Scoping Exercise EH2

Appendix 2 Policy context: full report

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO) Programme of Research on E-health

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Section 1 Introduction

> *The challenge for the NHS is to harness the information revolution and use it to benefit patients.*
>
> (Tony Blair, All Our Tomorrows Conference, London, July 1998).

This report analyses the policy context for health informatics in England. It will be viewed from four perspectives.

- English policies on information and communication technology (ICT) specific to health.
- English health policies that may drive or constrain e-health.
- Non-health policies that may drive or constrain e-health.
- EU policies that may drive or constrain e-health.

Each is considered in the following chapters. The impact of policy on health ICT applications is illustrated in a range of contexts in the Annexes.

In creating this document and its recommendations the study drew on a wide variety of sources and drew on the experience of many experts, as acknowledged above.

A range of preliminary suggestions for research was presented at a workshop at the Healthcare Computing Conference HC2004 and subjected to electronic voting: see Section 7.

The research for this part of the project was undertaken on a semi-structured basis, following a number of parallel tracks, as follows.

- A structured schema to frame the interviews was developed.
- The schema was used with a preamble describing the project aims, objectives and the research questions to be addressed, and seeking the views of the interviewees.
- A target list of key people involved with e-health policy was drawn up, and the individuals approached for interview, face to face or by phone. If preferred, the schema was sent direct for an e-mail response.
- Where necessary, the notes from the interview were drafted and sent back to the interviewee for review, amendment and confirmation.
- Key documents, identified by interview or market knowledge, were then processed, synthesised and their e-health impact documented.
- Draft recommendations were derived from the material evaluated.
- A list of e-health issues was then prioritised internally.
- The top issues, ranked by their potential effects on service delivery, were used to frame the Delphic workshop at HC2004.

- The workshop participants, numbering approximately 60, used a blind voting system to identify the areas that were felt to be most crucial to the support and enhancement of health care delivery.
- The research recommendations were refined during the workshop and others added as a result of participant input.
- The resultant recommendations and context appear in this document in Section 8.

Section 2 English policies on ICT specific to health

The documents used to frame this section were:

- *Information for Health* (NHS Executive, 1998) and its supplementary *Building the Information Core* (NHS Executive, 2001).
- Wanless 1 (Wanless, 2002), *Securing Our Future Health: Taking a long term view re-investment priorities*.
- *Delivering the NHS Plan: The next steps on investment, next steps on reform* (Department of Health, 2002a).
- *Delivering 21st Century IT Support for the NHS: National Strategic Programme* (Department of Health, 2002b).
- *Delivering 21st Century IT Support for the NHS: Summary of the overall procurement strategy* (Department of Health, 2002c).
- Wanless 2 (Wanless, 2004), *Securing Good Health for the Whole Population*.
- National Care Records Elements (National Programme for IT, NPfIT; www.bcs.org.uk/BCS/Forums/Health). A consultation document (BCSHIC, 2002) is currently exploring the data requirements in the client record to sustain synergy with social care and interaction with other local authority bodies such as housing.

In Scotland, the agencies are keeping a watching brief on developments in e-health in England before taking any major steps. There is a small on-going e-health project involving the local authorities, health and social care. The model for e-health delivery in Scotland differs from that of the NPfIT in that data content is core rather than standardised functional solutions, as in England. The data-content specification will allow Scotland to interface niche products on a long-term basis, not as an interim solution. The NPfIT solution only requires such interfacing on an interim basis until the standardised functional solutions are available. It may be worth considering joint research into the efficacy of the different delivery models at a later date when the projects have progressed further.

2.1 Views of the English NHS Executive Information Policy Unit

Dr P. Drury of the NHS Executive Information Policy Unit (IPU), whose remit includes outward-facing, indicates that the current priority is getting a nationwide infrastructure in place robustly (‘we must move e-health from a cottage industry to industrial strength’) through the national programme (NPfIT). When this is complete it will be possible to layer e-health requirements onto it, but only if requested and a good business case is made. There will be no blanket enablement unless facilities are really going to bring benefits. His perception is that England is way ahead of many other European countries, so he feels it has the power to set *de facto* standards and to provide a rigorous test-bed for them. He feels that the IPU has a constructive relationship with those developing and ratifying standards. The main IPU objective in this area is to be in a position to use e-health (and other technology) to satisfy the needs of the NHS professionals and the public vis-à-vis health data/information.

He realises that NHS development cannot be delayed while the NHS tests 'technologies and standards' to industrial-strength level for the wider (European/world) community, and that new technologies must not be adopted in the NHS without adequate testing.

The drivers of e-health policy are felt by the IPU to be various. In the mid-term the main effects on policy and delivery will be the Design Authority, Department of Health policy per se, the Government Interoperability Framework e-GIF initiatives and the European Commission. In the longer term, issues such as the need to support UK citizens wherever they are in the world when they need care services will become more prominent. Additionally the NHS has obligations regarding the treatment of non-UK individuals resident or visiting the UK that will have implications for handling their electronic health records (for example, they will have no NHS number).

The drivers for moving towards an e-environment are seen to be:

- to get agreement on how citizens (and their carers) can get access to good-quality (health) information;
- to ensure that wherever European mobility takes them, that relevant information can be accessed to achieve robust (holistic) decision support.

He feels that the NPfIT current work plan precludes consideration by IPU of significant e-health innovations at this time; but it is felt that in 5 years priorities can be different.

He saw the e in e-health as currently being an adjunct but that the NHS is working towards the e moving inside to become ubiquitous health. Whereas some IPU professional staff themselves are empowered to e-working (using extensive electronic applications from their desks), it is only on an as-required basis and is provided by inconsistent informatics environments.

After NPfIT has delivered over the next 5 years it will be possible to consider adding new technologies widely and other research-developed innovations. The NHS Chief Executive Officer, Sir Nigel Crisp, intends the ratio of national to local investment (currently 80/20 per cent) to swing to 20/80 per cent, with locals taking responsibility and the lead, and paying for the majority of the innovations. He feels there should be 'every encouragement' to take research into practice or to roll out proven solutions across Europe (similar to the Commission of the European Community (CEC) Information Society's R&D programme Exploitation Plan). The IPU feels that local areas are a ‘fertile breeding ground’ for e-health innovation. There is unfortunately no current blueprint for where the funding might come from for e-health when the e becomes integral. When eHealth becomes ubiquitous the following concepts will be facilitated:

- ‘international citizens’;
- authorised access to ‘MyHealthSpace’ and the like from anywhere where it is required, through portal access to (holistic) care records;
- health tourism/international mobility.

In all the interviews, there was little ‘off-the-shelf’ material highlighted that described the current situation in terms of the history of how decisions were made and which paths were taken. The IPU’s view was that there was a risk of not being able to rationalise what has happened retrospectively if investment is not put into capturing history. Much is implicit/virtual and currently locked in just a few heads.

These views are recognised in the recommendations that follow.

2.2 Information for Health

It would be possible to identify e-health potential and policy guidance in documents pre-1998 but in view of the changes to strategic direction and emphasis, the first milestone is taken at 1998 with *Information for Health* (NHS Executive, 1998). At this point the Department of Health expressed the e-health issues in terms of a ‘challenge for the NHS to harness the information revolution and use it to benefit patients’ (Tony Blair, All Our Tomorrows Conference, London, July 1998). Notably covered in the publication and explored in more detail below are the following relevant issues:

- genuinely seamless care …sharing information across the NHS information highway (*Information for Health, section* 1.3);
- fast and convenient public access to information (including good health and lifestyle advice (1.41);
- self-treatment and care (1.44);
- care through online information services (interactive television and multimedia kiosks to deliver accredited, independent, multimedia background information and advice (1.46));
- telemedicine to remove distance from health care, to improve the quality of that care, and to help deliver new and integrated services (1.29, 5.5), only where appropriate (5.8);
- a move away from the ‘previous’ Information Management and Technology (IM&T) strategy that was widely seen to give undue priority to management information (1.39);
- 24-hour/7-days-a-week access to information;

- elimination of unnecessary travel and delay for patients by proven remote online access to services, specialists and care wherever practicable;
- providing NHS professionals with online access;
- fast, convenient access for the public to accredited multimedia advice on lifestyle and health (1.46);
- electronic health records: a longitudinal record of a patient's health and health care, from cradle to grave (2.11);
- health care-delivery performance, particularly relating to waiting lists (4.9).

Information for Health indicated that e-health would deliver general practitioner's (GP's) test readings or images, record results and advice more quickly, provide telemedicine support to nurse practitioners in community minor injuries units and give access to specialists in regional teaching centres for online guidance. In addition, telecare would provide 'reliable but unobtrusive supervision of vulnerable people who want to sustain an independent life in their own home.' Personalised electronic records, online services for booking and diagnostic test results reporting (1.29), and fast, easy access to local and national knowledge bases would be provided to assist in evaluation of care that they (health care professionals) give (1.38). How far subsequent policy and policy guidance has enabled or constrained these aspirations will be considered later.

Additional policy indicators for the other home countries will, at appropriate points, be addressed later. Information has been drawn primarily from ICT Standards Northern Ireland, the Department of Health and Personal Social Services (www.hpssweb.n-i.nhs.uk), the Scottish documents available through www.show.scot.nhs.uk and the All Wales e-health telemedicine programme (www.wales.nhs.uk). In the main, the thrust of e-health is similar but on a slightly different (later) timescale.

How it all should work:

- *Information for Health* intended that NHS clinicians and managers would have the information they need to provide the best possible care to patients and that patients, carers and the public would have the information necessary to make decisions about their own treatment and care and to influence the shape of the health services provided for them. These laudable aims still persist today.
- *Information for Health* listed aspirations strategically rather than prescribing a tactical plan for delivery. Future documents prioritised the main themes and indicated at which level, national or local, such initiatives should be progressed. Many aspects remain un-delivered and are recommended as the subject of further Action Research such as establishing equity of access to NHS Direct content (see Section 6 of this appendix).

2.2.1 Research recommendation

Many of the issues raised by *Information for Health* were later addressed (in terms of recommendations) in considerations of National Service Frameworks (NSFs) and subsequent documents. The research theme below is identified here as the only one not covered later.

- That research be initiated to explore the reasons for limited use of repositories of clinical guidance and evidence; both the attitudinal views of the clinicians who appear reluctant to use such repositories and the mechanistic challenges, including the human–computer interface and performance-response issues, to extended use of decision-support tools in the health domain.

2.3 Building the Information Core – implementing the NHS Plan

The general context of e-government remains 'building services around citizens' choices' whereas the NHS Plan requires an 'NHS designed around the patient' and 'workable and person-centred systems'. *Building the Information Core* (NHS Executive, 2001) 'builds on and updates *Information for Health*…and provides a clearer focus on what our priorities for delivery need to be.' The document contains specific targets that relate to e-health, linked to the NHS core principles of a seamless service, respect for confidentiality of individual patients and open access about services, treatment and performance. Explicit target dates are set for:

- pathology messaging (hospital to GP);
- desktop support to all clinicians;
- all acute Trusts to have an operational level 3 electronic patient record system (covering electronic clinical orders and results reporting, e-prescribing and multi-professional care pathways processes).

The outline of a 'level 6' electronic patient record, including image data and telemedicine services, is also described in *Building the Information Core*, which divides its coverage into:

- information services (for both professionals and lay audiences);
- electronic records (within and between organisations);
- applications such as manpower and financial services at both national and local levels.

2.3.1 Revision of targets

Target dates set in 1998 in *Information for Health* have in some cases been vired by later Department of Health mandates, in part enacted by updated policy guidance such as *Delivering 21st Century IT Support to the NHS* (Department of Health, 2002b). For instance, all GPs e-booking some hospital appointments, exchanging messages routinely and looking at out-of-hours remote access has been shifted;

in this case forward from 2008 to 2005. Other dates have been shifted the other way.

2.3.2 Futures

Some of the areas of e-health that were identified by *Information for Health* as strategic aims are now starting to be addressed (2004) such as:

- 'cross-agency needs assessment' (*Information for Health*, section 2.14);
- working with other public service agencies (5.20);
- out-of-hours access by authorised local NHS organisations to a full patient record and occasional authorised remote access to a subset of critical data (2.67);
- patient-held records, possibly through smart cards (2.68).

The issues surrounding convergence between health and social care are still (in social-care eyes) delaying matters and are very challenging.

2.3.3 Technological recognition

In *Building the Information Core* consideration was given to technological opportunities such as making information available as required (2.80, the data-pull approach) and exploring messaging standards for a proactive 'data-push' (2.81). The report also acknowledged the need to look to object-oriented programming. It recognised supplier partnerships (2.87) as a means to exploit current capabilities provided these did not exclude the ability to adopt newer technology as and when appropriate. However, this is an area giving concern in the field (Dean, 2003), as outlined in the think tank and consultation series of exercises facilitated by the British Computer Society (BCS) Health Informatics Committee (BCSHIC) and called *RADICAL STEPS* (BCSHIC, 2002a).

2.4 Wanless 1

The brief to Wanless (Wanless, 2002) from the Treasury included identifying where it was possible to 'universalise the best' and to 'identify the key drivers of health need and cost over the next two decades'. The e-health implications of this report are discussed in Section 3.

2.5 Delivering the NHS Plan: The next steps on investment, next steps on reform (Department of Health, 2002a)

The impact of this document (the next chronologically) is considered in Section 3.

2.6 Delivering 21st Century IT Support for the NHS: National Strategic Programme (Department of Health, 2002b)

This document presented a considerable change of direction in practice; which in turn made it legitimate to change target dates in some areas. The focus became more centralist – in essence 'central procurement and local implementation' to get benefits of scale coupled with local fitness for purpose. The key themes of this document are:

- seamless support to patients;
- support to staff to access the evidence base through effective e-communication so as to improve management and delivery of services per se.

The report focused on electronic-records structure, content and processing, and e-booking and e-prescribing on top of a revamped infrastructure. The document emphasises the need for national standard specifications, working with industry partners to deliver national solutions and with a phased approach.

Taking 'greater central control over specification, procurement, resource management, performance management and delivery of the information and information technology (IT) agenda', has thrown up many research issues, not all relating to e-health and thus not to this study. All have been reconfirmed as very important by those in operational informatics to support care through a series of think-tanks referred to as *RADICAL STEPS* (BCSHIC, 2002a):

- ensuring the patient comes first (managing patient expectations, informing patients and introducing self-management support where appropriate);
- addressing the main problem, not the IT but the culture;
- determining that IT is for patient care, not just the need of the organisation;
- exploring how to ensure effective standardisation across the domain;
- how effectively to harness learning from prior experience;
- developing mechanisms to ensure that reference to current best practice is retained, especially where it leads the world;
- mechanisms to establish health informatics as a profession;
- how to get the best from training in the applications provided by the application providers, in awareness of the power of informatics and in the context of informatics to support care delivery and management.

There are many 'critical barriers' enunciated by *Delivering 21st Century IT Support* itself that need further study, including:

- ring-fencing of investment in informatics (current policy and process limits this: it does not protect the cash and allows resources to be diverted) (1.1);

- eclectic architectures abound and standards deployment is patchy (the mechanisms to proliferate and mandate standards need to be addressed by research, the applicability and efficiency of various architectures, the resources needed to coordinate and transition solutions from current to futures, including changing attitudes to progress/change) (1.1);
- methods to identify and evaluate best of working practices from non-health sectors and encourage their introduction across the NHS (3.1).

In a recent thought-provoking publication (Dean, 2003), Professor Pattison, then in a senior policy-making position in the Department of Health, made more observations about e-health potential. In summary he suggested that there is a risk of fragmentation of a patient's electronic record unless technology can bring together the disparate parts through: robust interfaces, common language and ontologies, secure sharing mechanisms, ethical agreement to interwork. He explored ways of delivering services (for example, using intermediaries, providing call-centre facilities for the public) underpinned by e-GIF. He advocated shifting power closer to the 'frontline' (of care delivery) and meeting the citizens' needs for more choice and knowledge about clinical conditions and service provision. He commended e-prescribing, e-booking, longitudinal holistic care and provision of both enduring and contemporary information about individual patients. He reprised the *Delivering 21st Century IT Support for the NHS* (Department of Health, 2002b) objectives: to improve the patient experience, support service reconfiguration, improve NHS capacity to deliver change and reform, and to reform working and clinical practices. In view of his position, these statements will have (had) a significant effect on e-policy including *Delivering 21st Century IT Support for the NHS* and its implementation, with particular reference to e-prescriptions, improving patient safety, making better-informed decisions involving patients and carers, and the provision of industrial-strength e-solutions.

