eHealth Strategies

Country Brief: England

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About the *eHealth Strategies* study

The eHealth Strategies study analyses policy development and planning, implementation measures as well as progress achieved with respect to national and regional eHealth solutions in EU and EEA Member States, with emphasis on barriers and enablers beyond technology. The focus is on infrastructure elements and selected solutions emphasised in the European eHealth Action Plan of 2004.

Disclaimer

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For England, Diane Whitehouse provided initial information on policy contexts and situations, policies and initiatives and examples for specific applications which has been further rigorously reviewed. Diane Whitehouse is a former European Commission project officer, and is currently a partner in a United Kingdom-based policy partnership.

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Executive summary

England has a long history with eHealth. The National Programme for IT in England had already begun in 2002 and acted as the basis for eHealth deployments. In conjunction with this the 2002 policy paper "Delivering 21st century IT support for the NHS: national strategic programme"[1] was created. Not that this was the first policy paper to focus on technology in healthcare: as far back as 1998, specific policy was developed for this field.

The current situation of the English eHealth strategy is under review due to changes in government. The newly elected Coalition Government is expected to indicate a new direction for the main IT programmes and develop a new Information Strategy towards the end of 2010 which will be subject to a public consultation exercise before finalisation.

In order to consider the progress that has been made so far in England towards reaching eHealth interoperability objectives the following eHealth applications have been examined: patient summaries, electronic health records, ePrescription, standards, and telemedicine. In England the situation is as follows:

A patient summary programme known as the Summary Care Record Programme has been nationally implemented in England since 2008. However, some form of electronic patient record has existed since the mid eighties due to the high level of computer use in General Practitioners' (GPs) practices from this time onwards.

In terms of ePrescription England has two programmes for electronic prescribing in existence. One, Electronic Prescription Service (EPS) is directed at the primary care sector, GPs and clinics, and synchronises all steps from the generation to the despatch of the prescription. The other, ePrescribing, is aimed at institutions such as hospitals and includes a decision support component. In 2009 the Department of Health confirmed that over 500,000 prescriptions had been transmitted electronically in England. It is also known that some institutions have been using some form of electronic prescribing for over ten years.

On standards, England is included in the United Kingdom and its membership of the IHTSDO (International Health Terminology Standardisation Organisation). Alongside this, a Health Informatics Service Benchmarking and Accreditation Scheme was launched in 2008[2] to help health informatics providers and Information Management &Technology departments.

Telemedicine initiatives in England are not combined under a single national programme but rather run at the local authority level. The Department of Health is currently funding three demonstrator projects, at local authority level, that aim to develop an evidence base for the use of telecare and telehealth in England. Aside from this, NHS direct, which provides health advice and reassurance on the phone as well as through an online library of medical advice, could also be considered as a form of telemedicine application.

Following the election of a new UK Coalition Government in May 2010 there have been clear indications of a change of direction for England's eHealth Strategy. The new Government has set out

[1] Department of Health 2002

[2] NHS Connecting for Health 2010

a major reform programme to radically alter the structure and processes of the National Health Service. This programme aims to have a health service more focussed on the successful patient outcomes from its services, an emphasis on taking decisions with patients and a significant reduction in bureaucracy.

On eHealth services the new Government has made significant announcements on:

- A review of the National Programme for it (see page 19)
- A review on the Summary Care Record (see page 21)
- A consultation exercise for a new information strategy.

A new Information Strategy will be one of the underpinning actions for the reform programme. To this end the Government has launched a consultation exercise under the title “Liberating the NHS: An Information Revolution”.

Key proposals for the Information Revolution include:

- people having greater access to and control of their health and social care records
- more information on treatments, conditions and lifestyle choices, helping people look after their own and their family’s health and care
- greater emphasis on information generated by patients and service users (for example, patient-reported outcomes measure (PROMs), experience data, and feedback)
- a wider range of providers to analyse and present information to the public
- improved use of digital technologies.

The results from this consultation are expected to be known in 2011.

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1 Introduction to the report

1.1 Motivation of the eHealth Strategies study

Following the *Communication* of the European Commission (EC) "eHealth – making healthcare better for European citizens: An action plan for a European eHealth Area" [3] all Member States of the European Union (EU) have generally committed themselves to develop and issue national roadmaps – national strategies and plans for the deployment of eHealth applications addressing policy actions identified in the European eHealth Action Plan. It should be underlined that the National Programme for IT in England is the basis for eHealth deployments which started in 2002, two years before the eHealth Action Plan was published.

The 2004 eHealth Action Plan required the Commission to regularly monitor the state of the art in deployment of eHealth, the progress made in agreeing on and updating national eHealth Roadmaps, and to facilitate the exchange of good practices. Furthermore, in December 2006, the EU Competitiveness Council agreed to launch the *Lead Market Initiative*[4] as a new policy approach aiming at the creation of markets with high economic and social value, in which European companies could develop a globally leading role. Following this impetus, the Roadmap for implementation of the "eHealth Task Force Lead Market Initiative" also identified better coordination and exchange of good practices in eHealth as a way to reduce market fragmentation and lack of interoperability[5].

On the more specific aspects of electronic health record (EHR) systems, the recent *EC Recommendation on cross-border interoperability of electronic health record systems*[6] notes under "Monitoring and Evaluation", that "in order to ensure monitoring and evaluation of cross-border interoperability of electronic health record systems, Member States should: consider the possibilities for setting up a monitoring observatory for interoperability of electronic health record systems in the Community to monitor, benchmark and assess progress on technical and semantic interoperability for successful implementation of electronic health record systems." This study is a contribution to monitoring the progress made in establishing national/regional EHR systems in Member States. It also provides analytical information and support for current efforts made by the European Large Scale Pilot (LSP) on cross-border Patient Summary and ePrescription services the epSOS- European patients Smart Open Services- [7], and its accompanying thematic network, CALLIOPE[8]. England has contributed substantially to the work of both these pan-European initiatives.

