absence of research data on new health care technologies is seen as presenting a potential legal minefield. If patients learn from the internet about technologies which are available but are refused these on the grounds that they are inappropriate for their particular condition, the absence of evidence may open up

SHA to legal challenge, along the lines of those made recently by women refused herceptin.

In addition to the specific research issues raised in relation to technology, GPs point to the difficulty in obtaining funding for primary care research. If care is being pushed 'up-stream' towards the patient, home and primary care, there will be an increased need for this.

Some participants argue that the government should commit to funding the evaluative and pilot studies which will form the basis of future ICT developments, providing evidence on their impact and effectiveness. At present, ICT evaluation is seen as inadequately resourced, largely because it is not seen as worthwhile. In their absence, choices about the future direction of ICT in healthcare may be '*based on political sensitivity rather than actual need.'*

> *'You need a commitment to the funding of studies…comparative studies…looking at the before and after…and case studies.'*
>
> *'We proposed to the Medical Research Council that they do a 'before and after' study of technology using the Quality Outcomes Framework but they weren't interested in it as it wouldn't be competitive.'*
>
> *'It's difficult to follow things up. I know things are happening in my programme and happening around me but there's a lot you don't hear about despite people trying to disseminate information.'*
>
> '[There needs to be] *a lot more evaluation and testing options at front line…a lot more innovation…piloting of concepts rather than solutions.'*
>
> (Healthcare professionals)

Appendices

Final interview guide – Healthcare professionals

26 September 2005

Introduction
This interview is part of a consultation OPM is carrying out on behalf of the Royal Society. We are doing some telephone interviews and running 2 workshops with health professionals and patient representatives. This consultation is part of a wider study being undertaken by the Royal Society.

Over the course of the project, we're going to be looking at how information and Communication technology impacts on patients and patient care and how it might impact on how NHS organisations and services are managed.

Confidentiality – information not attributed to individuals
Findings from this stage: contribute to the design of scenarios to be used in workshops; contribute to wider RS study.

Any questions?

Ask interviewee to provide brief details of their role / specialism.

General issues
What would you say are the 3 major issues facing the NHS over the next 10 -15 years?

- What role do you think information and communication technology could play in helping to deal with these issues? (Probe on awareness of specific technologies, different areas of healthcare)

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Practice / relationships

- What do you think the impact of new ICT might be on the relationship between patients and healthcare professionals? (positives / negatives: different impacts for different professional roles?)
- How do you think ICT might change the roles or responsibilities of healthcare professionals? How do you see healthcare professionals responding to these changing roles? What do you think the impact of these changing roles would be on the delivery of healthcare? On the NHS as a whole?
- What impact do you think ICT might have on existing systems - for example, the patient pathway? In what way might it improve this (or other systems identified)? Why?

Development/implementation

What ICT technologies have you / do you use in your work? (PROBE: information management; self-care; health-monitoring; risk-management; research; specific groups of patients – eg, chronic illness, prosthetics?; other)

- Did you or other healthcare professionals have any role in developing or preparing / planning the implementation process?
- Are there any lessons for the future use of ICT in health / healthcare that could be learned from your current/past experience? What positive changes could be made to how things are implemented in the future?
- At what stage in the development or implementation of new ICT do you think healthcare professionals are best involved? What do you think are benefits of involving healthcare professionals at this stage? What do you think the implications are of not involving healthcare professionals in the development or implementation of new ICT?
- ICT technologies and new products develop at a rapid pace. What implications do you think this might have for how we develop health care and processes?
- Have you heard or read about any technologies which might be used in health and healthcare in the future?

Organisational implications

- What do you see as the organisational implications for health and healthcare of new information and communication technology? Do you have any examples of organisational change taking place as a result of new information and communication technology? How smoothly did these changes take place? What factors would you say were important in its success / what factors presented difficulties?
- What advice would you give to those responsible for managing organisational change arising as a consequence of ICT? (eg, preliminary planning activities, staff training – any particular groups of staff? patient awareness etc)

Communication

What has been your experience of communicating with information and communication technology professionals?

- At a local level? At a national level?
- Do you think there is scope for greater understanding between ICT professionals and healthcare professionals?
- How do you think this might be achieved?
- What do you think might be the challenges?

What impact do you think new ICT in healthcare might have on communication between patients and health services and healthcare professionals? (PROBE: positives – negatives)

CLOSING

What would you identify as the three potential major advantages to health / healthcare of new ICT?

What are your three major concerns?

Thank you

Final interview guide – patients / patient groups & representatives

26 September 2005

Introduction

This interview is part of a consultation OPM is carrying out on behalf of the Royal Society. We are doing some telephone interviews and running 2 workshops with health professionals and patient representatives. This consultation is part of a wider study being undertaken by the Royal Society.

Over the course of the project, we're going to be looking at how Information and Communication technology impacts on patients and patient care and how it might impact on how NHS organisations and services are managed.

Confidentiality – information not attributed to individuals
Findings from this stage: contribute to design of scenarios to be used in workshops: contribute to wider RS study.

Any questions?

Ask interviewee to provide brief details of their role / group they represent.

General issues

What kinds of information and communications technology do you or other patients you come into contact with use? (PROPMT: could mean anything from use of NHS Direct to prostheses to remote consultations to booking appointments on-line to on-line patient support groups).

What are your views of this technology? (Prompt: ease of use, saving time, access to people / information not otherwise reachable)

Benefits and concerns

What do you see as the major benefits of these technologies? (To you personally, to the patients you represent?)

Are there any particular groups who you think will find it easier to use these technologies and others that might develop in the future? (Prompt: different age groups, social background, nature of condition)

Are there any particular groups who you think will benefit most from these technologies? PROBE on people with specific conditions

What are your major concerns about these technologies?

- What steps could be taken to overcome these concerns?
- How do you think these steps would help to build trust?

Future technologies

Have you heard or read about any technologies which might be used in health and healthcare in the future?

In what way do you think these might benefit patients? What concerns do you have about the future use of information and communication technology in health and healthcare?

Relationships and communication

What impact do you think new information and communication technology used in healthcare might have on your relationship with healthcare professionals? (PROBE: positives – negatives; changes to relationships with nurses? Doctors? Consultations? Other healthcare professionals?

CLOSING

What would you say are the three potential major advantages to health / healthcare of new information and communication technology?

What are your three major concerns?

Thank you

Royal Society – the impact of ICT on health and healthcare
Workshop Agenda – 1st November 2005

9.30 Coffee and registration

10.00 Introduction from Professor Peter Wells, Chair of the Royal Society Working Group

10.10 Welcome and overview of agenda from Jude Cummins, Principal, OPM

10.15 Breakout groups – discussion of future scenarios

11.00 Coffee

11.15 Breakout groups – continue discussion of future scenarios

12.00 Review scenarios from other groups

12.05 Plenary: Presentation of key findings from each breakout group

12.20 Plenary: Discussion of issues emerging

12.50 Closing comments from OPM and Prof. Wells

13.00 Lunch

Royal Society – the impact of ICT on health and healthcare

Workshop Agenda – 4th November 2005

9.30 Coffee and registration

10.00 Introduction from Professor Peter Wells, Chair of the Royal Society Working Group

10.10 Welcome and overview of agenda from OPM

10.15 Group discussion of future scenarios

11.00 Coffee

11.15 Continue group discussion of future scenarios

12.00 Review key points (drivers, challenges and opportunities)

12.15 Feedback from each group

12.30 Plenary - Patient involvement in development / design / implementation of technology

12.50 Closing comments from OPM and Prof. Wells

13.00 Lunch