Delivering 21st Century IT Support for the NHS also describes a vision for the NHS with digital television and other channels being used for informing patients and carers in addition to the professionals and practitioners. This is echoed in the NHS Direct strategic plan (Gann, 2004). In view of their minimal deployment as yet in the NHS, more research can be used to determine a viable pace of change, the likelihood of user acceptance of such technologies and value-for-money aspects of the technologies, now and emerging (*Delivering 21st Century IT Support for the NHS*, section 3.3, phase 3).

2.6.1 Research recommendation

That research be initiated to explore the best working practices from those other sectors that are recognised as being substantially ahead of the health sector (such as e-business) in order to:

- determine what lessons can be learnt in delivering efficient, effective support to the business of delivering health care;
- identify criteria for rejecting those technologies and e-working practices which are inappropriate to and inconsonant with care delivery;
- identify solutions that are technologically ahead of those currently used in the health domain and which offer a positive potential for the NHS to 'leapfrog' its current development and deployment path.

2.7 Implementing Information for Health: Even more challenging than expected? (Protti, 2002)

The first Department of Health-commissioned study from Canadian Professor Denis Protti (Protti, 1999) recognised the positive steps made by ERDIP, the electronic record development and implementation programme originating from *Information for Health* towards research and development of the electronic health record (birth to death). However, he clearly identified a risk that, despite the broad definition of the electronic health record contained in *Information for Health*, in practice electronic health records were being built on the 'increasingly obsolete concepts of inpatients and outpatients; historic models of face-face, hospital-based, consultant-led service delivery; and the existing organisational boundaries. They will not meet the challenges being faced of multi-professional, multi-organisation patient pathways, NSFs and clinical networks.'

This criticism has been borne out and continues with the on-going challenge of integrating record content/record linkage from social care and other agencies involved in the delivery of care, through use of the NHS number.

In addition, still outstanding are issues of who has access to what portions of the electronic health record, establishing consistent definitions and useful coding structures (ontologies) and how patient consent is tracked. As Protti states in his second evaluation (Protti, 2002) 'The consent issue will not diminish as the record itself becomes more complex and the number of legitimate users increases.' This, as identified again in the *More RADICAL STEPS* (BCSHIC, 2003) think-tank position paper for BCSHIC/ASSIST, the organisation for ICT professionals in health and social care, has proved to be the case and is a target for further research and joint policy determination.

2.7.1 Research recommendations

- That research be initiated to develop a code of collaboration under which organisations can explicitly share data and can input to overall records consistently and unambiguously, with reference to how other sensitive domains handle data collectively.

Protti (2002) and others (NHS, 2000; Dean, 2003; Wanless, 2004) have alerted us to situations where organisations are currently at 'legal risk'; for example, if, in a telemedicine application, data are corrupted during transmission, who is responsible?

- That research be initiated to develop guidance on the management and handling of 'legal risk', taking into account the experiences, policy, regulation and legislation beyond the health domain and the particular sensitivities of dealing with care data, particularly as convergence between health and social care extends.

2.8 Securing Good Health for the Whole Population (Wanless, 2004)

This report came out with a different take on the situation than the previous Wanless report, asking pertinent questions relating to determining, monitoring and changing the health status and attitudes of the population. Some observations and recommendations have research potential in the current informatics domain and the report is discussed in Section 3.

2.9 BCS involvement in e-health (policy) issues

The BCSHIC consists of a majority of interested specialist and liaison groups across the UK and produces expert commentary on government policy documents on all aspects of e-health. Details can be found on their website (www.bcs.org.uk/BCS/Forums/Health). It does not directly make policy but facilitates expert commentary, notably from its RADICAL STEPS think-tank series (BCSHIC, 2002a, 2003, 2004) and Open Source workshops (www.chirad.info/marwell04/marwellreportv01.htm). Key observations from the most recent position statements relating to e-health include the following.

- More attention must be given to communication. The community interested in harnessing informatics for health purposes is very large and can, if engaged, create very significant benefits for care from their actions.
- Few health informatics systems will perform up to their promise unless clinical involvement is enhanced and integral to day-to-day working.
- Top management must become well informed about health informatics issues and committed to addressing the problems and opportunities presented.
- Potentially useful (innovative) technologies should be evaluated as they emerge.
- Lessons from previous experiences have not been heeded.

- Costs appear to be escalating (and need to be projected more distinctly and in greater detail).
- Many end-user professionals are not yet on board and remain unconvinced.
- Partnerships (between NHS and its solution providers and between professionals and citizens in informatics terms) are not yet seen to be working.
- Management arrangements, areas of responsibility and accountability are still not well defined but must be clarified.
- Unless full funding for change management is forthcoming the likelihood of substantial returns on the informatics investment is very limited. Funded action should be escalated now service provision contracts are in place.
- Standards are required to represent workflows unambiguously across multiple care providers working together, both in and outside of the NHS family.

Informatics should be recognised as mainstream in any health-domain human resources agenda. To this end BCSHIC in conjunction with the NHS Information Authority and ASSIST have established the UK Council for Health Informatics Professions (UKCHIP), which is a registration and (ultimately) regulation body in a similar model to the General Medical Council for doctors. UKCHIP has three levels that map onto recognised mixes of academic qualification and vocational experience and link across to the Department of Health Human Resource specifications and Skills for the Information Age requirements, and can be related to the work of the e-Skills, the Sector Skills Council for IT, Telecoms and Contact [Call] Centres and Skills for Health where appropriate.

Entry to the register and continued registration require evidence of continuing personal development and adherence to a code of conduct. Increasingly. those involved in e-health and all other areas of health informatics will be required to register before taking up posts in the NHS. Also committed to the principles are commercial e-health solution providers and academic researchers and teachers. The numbers of staff holding UKCHIP registrations will be monitored and audited by the Commission for Healthcare Audit and Inspection when inspecting information processes in a health organisation.

The Open Steps (2004) initiative (www.chirad.info/imiaoswg), referred to as the Marwell meeting in view of its location, produced international consensus relating to free/libre/open-source software (FLOSS) advocacy and activity. Notably drivers and barriers to FLOSS used in the health domain were raised that have resonance in e-health scenarios, such as:

- adoption and use of the right standards;
- the development of an open-source ‘killer application’, either stand-alone or interoperable/interfaced with proprietary solutions;
- a political mandate towards the use of open-source software;

- producing positive case studies comparing financial benefits of open-source software budget reductions; for example,
  - well-written business cases for FLOSS;
  - descriptions of economics and total cost of ownership issues around FLOSS in comparison to proprietary software.

The strongest advantages of FLOSS approaches over proprietary software development in health-care applications were felt to be as follows, and research at health or governmental level could be used to confirm claims relating to:

- transparency of solutions, facilitating peer review and better quality assurance;
- reuse of components, stress on collaborative development, and resource sharing;
- encouraging accessibility to products in developing countries.

Participants rated the most important issues relating to why people do (and might) use FLOSS within the health domain as quality, stability and robustness of software and data, as well as long-term availability of important health data through data not being locked up in proprietary systems that do not allow interoperability and data migration. Major obstacles included a perceived ‘culture of closed standards’, with a potential for software use in the NHS being totally at the mercy of government policy, which had encouraged a monopoly situation. The monopolistic situation, wherein two or three large companies dominated, gave no opportunity for small and medium-sized enterprises, utilised closed/proprietary standards and had no room for innovation. This action was seen by many as, essentially, a continuation of the current situation while the national programme in England (NPfIT) takes a firm grip on NHS software.

Bearing in mind the recent European and UK Government pronouncements on FLOSS testing, research is needed into how the policy environment can support hybrid testing and an operational mixed ‘economy’ where proprietary solutions interface with an open-source environment and general open-source applications.

2.9.1 Research recommendation

That research be initiated into the catalysts, inhibitors and potential benefits from the deployment of open-source solutions in the health domain.

2.10 Integrated National Care Records Service

Under the National Programme for IT to support the NHS, the details of requirements for an integrated national care record service are still emerging, and some of them remain confidential/commercial in confidence. However, speculation in this area highlights a need for research into how different sectors can produce viable shared electronic records. Many challenges are felt to remain. Many of the situations indicate a need for further action research before deployment happens, especially in the areas of:

- Single assessments for care (by multiple sectors);
- use of the NHS number (or other national unique identifier) by other sectors for record linkage;
- the value attached to input from the subject of the record, their carers and the professionals involved in their care.

These elements are discussed in detail below.

Integrated (health and social) care records are a common core theme of today's visionary policies, such as the single assessment for older people (Department of Health, 2004a) and the identification, referral and tracking of vulnerable children (IRT), a Government initiative that will ensure that all children's agencies identify children that may need additional support, refer them to appropriate services and track their development to make sure the right support is delivered to children across the board. The fluidity of the Care Records elemental specification (Bentley, 2004) casts questions over when these requirements will be met. Current interim solutions will probably be redundant by 2008 (at currently declared targets) as a consequence of the full implementation of the Care Records Service by local service providers under NPfIT contracts. Ongoing experiments could help reveal the problems and solve them before the shared solution is designed or emerges.

Guidance in *Delivering 21st Century IT to the NHS* (Department of Health, 2002b) stated that the NHS number could be recorded on social care records only where there was a care plan that included the provision of health services. This means that the NHS number cannot be used consistently to 'map' between health, social care and other agencies. This issue has not been resolved by the *NHS Care Records Elements: Consultation on version 1.1 7* (Bentley, 2004), which states that 'A person must be identified by an NHS number if one has been allocated.' The circumstances where one might not have one (unless a visitor or asylum seeker, etc.) are unclear.

Another area of concern from the above consultation is that of the priority/supremacy of comments made by professionals, patients, informal carers or third parties in support within the record. Policy on whose comments are retained/expunged or overridden by other comments from other people is a grey area and will require much attitudinal research to resolve.

In early 2004, all chief executives of NHS organisations received a letter indicating that the NHS number is now to be regarded as the national identifier within the NHS. This is intended to support the development of the national spine record (as defined in the NPfIT specification). As it is anticipated that social care information will eventually be posted to the national spine record it does now seem increasingly likely that the Government will act to lift the current restrictions on the use of the NHS number in social care. However, the residual lack of comfort with this recommendation is not about social services per se, but the agencies – such as education and the police force – that they deal with, and about whom health professionals have some great concerns regarding the sensitivity of health data.

Aspects of the birth-to-death record are considered in Annex A.

2.10.1 Research recommendation

That research be initiated to evaluate the efficacy of available and proposed records structures to support the needs of the multi-sectoral professionals in their joint care of patients and clients, in terms of:

- transition and merging of existing records;
- using a shared numbering system;
- primacy of input from multiple sectors – developing paradigms and managing cultural custom and practice.

2.11 Involvement of the public

The NHS Plan(s) recognises the increasing involvement of the public in their own care and as informal carers for others. In *Information for Health*, the sentiments are echoed: section 1.41 states that the public wants access to information on good health and lifestyle advice; section 1.44 presents a case for giving 'the public more systematic access to information to support self-treatment and care'. In carrying out such responsibilities there is a strong demand for clinical information in a lay form, on a just-in-time basis, coupled with a willingness to be proactive and input personal observations on treatment effects and clinical status. The concept of MyHealthSpace mentioned in the interview relating to NHS Direct (B. Gann, personal communication) is an emerging response to such attitudes and demands. Other issues that are identified in a major but not exclusive way on public involvement include:

- a need for informative quality-marking of health websites to give guidance about information unfit for purpose and to recognise quality information (for example, the Health on the Net (HON) foundation criteria) (HON Foundation, 2004);
- risks of alienation of sections of the population, for example ethnic minorities and itinerant travellers, by the so-called digital divide (e-government strategy; Office of the Deputy Prime Minister, 2002);
- a requirement, as recognised by the *Scotland's Health on the Web* (Scottish Office, 2004), for interpretation of professional text into lay language or an indication that text has an explicit intended audience;
- issues of consent and data sharing (IT EDUCTRA, 2000; Freedom of Information Act 2000);
- the purpose and position of information repositories such as NHS Direct (Gann, 2004), EQUIP (www.equip.nhs.uk), an information

service developed by the West Midlands Library Services Development Unit, and UK Online (now called UK Direct Gov (www.direct.gov.uk);

- lifestyle guidance (teenage pregnancy, pregnancy prevention, safe sex, nutrition, antenatal care, etc.);
- awareness-raising, reassurance, just-in-time information available as required to answer queries immediately rather than awaiting face-to-face access with an expert;
- fetal monitoring, blood pressure, diabetic state;
- appointment confirmations;
- family support, benefits entitlement, good practice;
- communication as and when needed;
- MyHealthSpace, e-mail welfare consultations.

Reducing the digital divide wherever it occurs will theoretically, and according to some early pilot studies, make a difference both to the recipient of care and also to how care can be delivered. Many of the public still do not have technology at home and nor could they use it if they had. Many still do not have mobile phones either, but access through public places (for example health centres, shopping centres, and bus and train stations through kiosks; IT EDUCTRA, 2000) could make a real difference.

Making information readily available in alternative languages and media presentation styles also would reduce the dislocation of ethnic minorities, and those with visual or other impairment. However, further research is necessary to see what does make ‘fit for purpose’ in various situations.

2.11.1 Research recommendation

That research be initiated to explore ways to minimise the digital divide to ensure equity in informing citizens about health matters, through:

- determination of what constitutes fit-for-purpose communication of information that is of appropriate quality;
- developing effective means of raising public competence in accessing, evaluating and interpreting health information (predominantly web-based). This may also include exploring the feasibility and desirability of clinical professional mediation (for interpretation);
- capitalising on mechanisms to bring facilitating technology solutions into the consciousness of the widest public possible (Gann, 2004).

Section 3 English health policies that may drive or constrain e-health

The areas considered here are:

- *The NHS Plan* (NHS, 2000);
- Wanless 1: *Securing Our Future Health: taking a long term view* re investment priorities (Wanless, 2002);
- *Delivering the NHS Plan: The next steps on investment, next steps on reform* (Department of Health, 2002a);
- Wanless 2: *Securing Good Health for the Whole Population* (Wanless, 2004);
- NSFs and equivalents;
- The blurring of boundaries between primary, secondary and community care (including walk-in centres and minor injury clinics);
- Foundation Hospitals;
- Single assessment plans.

3.1 The NHS Plan (NHS, 2000)

The NHS Plan (NHS, 2000) and *Delivering the NHS Plan* (Department of Health, 2002a) cover an extensive agenda including partnership, performance, professions and the wider NHS workforce, patient care and prevention. Whereas not all the areas have informatics implications, many do provide pointers to areas where e-health may play a role, and which are confirmed by interview reports, for example with Bob Gann about NHS Direct (Gann, 2004). The key principles of the NHS Plan (NHS, 2000) are listed below and their e-health implications are outlined.

- Provision of a universal service based on clinical need not ability to pay;
- a flexible service which aims to provide just-in-time support wherever, whenever and to all eligible persons requires an extensive informatics infrastructure, which is already being addressed by the NPfIT;
- provision of a comprehensive range of services (including support to individuals with regard to health promotion, disease prevention, self-care, rehabilitation support and after care).

In order to provide a service as described, informatics solutions must be available to handle data on the individual and the population and must be presented for both lay and professional audiences. As also recognised later in Wanless 2 (Wanless, 2004), the involvement of the individual as the subject of care in the maintenance of their own care adds a new dimension to the requirements for information.

- Shaping of the provided service around the needs and preferences of individual patients, their families and carers.

This principle is addressed in the actions of the NPfIT, by the introduction of NHS Direct and the development of the emerging MyHealthSpace concept.

- Provide a response to the different needs of different populations (reducing unjustified variations and raising standards overall).