Earlier, in line with the requirement to "regularly monitor the state of the art in deployment of eHealth", the Commission already funded a first project to map national eHealth strategies – the eHealth ERA: "Towards the establishment of a European eHealth

[3] European Commission 2004

[4] European Commission 2007

[5] European Communities 2007

[6] European Commission 2008

[7] European Patients Smart and Open Services (epSOS)

[8] Calliope Network

Research Area" (FP6 Coordination Action)[9] -and a project on "Good eHealth: Study on the exchange of good practices in eHealth"[10] mapping good practices in Europe - both of which provided valuable input to the present *eHealth Strategies* work and its reports. Member States' representatives and eHealth stakeholders for example in the context of the *i2010 Subgroup on eHealth* and the annual European High Level eHealth Conferences have underlined the importance of this work and the need to keep it updated to continue to benefit from it.

This country report on England summarises the main findings and an assessment of progress made towards realising the key objectives of the eHealth Action Plan in that country. It presents lessons learned from England's national eHealth programme, planning and implementation efforts, and provides an outlook on future developments.

1.2 Survey methodology

National level information has been collected through a Europe-wide network of national correspondents which was enhanced by materials provided directly by the health authorities concerned.

The key tool used to collect this information from the different national correspondents was an online survey template containing six main sections:

A. National eHealth Strategy

B. eHealth Implementations

C. Legal and Regulatory Facilitators

D. Administrative and Process Support

E. Financing and Reimbursement Issues

F. Evaluation

Under each section, specific questions were formulated and combined with free text fields and drop-down menus. The drop-down menus were designed to capture dates and stages of development (planning/implementation/routine operation). In addition, drop-down menus were designed to limit the number of possible answering options, for example with regard to specific telemedicine services or issues included in a strategy document. The overall purpose was to assure as much consistency as reasonably possible when comparing developments in different countries, in spite of the well-known disparity of European national and regional health system structures and services.

Under Section B on eHealth implementation questions regarding the following applications were formulated: existence and deployment of patient and healthcare provider identifiers, eCards, Patient Summary, ePrescription, Standards as well as Telemonitoring and Telecare.

The data and information gathering followed a multi-stage approach. In order to create a *baseline* for the progress assessment, the empirica team filled in those parts of the

[9] empirica, STAKES et al. 2007

[10] European Commission; Information Society and Media Directorate-General 2009

respective questions dealing with the state of affairs about 3 to 4 years ago, thereby drawing on data from earlier eHealth ERA reports, case studies, etc. to the extent meaningfully possible. In the next step, national correspondents, and respectively partners from the study team, filled in the template on recent developments in the healthcare sector of the corresponding country. These results were checked, further improved and validated by independent experts whenever possible.

Progress of eHealth in England is described in chapter 3 of this report, in the respective thematic subsections.

This report was subjected to both an internal and an external quality review process. Nevertheless, the document may not fully reflect the current situation. The analysis may not be exhaustive due to focusing on European policy priorities as well as due to limited study resources, and the consequent need for preferentially describing certain activities over others. Also, the views of those who helped to collect, interpret and validate contents may have had an impact. Particularly in the case of England and the United Kingdom, since May 2010, a number of potentially large-scale changes are anticipated in the health system that it has not been possible to reflect fully in this report.

1.3 Outline

The report provides general information on the English healthcare system, as well as on specific issues of the eHealth structure and the ongoing development. It is structured as follows:

Chapter 2 is concerned with the overall system setting, such as decision making bodies, healthcare service providers and health indicators data

Chapter 3 presents the current situation of selected key eHealth developments based on detailed analyses of available documents and other information by national correspondents and data gathered by them through an online questionnaire. It touches on issues and challenges around eHealth policy activities, administrative and organisational structure, the deployment of selected eHealth applications, technical aspects of their implementation, legal and regulatory facilitators, financing and reimbursement issues, and finally evaluation results, plans, and activities

Chapter 4 provides a brief summary of the current situation.

2 Healthcare system setting

Key figures about healthcare in the United Kingdom[11]:

Total population: 61,411.69 (OECD 2008);

Life expectancy at birth: 79.9 years (OECD 2007);

Healthcare expenditure as a % of GDP: 8.4% (OECD 2007);

Public sector healthcare expenditure as a % of total healthcare expenditure: 82% (OECD 2007).

2.1 Healthcare governance

Following elections in the UK in May 2010, the set-up of the National Health Service (NHS) is under an important review. The policy changes at hand will impact on the eHealth policy in NHS England. These changes are taken into account in this report to the extent that they are already discernible today in October 2010. However, much of this report focuses on the organisational conditions that prevailed in the NHS at the time that the first draft of this report was finalised (in early May, 2010).

We outline here, however, some developments since May 2010. The following information on healthcare governance should be seen in the light of government documents published on 12 July 2010, notably a White Paper entitled "Equity and Excellence: Liberating the NHS". A declared objective of this policy document is to make the NHS more efficient and productive so as to ensure that it can cope with increasing demands on its services.

The White Paper sets out four key points:

- putting patients first through giving them more information and greater choice and control over their care – 'no decision about me without me'
- improving healthcare outcomes by ensuring that professionals are free to focus on improving health outcomes so that these are among the best in the world. Improving the quality of care will become the main purpose of the NHS
- autonomy and accountability involving giving power back to NHS professionals and healthcare providers, giving them more autonomy and, in return, making them more accountable to patients and the public
- cutting bureaucracy and improving efficiency by continuing to reinvest savings of up to £20 billion in front-line services by 2014 in line with the Quality, Innovation, Productivity and Prevention agenda.

Regarding the first point, it is intended to give patients more choice and control through the modernisation of IT ("an information revolution"). Patients will be able to rate the quality of the care they receive. "Healthwatch", a separate organisation, will ensure "that patients are involved in decisions about their care and that their views are considered when commissioning services".

[11] These figures relate to the United Kingdom as a whole rather than to England specifically.

When it comes to improving healthcare outcomes (the second point), the White Paper announces a move away from "top-down targets" towards health outcomes targets. "A new outcomes framework will be introduced based on effectiveness of treatment; safety of treatment and care; and broader patient experience of care. " This framework will use quality standards developed by the National Institute for Health and Clinical Excellence. In addition, commissioning care, payment systems, and inspection processes will all be built on the outcomes framework.

