Prospects for Health IT

Response by FIPR to the Royal Society's call for evidence on technology trends likely to impact on healthcare

The Foundation for Information Policy Research (FIPR) is an independent body that studies the interaction between information technology and society. Its goal is to identify technical developments with significant social impact, commission and undertake research into public policy alternatives, and promote public understanding and dialogue between technologists and policy-makers in the UK and Europe.

FIPR has been involved in health IT policy since our inception in 1998. Most recently we completed a study for the National Audit Office on comparative expenditures on health IT in France, Germany, Italy, Spain, Sweden, the Netherlands, Poland and the USA. We have also conducted studies on the balance between privacy and state powers for the Information Commissioner, and on the pros and cons of using smartcards for delivering public services. Prior to FIPR's establishment, its trustee Dr Fleur Fisher was Head of Ethics, Science and Information at the BMA; its chair Professor Ross Anderson worked with the BMA, the Icelandic Medical Association and other bodies on the safety and privacy of medical information systems., and has published extensively on the subject[i].

We welcome the Royal Society's interest in health IT, a field that combines opportunity with complexity, and which in the past has been the scene of numerous disasters in public investment. We would be delighted to meet the committee and share our experience of this field. In this paper we set out brief responses to the committee's initial questions.

Summary

Health IT in Britain – as elsewhere – comes in three basic flavours.

- First, there are computers embedded in specialist systems such as scanners and monitors.
- Second, there are systems developed from the ground up by health professionals to support their work, such as the PC systems used by most GPs to keep records.
- Third, there are top-down attempts to build a 'system of systems' that will link up different providers and allow seamless service management.

In general, the first two types of systems are in good shape, while the attempts at large-scale integration have generally failed to deliver the anticipated benefits.

It is well known that, compared with most other industries, progress in large-scale health IT has been glacial; the sector lags finance, retailing and manufacturing by a generation.

The reasons are partly understood: modern medicine is highly complex, with more variability and uncertainty at the point of service than any other industry; services are customised on delivery; and more specialities collide at the point of care than elsewhere[ii].

Britain differs from other developed countries in our 'National Program for IT' (NPfIT), an expensive and centrally-driven programme of large-scale systems integration. Other countries are taking a more incremental approach by specifying interoperability standards and letting integration evolve over time; they look with both interest and apprehension at the UK's 'moon-shot' approach. Meanwhile, there are signs that the NHS is starting to realise the sheer scale and complexity of the work needed to meet the NPfIT's stated ambition, and is scaling this back. In this context, the committee could provide independent guidance at a critical time.

Relevant technology trends

Pervasive computing offers some interesting possibilities. As vendors embed processors and communications in more and more devices, and as implantable electronics becomes cheaper, new kinds of monitoring functions will become possible and many others will become easier. There will be positive and negative aspects. On the positive side, implanted insulin pumps may make life much easier for diabetics; implanted sensors may improve post-operative care; and care-home surveillance may reduce the abuse of elderly residents, both by each other and by staff. On the negative side, surveillance may be resisted, for example by care-home staff.

The trend towards centralisation of personal health data will probably provide the main policy headaches. In some service industries, such as finance, centralisation has brought huge economies of scale. In healthcare, the potential economies are less obvious, while the privacy concerns are real and growing.

Areas positively or negatively affected

First, the UK is probably spending too much on health IT integration, at the expense of other health priorities. This is now being examined by the NAO.

Second, concerns about patient privacy and professional autonomy may well put many doctors off cooperating with some of the systems delivered under NPfIT – particularly the Care Records Service (CRS). This could derail its deployment. The NHS now realises there's a problem, and recently ran a consultation[iii] on the CRS, which led them closer to the position traditionally held by doctors and patients[i]. While this is welcome, it may be rather late – given that the system architecture has been established and contracts for development have been let.

Third, CRS may suffer loss of public confidence, or there might be a legal challenge under human-rights or data-protection law. In Iceland 11% of the population boycotted a national medical records database, and in the USA where the Health Insurance Portability

and Accountability Act (HIPAA) has recently mandated substantial investment by hospitals and other providers in information security measures. Building insecure systems, and fixing them later when scare stories lead to political pressure, is expensive.

Finally, there is an appreciable risk that NPfIT will just not work, and become yet another health IT disaster. It has most of the hallmarks.

The NPfIT goal of making medical records available throughout the NHS (and related public-sector organisations) is starting to cause public concern; the recent parliamentary debate on the Wilkinson case may be the first of many. A particular area to watch is data on children. Current plans to link up children's health records, school records, social work records and police records will create numerous, poorly-understood hazards – safety, privacy, legal and political.

Wider Implications – risks, privacy, ethics, standards, roles etc.

FIPR believes NPfIT was a mistake. Britain should develop health IT as other countries do: central bodies should focus on standards rather than trying to integrate systems in new and ambitious ways. It should be up to healthcare providers to buy systems in a competitive market and evolve interconnectivity in response to actual business pressures.

Britain's health technology spend is highly skewed, compared with other developed countries, on integrating systems that collect personal data – a long-standing priority for the Department of Health. This may be simply a consequence of our highly-centralised NHS: systems purchased in Whitehall will place more emphasis on Whitehall priorities. By comparison, countries such as the Netherlands and Sweden (with hospitals essentially run by local government) and the USA (where they are run by charities or companies) invest more in medical equipment and in systems that support care directly. If the NHS were reformed – whether along Scandinavian lines, or with a more free-market model – one might expect that more money would be spent on front-line systems and less on the back office.

We do not think it is helpful to encourage the Department of Health to invest in new infrastructures. In the past, when the Department has tried to take strategic decisions, it has almost invariably got them wrong – for example, choosing X.400 as an email standard just as the rest of the world was standardising on SMTP, and trying to build private networks when everyone else was turning to the Internet. Information goods and services markets generally have strong network externalities, low marginal costs and high lock-in, which all lead to the emergence of dominant standards. If it is public policy to fight this, it should be done via competition law and policy – not by spending the health budget on buying obsolete equipment from firms who have lost standards races. The NHS should use standard commercial off-the-shelf equipment, plus free/open-source software where appropriate. Central standardisation work should be limited to what is required for interoperability,; it should also be done in an international context. There should be no new development of purely national standards (such as Read codes) as these

simply cut off UK health IT markets from the rest of the world, to the detriment of health providers and system vendors alike.

Given the huge amount of political capital invested in the NPfIT programme, perhaps the best that the committee can do on this particular topic is help it to evolve quietly into something much less ambitious, more normal and cheaper.

The committee should also emphasise the positive benefits that IT can bring to health, specifically in front-line systems and in medical devices. Here there are real opportunities to develop world-class products that can form the basis of valuable industries. The policies to follow here are generally the same as in the rest of scientific, technological and medical research: we need to sustain and enhance our world-class universities; we need to attract and retain the best researchers in the world, and then let them do whatever turns them on rather than trying to micromanage their research from the centre; and we need a fiscal, legal and cultural environment that supports technology entrepreneurs, including academics. These issues are familiar enough to the Royal Society. Britain has contributed hugely to medical technology in the past, and must in the future. When NPfIT collapses – or is quietly downsized – a good outcome would be for some of the money thus saved to be spent on postdoctoral research fellowships instead.

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[i] Ross Anderson, *Security in Clinical Information Systems*, BMA 1996
[ii] Jeff Goldsmith, 'The Healthcare Information Technology Sector', in LR Burns (ed) *The Business of Healthcare Innovation*, CUP 2005
[iii] 'The Clinical development of the NHS Care Records Service', NHS, 29 July 2005