The availability, accessibility and use of the Internet to access data relating to health issues raises new paradigms. Material must be configured for a range of receivers, in terms of both technological/multimedia formats and content. These issues coupled with a requirement for wide access, by non-frontline care deliverers, to national and local data to analyse demand, need and delivery on a population basis, provide challenges to e-health working. These are predominantly being addressed by on-going tactical and strategic programmes and in recommendations made elsewhere in this report.

- Work continuously to improve quality services and to minimise medical errors.

Again this principle will be underpinned by comprehensive functionality for data handling and information analysis for authorised professionals, for management, monitoring and crisis resolution actions. In terms of e-health per se, the establishment of the UKCHIP (www.ukchip.org.uk) contributes to this principle and the following one. Use of IM&T to minimise medical errors is addressed in Annex E.

- Support and value its staff.

Clinical, management and other health-care practitioners need access to information and functions to support their day-to-day decision making and personal professional development, in addition to any input they have to strategic planning and service monitoring. Various recommendations throughout this report address this area.

- Public funds for health care will be devoted solely to NHS patients (not used to subsidise individual, privately funded, health care).

Probity determines that this statement has to be confirmed by statistical and profile information based on operational practice data. This requires considerable informatics investment, as described in the *Delivering 21st Century IT Support to the NHS* strategic document (Department of Health, 2002b). The situation is compounded by the inclusion of private health facilities to the range of choices of locations to deliver selected procedures; and the emerging operation of Foundation Hospitals within the NHS but with greater autonomy. This presents challenges such as agreed coding schema for defining activities and procedures, increased data sharing and changes to the e-business working processes of the NHS (the latter of which is not within the remit of this study).

- The NHS will work together with others to ensure a seamless service for patients.

As individuals do not choose the locations in which they have accidents and are involved in incidents, but do have choice of where they can have their non-emergency care and treatment delivered, the whole information support to a seamless service is very complex. E-health issues raised by this scenario are covered in recommendations elsewhere, including consistent definitions, access to patient information and the evidence base, protocols for sharing data and subject confidentiality.

- The NHS aims to help keep people healthy and work to reduce health inequality.

To monitor and plan developments to achieve this will require extensive information analysis capability and systems (and/or interfaces) that will facilitate bringing together disparate databases. Functionally this has already been done but there will be additional requirements to interwork new versions of solutions and legacy systems in transition in order to create the ‘pictures’ of outcome distributions necessary to monitor changes.

- Respect confidentiality of individual patients and provide open access to information about services, treatment and performance.

The confidentiality of records is critical and will get more complex once other sectors become more involved. On the other side, the Freedom of Information Act 2000 states that no data held by a public authority should be withheld (except institutions of subject confidentiality or national security). Balancing these requirements and putting in place the mechanisms within informatics solutions to log status, list-sharing options and track changes across all the spectrum of valid users of each record will be challenging but is within the remit of the National Programme. Annex F deals with this area in detail.

3.1.1 Research recommendation

That research be initiated to explore the development of tools and techniques that will be able to assess the efficacy, efficiency and effectiveness of the processes which public sector bodies (particularly health) will have in place to comply with the Freedom of Information Act 2000, and related Acts such as the Data Protection Act 1998.

3.2 Wanless 1 (Wanless, 2002)

The brief from the Treasury to Professor Wanless included identifying where it was possible to ‘universalise the best’ and ‘ to identify the key drivers of health need and cost over the next two decades’. There are many informatics issues around these laudable aims, which have extensive informatics investment implications, as Wanless took up in section 2.29. Those with an e-health specific impact include:

- (2.26) the answer to reducing the differences [between sub-population cohorts described by different UK lifestyles, nutritional

> patterns and poly-cultures] will probably include investment in preventative measures and lifestyle management advice not just the NHS per se.

This implies that funding will need to be spread even wider, health-care practitioners will need to be incentivised and remunerated for taking precautionary actions and giving guidance, and investments which affect health may need to be made on a wider basis, to include home support and rehabilitation.

Wanless 1 states that (2.62) 'Around 1.5 per cent of health spending is on ICT compared to 6 per cent in the US'. This claim is internationally recognised (Patel *et al.*, 2001a) as needing to be researched and quantified to determine the benefits in improved outcomes gained from that increased spending. The simplistic 'throw informatics at the problem' is felt by many to be inadequate.

Wanless 1 highlights an area where concern has been raised over many years (BCSHIC, 2002a) and recognises an explicit change from informatics provision by informatics professionals to the inclusion of contributions from informatics-literate end-users. To this end, the UK has established UKCHIP for registration and ultimately regulation purposes. UKCHIP is carrying out definition and implementation of:

- robust registration processes;
- entry standards;
- Code of Practice;
- continuing professional development;
- accreditation of in-house training schemes;
- promotion of health informatics as a profession (including positioning to join the Health Professions Council (www.hpc-uk.org) as and when appropriate, probably 2008).

This innovation is new internationally and research could usefully be carried out to determine its impact and acceptability to care models worldwide.

Wanless 1, in sections 2.73 and Q11.7, recognises a need for 'better use of ICT'. The report adds that more systematic use of ICT should be coupled with 'increased training in the value of quality information, the risks from bad information and the techniques of sensitive information handling supported by technology'. Whether the introduction of new ICT will meet the expressed objectives will need research to be proved, and has been included in Section 6 of this appendix.

The main research thrust indicated by Wanless 1 is that of dealing with issues on the cusp, brought about by health and social care convergence. In practice the dates suggested for checkpoints in this process are very fluid. There are considerable service-delivery implications from this report that need further research.

3.2.1 Research recommendation

That research be initiated to examine the e-health implications that arise from joint multi-sectoral working, as described in the Wanless 1 report, including developing policy relating to:

- management of risk, severally and singly;
- ethical issues of data sharing;
- legal issues of responsibility, accountability and dealing with litigation brought by stakeholders;
- the logistics of disseminating such policies in such a way that they are incorporated into local custom and practice.

3.3 Delivering the NHS Plan (Department of Health, 2002a)

After the NHS Plan in 2000, this 2002 policy document purports to answer questions about funding and investment, in order to:

- get the UK to reach health spending of 9.4% on par with ‘European levels’ (note: Europe pre inclusion of Acquisition States);
- telegraph that NHS has moved from the 1948 version (monolithic and top down) to devolved, wider choice and greater diversity bound together by common standards, tough inspection and NHS values;
- accommodate more staff, greater flexibility;
- shorten waits, provide better cancer and heart treatment with modern but compassionate care.

There are e-health implications of the issues raised, including:

- coping with a larger population in terms of training to utilise informatics (professionals need to be taught to work smarter, new jobs will cross traditional sectoral boundaries and it will be necessary to cope with scarce resources in a competitive market);
- a growing requirement to support increased patient/lay involvement in (health) care;
- a need for development of a national architecture and infrastructure, to include the National Institute of Clinical Excellence information repositories relating to best practice;
- implications of primary care trusts being able to purchase from the most appropriate (public, private or voluntary) care deliverers. The report suggests that payment will be by results but is not clear on whether that implies by clinical outcomes or throughput numbers;
- patient choice indicates a need for information on alternative providers and their performance and a concomitant ability to share clinical history records and to update them wherever the patient has their treatment;

- how to include the information needs of Foundation Hospitals (who will by necessity interwork with other NHS care-delivery facilities even though the financial basis of each is different);
- the implications of health and social care convergence, particularly where a priority focus is on supporting older persons (to continue to live at home supported by technology, reducing bed blocking in hospitals); additionally, the liability for records and reliance on records accessed by many professionals needs further research.

3.3.1 Research recommendation

That research into be initiated into e-health policy relating to:

- maximising the robustness of cross-sectoral record keeping; including maintaining effective access, managed updating and clarifying areas of legal liability;
- the interoperability obligations of different care providers in terms of the informatics requirements of delivering, managing and monitoring the care given.

3.4 Wanless 2 (Wanless, 2004)

This report came out with a different take on the situation than the previous Wanless report, asking pertinent questions relating to determining, monitoring and changing the health status and attitudes of the population. Some observations and recommendations have little/no e-health research potential in the current informatics domain and are omitted from this analysis. Wanless 2 explores various relevant questions, as follows.

- How can we compare and prioritise between different public health interventions?
- What is the best way to develop a cost-effective way of managing diseases (this can be with reference to one specific disease area)?
- Is there a measure of cost-effectiveness that can be applied consistently across different interventions to improve population health?
- What are the difficulties and barriers to implementing a cost-effectiveness approach?

Wanless 2 also indicates that there is risk in too much haste or development that is too slow: the NHS needs a balance between organic evolution and forced growth in its informatics. For instance, smart homes and ambient technologies were touched on by Wanless, and are also discussed in Dean (2003). They are emerging but will not be applicable or cost-effective in all situations, at least in the short term.

The Wanless 2 document highlights areas for action rather than makes explicit recommendations. However, there is a White Paper imminent (as of July 2004) that, it is anticipated, will put flesh on the February 2004 bones. The recommendation below is therefore based on Wanless 2 with the reservation that a subsequent White Paper might create the need for it to be modified.

3.4.1 Research recommendation

That research be initiated to explore what are the relevant criteria necessary to determine how to measure cost-effectiveness of disease management and population health improvement as recommended in Wanless 2. The criteria will be identifiable from available health data, for example in the care records and the data spine (outlined in the NPfIT specification documentation).

3.5 NSFs and equivalents

The NSF programme was initiated in 1998 and built on established frameworks for cancer care and paediatric intensive care. The NSFs comprise pronouncements issued by the Department of Health that set the national standards and define service model(s) for particular service areas (such as for children) or a care groups (such as cancer patients). They establish performance milestones against which progress within an agreed timescale must be measured. They take extensive research and deliberation by experts in the field (Expert Reference Groups) and have major ramifications for the NHS. In the first instance local plans for addressing their requirements must be developed within 6 months of their issue. They were initially intended to be issued two per year but the timeframes have now extended. To date, there are NSFs and/or equivalent with their (release date shown) for:

- Mental Health (1999);
- Coronary Heart Disease (2000);
- Children's Services (2000);
- The related National Cancer Plan (2000);
- Older People (2001);
- Diabetes (2004);
- Long-term Conditions (in preparation for release late 2004).

A warning is given by Protti (2002) about the potential development of NSF datasets in isolation from each other, resulting in needless duplication. He outlines a distinction between information to support day-to-day care delivery and to support retrospective governance requirements. A better balance is encouraged between being seen to be able to demonstrate that we did it right and the safe, effective, efficient operation of health-care delivery and patient management. There is a perceived danger in the implied shift (expressed in the *21st Century* document; Department of Health, 2002b) from the Korner principle 'of data only being available to other levels if it is required at the operational level'. Fragmented datasets to address particular non-operational requirements in an *ad hoc* way are not recommended.

NSF-driven actions are intended to 'raise quality and decrease variation' and as such there are considerable informatics implications to their implementation. The comparative nature of the scrutiny requires local data nationally in a consistent form, and a systematic approach to analysis and care. Some e-health implications of each NSF area are taken in chronological turn, but are not exhaustive as some issues apply to more than one.

3.5.1 Mental health

This NSF was the first issued in 1999 and covers seven standards addressing promotion, access to service, effective service, carers' support and suicide prevention. The care is delivered cross-sectorally to a vulnerable population. An extra £700 million for the first 3 years of the programme together with main clinical allocations of money supported the roll-out of this NSF. The challenges for e-working focus on sharing data and collaborative working. Policy documents which frame the NSF are:

- *The New NHS: Modern dependable* (Department of Health, 1997);
- *A First Class Service Quality in the New NHS* (Department of Health, 1998a);
- *Modern Social Services: A commitment to deliver*, 10th Annual report of the Chief Inspector of Social Services, 2000/2001, which looks at a new approach to Social Service performance.

It is anticipated that e-working could facilitate a number of action areas. Some of the actions (like drug compliance) are in research currently by the European Union Information Society (Health) programme. Others are being researched, some internationally, such as Internet-based solutions for patient and carer reassurance. Some are still to be addressed. Some research needs are common to all NSFs and are described elsewhere, such as shared records and efficient access to the evidence base. There is the risk, in too much concentration on e-health support to patients in general, of social exclusion of people with mental health conditions.

Research recommendation

That research be initiated to investigate the potential of e-health to enable effective interfaces in the mental health domain such as between:

- health and social care;
- local specialists and specialist services;
- carers and professionals;
- the community and vulnerable groups (for example prisons);
- self-management and institutional/professional care;
- patients and their therapy.

3.5.2 Coronary heart disease

Coronary heart disease is the single most common cause of premature death in the UK (killing over 110 000 people per year, of whom over 41 000 are under age 75). The diagnosis and monitoring of cardiac problems present many opportunities for e-health. The NSF contains 12 standards relating to reduction, prevention, coping with acute and chronic conditions, clinical procedures and rehabilitation.

E-opportunities present relating to:

- the development and revision of targets based on reported data from all over the country;
- the actual measuring, monitoring and reporting of such targets/standards and feedback to operational locations to bring about change (such as through Smoking Cessation clinics, Rapid Access Pain clinics, reductions in call-to-needle time for thrombolysis, better use of effective medication (statins, ß-blockers and aspirin) and increasing numbers of revascularisation procedures.

As indicated in Wanless 2 (Wanless, 2004) coronary heart disease can be reduced by actions of citizens themselves. Like all other areas of health, the public need information on causes, symptoms, reducing risk, service availability and the like. Strategic planners/public health leaders also need profiles of incidence, prevalence, target monitoring nationally from disparate data sources. These topics are covered in either existing/planned operational systems or research recommendations made from other places in this report. For example, the Health Informatics Plan for Coronary Heart Disease (www.hipforchd.org.uk) provides guidance for primary-care action and support to GPs in their consultations with patients.

Coronary heart disease is an area where coordinated care is already seen to be beneficial. The call-to-needle time can be reduced by using teleconsultation from ambulance to hospital, based around ground-breaking work such as that done in the CEC HECTOR project (European Commission IS, 1999) that created a teletriage system. Other projects from the same Information Society Research base (the Framework Programmes) looked at heart-signal trace transmission from remote locations in order to reduce the time from diagnosis to first treatment.

Whereas there is a body of research work in this area, it has not all been evaluated in operational situations.

Research recommendation

That research be initiated to look at the research to date in the areas of telediagnosis, teletriage and teleconsultation using both signal traces and pictorial images to determine the feasibility, cost-effectiveness and appropriateness of deploying such techniques in routine operational coronary heart disease practice.

3.5.3 Children's services

The distinguishing features of children's services are:

- a history of multi-disciplinary care;
- a service-delivery structure which crosses all sector boundaries, including acute, primary and health-social care;
- an emotive involvement of informal carers to a greater extent than any other area, and a demand for information from the public (see Section 2.11, on involvement of the public);
- a demonstrable interworking between professionals and service users to a significant extent (see section on Professional – Service Users).

Following on work in the USA relating to e-solutions to improve the quality of family support (such as the Boston Virtual Goodnight Kiss; Patel and Rogers, 2001) and the Patient Reassurance work in Wisconsin (Patel *et al*., 2001b), there are pilot projects that could provide improved quality of service, but which require evaluation for effectiveness in UK terms and for wider deployment.

Research recommendation

That research be initiated to identify e-health technologies that could support improved effectiveness in family support for children's services, for example:

- technology to support families with hospitalised seriously ill children and siblings at home;
- information systems that provide just-in-time information tailored to individuals (in conjunction with an appropriate phase of NHS Direct; Gann, 2004).

3.5.4 Cancer services

The *Policy Framework for Commissioning Cancer Services*, by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales (1995), set the scene for better-coordinated cancer services creating cancer units and cancer centres. It set out the following principles that should govern the provision of cancer care.

- All patients should have access to a uniformly high quality of care in the community or hospital wherever they may live to ensure the maximum possible cure rates and best quality of life. Care should be provided as close to the patient's home as is compatible with high-quality, safe and effective treatment.
- Public and professional education to help early recognition of symptoms of cancer and the availability of national screening programmes are vital parts of any comprehensive programme for cancer care.
- Patients, families and carers should be given clear information and assistance in a form they can understand about treatment

options and outcomes available to them at all stages of treatment from diagnosis onwards.