In the field of decision-making (autonomy and accountability), more freedom is given to healthcare professionals and service providers "to shape services around the needs and choices of patients." The Strategic Health Authorities which currently oversee commissioning will be phased out by 2012/13, to be replaced with a new independent NHS Commissioning Board. In addition to this development, the White Paper mentions the following changes in the governance of the NHS:

• All NHS trusts will become foundation trusts and have more freedom. Any provider that can meet safety and quality standards will be able to provide NHS services. This greater freedom will also apply to the way in which local community health services are delivered.

• Monitor will be developed into an economic regulator and the Care Quality Commission will act as a quality inspectorate across health and social care.

• Monitor and the Care Quality Commission will act as regulators. Providers will need a licence to ensure that safety, quality and the continuity of essential services are maintained.

• Primary Care Trusts and practice-based commissioning will be replaced by General Practitioner (GP) Consortia, which will work with other health and care providers, in partnership with local authorities and local communities, to commission the majority of NHS services for their patients. The role of the Secretary of State in the NHS will span five key areas:

i. setting a formal mandate for the NHS Commissioning Board;

ii. holding the NHS Commissioning Board to account on delivering improvements in choice and patient involvement, and in maintaining financial control;

iii. arbitration, where disputes arise between NHS commissioners and local authorities;

iv. responsibility for Department of State functions including setting the overall NHS policy and legislative frameworks, and determining the comprehensive service which the NHS provides;

v. accounting annually to Parliament for the overall performance of the NHS, public health and social care systems.

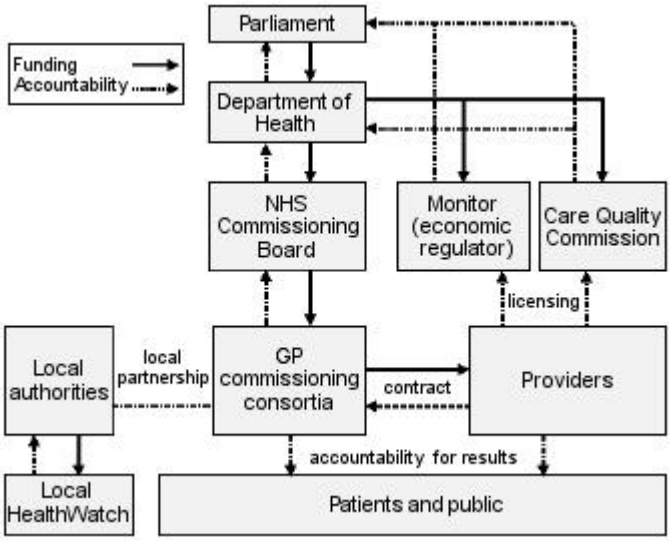
• Local authorities will have new functions that join up with the commissioning of local NHS services, social care and health improvement. This will provide efficiencies and build partnerships to drive service change and priorities.

Finally, with regard to the objective of "Cutting bureaucracy and improving efficiency", the White Paper announces a reduction in management costs and in any duplication in the system. "There will also be reductions to budgets for centrally managed programmes,

such as consultancy services and advertising spend. NHS services will increasingly be empowered to be the customers of a more plural system of IT and other suppliers."

Some of these changes will require primary legislation, and a Health Bill will be produced in autumn 2010.

The figure below presents an outline of the new processes envisaged within the NHS in England:



Decision making bodies, responsibilities, sharing of power

In England, ten Strategic Health Authorities (SHAs) are responsible for healthcare in their region. This includes the development of strategies for health services in their local areas, ensuring quality and the appropriate capacity for different services. SHAs are accountable to the Secretary of State for Health, who is the government minister responsible for the NHS in England and answerable to Parliament for its work. The new Coalition Government has indicated its intention to abolish SHAs. A new national Commissioning Body is proposed which may absorb many of the functions of SHAs.

Healthcare service providers[12]

There are 152 Primary Care Trusts (PCTs) in England which are responsible for the commissioning of health services for their local population, and for the provision of a variety of primary healthcare services. PCTs handle approximately 80% of the total NHS budget, managing budgets for local services. PCTs are performance managed by the SHAs. The new Coalition Government has indicated its intention to abolish PCTs. Their proposed replacements will be known as GP Consortia.

NHS secondary care services are run and managed by NHS Trusts. There are three main types of trusts:

[1] Acute trusts, providing medical and surgical care and are usually centred on a teaching or district general hospital; an acute trust may manage more than one hospital.

[2] Mental health trusts, either providing services in hospitals or in the community.

[12] Department for Work and Pensions 2008

[3] Ambulance trusts.

Some NHS Trusts are performance managed by the SHAs and accountable to the Secretary of State. Since April 2004, certain NHS trusts (the best performing hospitals) have been allowed to receive foundation status. These hospitals have greater freedoms to manage their own affairs and are accountable to the local community through a stakeholder board of Governors, rather than to the Secretary of State. Monitor is an independent body responsible for authorising, monitoring and regulating foundation trusts. Foundation Trusts represent the Government's commitment to decentralising the control of public services and are viewed as a way to improve service responsiveness and quality of care in the NHS. Since May 2010, the new Coalition Government has indicated it wants all trusts to be transformed into Foundation status.