- The development of cancer services should be patient-centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional. Communication between professionals and patients is especially important.
- The primary care team is a central and continuing element in cancer care for both the patient and his or her family from primary prevention, pre-symptomatic screening and initial diagnosis through to care and follow up or, in some cases, death and bereavement. Effective communication between sectors is imperative in achieving the best possible care.
- In recognition of the impact that screening, diagnosis and treatment of cancer have on patients, families and their carers, psychosocial aspects of cancer care should be considered at all stages.
- Cancer registration and careful monitoring of treatment and outcomes are essential.

The *NHS Plan* (NHS, 2000) announced substantial extra investment in cancer services with the aim that England would have the fastest improvement in cancer services across Europe over 2000 to 2005. Many initiatives have followed, including the NHS Executive's *Cancer Information Strategy* (2004) allied to *Information for Health*. This dealt only with information rather than ICT but would rely on ICT systems to be realised.

Many of the policy developments and reports emphasise the need for close interworking between all carers: specialists, secondary hospital care, community and primary care and the importance of continuity of care. All need to be patient-centred with the patient always informed by, and in touch with, their carers, which include family and friends and the voluntary sector. Treatment needs to be as close to the patient's home as practicable. This is particularly so in palliative care where primary care, social services and the voluntary sector should all be involved. Whereas most patients would prefer to die at home only 25% get to do so (Department of Health, 2002d).

ICT might substantially enable these aims. Broadband is easily and cheaply available to (most) private homes combined with cheap home ICT including interface with smart cards, CDs or memory sticks with patient-specific information, including their own cancer-management record. Websites specific to patients are easy to create and patients are increasingly familiar with ICT.

Research recommendations

That research be initiated to investigate use of ICT to support cancer patients when in their home, for example:

- supply of broadband and PC with video to patients;

- links (video, e-mail, Internet) for the patient to NHS cancer services, the patient's carers, voluntary support services and quality websites;
- ICT provision for voluntary services to which patients are linked;
- links to a website and advice specific to a patient;
- smart cards with patient records, etc.

That research be initiated to investigate use of ICT to support professional carers for cancer patients (such as community nurses, primary-care staff and Macmillan nurses giving palliative care), for example:

- supporting them in non-hospital locations including a patient's home (such as through the supply of a notepad computer with wireless dial-up from a third-generation mobile phone for e-mail and access to websites);
- electronic links to social services and other supporting organisations;
- access to teleconferencing for joint sessions with other carers and clinicians involved with a patient's care programme.

3.5.5 Care for older people

The potential for e-health to support the older person in their own homes is now considerable, as care of older people takes a disproportionate amount of NHS funding (Wanless 1 (Wanless, 2002) says that over 25% of the health-care funding for an individual is consumed in the last year before death). The NSF for Older People was established in 2001 and consists of eight standards relating to discrimination, person-centric care (intermediate and hospital), clinical (stroke, falls, mental health) and the promotion of an active life. It could be suggested that the e-revolution had passed this aged cohort by, but in fact they are becoming relatively heavy Internet users, referred to in the vernacular as silver surfers. In order to keep up the quality of life for such individuals much emphasis is being placed on technologies and care practices that will allow them to live independent lives for as long as possible, thus creating a shift to home care and an increased demand for care support in non-hospital locations. A major focus for this cohort is to add 'life to years' and not just prolong life by adding 'years to life' (the QALY principle).

Key documents that frame the direction of policy for this cohort are *Better Government for Older People* (Department of Health, 1998b) and *Better Care Higher Standards* (Department of Health, Social Services Directorate, 2000).

The following areas of care for older people could benefit from e-health concepts. Typically:

- in facilitating multi-sectoral professionals in developing and utilising coordinated care pathways;
- in using technology to carry out vital-signs monitoring on people at risk, such as after cardiac problems have been identified, or by

monitoring personal outputs. These areas are already being researched for example by European Commission-funded projects such as @HOME, HUMAN, HEALTHMATE and TELEMEDICARE (www.cordis.lu);

- by extending home-based care; developing, for example, smart houses that monitor behaviour patterns, call alerts when abnormal behaviour occurs, teleconsultation to avoid unnecessary travelling and trauma, specialist care at a distance, and ensuring drug compliance by monitoring when pills are taken and alerting the subject or a relevant practitioner when they are not;
- by reassurance and reinforcement of information about clinical conditions and practices. This may entail local health organisations and practitioners making non-patient-specific information available as and when required, specialist voluntary groups providing information to sufferers, and additionally personal sufferers communicating their experiences through the Internet.

Some of the above are being researched already, but it is felt important to consider the professional working changes brought about by this potential shift in emphasis for care delivery, as follows.

Research recommendation

That research be initiated into changes in work patterns of non-hospital-based professionals utilising e-health opportunities to sustain home-based care, brought about by, for example:

- patient involvement in self-management of chronic conditions;
- remote (vital-signs) monitoring.

Liability and legality of remote working should be encompassed by the research.

3.5.6 Diabetes care and management

This condition manifests in acute and chronic scenarios and, as such, can benefit from patient monitoring, drug-compliance monitoring, patient reassurance and self-management support from e-solutions in a similar way to many other clinical conditions. As the second most frequently occurring condition in the UK (second only to epilepsy), any e-health solution would be in great demand and therefore will require strict cost-effectiveness and added-value analysis. The CEC Information Society research programme and its predecessors the Framework Programmes have numerous examples of technology contributions to support diabetic practice, for example BlackSea TeleDiab (www.telemed.ro), M2DM and the more general INFOPHARMA relating to self-medication. Details of these projects can be found on the European Commission website (www.cordis.lu). They can usefully be scrutinised and evaluated for operational care in the UK.

The Wanless reports (2002, 2004) also highlight the expected increase in prevalence of type 2 diabetes (by between 30 to 60 per cent) unless issues of obesity and physical inactivity are addressed and demographic changes are monitored and managed. Particularly singled out by Wanless 2 (Wanless, 2004) are those who do not yet know they have diabetes and if treated can reduce the considerable burden of end-stage diabetic interventions. As key risk factors are unhealthy diet, inadequate physical activity, genetic endowment and socioeconomic conditions, many citizen information initiatives, such as NHS Direct, can contribute significantly to improvements.

In addition, the work of the UK BioBank (www.ukbiobank.ac.uk) will be most useful in analysis of genetic patterns once it has reached a critical mass of content. Policy and ethical considerations will frame how rapid will be the deployment of this source to operational care deliverers.

3.5.7 Long-term (chronic) care

Features particular to long term/chronic care relate to:

- multi-disciplinary care and care pathways; requiring shared records;
- patient reassurance and self-monitoring; requiring Internet access to evidence repositories and fast-response test analysis and reporting;
- general information for informal carers and for primary-care practitioners;
- NHS Direct services for immediate guidance in case of critical incidents.

These areas and the e-health opportunities they present are covered in principle elsewhere. The policies governing roll-out of services to this cohort will cross sectoral boundaries, breach professional barriers and present professional-to-lay-person dialogue challenges.

Research recommendation

The disparate nature of themes that could be reapplied in a different context is well-demonstrated by the features described above. It is suggested that research be initiated to establish a mechanism to make available a repository of e-health project information containing contacts, progress reports, general and specific findings, exploitation opportunities and operational deployments. Commissioned research should be complemented by investing in the dissemination of findings so that tools, techniques and deliverables can be considered for innovative re-enactment in different situations, modes and locations.

Section 4 Non-health policies that drive or constrain e-health

The major UK non-health policies which may drive or constrain e-health are the:

- Government's Interoperability Framework, e-GIF;
- Government Communications Initiative;
- Citizen's Information Project;
- Government policy on identity cards;
- Government security and confidentiality policy;
- policies of the Information Commissioner's Office.

The present UK Government has a strong commitment to ICT in the UK and in particular to e-government (Cabinet Office, 2000), which it sees as a major driving force across all UK domains. The NHS is deemed to be encompassed within e-government and thus expected to conform with initiatives within this context.

4.1 e-GIF

One of the most significant policies within the e-government strategy is the Government Interoperability Framework e-GIF (Office of the e-Envoy CO, 2003a, b, c). This is the responsibility of the Office of the e-Envoy within the Cabinet Office. Its aim is to lay down policies and standards that all public sector bodies are expected to follow to ensure interoperability across this whole domain.

The e-GIF defines a minimum set of technical policies and specifications governing information flows across government and the public sector. They cover interconnectivity, data integration, e-services, access and content management.

Until recently the NHS Information Authority (NHSIA) supported an e-GIF team to assist the NHS in complying with e-GIF requirements. Although the team has now closed, the obligation on the NHS to comply remains, including procurements within the NPfIT. Indeed, all e-services within the domain, including the NHS, are expected to comply by 2005. This poses significant constraints and, in terms of migration, produces major challenges at the level of technical detail.

4.2 Government Communications Initiative

In its White Paper on *A New Future for Communications* (Department of Trade and Industry and Department for Culture MaS, 2000) the Government set out, through the Department of Trade and Industry, its vision and objectives on communications in the 21st century. It encompassed the whole range of communications including the

Internet, digital terrestrial and satellite television, mobile and wireless devices, telephone and broadband accessibility. The thrust of the objectives is to make the best of digital communications universally available in the UK.

The significance for health in terms of the public, is the availability to individuals of a variety of communication technologies, for example third-generation mobile phone, digital television and broadband telephone connections to the home, all of which can facilitate improved access to health information and to health applications such as telemedicine, e-consultations, etc. Broadband telephone connections are now widely available (over 80% coverage) and are relatively cheap, allowing fast downloading of health information, including voice and video. At present bandwidth for uploading of information, for example for video contact from home to carer is less available at low cost (ADSL provides 2 Mb download but only 0.5 Mb upload). However, services providing 2 Mb both ways (SDSL) are becoming available. The government is encouraging such provision, although availability to remote rural areas may be some time distant and this could include GP practices in some rural areas. Overall one can expect to witness over the next few years rapid improvements in access to increasing bandwidth and at lower cost to most homes in the UK, a prerequisite for the success of a number of telemedicine applications involving individuals in their homes.

Part of the Department of Trade and Industry's broadband initiative is to coordinate and aggregate procurement of broadband communications across the public sector. The recent NPfIT contract for the supply of a broadband to the NHS network (N3) to replace NHSnet falls within that initiative.

4.3 The Citizen's Information Project and Government policy on identity cards

About 10 years ago the NHS issued a new NHS number as a unique identifier for all individuals and subsequently implemented a database for an NHS number-tracing service. The latter contains administrative data on all persons registered with the NHS: name(s), address(es), sex, age, GP and NHS number. Over several years, and including the present time, the NHS has considered whether to issue all NHS patients with some form of data card (for example, a smart card) containing administrative data including NHS number and perhaps clinical data such as emergency information and allergies and even a full summary medical record. Such a card might be used as the means for authenticating an individual, for example, to authorise access to personal information such as an e-prescription or MyHealthSpace on the NHS spine. These matters may be affected by two government initiatives:

- a national identity card;
- the Citizen's Information Project.

The Government has announced that it intends to proceed with the issue of national identity cards containing biometric identifying information. They are to be voluntary, at least until 2013, and possibly mandatory sometime thereafter. It has been suggested that the identity card might be multi-functional, including the holding of some medical data, and, in the EU, acting as an electronic E111.

There exists therefore the possibility that the identifying data and number on a national identity card would in due course replace the NHS number for identification purposes. If it were multi-functional it could facilitate some of the applications that have been envisaged for a medical data card.

The Government is also considering the feasibility of a national population register under the name of the Citizen's Information Project (www.statistics.gov.uk/registration/cip.asp), which is being managed by the Office of National Statistics. The project is at the feasibility stage. The vision is a national population register for sharing basic, non-sensitive contact data about people and is regarded as a core building block in the e-government strategy. It is seen as a support to other public services, for example for identification, referral and tracking children at risk, as well as for identity cards. It is possible therefore that this might in due course replace the NHS number-tracing service.

Whether or not the identity card and population register come to pass, the need to consider these possibilities might constrain any NHS developments regarding unique identification, security means for authentication and authorisation and possible 'medical' cards. Unique identification, authentication and authorisation are of course key aspects of the proposed electronic care record on the NHS spine.

4.4 Government security and confidentiality policy

The Government's security and confidentiality policies are set by the Office of the e-Envoy in the documents:

- *Security: e-Government Strategy Framework Policy and Guidelines* (Office of the e-Envoy CO, 2002a);
- *Confidentiality: e-Government Strategy Framework Policy and Guidelines* (Office of the e-Envoy CO, 2002b).

The NHS is committed to comply. Annex F deals in detail with the NHS position.

4.5 Information Commissioner's Office

National responsibility for protection of personal data (data protection) lies with the Information Commissioner's Office under the Data Protection Act 1998. The latter supplemented and incorporated the provisions of earlier acts such as the Access to Health Records Act 1990 and applies to personal health data, whether held on computer or not; that is, it applies fully to patient records whether they are computerised, in paper files, hand-written case notes or X-rays, etc. The Office has published advice on the use and disclosure of health data (Information Commissioner's Office, 1998).

The Information Commissioner's Office is also responsible for the Freedom of Information Act 2000 and has published advice on the Act for the NHS organisations (for example, NHSIA, 2003).

The NHS has in recent years directed considerable attention to the protection of personal health information and is thus well versed in the application of the Data Protection Act 1998 and the issues it raises in the context of health data, such as matters of consent (see Annex F).

4.6 e-Skills Council

The e-Skills Council is government-backed. It addresses the requirements for the IT sector (services and suppliers), telecommunications, and call and contact centres. There is an overlap with the NHS through the Health Sector Skills Council (Skills for Health), particularly in the areas of NHS Direct and the NPfIT and the skills and competencies necessary to their success. It has been agreed that in the technology aspects of the health domain that the e-Skills Council will take the lead. Although it addresses education in its widest sense, there are few links to date between it and the NHS University (NHSU) activities in the informatics area. The Sector Skills Councils operate by consulting employers (like the NHS) for details of their requirements and then enable, commission or develop tools to generate the necessary skills.

From an interview with the e-Skills health lead person (T. Hook, personal communication, July 2004) on health topics, a number of work practice issues that they are scrutinising arose. This work will have a resonance with the introduction of e-health, notably:

- exploring remote technology needs and how effectively to provide remote support to informatics users in that situation (community health staff and any other care practitioner or manager who works from more than one base);
- sorting out how management can be sustained on a remote basis, so that the requirement of field staff to come into the office/base is minimised;
- addressing human issues – such as how to (re-)generate stimulation by peer group and peer-group bonding (when staff work remotely), in order to minimise the 'fish out of water' syndrome of remote field workers;
- exploring how to make formal time management less of an issue. Research has shown that remote workers feel guilty about popping to shops during their working hours, even though they are frequently available 24 hours a day, 7 days a week, and they work out of hours anyway (because the technology enables work

at any time and not during strict work hours). This will only be appropriate for peripatetic and non-hospital staff. The increase in primary care cooperatives, off-site on-call estates facilities and the like make this way of working useful in health.

Hansske, from France, in Dean (2003) also questions how a physician can take real advantage of a new tool (such as e-health) when s/he has not benefited from the appropriate training required to understand and use it.

Whereas the Industrial Society (now called the Work Foundation) may have already done some work on such social change, there remains a requirement to research the feasibility and appropriateness of such flexible working in the health domain.

4.6.1 Research recommendation

That research be initiated into the applicability, acceptance and requirements of flexible, multi-site working, including from-home bases, particularly looking at:

- necessary technologies;
- cultural changes;
- management of change and governance issues of 24-hour/7-days-a-week working in non-traditional areas.

Section 5 European e-policies and initiatives

5.1 eEurope 2005

The EU Commission is actively engaged in promoting an ‘eEurope’. Its first action plan, eEurope 2002 ran from 2000 to 2002 and has been succeeded by eEurope 2005 (EU Commission, 2002a). Key targets are:

- connecting public administrations, schools, health care to broadband;
- interactive public services, accessible for all, and offered on multiple platforms;
- provide online health services;
- removal of obstacles to the deployment of broadband networks;
- review of legislation affecting e-business;
- creation of a Cyber Security Task Force.