Figure 1: Important features of primary healthcare organisation in England

Political/administrative unit responsible for primary healthcare	The National Health Service provides the majority of healthcare in England, including primary care, in-patient care, long-term healthcare, ophthalmology and dentistry. The National Health Service Act 1946 came into effect on 5 July 1948. Private healthcare has continued parallel to the National Health Service, paid for largely by private insurance: it is used by about 8% of the population, generally as an add-on to NHS services. In the first decade of the 21st century the private sector started to be increasingly used by the NHS to increase capacity.
Consumer Choice	General practitioners are usually the first point of contact for nearly all National Health Service patients. They can direct a patient to other National Health Service services. A person has the right to be registered with the general practitioner surgery (i.e., office) of their choice. It is the general practitioner who advises the patient about choosing the best specialist care when it is needed.[13]
Financing	The National Health Service is largely funded from general taxation (including a proportion from National Insurance payments). The government department in England responsible for the National Health Service is the Department of Health. Scotland, Wales and Northern Ireland have their own devolved health administrations. Most of the expenditure of the Department of Health in England (£98.7 billion in 2008/2009) is spent on the National Health Service.
Public or private providers	Many general practitioners are self-employed. They hold contracts, either on their own or as part of a partnership, with their local primary care trust. The profit made by general practitioners varies according to the services they provide for their patients and the way they choose to provide these services. Those salaried general practitioners who are employed directly by primary care trusts earn between £53,249 to £80,354 a year depending on their length of service and experience.[14]
Gatekeeping function of the General Practitioner (GP)	General practitioners are usually a patient's first contact point. If a patient needs to go to hospital to see a specialist, she/he has the right to choose to which hospital the general practitioner refers him/her. This legal right was introduced in April 2009. It enables the patient to choose from any hospital offering a suitable treatment that meets National Health Service standards and costs. The patient can choose the hospital according to what factors matter most, including location, cleanliness, waiting times, reputation, clinical performance, visiting policies, parking facilities or patients' comments.[15]

[13] NHS Choices 2009

[14] NHS Careers 2010

[15] NHS Choices 2009

2.2 Reforms and priorities of health system/public health

The government introduced a large number of different healthcare reforms in England over the nine years until early 2010. To summarise, they focused on the following issues:[16]

- Substantial real terms increases in NHS expenditures (not a reform in itself, but very important, and primarily motivated by the Government's objective to bring healthcare spending in line with the EU average but also used as "investment" to enable reform);
- Commitment to markets, choice and payment-by-results as incentives for hospitals to reduce waiting times/lists and improve various indicators of quality (e.g. mortality rates);
- Emphasis on targeting more resources towards primary care services (and in particular with respect to improving services in deprived areas, as part of their effort to reduce inequalities in health outcomes across socio-economic and geographically-defined groups), and
- Attempts to better integrate health and social care.

A central policy document, which followed up on a 10-year healthcare reform from 2000, is the "Health reform in England: update and commissioning framework"[17] (2006). It outlines past achievements and future plans for healthcare in England. The new Coalition Government published a White Paper *(Equity and Excellence: Liberating the NHS)* in summer 2010 which sets out major reforms to the structure and functions of the different parts of the NHS in England.

3 eHealth Strategies survey results

The following sections present the results of the eHealth Strategies country survey in Europe. In a first section, the eHealth policy actions undertaken in Europe generally are presented briefly, in England until 2002, and again in 2010, are presented briefly. This is followed by a presentation of administrative and organisational measures taken. Section 0 presents results on key eHealth applications. Section 3.4 focuses on the technical side of eHealth, namely the role of patient and healthcare provider identifiers and the role of eCards. Legal and regulatory facilitators as well as financing and reimbursement issues are presented in the following chapters, 3.5 and 3.6. The report concludes with evaluation activities (3.7) in the country and an outlook (4).

[16] Oliver 2006

[17] Department of Health 2006

3.1 eHealth policy action

The eHealth strategies of EU and EEA countries are not always labelled as strategies. Some countries may indeed publish a policy document which refers to the ICT strategy in the healthcare sector. Other countries such as France and Germany have enshrined the central eHealth activities in legislation governing the healthcare sector. In Germany, the relevant law is the law on the modernisation of healthcare; in France the introduction of an electronic medical record is included in a law concerning social security.

Sometimes, documents from domains such as eGovernment or Information Society strategies may also contain provisions which concern eHealth. In cases where the healthcare system is decentralised, i.e. where power is delegated to the regional level, there may even be strategy documents regarding eHealth available from regional authorities.

3.1.1 Current strategy/roadmap

Due to changes in the English NHS in the wake of elections in the United Kingdom in May 2010, the English eHealth strategy is currently under review. The summary of the policy documents which follows is therefore to be read with the appropriate caution as the direction of policy may still change. The new Coalition Government is expected to carry out a public consultation on a proposed Information Strategy and indicate a new direction for the main IT programmes during the latter part of 2010.

The White Paper: 'Equity and excellence: liberating the NHS'

In September 2010, the Minister of State, Department of Health (Mr. Simon Burns) declared:

> *"The National Programme for IT is being reconfigured to reflect the changes*
>
> *described in the White Paper "Equity and Excellence: Liberating the NHS" and the outcome of the cross-Government review of ICT projects initiated in May.*
>
> *A departmental review of the National Programme for IT has concluded that we deliver best value for taxpayers by retaining a national infrastructure and applications whilst devolving leadership of IT development to NHS organisations on the principle of connected systems and interoperability with a plural system of suppliers.*
>
> *The programme has delivered a national infrastructure for the NHS, and a number of successful national applications such as choose and book, the picture archiving and communications (digital imaging) system, and the electronic prescription service should now be integrated with the running of current health services.*
>
> *The remaining work of the programme largely involves local systems and services, and the Government believe these should now be driven by local NHS organisations. Localised decision making and responsibility will create fresh ways of ensuring that clinicians and patients are involved in planning and delivering front line care and driving change. This reflects the coalition Government's commitment to ending top-down government."*

It is understood that certain commitments under the National Programme will continue up until their completion in 2012. From then on, it is envisaged that most future applications will be locally driven and delivered while they remain consistent with national information standards.

Delivering 21st century IT support for the NHS: national strategic programme

Prior to the recent changes, the "Delivering 21st century IT support for the NHS: national strategic programme"[18] from 2002 had been the policy paper concerned with the major developments in the deployment and use of information technology in the National Health Service (NHS). The document outlined the vision, strategy, and work streams that would connect the delivery of the NHS Plan with the capabilities of modern information technologies.

The following five documents were the policy papers that referred to eHealth strategies in England between 1998 and 2002 until the publication of the Delivering 21st century IT support for the NHS: national strategic programme.