Many of these targets are well in hand within the EU, for example through directives, and are well advanced in the UK. Through the e-Envoy and the Department of Trade and Industry communication initiatives (see Section 4.2, above), broadband is becoming readily available and cyber security is being addressed. NHS initiatives are underway to connect health care organisations to broadband (N3) and public and professional access to health information is being facilitated in many ways, not least through NHS Direct and National Electronic Library of Health.

In the area of e-business, legislative steps are in train in EU countries as a result of a series of EU directives such as those for electronic signatures (Directive 1999/93/EC Community Framework for Electronic Signatures, December 1999), contracts at a distance (Directive 97/7/EC The Protection of Consumers in Respect of Distance Contracts, May 1997) and e-commerce (Directive 2000/31/EC Electronic Commerce, June 2000), all of which have an impact in areas of e-health.

The Europe 2005 Action Plan (EU Commission, 2002a) includes three proposed actions particular to e-health, as follows.

- Electronic health cards: a European Health Insurance Card (EHIC) will replace paper-based forms needed for health treatment in another Member State. The Commission intends to support a common approach to patient identifiers and electronic health record architecture through standardisation and will support the exchange of good practices on possible additional functionalities, such as medical emergency data and secure access to personal health information.

- Health information networks: by the end of 2005, Member States should develop health information networks between points of care (hospitals, laboratories and homes) with broadband connectivity where relevant. In parallel, the Commission intends to set up Europe-wide information networks of public health data and co-ordinate actions for Europe-wide rapid reactions to health threats.
- Online health services: by the end of 2005, the Commission and Member States will ensure that online health services are provided to citizens (for example, information on healthy living and illness prevention, electronic health records, teleconsultation, e-reimbursement). Some of the health and related preventative services (for example, online information about air and water quality) could be expanded to a trans-European level through the eTEN programme. The Commission will monitor actions taken by Member States to make health information as accessible as possible to citizens as well as initiatives to implement quality criteria for websites.

eEurope has spawned a variety of initiatives within the e-health context in order to pursue the key targets above. In its latest action plan (EU Commission, 2004a) the Commission envisages a European e-Health Area 'as a framework built on a wide rage of European policies and initiatives'. It seeks to face the challenges of:

- rising demand for health and social services, due to an ageing population and higher income and educational levels. In particular, by 2051, close to 40% of the Union's population will be older than 65 years old (Braun *et al.*, 2003);
- the increasing expectations of citizens who want the best care available, and at the same time to experience a reduction in inequalities in access to good health care;
- increasing mobility of patients (EU Commission, 2004b) and health professionals (EU Commission, 2002b) within a better-functioning internal market;
- the need to reduce the so-called disease burden, and to respond to emerging disease risks (for example, new communicable diseases like SARS);
- the difficulties experienced by public authorities in matching investment in technology with investment in the complex organisational changes needed to exploit its potential;
- the need to limit occupational accidents and diseases, to reinforce well-being at work and to address new forms of work-related diseases;
- management of huge amounts of health information that need to be available securely, accessibly, and in a timely manner at the point of need, processed efficiently for administrative purposes;
- the need to provide the best possible health care under limited budgetary conditions.

Actions proposed for the period to 2010 are listed in Table A1, below.

Table A1 Actions proposed for the period to 2010

Action	Time	Responsibility
Issue 1 Addressing common challenges		
The Commission Communication on patient mobility (EU Commission, 2004b) is presented as part of an overall strategy on health care. Work is already underway to improve information on patient mobility and mobility of health professionals at the European level and is being taken forward in particular through the health systems working party under the information strand of the public health programme.	2004	Commission
By mid 2005 the Commission should produce a summary of European best practices as guidance for Member States.	Mid 2005	Commission
By the end of 2005, each Member State is to develop a national or regional road map for e-health. This should focus on deploying e-health systems, setting targets for interoperability and the use of electronic health records, and address issues such as the reimbursement of e-health services.	End 2005	Member States
By the end of 2006 Member States, in collaboration with the European Commission, should identify a common approach to patient identifiers. This should take account of best practices and developments in areas such as the EHIC and identify management for European citizens.	End 2006	Member States, Commission
By the end of 2006, Member States, in collaboration with the European Commission, should identify and outline interoperability standards for health data messages and electronic health records, taking into account best practices and relevant standardisation efforts.	End 2006	Member States, Commission
By the end of 2006, a collaborative approach should be undertaken among Member States to supporting and boosting investment in e-health.	End 2006	Member States
By the end of 2007, Member States should adopt conformity testing and accreditation schemes following successful best practices.	End 2007	Member States
During the period 2004–8, Member States should support deployment of health information networks for e-health based on fixed and wireless broadband and mobile infrastructures and Grid technologies.	2004–8	Member States
By the end of 2009, the European Commission, in collaboration with Member States, should undertake activities to: set a baseline for a standardised European qualification for e-health services in clinical and administrative settings; provide a framework for greater legal certainty of e-health products and services liability within the context of existing product liability legislation;	End 2009	Commission, Member States

improve information for patients, health insurance schemes and providers regarding the rules applying to the assumption of the costs of e-health services;		
promote e-health with a view to reducing occupational accidents and illnesses as well as supporting preventive actions in the face of the emergence of new workplace risks.		
Issue 2 Pilot actions: accelerating beneficial implementation		
By the end of 2005, a European Union public health portal will give access to European level public health information. Health portals shall offer dedicated information on safety at work and health risks in the workplace. By the end of 2005, there will be a strengthening of early warning, detection and surveillance of health threats through enhanced ICT tools.	End 2005	Commission
Promoting the use of cards in the health care sector. Adoption of implementation of an EHIC by 2008.	2008	Commission, Member States
By the end of 2008, the majority of European health organisations and health regions (communities, counties, districts) should be able to provide online services such as teleconsultation (second medical opinion), e-prescription, e-referral, telemonitoring and telecare.	End 2008	Member States
Issue 3 Working together and monitoring practices		
In 2004, a high-level e-health forum will be established, the role of which will be to support the Commission services. It should involve all necessary stakeholders, including at national, regional or local hospital authority levels, thereby enhancing the understanding of the Commission services with regard to the current and planned status of development of e-health in Member States. Its task should be to follow up the various roadmaps, and to identify further actions including a strong focus on users and access for all to e-health, as well as to develop a strong evidence basis for the case for e-health. The work of the e-health forum will also be closely associated with the implementation of the Community Public Health Programme.	2004	Commission
By the start of 2005, Member States, in collaboration with the European Commission, should agree on an overall approach to benchmarking in order to assess the quantitative, including economic and qualitative impacts of e-health.	Start 2005	Member States, Commission
By the end of 2005, the European Commission, with contributions from Member States, should establish an effective way of disseminating best practices and supporting actions within the European e-health area.	End 2005	Commission, Member States
An assessment of e-health developments should be completed ahead of the second part of the World Summit to be held in Tunis in 2005.	2005	Commission, Member States

During the period 2004–8, Member States with the support of the European Commission will organise special events such as high-level conferences in order to disseminate best practices.	2004–8	Member States, Commission
During the period 2004-10, every 2 years, the European Commission will publish a study on the state of the art in deployment, examples of best practices, and the associated benefits of e-health.	2004–10	Commission

Again, for most of the actions proposed, there are NHS and wider UK initiatives that are being pursued through, for example, NHSIA and NPfIT. However, there are areas that are not being fully addressed and which might warrant research namely in the context of:

- increased patient mobility between countries;
- health data cards.

5.2 Health data cards

Issues relating to health cards are dealt with in Annex G.

5.3 Patient mobility between countries

Whereas patients will wish to benefit from high-quality health care as close to home and as quickly as possible, this may not always be practicable, for example, if:

- an individual is taken ill while on holiday or business abroad;
- the necessary treatment is not available within a reasonable time in the patient’s home country;
- the necessary treatment is not available, at the necessary quality, in the patient’s home country.

When patients are taken ill while abroad in an EU country, arrangements exist for payment of costs through the so-called E111 form and associated provisions (the E111 is to be replaced with an EHIC; see Annex G). However, there remains the matter of access to a patient’s health records from abroad, particularly where they are in electronic form residing on a website (MyHealthSpace) or, for NHS patients, on the NHS national spine.

Where a patient seeks treatment in an EU country other than his/her own because of the quality and/or timeliness of services in his/her own country, a number of issues arise which the EU Commission is addressing actively (EU Commission, 2004b). That the EU provides freedom for citizens to seek health care in other Member States has been confirmed by the European Court of Justice and the latter has clarified the circumstances under which costs may be reimbursed[1]. In essence, a patient may seek in another Member State:

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[1] Kohll judgement, Case C-155/96 of 28.04.98, ECR 1998, p. 1-1931; Smits et Peerbooms judgement, Case C-157/99 of 12.07.01, ECR 2001 p. 1-05473; Vanbrackel judgement, Case-C368/98 12.07.01, ECR 2001 p. 1-05363;

- any non-hospital care to which a patient is entitled in his/her own Member State, and the patient will be reimbursed up to the level of reimbursement provided in his/her own Member State;
- any hospital care provided for which the patient has authorisation from his/her own health system. That authorisation must be given if a patient's own system cannot provide the care within medically acceptable time limits considering the patient's condition. Again, reimbursement would be at least up to the level of reimbursement which the patient would receive from his/her own health system.

The Commission has proposed a Directive on Services in the Internal Market that will clarify the authorisation of reimbursement of medical costs incurred by a patient in another Member State.

Patients are already seeking medical treatment in countries other than their own in the EU and elsewhere (for example, India and Africa). UK patients are doing so and the practice is likely to increase. EU citizens from continental Europe are likewise coming to the UK.

Such mobility again raises the issues of access to a patient's electronic medical records from another country and their incorporation into, or handling within, the electronic medical record systems within the other country's health care provider. Some of these issues relate to health data cards dealt with in Annex G and to the handling of electronic care records in Annex A.

5.3.1 Research recommendation

That research be initiated to investigate how access by UK citizens to health care in other countries, particularly the EU, might be improved through ICT systems, especially considering:

- access to electronic health care records located in the UK or held on a health data card (see Annex G);
- harmonisation of electronic health record structures across the EU including semantic/terminological aspects;
- matters of confidentiality, security and data protection;
- language translation.

Inzan judgement, Case C-56/01 of 23.10.03, not yet published; Leichtle judgement, Case-C 8/02 of 18.3.04, not yet published.

Section 6 Other observations

Below are some general observations that derive from the interviews undertaken, general reading and contacts.

It has been pointed out to us on a number of occasions that in the area of IM&T, research projects extending over long periods, for example 3–5 years, are often out of date by the time they report because of the speed at which IT changes. Short research studies are more likely to be valuable.

Similarly, it is usually better to evaluate IM&T applications/pilots as implementation proceeds rather than retrospectively. In the latter case, the passage of time can render results out of date and, additionally, to observe implementation as it happens can result in significant added value.

Section 7 Workshop at HC2004

An interactive workshop was conducted at the Healthcare Computing Conference HC2004 aimed at identifying the research areas necessary to develop effective e-health working in the UK, to gauge the issues and policies constraining and promoting successful e-health in the general health informatics domain and to seek contributions to recommendations for research priorities.

Preparatory work had been done to identify possible areas of investigation that might contribute to the major health priorities of today. These were then set in the context of e-working in general and NHS policy in particular. Each proposal was subjected to secret individual electronic voting, scoring each proposal for its relevance on a scale of 1 to 9. The middle-scoring themes were re-considered to see how they might be improved. The results of the voting and views expressed at the workshop have been taken into account in framing the recommendations in this report.

The participants were invited to propose other areas for research. Suggestions included:

- to determine what the specific training needs were to enable an effective e-health environment;
- to ground the present national programme in an evidence-based scenario, and to determine whether the impact of the programme would be different if the programme were to be developed by management dictate or based on international evidence;
- to explore the availability and accessibility of citizen's information outside the UK, and to determine what information patients expect to be available and whether it already exists elsewhere;
- to investigate areas of excellence in UK general practice computing and make recommendations to ensure that these are not lost in the national programme;
- to explore the breaking down of silo-barriers between profession-specific 'areas of excellence' and research;
- to re-design GP computing to address the wider multi-professional area of primary care and to research the context to determine how applicable and relevant are current areas of expertise to the wider primary care area.

The essential aspects of many of these suggestions are incorporated in the recommendations in this report.

Section 8 Summary of recommendations

Although this report is to the SDO, the recommendations it makes, as summarised below, may best be undertaken through joint commissioning with other organisations or agencies, or indeed some of them may be better pursued by some other organisation or agency entirely.

8.1 Section 2 Information for Health

That research be initiated to explore the reasons for limited use of repositories of clinical guidance and evidence; both the attitudinal views of the clinicians who appear reluctant to use such repositories and the mechanistic challenges, including the human–computer interface and performance-response issues, to extended use of decision-support tools in the health domain.

8.2 Section 2 Delivering 21st Century IT Support for the NHS: National Strategic Programme

That research be initiated to explore the best working practices from those other sectors which are recognised as being substantially ahead of the health sector (such as e-business) in order to:

- determine what lessons can be learnt in delivering efficient, effective support to the business of delivering health care;
- identify criteria for rejecting those technologies and e-working practices which are inappropriate to and inconsonant with care delivery;
- identify solutions that are technologically ahead of those currently used in the health domain and which offer a positive potential for the NHS to ‘leapfrog’ its current development and deployment path.

8.3 Section 2 Implementing Information For Health: Even more challenging than expected?

That research be initiated to develop a code of collaboration under which organisations can explicitly share data and can both input to overall records consistently and unambiguously, with reference to how other sensitive domains handle data collectively.

That research be initiated to develop guidance on the management and handling of ‘legal risk’, taking into account the experiences, policy, regulation and legislation outwith the health domain and the particular sensitivities of dealing with care data, particularly as convergence between health and social care extends.

8.4 Section 2 BCS involvement in e-health (policy) issues

That research be initiated into the catalysts, inhibitors and potential benefits from the deployment of open-source solutions in the health domain.

8.5 Section 2 Integrated National Care Records Service

That research be initiated to evaluate the efficacy of available and proposed records structures to support the needs of the multi-sectoral professionals in their joint care of patients and clients, in terms of:

- transition and merging of existing records;
- using a shared numbering system;
- primacy of input from multiple sectors – developing paradigms and managing cultural custom and practice.

8.6 Section 2 Involvement of the public

That research be initiated to explore ways to minimise the digital divide to ensure equity in informing citizens about health matters, through:

- determination of what constitutes fit-for-purpose communication of appropriate-quality information;
- developing effective means of raising public competence in accessing, evaluating and interpreting health information (predominantly web-based). This may also include exploring the feasibility and desirability of clinical professional mediation (for interpretation);
- capitalising on mechanisms to bring facilitating technology solutions into the consciousness of the widest public possible.

8.7 Section 3 The NHS Plan

That research be initiated to explore the development of tools and techniques that will be able to assess the efficacy, efficiency and effectiveness of the processes which public-sector bodies (particularly health) will have in place to comply with the Freedom of Information Act 2000 and the Data Protection Act 1998.

8.8 Section 3 Wanless 1

That research be initiated into the e-health implications that arise from joint multi-sectoral working, as described in the Wanless 1 report, including developing policy relating to:

- management of risk, severally and singly;
- ethical issues of data sharing;
- legal issues of responsibility, accountability and dealing with litigation brought by stakeholders;
- the logistics of disseminating such policies in such a way that they are incorporated into local custom and practice.

8.9 Section 3 Delivering the NHS Plan: The next steps on investment

That research be initiated into e-health policy relating to:

- maximising the robustness of cross-sectoral record keeping; including maintaining effective access, managed updating and clarifying areas of legal liability;
- the interoperability obligations of different care providers in terms of the informatics requirements of delivering, managing and monitoring the care given.