Earlier eHealth strategies:

Information for health: an information strategy for the modern NHS (1998)

The NHS Plan: a plan for investment, a plan for reform (2000)

Building the information core implementing the NHS Plan (2001)

Securing our future health: taking a long-term view - the Wanless Report (2002)

Delivering the NHS Plan: next steps on investment, next steps on reform (2002)

Information for health: an information strategy for the modern NHS 1998-2005[19] (September 1998): The purpose of this information strategy was to ensure that information is used to help patients receive the best possible care. The strategy was to enable NHS professionals to have the information they need both to provide that care and to play their part in improving the public's health. The strategy also aimed to ensure that patients, carers, and the public were to have the information necessary to make decisions about their own treatment and care, and to influence the shape of health services generally.

The NHS Plan: a plan for investment, a plan for reform[20] (July 2000): outlined the vision of a health service designed around the patient: a new delivery system for the NHS as well as changes between health and social services, changes for NHS doctors, for nurses, midwives, therapists and other NHS staff, for patients and in the relationship between the NHS and the private sector.

Building the information core implementing the NHS Plan[21] (January 2001): considered the implications of The NHS Plan for the necessary information and IT infrastructure to support a patient-centred delivery of care and services. It built on and updated Information for Health, the information strategy for the NHS, and provided a clearer focus on what priorities for successful delivery should be.

[18] Department of Health 2002

[19] Department of Health and NHS Executive 1998

[20] Department of Health 2000

[21] Department of Health 2001

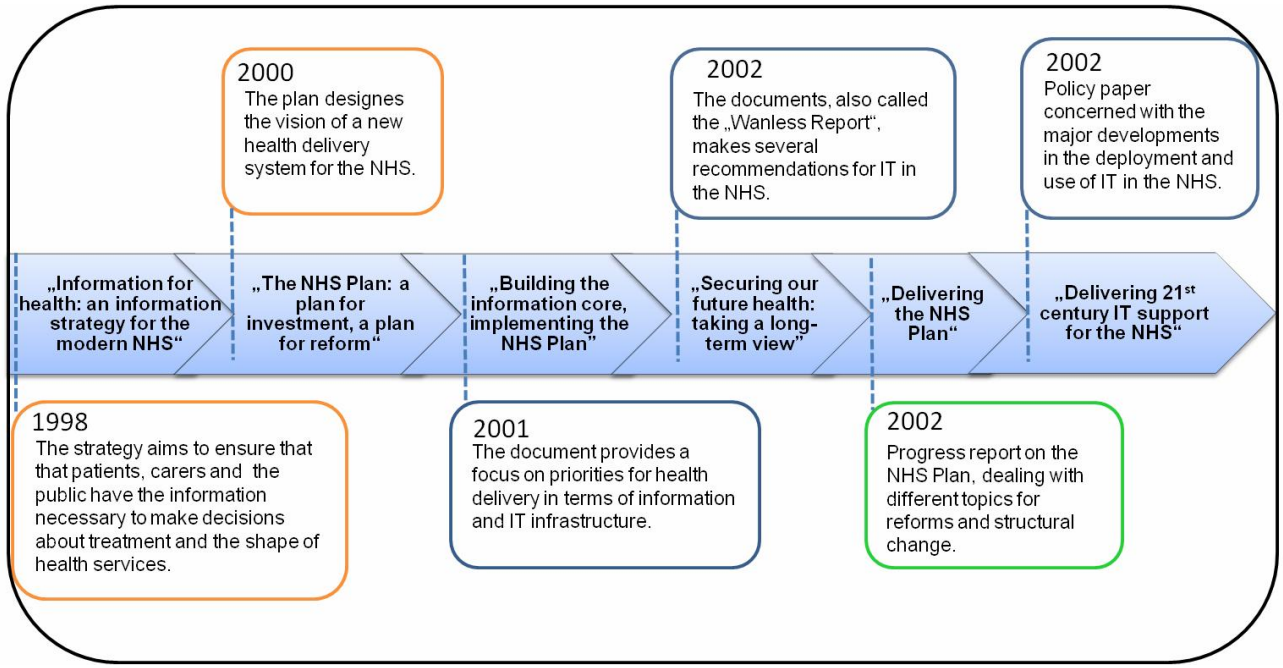
Securing our future health: taking a long-term view - the Wanless Report[22] (January 2002): assessed the long-term resource requirements of the health service in the United Kingdom. It makes several recommendations for IT in the NHS: doubling and ring-fencing IT expenditure; using stringent, centrally-approved standards; and auditing achievements.

Delivering the NHS Plan: next steps on investment, next steps on reform

Delivering the NHS Plan: next steps on investment, next steps on reform[23] (April 2002): was a progress report on the NHS Plan up to 2002, that noted achievements and provided details of planned changes to the programme. Among other topics, it dealt with supply-side reforms and structural changes to the health service, payment by results, explicit patient choice, diversity of supply, devolution of decision-making away from the centre, and changes in job design and work organisation.

The figure below shows a timeline for the different policy documents in England.

Figure 2: English policy documents related to eHealth 1998-2002



Recent Developments

The new Coalition Government is now developing a new Information Strategy during 2010-11 which will be subject to a consultation exercise before finalisation.

[22] Department of Health 2002

[23] Department of Health 2002

3.2 Administrative and organisational structure

NHS Connecting for Health delivers the National IT programme

Since 2005, NHS Connecting for Health, which is currently within the Department of Health's Informatics Directorate, [24] has been responsible for the delivery of the National Programme with the management of the IT-related functions and financed by the English Department of Health (NPfIT).

The National Programme was originally expected to operate for up to five years, but continued for a longer period, and has seen changes to its content and revisions to its delivery timetable.

Local NHS elements define own IT priorities supported by Connecting for Health

In 2006, the NPfIT Local Ownership Programme was commissioned. Through this programme, the local elements of the NHS (its Strategic Health Authorities and Primary Care Trusts) were able to define their own IT priorities to improve healthcare standards and delivery. These local NHS organisations also became accountable and responsible for the delivery of the National Programme for IT. NHS Connecting for Health supports this delivery.

The maintenance of the national eHealth infrastructure is the responsibility of the two remaining Local Service Providers, British Telecom and the Computer Services Corporation.

Regarding the involvement of stakeholders, England found several solutions varying from informal consultation to temporary working groups and stakeholder representation in official decision-making bodies. These mechanisms are used to solicit and integrate the different views – this is also expressed e.g. in the "Information for health: an information strategy for the modern NHS" strategy. Here, it is stated that: "the development of policy, and the management of national IM&T projects, must be guided by the needs of the various stakeholders"[25]. The arrangements defined include e.g. a Clinical Systems Group, and associated clinical information advisory groups, local involvement of patients and carers as well as collaboration with other public services expressed in partnership arrangements both nationally between government departments and locally between individual NHS and other organisations.

Overall, in England, considerable effort has been expended to engage with clinical and patient stakeholders so that they can appreciate the benefits as well as the challenges in implementing what are complex new information systems. Clinical Leads (or champions) bring their expertise to bear on the design of these new joined-up systems. Patient or consumer concerns can be expressed through an independent National Information Governance Board that promotes a published guarantee on the way personal data are managed within the electronic health records.

Main challenges connected to issues of organisation and finance

The main challenges for the administrative framework for eHealth in England are largely connected to organisational and financial issues: The Local Ownership Programme has devolved responsibility for implementation to Strategic Health Authorities and local Trusts. This brings with it demands for additional skills and resources to carry out these responsibilities. Furthermore, eHealth activities will not stop with the completion of the National Programme, but will continue with the upgrading and replacement of older

[24] NHS Connecting for Health 2010

[25] NHS executive 1998, p.87

systems and with the addition of new functionalities. Such continuing costs will need to be assessed[26].

Recent Developments

On 9 September 2010 the English Health Minister, Simon Burns, made the following announcement on the outcome of a Review of the NPfIT:

> "The National Programme for IT is being reconfigured to reflect the changes described in the White Paper "Equity and Excellence: Liberating the NHS" and the outcome of the cross government review of ICT Projects initiated in May".

A Department of Health review of the National Programme for IT has concluded that we deliver best value for taxpayers by retaining a national infrastructure and applications whilst devolving leadership of IT development to NHS organisations on the principle of connected systems and interoperability with a plural system of suppliers.

The programme has delivered a national infrastructure for the NHS, and a number of successful national applications such as Choose and Book, the Picture Archiving and Communications (digital imaging) System, and the Electronic Prescription Service should now be integrated with the running of current health services.

The remaining work of the programme largely involves local systems and services, and the Government believes these should now be driven by local NHS organisations. Localised decision making and responsibility will create fresh ways of ensuring that clinicians and patients are involved in planning and delivering front line care and driving change. This reflects the coalition government's commitment to ending top-down government.

The new approach to implementation will be modular, allowing NHS organisations to introduce smaller, more manageable change, in line with their business requirements and capacity. NHS services will be the customers of a more plural IT supplier base, embodying the core assumption of connecting all systems together rather than replacing all systems.

This approach will also address the delays, particularly in the acute sector, that resulted from the National Programme's previous focus on complete system replacement. It will allow NHS Trusts to retain existing systems that meet modern standards, and move forward in a way that best fits their own circumstances.

An appropriate structure for health informatics is a key element of the organisational design work currently underway following the publication of the White Paper "Equity and Excellence: Liberating the NHS". The direction of travel being announced today for IT services very much reflects the key theme of the White Paper, of bringing decisions closer to the front line. It follows that the National Programme will no longer be run as a centralised programme. Some elements will need to continue to be nationally managed and it is expected that new structures will be fully in place by April 2012.

Existing contracts will be honoured and it is vital that their value be maximised. However, by moving IT systems closer to the frontline, it is expected to make additional

[26] Within the NHS in England, a distinction is made between national costs of NPfIT which are in the public domain and local cost consequences of these investments which are not collected centrally.

savings of £700 million, on top of the £600million announced by the previous administration in December 2009. These savings will mean that the total cost of the programme will be reduced significantly from the original forecast of £12.7billion for combined central and local spending to £11.4 billion."

3.3 Deployment of eHealth applications

3.3.1 Patient summary and electronic health record

In this study, the epSOS project's definition[27] of a patient summary was used as a general guideline. There a patient summary is defined as a minimum set of a patient's data which would provide a health professional with essential information needed in case of unexpected or unscheduled care (e.g. emergency, accident), but also in case of planned care (e.g. after a relocation, cross-organisational care path).

Lacking a standard definition, a patient's electronic health record (EHR) is here understood as an integrated or also interlinked (virtual) record of ALL his/her health-related data independent of when, where and by whom the data were recorded. In other words, it is an account of his diverse encounters with the health system as recorded in patient or medical records (EPR or EMR) maintained by various providers like General Practitioners, specialists, hospitals, laboratories, and pharmacies. Such records may contain a patient summary as a subset. As of yet, fully-fledged EHR systems rarely exist. Examples where they are used include regional health systems like Andalucia in Spain or Kronoberg in Sweden, and in HMOs (health maintenance organisations) like Kaiser Permanente in the USA.

It should be noted that in most policy documents reference is made simply to an "EHR" without any explanation of what is meant by it, thereby - in reality - even a single, basic electronic clinical record of a few recent health data may qualify. As a consequence, this section can only report on national activities connected to this wide variety of health-related records without being able to clearly pinpoint what (final) development stage is actually aimed for or has been reached so far.

Summary Care Record Implementati-on started in late 2008

In England, a basic patient summary is known as the Summary Care Record[28] (SCR). The Summary Care Record Programme has been piloted since 2007 and national implementation started in late 2008.

As the vast majority of General Practitioners (GPs) in England have used computers since the mid-nineteen eighties, and have hence used some form of patient record, the record "is created from the records of organisations already delivering care to a patient"[29] such as GPs' practices. The Summary Care Record contains a core set of essential information of demographic details, medications, allergies and adverse reactions to support safe treatment in emergency care.

Data storage terms

In terms of storage, the data are saved in the Personal Spine Information Service (PSIS) database. The PSIS is one part of the NHS Care Records Service (NHS CRS). The other

[27] European Patients Smart and Open Services (epSOS)

[28] NHS Connecting for Health 2010

[29] NHS Connecting for Health 2009, p.5

major data component is the Personal Demographics Service (PDS) database. This database holds each patient's demographic information. The PDS was created in 2004, and it will eventually replace the four existing demographic services so as to become the sole source of patient demographic information for all NHS healthcare systems. The PSIS database and the PDS database are also components of the Spine.