8.10 Section 3 Securing Good Health for the Whole Population

That research be initiated to explore what are the relevant criteria necessary to determine how to measure cost-effectiveness of disease management and population health improvement as recommended in Wanless 2. The criteria will be identifiable from available health data, for example in the care records and the data spine (outlined in the NPfIT specification).

8.11 Section 3 Mental health

That research be initiated to investigate the potential of e-health to enable effective interfaces in the mental health domain such as between:

- health and social care;
- local specialists and specialist services;
- carers and professionals;
- the community and vulnerable groups (for example, prisons);
- self-management and institutional/professional care;
- patients and their therapy.

8.12 Section 3 Coronary heart disease

That research be initiated to look at the research to date in the areas of telediagnosis, teletriage and teleconsultation using both signal traces and pictorial images to determine the feasibility, cost-effectiveness and appropriateness of deploying such techniques in routine operational coronary heart disease practice.

8.13 Section 3 Children's services

That research be initiated to identify e-health technologies that could support improved effectiveness in family support for children's services, for example:

- technology to support families with hospitalised seriously ill children and siblings at home;
- information systems that provide just-in-time information tailored to individuals (in conjunction with an appropriate phase of NHS Direct).

8.14 Section 3 Cancer services

That research be initiated to investigate use of ICT to support cancer patients when in their home, for example:

- supply of broadband and PC with video to patients;
- links (video, e-mail, Internet) for the patient to NHS cancer services, patients' carers, voluntary support services, quality websites;
- ICT provision for voluntary services to which patients are linked;
- links to a website and advice specific to a patient;
- smart cards with patient records, etc.

That research be initiated to investigate use of ICT to support professional carers for cancer patients (such as community nurses, primary care staff and Macmillan nurses giving palliative care) for example:

- supporting them in non-hospital locations including a patient's home (such as through the supply of a notepad computer with wireless dial-up from a third-generation mobile phone for e-mail and access to websites);
- electronic links to social services and other supporting organisations;
- access to teleconferencing for joint sessions with other carers and clinicians involved with a patient's care programme.

8.15 Section 3 Care for older people

That research be initiated into changes in work patterns of non-hospital-based professionals utilising e-health opportunities to sustain home-based care, brought about by, for example:

- patient involvement in self-management of chronic conditions;
- remote (vital signs) monitoring.

Liability and legality of remote working should be encompassed by the research.

8.16 Section 3 Long-term (chronic) care

That research be initiated to establish a mechanism to make available a repository of e-health project information containing contacts, progress reports, general and specific findings, exploitation opportunities and operational deployments. Commission of research should be complemented by investing in the dissemination of findings so that tools, techniques and deliverables can be considered for innovative re-enactment in different situations, modes and locations.

8.17 Section 4 e-Skills Council

That research be initiated into the applicability, acceptance and requirements of flexible, multi-site working, including from home bases, particularly looking at:

- necessary technologies;
- cultural changes;
- management of change and governance issues of 24-hour/7-days-a-week working in non-traditional areas.

8.18 Section 5 Patient mobility between countries

That research be initiated to investigate how access by UK citizens to health care in other countries, particularly the EU, might be improved through ICT systems, especially considering:

- access to electronic health care records located in the UK or held on a health data card (see Annex G);
- harmonisation of electronic health record structures across the EU including semantic/terminological aspects;
- matters of confidentiality, security and data protection;
- language translation.

8.19 Annex A Birth-to-death records

That research be initiated to explore what policy changes would be required to underpin use and content for joint health and social care birth-to-death patient/client records, given that the current concerns about shared records are resolved, in order to support care in its widest sense, covering, for example:

- health care activity;
- social care activity;
- socioeconomic indicators and risk factors;
- requirements of other agreed agencies whose actions have an impact on the health status of an individual;
- input content that could be provided by the subject of the record.

8.20 Annex B Countrywide access to quality health advice

That research be initiated in to the state of UK-based health-related websites, in terms of their adherence to existing standards and procedures and their recognition, where appropriate, under different methods of recording quality. Additionally research should be conducted into ways of bringing about the withdrawal of quality marks from sites that fail the criteria, and how such status changes could be disseminated to the health community and other interested parties.

That research be initiated to explore the criteria which underpin the implementation of information provision through websites in other sectors to determine if, and what, are the most appropriate key markers for evaluating when to implement similar (e-health) solutions for citizens, including:

- how to quantify value;
- how to describe and monitor risk and contingency;
- how to define and evaluate benefits and their realisation;
- how to state opportunity costs and the no-change option.

8.21 Annex C Application of IM&T to pharmacy

That research be initiated to investigate:

- what services patients desire for electronic ordering and home delivery of pharmacy only and prescription only medicines and how can they be safely realised, where appropriate utilising the electronic transfer of prescriptions to the national spine;
- how ICT can best contribute to clinic services – such as for asthma, diabetes, hypertension and obesity – run by community pharmacists, utilising for example:
  - access to a patient’s medication record and wider electronic health record, for example on the national spine;
  - electronic remote consultation, for example through e-mail, video phone or PC video link, etc;

- – electronic supplementary (or full) pharmacist prescribing and home delivery of medicines;
- – provision of advice through a local pharmacy website;
- – provision of a patient security protected space on a local pharmacy website containing advice specific to a patient, the patient's medication record and means for a patient to input data such as over-the-counter purchases and confirmations of medicines administered.

8.22 Annex D Telemedicine

That research be initiated to:

- evaluate telemedicine applications that are in use, or have been piloted, to identify those with most promise for service developments (for example, for facilitating NHS Frameworks) and ascertain the barriers to their widespread adoption particularly human, cultural, organisational and funding barriers.

8.23 Annex E Reduction of adverse incidents

That research be initiated to undertake:

- a review of the decision support/expert systems on the market and installed in the NHS to ascertain their impact, both positive and negative, on safer and more efficacious patient services and to determine the factors which might maximise their positive impact and ease their wider implementation. The investigation should encompass primary, secondary and community care and the boundaries between them particularly in the context of continuity of care. In the area of medication management, any research would build on, not duplicate, research already commissioned by the Department of Health and National Patient Safety Agency (NPSA) on medication errors.

That research be initiated into the implementation of a hospital system combining the best of e-prescribing with order entry and decision support, bar coding for medication management, and robotic dispensing. Research should identify:

- costs and benefits;
- implementation issues, particularly human issues;
- adverse aspects;
- extent of reduction in adverse incidents and errors and the introduction of any new risks;
- actual, and opportunities for, improved efficiency;
- improvements to patient services additional to safety.

8.24 Annex F Safeguarding confidentiality, security and data protection

That research be initiated to investigate:

- whether measures to safeguard confidentiality of patient data have been implemented satisfactorily;
- whether patients have been informed to the extent which is expected by the NHS Code of Practice and whether patients have understood the information provided;
- what further steps should be taken to ensure that the public is fully informed and is confident about NHS measures.

8.25 Annex G Health data cards

That research be initiated to:

- investigate the national and local applications which a patient health data card could beneficially serve;
- evaluate the business case for their issue at a national or local level with the possibility of utilising the existing process for issuing medical cards;
- ascertain whether any national patient health data card should, or could, serve also as an EU EHIC or vice versa;
- investigate the views of the public to health data cards being encompassed within a national identity card if such is proposed.

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Annexes

Annex A Birth-to-death records

There has been widespread recognition of the potential value of electronic patient records since the early 1960s (Abbott *et al.*, 2004). In the first instances the records were used for administration and bed management with little clinical content but the direction of the current national programme is towards holistic records containing all pertinent data and kept from birth to death. That concept places extremely large requirements for storage so various initiatives and policies address the requirement to keep content volume manageable and the opportunities to cull data. Recent policy, summarised in HSC 1999/053 *For the Record* (Liddell, 2002), exists on:

- Retention and Disposal, HSC 1998/217 (GP), HSC 1999/053 (hospital);
- Protection and Use of Patient Information, HSG (96) 018;
- Patient-Identifiable Data, HSC 1998/089; and Caldicott Guardians, HSC 1999/012;
- Disposal of records that have lost their value (ECL 2/68), covering destruction of other (non-patient specific) forms;
- Use of Electronic Patient Records in Hospitals: Legal requirements and Good Practice, HSC 1998/153.

Information for Health (NHS Executive, 1998) contains the precursor to current records handling and their place within the strategic direction of informatics in support of health care. *Information for Health* first made the distinction between electronic patient records, effectively of episodes of care or primary care activity in isolation, and the electronic health record that documents a birth-to-death data collection. Various policies and detailed content specifications on handling records then followed, with the most recent (2004) being currently out for consultation (Bentley, 2004) and responded to by BCS groups (BCSNSG and BCSHIC, 2004).

The report describing the 'how' for *Information for Health* – that is, *Building the Information Core* (NHS Executive, 2001) – targeted a primary care electronic record by 2005, all acute Trusts to be at Level 3 EPR by the same date (2005) and also a first-generation electronic health record for emergency care by 2005.

There is still considerable discussion (NHS Executive, 1998; Department of Health, 2002b; Protti, 2002; BCSNSG and BCSHIC, 2004) about both the feasibility of the targets and the content of electronic patient records in any form. Even *Information for Health* (3.6) contains observations that there are 'issues and problems' including ‘uncoordinated approach to developing condition-specific clinical minimum data sets without a common core’. It also questions in section 4.31 why ‘the most valuable repository about the current health of the population may well be GP records and it is ironic that these are virtually unused for local health surveillance and service audit’.

Information for Health explores a number of opportunities for joint working with other sectors, notably relating to improving mutual access to health and social care information (section 3.2) and establishing links with public service delivery agencies through local authorities (section 5.20). These policy directions are still giving cause for concern today and require further research.

Research recommendation

That research be initiated to explore what policy changes would be required to underpin use and content for joint health and social care birth-to-death patient/client records, given that the current concerns about shared records are resolved, in order to support care in its widest sense, covering, for example:

- health care activity;
- social care activity;
- socio-economic indicators and risk factors;
- requirements of other agreed agencies whose actions have an impact on the health status of an individual;
- input content that could be provided by the subject of the record.

Annex B Countrywide access to quality health advice

There are a number of ways in which the citizen can access information about health-related matters. The quality of the information found is very variable. The means for accessing such data include:

- traditional hard-copy publications;
- face-to-face consultation with care professionals;
- self-directed Internet searches;
- an infomediary like NHS Direct, which provides a nurse-led triage and advisory service.

The need for quality information for the public is recognised in *Information for Health* (NHS Executive, 1998), particularly:

- section 1.3 - fast and convenient public access to information and care through online information services and telemedicine;
- section 1.10 - in 1998, 6.2 million people had access to the Internet. UK companies covering 37% of our workforce then had websites and 33% of all companies were doing business over the Internet; thereby helping to break down technological phobias and to encourage e-working through a range of non-health initiatives;
- section 1.12 - the White paper on Better Government provided detail at that time of the target for government services to be accessible electronically (whereas there have been some successes not all government departments can yet talk to each other or to all their clients by e-means);
- section 1.14 - the People's Network for public library services, and the National Grid for Learning in schools played a part in reducing the mythology of e-working.

NHS Direct is subject to all major NHS policies and produces its own annual plans (Gann, 2004). All NHS Direct sites (and walk-in sites) were using NHS clinical assessment tools by summer 2001, as per the necessary strategic guidance. NHS Direct is a multi-channel service using call centres, Internet, digital television, touch-screen kiosks and print media. Not much work has yet been done with mobile devices. Said Gann, “We wouldn't reach all populations with a single technology – a multi-channel service makes it happen in terms of social inclusion.” International (for example EU) frameworks and codes are interesting but do not significantly impact on real service delivery at this point in time. In terms of policy it was felt that the most important new document is the ‘choice’ White Paper *Building on the Best* (December 2003) that covers topics such as digital television and information kite-marking.

Wanless 2 (Wanless, 2004) sees particular value in investing in support for self-care: an area on which NHS Direct also provides guidance. In Dean (2003), Gann stated that by end of 2002 45% of UK homes were connected to the Internet (previously 10% in 1999), with an average online time of 8-9 hours/week. He makes a distinction between 'expert users' (who live or work with a health issue on a daily basis) and 'occasional users' (who may have only occasional information needs on the topic) but acknowledges that even the expert user may check the health area as a citizen.

Further research areas were described by the Director of NHS Direct in an interview for this project, notably:

- reducing the digital divide (highlighted elsewhere);
- stimulating patient involvement by using technology;
- introduction of the virtual consultation (including with an NHS Direct nurse on a (digital television) screen at an NHS Direct call centre);
- facilitating home monitoring of chronic conditions;
- utilisation of MyHealthSpace using individual media of choice.

Wanless 1 (Wanless, 2002) looks at lay use of technology by 'tomorrow's patient' (reference Box 2.1) and his suggestions are considered by BCSHIC (2002b) to be 'motherhood' in health terms but to have a considerable impact on information and the informatics used to deliver it effectively.

'Increasing patients' access to information…raises issues about its 'quality and reliability': a major issue here is 'fitness for purpose' given that Internet sites from which most health information is drawn are of very variable quality, all are open and some are couched in professional jargon, personal perceptions, marketing speak and other presentations, not always declared clearly. Roberts and Copeland (2001) highlight some of the other key issues that need addressing. 'Many health information websites developed by professionals but accessible by a lay audience require urgent review' (BCSHIC, 2002b).

Wanless 2 asks how are future elderly peoples' demands for health care 'likely to differ [because there are] changing expectations [that] relate to health service use' (Wanless, 2004: Q9.6). The BCSHIC recognises that as the emergence of more 'silver surfers' as technology becomes more widespread and as the current generation using the Internet in work situations retire and continue their use post-retirement, more pressure will be created for fit-for-purpose health and lifestyle information. Similarly the demand to be 'involved' rather than be solely the subject of care will also generate a greater need for home-based information about care, home-accessible clinical guidance in lay language and personal involvement. The technological infrastructure and costings will have to improve greatly to support this change.

Wanless' projections are borne out by the EU-funded CarePlus project (Emery *et al.*, 2001), which provided local health information in a web-based form for various locales in the Sheffield area, particularly for the older person. It is apparent that the priorities for information via e-health solutions will vary by types of people, clinical status, technological aptitude and available information. The recommendations relating to the provision of quality information are interspersed through this report. The appropriate criteria to underpin a business case for the introduction of more quality citizens' web-based information solutions and citizen health-support systems are not yet rigorously defined.

European actions

Across the whole of Europe, citizens are 'avid consumers of health-related information' and the European Council of Ministers in 2000 gave their support to an action under eEurope 2002 to develop a core set of quality criteria for health related websites. The criteria were developed by experts from the EU, Norway, Switzerland and the USA and are described in detail in *eEurope 2002: Quality Criteria for Health related Websites* (EU Commission, 2002c).

The overall aim was to produce 'commonly agreed set of simple quality criteria on which Member States, as well as public and private bodies may draw'. Preparation was followed by public consultation. The objectives for the quality criteria are defined as addressing:

- supplier and user education;
- passive information-giving sites and those that allow interactive transactions;
- facilitation of compliance with EU Directives, other current guidelines and technical standards.

Underpinning the development is the premise that information will be accessed by many individuals of different nations, cultures, competencies and with different motives. The development does recognise that it is legitimate to present material for a specific purpose/audience but that this should be clearly indicated.

The agreed criteria cover six key areas and are applied on two levels – to sites per se and to content. The criteria cover:

- transparency and honesty – what perspective the site is operated from and the provenance of the content;
- authority – credentials of both operators and authors;
- privacy and data protection – adherence to Directives and legislation;
- updating of information – dated sources, regular updates and verification;
- accountability – mechanisms for feedback, obligations with regard to the content selection and validation;
- accessibility – meeting 'fit for purpose' guidance with regard to content level and equitable access regardless of user ability and competence.

Underpinning these specific criteria is an implicit adherence to international standards where available.