The Spine is the collection of databases and applications that provide several services to NHS staff.

As well as the PDS (to maintain patient demographic details) and the PSIS (to maintain patient clinical records), the Summary Care Record Application allows healthcare staff - with appropriate access rights - to gain controlled access to patient information provided by the PDS and the PSIS. Other systems and services supported by the Spine include the Electronic Prescription Service and Choose and Book (which enables the making of appointments).

While the Summary Care Record application is a Spine application, ePrescriptions and Choose and Book are services that the Spine supports. However, they are not themselves databases or applications on the Spine.

Planned EHR, extending SCR functionality

The scope of the content of the Summary Care Record has been subject to a review which reported in October 2010. The review concluded that the core record should only contain a patient's demographic details, medications, allergies and adverse reactions. Any further information added to the Summary Care Record should require explicit consent from the patient[30].

Summary Care Records are viewed in urgent and emergency care settings, for example in GP Out of Hours Services, Walk in Centres and Hospital Emergency Departments. Summary Care Records can be viewed by authorised healthcare staff either through the web based Summary Care Record Application or through clinical systems which are integrated directly with Summary Care Records. Systems that are provided centrally and existing local clinical systems are being integrated with the Summary Care Record.

3.3.2 ePrescription

Two programmes: ePrescribing and the Electronic Prescription Service

In the framework of this study and following work in epSOS[31]*, ePrescription is understood as the process of the electronic transfer of a prescription by a healthcare provider to a pharmacy for retrieval of the drug by the patient. In this strict sense, only a few European countries can claim to have implemented a fully operational ePrescription service.*

There are two programmes for electronic prescribing in the United Kingdom, ePrescribing[32],[33] and the Electronic Prescription Service[34] (EPS).

The latter is aimed at the primary care sector (general practitioner surgeries and clinics). EPS involves the generation, transmission, receiving and despatching of the prescription for payment. The implementation of release 1 of the EPS started in February 2005 and is

[30] NHS Connecting for Health 2010

[31] European Patients Smart and Open Services (epSOS)

[32] NHS Connecting for Health 2010

[33] There are certain exclusions under ePrescribing in England which refer to controlled drugs.

[34] NHS Connecting for Health 2010

almost complete[35]. The implementation of release 2 began in 2008 and includes electronic signatures and the transmission of the prescription automatically to a pharmacy nominated by the patient[36].

NHS Connecting for Health issued organisational and technical guidelines to support the implementation of EPS software at the primary care and community pharmacy level.

In terms of an estimated ePrescription share, the Department of Health stated in September 2009 that "In terms of services currently routinely being used by clinicians and patients, on any typical day in the NHS the national programme already enables: Over 500,000 prescriptions to be transmitted electronically (33% of average total daily prescriptions), reducing errors and inefficiencies"[37].

Most, if not all, of the EPS Release 2 systems for GPs 'practitioners' surgeries have been accredited and approved for roll-out nationally. However, the majority of the EPS Release 2 dispensing systems are awaiting technical accreditation followed by further testing in an initial implementation before being approved for roll-out.

The second programme, called ePrescribing, is aimed at hospitals and other acute healthcare settings. In addition to the functions that are part of EPS, ePrescribing has a decision support component. Several institutions have used some form of electronic prescribing for over ten years. Connecting for Health has issued guidelines for evaluating ePrescribing software products, and it has commissioned research to explore the challenges related to, and provide guidelines for, the implementation of ePrescribing.

Challenges for organisation, resources and technology

Currently, there are three broad types of challenges in England for ePrescription, including organisational, resourcing and technological issues:[38]

From an organisational perspective, healthcare staff must acquire confidence in the technology in order to adopt it. Adopting the technology also means changes to job design and work organisation. This partly results in resistance e.g. of senior hospital clinicians or medical staff to the making of these changes.[39]

Further challenges include the fact that significant external and internal IT support and healthcare staff time are required for implementation and for training. Training occurs not only prior to implementation but also continues afterwards and is dependent on available resources.

3.3.3 Telemedicine

The use of telemedicine applications is recognised as beneficial to enable access to care from a distance and to reduce the number of General Practitioner visits or even inpatient admissions. Commission services define telemedicine as "the delivery of healthcare

[35] NHS Patient Advice and Liaison Service 2006; NHS Connecting for Health March 2010

[36] NHS Connecting for Health 2010

[37] House of Commons and Health Committee 2010

[38] NHS Connecting for Health 2009

[39] Evidence for this can be found e.g. in the oral records of the Health Committee of the House of Commons – example: "It is partly to do with the leadership, and my two colleagues here might not agree with me, but it is partly to do with the resistance of senior hospital clinicians to the introduction of changes to their working processes that fundamentally affect them directly ..." (House of Commons 2007)

services through the use of Information and Communication Technologies (ICT) in a situation where the actors are not at the same location"[40]*. In its recent communication on telemedicine for the benefit of patients, healthcare systems and society, the Commission re-emphasises the value of this technology for health system efficiency and the improvement of healthcare delivery*[41].

Telemedicine and Telecare services in England are mostly determined at the local level. Currently the following services are developed and available:[42]

Telecare services

Different alarm systems (including e.g. a personal alarm or motion sensors)

Telehealth equipment for home monitoring of e.g. blood pressure, blood glucose

Telemedicine initiatives in England are not combined under a single national programme but rather treated as a combined healthcare and social service that is run at the level of local authorities. Therefore, the Department of Health has provided seed funding for trials of telecare services at local authority level. It is currently funding three demonstrator projects that aim to develop an evidence base for the use of telecare and telehealth in England. Hereby, the Telecare Living and Improving Network[43] (LIN) serves as an information repository and an information and news distribution hub for developments in telehealth.

Examples of other national funding initiatives are 1) the Preventive Technology Grant and 2) the Whole System Demonstrator Programme[44].