The eEurope 2002 action (EU Commission, 2002c) defined the criteria but it was not within its remit to mandate how they should be implemented. That implementation can occur on many levels and existing examples demonstrate the concepts:

- a Code of Conduct as a method of achieving a consensus on what constitutes self-assessment processes without enforcement requirements, such as that of the Internet Health Coalition (www.ihealthcoalition.org);
- self-applied quality labelling, such as the HON Code (www.hon.ch), which draws attention to the adherence of a site to defined criteria;
- user guidance tools, like DISCERN (www.discern.org.uk), where site users can follow the actual process of validation themselves to satisfy that a site meets specified standards;
- filtering tools, like OMNI (Organising Medical Networked Information; www.biome.ac.uk) where trained experts search for, abstract and classify information to be entered into an 'approved' database;
- third-party quality and accreditation labels, like MEDCERTAIN (www.medcertain.org) and TNO QMIC (www.health.tno.nl/en/news/qmic_uk.pdf).

Overarching the detailed work are requirements to protect the consumer by improving the competence of users, assisting the searchers in finding quality material, educating site providers in good practices while ensuring quality in all its dimensions.

The eEurope 2005 Action Plan confirms a desire to have 'Modern on-line public services' by 2005, commits the European Commission to monitor 'actions taken by Member States' and affirms that 'it is critical that e-health content and services are developed efficiently, are available for all and health related websites comply with established quality criteria'.

There is a challenge to each Member State to demonstrate their compliance to the above. This will require considerable research, as a benchmark, into what the UK has, what its quality is and to take steps as necessary to promulgate the ideas of the Action Plan and to draw up recommended steps to be considered for the withdrawal of recognition from sites that do not adhere to the standards set.

Research recommendations

That research be initiated into the state of UK-based health-related websites, in terms of their adherence to existing standards and procedures and their recognition, where appropriate, under different methods of recording quality. Additionally research should be conducted into ways of bringing about the withdrawal of quality marks from sites that fail the criteria, and how such status changes could be disseminated to the health community and other interested parties.

That research be initiated to explore the criteria which underpin the implementation of information provision through websites in other sectors to determine if, and what, are the most appropriate key markers for evaluating when to implement similar (e-health) solutions for citizens, including:

- how to quantify value;
- how to describe and monitor risk and contingency;
- how to define and evaluate benefits and their realisation;
- how to state opportunity costs and the no-change option.

Annex C Application of IM&T to pharmacy

There are three Department of Health publications of particular relevance in setting the policy context of e-health and pharmacy:

- *Pharmacy in the Future – Implementing the NHS Plan*, September 2000 (Department of Health, 2000).
- A Vision for Pharmacy in the New NHS", July 2003 (Department of Health, 2003a).
- *Building a Safer NHS for Patients: Improving medication safety*, January 2003 (Department of Health, 2004b).

Each looks to ICT to enable some key objectives and envisages a forthcoming ‘e-pharmacy’ environment.

Pharmacy in the Future (Department of Health, 2000) recognises that pharmacy will have to respond to a world where people will demand a greater variety of ways of accessing services at times convenient to them. Whereas face-to-face contact with a pharmacist will always be valued, many will increasingly look to services such as NHS Direct Online for information about medicines and will want the convenience of electronic ordering and home delivery. Electronic transfer of prescriptions and web pharmacies may enable such services to be realised.

Additionally Wanless 1 (Wanless, 2002) observed (point 10.53) that to ‘the extent to which individuals are willing to take personal responsibility for their health…pharmacological developments may increasingly be focused on the treatment of risk rather than disease’.

UK Web pharmacies

Already web pharmacies are offering people new ways of purchasing over-the-counter medicines and for having private prescriptions dispensed. The Government believes (Department of Health, 2000) that the law permits the distance sales and supply of medicines by electronic means provided normal safeguards apply, for example that sales of pharmacy-only (P) medicines are made under the supervision of a registered pharmacist and from a registered pharmacy. It further believes that this advice should also be available for NHS prescriptions and is seeking to remove obstacles to pharmacies offering such services. However, the need to supply a prescription form before any medicine could be sent is a major barrier as long as prescriptions are on paper. Electronic transfer of prescriptions offers the opportunity to realise all the benefits that web pharmacies could proffer.

Electronic Transfer of Prescriptions (ETP)

Electronic transfer of prescriptions has been piloted and pilots evaluated by the Sowerby Centre (2003). The recommendations derived from the evaluation demonstrate that significant practical and policy issues need to be overcome if ETP is to be successful. Nevertheless implementation of ETP nationwide is part of the NPfIT to be realised by 2006. Electronic prescriptions will be held on the national data spine available to be 'pulled down' by authorised persons.

ETP should be particularly advantageous for repeat prescriptions. It could also add value to repeat dispensing due to be in place nationwide in 2004. (Repeat dispensing allows patients to obtain prescriptions form GPs that they can then have dispensed in several instalments instead of having to go back to their GP surgery each time for a new prescription. Such prescriptions, if sitting on the national data spine, would potentially allow patients electronically to order their next 'instalment' with home delivery).

Access to Electronic Health Records

A Vision for Pharmacy in the NHS (Department of Health, 2003a), takes forward the programme for change in *Pharmacy in the Future* (Department of Health, 2000). Part of the 'vision' is an increasing role for pharmacists including:

- in medication management and review; for example, as required in the Older People NSF, for people taking a complex range of medicines and people with specific conditions such as coronary heart disease;
- supplementary prescribing within agreed clinical management plans; for example, for people with enduring conditions such as asthma, hypertension or diabetes. This may be the precursor for full independent prescribing by pharmacists;
- diagnostic or monitoring services; for example, for hypertension or diabetes, as part of an integrated local service.

Whereas many pharmacists will keep computerised records of medication they have dispensed to individual patients, such records will fall short of a full medication record for a patient and will not contain all the other information that a pharmacist might require to fulfil these new roles.

The NPfIT is committed to implementing an electronic health record for every individual by 2006, to be accessible to authorised persons 24 hours a day. This record should contain the information which a pharmacist would require for extending services into areas such as those above including a patient's medication record (at least for prescribed medicines). However, details of what data a pharmacist will be able to access and the necessary security measures will need to be resolved including connection to the NHS network NHSnet or its broadband successor (N3).

Web pharmacies and electronic procurement of medicines on the World Wide Web

Anyone with an e-mail address will quickly experience 'spam', much of which will be health-related, frequently offering the supply of medicines. It is probably possible to procure almost any medicine through the Internet whether or not it is designated in the UK as pharmacy- or prescription-only. The quality of such medicines, for example in terms of pharmaceutical content, labelling and packaging, can be poor and may be dangerous. This puts at risk those who wish to seek out medication without exposing their requirements or conditions to a qualified practitioner.

Those seeking medicine-related information through the Internet are likely to encounter a plethora of websites of varying quality, some of which will present a hazard to the enquirer. The professional standing of any website may not be apparent: even the poorest may appear professional and authoritative. Additionally, even the best of websites located outside the UK may provide information deemed unsuitable within the UK.

In the UK there are legal controls on the retail sale, supply and advertising of medicines which are set out in the Medicines Act 1968 and supporting regulations. These apply without distinction to medicines advertised, sold or supplied through the Internet and by mail order.

This means that prescription-only medicines (POMs) and pharmacy-only (P) medicines can only be sold or supplied at registered pharmacy premises by, or under the supervision of, a pharmacist. Furthermore, POMs can only be sold or supplied in accordance with a prescription from a doctor, dentist or relevant health care professional. POMs cannot be advertised to the general public.

However, these restrictions do not apply to countries outside UK jurisdiction where medicines may be classified and regulated differently. For example, in the USA and other countries some medicines that would be prescription-only the UK may be available without prescription.

These issues are part of the wider problem of the quality of all health-related information available through the Internet and are dealt with in more depth in Annex B.

Whereas there are excellent, high-quality websites dealing with medicines, and with health in a wider sense, for example NHS Direct Online, it is not clear how well known these are to the public generally, the extent to which the public understands the risks involved and the extent to which those risks are being realised.

Hospital pharmacy

Medicines management is a key component of hospitals services and the medication record is an important part of the patient record. The main applications of ICT to medicines management and the medication record in hospitals are:

- e-prescribing including decision support;
- bar coding;
- robotic dispensing.

These can make substantial contributions to patient care with e-prescribing and bar coding contributing to a patient's medication record as part of a wider electronic patient record.

However, some the most significant contributions which these technologies make to patient care are in the reduction of adverse incidents (medication errors). These aspects are dealt with in Annex E and are the subject of *Building a Safer NHS for Patients – Improving medication safety* (Department of Health, 2004b).

Research recommendations

That research be initiated to investigate:

- what services patients desire for electronic ordering and home delivery of pharmacy-only and prescription-only medicines and how can they be safely realised, where appropriate utilising the electronic transfer of prescriptions to the national spine;
- how ICT can best contribute to clinic services, such as for asthma, diabetes, hypertension and obesity, run by community pharmacists utilising for example;

  - access to a patients medication record and wider electronic health record for example on the national spine;
  - electronic remote consultation, for example, through e-mail, video phone or PC video link, etc.;
  - electronic supplementary (or full) pharmacist prescribing and home delivery of medicines;
  - provision of advice through a local pharmacy website;
  - provision of a patient security-protected space on a local pharmacy website containing advice specific to a patient, the patient's medication record and means for a patient to input data such as over-the-counter purchases and confirmations of medicines administered.

The timing of any research, such as above, may depend on the stage reached in implementation of national ICT initiatives. It will also critically depend on progress in agreeing and implementing the new service quality contract (Department of Health Medicines Pharmacy and Industry Group PaPB, 2003) since, at the time of writing, new pharmacy service developments will be heavily dependent on the outcome of on-going negotiations.

Annex D Telemedicine

Telemedicine has been defined in many ways and incorporates many similar terms, such as telecare, teleconsulting, etc. It is not the purpose of this Annex to attempt a single definition except to note that telemedicine and similar terms normally have these characteristics:

- at least one clinician;
- a client, patient and/or carer;
- a separation in space (and possibly time) between the two.

Telemedicine applications have been subject to many reviews (Department of Health, 1998c) and are often quoted as important in achieving increased efficiency and better quality services, for example *Information for Health* (point 1.29) observed that:

- 'opportunities in the field of telemedicine will be seized to remove distance from health care, to improve the quality of that care, and to help deliver new and integrated services. GPs will be able to send test readings or images electronically to hospital specialists many miles away and in the same way receive results and advice more quickly';
- 'through telemedicine, nurse practitioners in a community minor injuries unit will be able to consult doctors in the local A&E department, improving the quality of care and preventing unnecessary travelling and referrals. Specialists in regional teaching centres will provide online guidance and support to colleagues in local general hospitals and beyond';
- 'telecare technology will be used to provide reliable but unobtrusive supervision of vulnerable people who want to sustain an independent life in their own home. Video links with electronic monitoring will allow community health and social workers to 'visit' patients at home more easily'.

Whereas many telemedicine applications in the NHS can be identified (Portsmouth University), many have not proceeded beyond a project stage into routine use, and the full potential of telemedicine seems not yet to have been realised. A number of possible reasons can be surmised as illustrated in the following text.

Technological aspects

Telemedicine entails the exchange of information (overwhelmingly digital) between two or more locations (separation by distance). The sender(s) and recipient(s) may exchange such information in real time (videoconference) or the information may be accessed at a later time (transmitted and stored, often known as store and forward; that is, separation by time).

The speed at which data can be transmitted depends on the bandwidth of the connection, be that by land line, satellite or wireless.

If a large amount of data has to be transmitted to and fro in a live session, for example in a videoconference, then high bandwidth will be required in both directions. Many NHS organisations such as hospitals have videoconference facilities on the premises or nearby. Thus videoconferencing between, for example, clinicians dispersed at different videoconference facilities, can now be fairly readily arranged. As the numbers of videoconference facilities grow and the associated information-handling systems become increasingly sophisticated, videoconferencing will comprise a very efficient means of bringing professionals together without the need for travel.

The demand for integrated care across organisational boundaries is requiring more frequent and more varied inter-working between professionals in different locations and videoconferences will be, and are, an excellent facilitator. This has been demonstrated, for example, in cancer networks. Videoconference facilities, by their nature, have fairly high-bandwidth connections and, although higher bandwidth than that usually provided currently can be desirable, bandwidth and technology are generally not a problem. The main issue is one of availability and of course the need for participants to be present at the same time (a diary problem).

However, for many other applications bandwidth was, and to an extent still is, a problem. One of the earliest telemedicine applications involved the transmission of radiographs from one location for the opinion of an expert located elsewhere. Low bandwidth availability meant that a radiograph took a great deal of time to transmit and the digitisation of the image, the protocols for transmission and the receiving viewing device degraded the image significantly.

Modern technology has essentially solved the image-quality problems and significant bandwidth is now available to most locations at low cost (see Section 4.2, above). The NHS network (NHSnet) is to be replaced over the next few years by a broadband network (N3) through a contract recently let to BT. This will interconnect all NHS organisations including GP practices. Speed of downloading will increase markedly as will uploaded transmission of data (albeit to a lesser extent). Although speed of transmission is less important with store and forward applications, it nevertheless reduces transmission time and makes many applications more attractive. Additionally, web technologies and browsers have eased many types of implementation and created new opportunities. Thus for professional-to-professional applications located in NHS organisations bandwidth, and technology in general, should not present great major problems or, in very many cases, represent significant costs.

To a considerable degree this will also apply to telemedicine applications involving patients or clients in their homes. The Internet has driven down the costs of a broadband telephone connection. Such a connection is available to most households in the country.

Moreover, it is a Government objective to ensure that broadband is available to all households (see Section 4 of this appendix) in the near future. By 'broadband connections in the home' is currently meant 2 Mb for downloading but only 0.5 Mb for uploading (ASDL). For very many applications this would be sufficient and particularly so for store-and-forward applications and for downloading into the home. However, 0.5 Mb uploading can be limiting, particularly for a video link (for example from a videoconferencing telephone, a video camera or a PC, or from a more specialised installation). That having been said, a greater bandwidth (for example 2 Mb in both directions; SDSL) is becoming available in many areas and costs will not be high.

Thus over the next 1 or 2 years bandwidth will not pose a technical or cost problem for most telemedicine applications, even those involving clients or patients in their own homes.

Of course, more than a broadband connection is required. Receiving, transmitting and processing devices are required at the ends of an application. However, PCs, high-resolution monitors, fast modems and video cameras, etc., are now high-street items and low cost in health care terms.

In conclusion, technology, including bandwidth, should no longer present technological or financial problems for most telemedicine applications including those involving a client or a patient in their home.

Organisational aspects

Telemedicine applications comprise new ways of *delivering* health care as distinct from being new *forms* of health care, such as new clinical procedures. Success will rarely be achieved with telemedicine if the approach concentrates primarily on technology and simply computerises existing processes. Many telemedicine projects have been pursued primarily on that basis, such as:

- whether radiographic images can be successfully transmitted electronically for an expert opinion;
- whether the image of a skin condition can be successfully transmitted from a GP to a hospital dermatology consultant;
- whether blood-pressure readings, ECGs, blood glucose measurements, renal dialysis or fetal monitoring medical parameters can be transmitted from the home of an at-risk patient to a hospital or GP's clinic for monitoring.

Funding for such projects has often been targeted at establishing technological feasibility with the result that, when project funding has been exhausted, projects have failed to proceed into routine practice even though the technology has been shown to work.

In some cases projects have failed to proceed into routine implementation because, at the project stage, the application has relied on sessions being live rather than stored and forwarded. Whereas diary difficulties at both ends of a telemedicine application may be solvable on a project basis, solving them on a day-to-day basis may not be practicable.

Those experienced in telemedicine generally assert that success will be achieved only where the approach is one of seeking reorganisation of health care services to improve efficiency and quality with technology solely as a facilitator for change.

For example, it has been established that satisfactory images of skin conditions can be successfully transmitted from a GP practice to a hospital dermatology department for expert opinion. Technology is not the problem. However, dermatology telemedicine applications present significant opportunities for raising the skills of GPs, thereby reducing the number of GP referrals and lessening the need for dermatological consultants. This presents an opportunity for concentrating dermatological services into fewer centres. Thus an approach that seeks to rationalise dermatology services over a wide catchment area with increased efficiency and lower costs may find telemedicine to be a key facilitator for major change. On the other hand an approach solely to establish technological feasibility between a few GP practices and a single dermatology department will deliver far fewer benefits and probably too few benefits to survive into widespread practice.

Many telemedicine applications have the potential to facilitate skills transfer, changes in skills mix, centralisation and rationalisation of services on a significant scale. However, many telemedicine applications have failed to deliver such extensive benefits because their focus has been primarily technology, their vision too restricted, participation limited to a few enthusiasts and key players resisting change because of, for example, a fear of losing their jobs or influence.

Funding aspects

Telemedicine has considerable potential to facilitate inter-working between organisational entities, including a client or a patient’s home. However, the realisation of maximum benefits may require significant changes in the participating organisations, including transfer of skills or personnel and changes in skill mix. This implies transfer of funds between organisations on a permanent basis. A reduction in budget is a matter that most organisations tend to resist.

Additionally, some applications may require investment in one organisation but with benefits accruing to another, for example:

- investment in a GP practice to reduce demand on a hospital;
- investment in a hospital resulting in fewer hospital attendances with benefits accruing to an ambulance trust;
- investment in a home location to minimise hospital admission and aid recovery rates overall.

Whereas the distribution of NHS funding through primary care trusts has the potential to reduce such funding barriers to telemedicine, a willingness to engage in substantial change may remain a barrier.

Research recommendation

That research be initiated to:

- evaluate telemedicine applications that are in use, or have been piloted, to identify those with most promise for service developments (for example, for facilitating National Health Service Frameworks) and ascertain the barriers to their widespread adoption, particularly human, cultural, organisational and funding barriers.

Annex E Reduction of adverse incidents

Background

The report *An Organisation with a Memory* (HMSO, 2000) estimated that about 10% of inpatient episodes in the UK lead to harmful and adverse events. This translates into 850 000 admissions costing up to £2 billion solely for additional bed-days. About half of these events were preventable.

The UK health service is not alone in experiencing adverse events on this scale. Studies in the USA (US National Institute of Medicine, 2000) and in Australia (QAHCS, 1995) have reported similar results. These results were major stimulants for studies in other developed nations such as Canada, Denmark, The Netherlands, Sweden and New Zealand. Efforts to tackle the reporting, analysis and ultimate reduction of adverse incidents are on an international scale. The World Health Organization has expressed its concerns and proposed measures to address them (WHO Secretariat, 2001). They have observed that the level of adverse incidents will be substantially greater in developing countries and those in economic transition.

The role of ICT

Building a Safer NHS for Patients (Department of Health, 2001) announced steps in implementing *An Organisation with a Memory* (HMSO, 2000), including the creation of a National Patient Safety Agency (NPSA). Among the areas specifically identified where action could provide early gains in risk reduction was ‘examining across the board the potential for computers to reduce the occurrence and impact of error’.

The NPSA, in its Business Plan for 2003/4 (NPSA, 2003), recognised that ICT could play a key role in modernisation of the NHS, including greater emphasis of its use for electronic patient records to improve the delivery of patient care and improvement of safety.

Access to decision-support systems with clinical protocols and care pathways and to a patient’s electronic care record at the right place and right time could thus significantly reduce adverse incidents.

NPfIT initiatives aim to ensure that all hospitals have an electronic patient record system supporting functions such as order entry and protocols/decision support. This should therefore present a potential for reducing adverse incidents in all hospitals in the near future.

Medication-related adverse events

Due to historic low reporting of incidents, the true level of medication-related adverse events is unknown. Nevertheless, discussions between representatives of the NHS in England, Australia and USA (Department of Health, 2001) indicate that 'medication error accounts for around a quarter of the incidents which threaten patient safety'.

New incident-reporting processes being introduced by the NPSA should improve knowledge. Whereas a NPSA breakdown of 30 000 electronic incidents reported (NPSA, 2003) showed that 41% of all incidents involved slips, trips and falls, nearly 9% were related to medication management and 6% to medical records.

The report *Building a Safer NHS for Patients – Improving medication safety* (Department of Health, 2004b) comprehensively addresses means for reducing related risks, including the target 'to reduce by 40% the number of services errors in the use of prescribed drugs by the end of 2005'. It is recognised that greater use of electronic prescribing in hospitals, bar-coding technology and robotic dispensing has the potential to reduce the risk of medication errors.

Electronic prescribing and order entry

Studies in the USA have attributed substantial reductions in errors to the implementation of computerised order-entry systems and reductions have also been seen in the few NHS hospitals that have introduced electronic prescribing with some degree of decision support.

Despite evidence of the benefits of electronic prescribing in hospitals, take up has been extremely weak. A survey in 2002 by UK Trust Chief Pharmacists (AST CP, 2002) showed only 3% of hospitals having what could be described as an electronic prescribing system. This compared with 2% in year 2000, demonstrating exceedingly slow progress.

However, *Building a Safer NHS for Patients* (Department of Health, 2004b) observed that, whereas electronic prescribing has the potential significant to reduce medication errors, there also exists the possibility that they might introduce new errors. Rigorous design and user assessment was required before widespread implementations.

Electronic transfer of prescriptions

Computer generation of prescriptions is the usual practice in GP surgeries, thus eliminating hand-writing and other errors. However, prescription details are still required to be entered manually into community pharmacy systems, leading to potential transcribing problems. The NPfIT is planning to introduce electronic transfer of prescriptions, which should eliminate such errors.

Bar coding

Bar coding appears to have significant potential for reducing adverse incidents in a number of areas including medication management. For example, bar coding of administrative details, etc., on a patient's wrist band, plus bar coding of medicines linked into electronic prescribing and decision support, and thence to robotic dispensing, would appear to represent a powerful combination for improving the efficiency, effectiveness and safety of patient services. The Department of Health (2004b) recognises this.

Department of Health and NPSA research

The Department of Health's Patient Safety Research Programme and the NPSA have commissioned two significant research projects relating to ICT and medication errors (Barber and Cantrill, 2003; Karnon, 2003). Karnon (2003), a 6-month study commencing mid-2003, comprises a review of medication errors in all the different stages of a patient's journey and an examination of possible cost-benefits of plausible interventions including ICT, such as hospital order-entry systems.

Barber and Cantrill (2003), a 5-year core programme, concerns IT in particular and comprises several projects. The first will compare medication error rates in hospitals with sophisticated IT such as e-prescribing order-entry and decision support, with those without. The second will identify proposed new implementations so that, if appropriate, projects to evaluate medical errors before and after implementation can be commissioned. The third will investigate systems in other countries, particularly Europe and USA.

These research projects should provide a good baseline for steps to improve services to patients and safety.

Non-hospital environments

Most studies on adverse incidents, particularly those that are medication-related, have concentrated on the hospital sector. However, IT and associated decision-support systems have the potential also to improve the safety and effectiveness of patient services in non-hospital environments such as primary and community care, including the boundary between NHS services and social care and in community pharmacy.

Whereas almost all GP practices are computerised and will have some decision-support software associated with prescribing, for example PRODIGY, the extent to which such support is used and its impact on medication-related adverse incidents is less clear.

Other non-prescribing decision support/expert systems with supporting protocols are available to primary and community care but again the extent of take-up and the impact they are making, or could make, to safer and more efficacious patient services is unclear.

Research recommendations

That research be initiated to undertake a review of the decision support/expert systems on the market and installed and used in the NHS to ascertain their impact, both positive and negative, on safer and more efficacious patient services and to determine the factors which might maximise their positive impact and ease their wider implementation. The investigation should encompass primary, secondary and community care and the boundaries between them particularly in the context of continuity of care. In the area of medication management, any research would build on, not duplicate, research already commissioned by the Department of Health and NPSA on medication errors as described above (Department of Health, 2000, 2004b).

That research be initiated into implementation of a hospital system combining the best of e-prescribing with order-entry and decision support, bar coding for medication management, and robotic dispensing. Research should identify:

- costs and benefits;
- implementation issues, particularly human issues;
- adverse aspects;
- extent of reduction in adverse incidents and errors and the introduction of any new risks;
- actual, and opportunities for, improved efficiency;
- improvements to patient services additional to safety.

Research already commissioned by the Department of Health and NPSA will identify systems aimed at reducing medication errors that are available to the NHS and which are already installed and that are proposed to be installed.

Annex F Safeguarding confidentiality, security and data protection

Legal obligations

The duty to safeguard the confidentiality of personal data is subject to a number of legal instruments, including:

- Common Law;
- Data Protection Act 1998;
- Human Rights Act 1998;
- Freedom of Information Act 2000;
- regulations specific to particular health aspects, such as sexually transmitted diseases (NHS (Veneral Diseases) Regulations 1974; NHS Act 1977; Aids (Control) Act 1987; NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000) and human fertilisation and embryology (Human Fertilisation and Embryology Act 1990; Human Fertilisation and Embryology (Disclosure of Information) Act 1992);
- a variety of statutes requiring disclosure in particular circumstances.

Health professionals

Most organisations/colleges, societies and associations of health professionals, particularly clinical, have codes of practice or equivalent that cover ethical behaviour including the safeguarding of patient confidentiality. These may be associated with disciplinary measures in cases of non-compliance.

NHS provisions

Over the last 5 years or so the NHS has substantially strengthened provisions for safeguarding patient confidentiality and for security measures to protect personal health data.

A significant step was the appointment of so-called Caldicott Guardians in all health organisations following publication of the Caldicott report (Caldicott Committee, 1997; Department of Health, 1999). Caldicott Guardians are responsible for overseeing measures to safeguard confidentiality in their organisation. After extensive consultation during 2002, the Department of Health publicised an NHS Code of Practice on confidentiality (Department of Health, 2003b). This provides guidance to all NHS staff on measures to safeguard confidentiality. It recognises that the duty to safeguard confidentiality:

- is a legal obligation deriving from case law;
- is a requirement within professional codes of conduct; and
- must be included within NHS employment contracts as a specific requirement linked to disciplinary procedures.

A major theme is that of consent to use and/or disclose personal data. In essence, information that can identify individual patients must not be used or disclosed for purposes other than health care without the individual's explicit consent, some other legal basis or where there is a robust public interest or legal justification to do so.

When patients have been informed of the use of and disclosure of their information associated with their health care, the choices that they have and the implications of choosing to limit the information which may be used or shared, then explicit consent is not usually required for information disclosures needed to provide that health care. Implied consent would be sufficient. Even so, the Code suggests that opportunities to check that patients understand what may happen and are content should be taken.

The Code concentrates on guidance on when explicit or implied consent is required and on the measures that individuals and organisations should take to ensure patients are informed, including the availability of leaflets, etc. in appropriate languages.

The Code of Practice is backed by a Department of Health National Confidentiality and Security Advisory Body.

The Government has signalled its intention to write to every household in the UK during 2004 to provide information about the development of the national care records, however finally constituted, and to explain how information about individuals will be shared to improve the delivery of care. Individuals will be expected to (explicitly and with informed consent) 'opt out' rather than 'opt in' to information-sharing arrangements. At the moment it is intended that the communication will be purely about health information. However, the National Programme and the Department of Health are being lobbied by health and social care professionals who see this as being an opportunity to achieve consent for the sharing of information across health and social care rather than just within the NHS.

Safeguarding confidentiality of personal health data requires technical and organisational data-protection measures. In this context and in accordance with Government policy, the NHS has chosen to implement a British Standard (Information Security Management, BS7799 parts 1 and 2, 2004), which is identical to the international standard ISO 17700 that a number of other countries are implementing.

The NHS has undertaken substantial consultation and, over recent years, has sought to put in place a range of comprehensive measures to safeguard the confidentiality of personal health data. Further research into such measures and advice is not seen as necessary. On the other hand one of the major concerns of the public remains that of ensuring that the confidentiality of their health data is assured in a manner they would expect. Strong concern has been expressed in public stakeholder groups about access to their birth-to-death health records on the national spine (Annex A). Who will be able to see what? How can data that the subject of which thinks is sensitive be protected from access other than by those with whom a patient is comfortable?

Whereas the measures to protect confidentiality that the NHS is expected to adopt are comprehensive, assurance is necessary that such measures have been implemented satisfactorily and that, in so far as patients are expected to be informed, they actually are.

Research recommendations

Thus research should be initiated to investigate:

- whether measures to safeguard confidentiality of patient data have been implemented satisfactorily;
- whether patients have been informed to the extent that is expected by the NHS Code of Practice and whether patients have understood the information provided;
- what further steps should be taken to ensure the public is fully informed and is confident about NHS measures.

Annex G Health data cards

Data cards can take a variety of forms, for example stripe cards, cards with computer memory chips, CDs, DVDs or memory sticks. The public has an increasingly familiarity with most or all of these forms. Memory capacity is substantial and growing, and most forms are inexpensive, with prices steadily falling. Interfaces with computers are also low-priced.

Many therefore believe that data cards will play a significant role in the application of IM&T as patient cards in one or all of the following roles:

- identification and/or proof of entitlement to health care including E111;
- secure access to computerised information such as electronic health records;
- storage of emergency health data;
- storage of a summary (or 'full') health record.

They will also have a role as 'professional' cards for identification, authentication and access control for health care professionals.

Applications

The range of applications to which health data cards could be applied is extensive. They are already in widespread use in a number of countries in Europe and are due to increase very significantly. It is not the purpose of this Annex to review applications comprehensively but important examples are:

- proof of entitlement to health care – health insurance cards;
- patient identification and control of access regarding;
    - electronic prescriptions;
    - electronic health records;
- emergency health data, for example allergies, blood group or next of kin;
- store of medical records in particular areas such as for;
    - medication record;
    - maternity;
    - oncology;
    - diabetes;
    - renal dialysis;
- store of summary patient record or whole record;
- replacement of the current paper medical card.

Within the NHS the extent to which health data cards will have a significant role is unclear (see Issues, below).

However, a number of significant national applications are under consideration, including control of access to, and patient authentication for, electronic prescriptions and patient electronic health records on the national spine.

Within the EU, the intention is to replace the E111 paper form with an EU EHIC (EU Commission, 2003). This commenced on 1 June 2004 in 13 EU countries including Belgium, Ireland, Spain, Estonia and Slovenia. Germany intends to issue a patient data card to all its citizens within the next few years and they are now in extensive use in France.

The UK will not be replacing the E111 with an EHIC for at least 18 months (the E111 paper form will be phased out from the end of 2005). How this will interface with applications within the NPfIT is not yet clear.

It is envisaged that the EHIC will be a chip card and facilitate connection to a health insurance database in a patient's home country. Such a database could contain name, address, next of kin, any unique identifying number and perhaps basic medical information such as an emergency dataset. Security might be afforded by a pin number (the so-called chip-and-pin system as being adopted by retail outlets for credit and debit cards in the UK).

Issues

Within the UK a number of complex issues arise.

Should the NHS wish to issue a patient data card to all citizens for health purposes then it would be possible to do so by replacing the current paper medical card with a data card since there is already an 'issuing authority' for medical cards (currently issued at birth). This could be accomplished through primary care trusts and GPs and by reference to the NHS Number Strategic Tracing Service.

Issuing a data card to all citizens as a replacement for the medical card would not only facilitate secure identification and access control for national applications such as electronic prescribing and the electronic health record, but would also provide an infrastructure for local applications such as maternity, oncology, etc. and access by patients to their health records held by their GP (for example, through a dedicated PC within a practice).

However, NHS issue of a health data card to all citizens may be complicated by the issue to all citizens of:

- an EU EHIC;
- a national identity card.

Should there be one card for each citizen and encompassing all these functions (plus others)? If so, how would the public react? Would they see a multi-function card as a ‘Big Brother’ step towards linking national databases?

Research recommendations

That research be initiated to:

- investigate the national and local applications which a patient health data card could beneficially serve;
- evaluate the business case for their issue at a national or local level with the possibility of utilising the existing process for issuing medical cards;
- ascertain whether any national patient health data card should, or could, serve also as an EU EHIC or vice versa;
- investigate the views of the public to health data cards being encompassed within a national identity card if such is proposed.

Such research should be undertaken in collaboration with, or commissioned jointly with, other agencies, not least the NPfIT.