The Preventive Technology Grant distributed £80 million in the financial years of 2006/2007 and 2008/2009 to local authorities in order to change the design and delivery of health, social care and housing services. It is said that through the Grant, the number of new telecare and telehealth users have increased by over 200,000.

Examples of concrete telemedicine applications currently running in the NHS England include Teleradiology, where a fully operational Picture Archiving and Communications System - under the aegis of NHS Connecting for Health - enables the digital transmission of radiological images between healthcare providers. The British Teledermatology Society has elaborated an information resource on teledermatology. The Pathology Messaging Implementation Programme (PMIP), which is also managed by NHS Connecting for Health, enables the transmission of digitised pathological results, such as microscopic images of cells, for the purpose of interpretation and/or consultation. Finally, pilot projects in the Doncaster and South Humber Mental Health NHS Foundation Trust should be mentioned as an example of Telepsychiatry services. The Trusts have established

[40] Europe's Information Society 2009

[41] European Commission 2008

[42] NHS Choices 2009

[43] Telecare LIN was established in 2005 under the auspices of the Health and Social Care Change Agent Team in the Care Service Improvement Service at the Department of Health; it is one of several groups that are collectively known as DH Care Network. (Department of Health , http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Telecare/)

[44] Department of Health 2009

"eClinics" for psychological therapies for mental health issues such as depression and anxiety.

In 2008, the Whole System Demonstrator (WSD) programme started. It is a two-year research project funded by the Department of Health to find out how technology can help people manage their own health while maintaining their independence. Its results are due to be published in late 2010.

Furthermore, the Department of Health produces an annual report[45] on research and development work relating to assistive technologies, including telecare and telehealth. The reports are produced for the Department of Health by the Foundation for Assistive Technology[46] (FAST). FAST is a charity funded by the Department of Health that works with the assistive technology community to promote useful research and development for disabled and older people. The reports include research funded by the United Kingdom Government or the European Union and research projects located in England, Scotland, Wales and Northern Ireland.

Finally the NHS-Direct Service could be considered, at least tenuously by some, as a telemedicine service. The NHS-Direct website provides patients with access to a library of medical advice and the NHS-Direct Telephone assistance service provides patients with a 24-hour service providing health advice and reassurance on the phone[47]. Its benefits include a reduction in inappropriate referrals to direct services such accident and emergency departments or GP/primary care services. It may undergo significant reform within the near future.

Public financing of telemedicine and telehealth services (and eHealth more generally) in England is provided in many forms. Examples include ICT equipment, software, and skills training in eHealth, scholarships for formal education in eHealth, initiation of regional pilot projects, and ongoing support for eHealth programmes. In addition, public-private partnerships in England support the deployment and use of telemedicine and telehealth services. An example of such cooperation is provided by the Continua Health Alliance. Continua is dedicated to establishing a system of interoperable personal health solutions based on a commitment to the fact that extending those solutions into the home fosters independence, empowers individuals, and provides the opportunity for personalised health and wellness management.

For the wellness agenda, for people with chronic diseases, and for telehealth and telecare, the target group(s) for this cooperation are all citizens of England. The NHS is working with Continua to facilitate a system of connected technologies, devices, and services that will enable a more efficient exchange of information on fitness, health, and wellness. This "ecosystem" will be made possible by the creation and implementation of interoperability guidelines which specify how systems and devices produced by different companies can be designed to work together to provide better access to information.

A possible obstacle to telemedicine deployment in England is the loose coordination at national level. Despite some funding support from the Department of Health, local authorities are responsible for evaluating and implementing telecare and telemonitoring.

[45] Department of Health 2009

[46] Foundation for Assistive Technology (FAST) 2010

[47] NHS Direct 2010

While this might allow for the deployment of appropriate solutions at the local level, it does not prevent duplication of effort.

3.4 Technical aspects of implementation

A key prerequisite for the establishment of an eHealth infrastructure is the ability to uniquely identify citizens/patients and healthcare professionals. This part of the survey deals with identifiers and how they are stored. This section does not deal with the tokens through which identification can or will take place. One such possibility would be via an eCard. This topic is dealt with in the following section. The current section focuses solely on whether or not unique identifiers are in place in England and for which purpose.

3.4.1 Unique identification of patients

National Health Service Number as unique patient ID

The NHS number[48] is the unique patient ID for health purposes in England. In its current 10-digit form, it was formally introduced in 1996. Its foundation is, however, much older[49]. The NHS number is the only unique national patient identifier used by all NHS organisations in England. Babies are given an NHS number at birth and any individual who does not have an NHS number is given one when he or she registers at an NHS general practitioner's surgery or health centre. In addition, an increasing number of Trusts are now able to allocate an NHS Number themselves, usually to overseas visitors who present themselves for treatment in England for the first time.

Use of the NHS Number ensures that a patient's information is linked correctly to different sources as s/he moves through the care system. This reduces risks to patient safety and improves the ease and quality of information transfers across organisational boundaries. The NHS number is provided to patients in a letter or on a medical card when they register with a GP It is also given to a baby at birth or to a person who presents for secondary care if no NHS Number is found for him or her.

Increasingly organisations are including the NHS Number on appointment cards and letters to patients. This approach enables patients to provide their NHS Number when they access NHS services. The NHS Number Information Standards[i] approved by the Information Standards Board (ISB)[50] outline the requirements that organisations must follow to use NHS Numbers correctly.

The NHS Number is stored together, together with other patient demographic information, in the Personal Demographics Service[51] that is a component of the "Spine". The Spine[52] is the name given to the collection of information technology services and national databases that contains key information about patients' health and care. It forms the core of the NHS Care Records Service[53] (NHS CRS). As systems connect to the Spine, the NHS Number provides a means of linking together information from various sources.

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48 NHS Connecting for Health 2010

49 For the history of the NHS number in England see NHS Connecting for Health , http://www.connectingforhealth.nhs.uk/systemsandservices/nhsnumber/staff/history

50 Information Standards Board for Health and Social Care

51 NHS Connecting for Health 2010

52 NHS Connecting for Health 2010

53 NHS 2010

3.4.2 Unique identification of healthcare professionals

The identification of healthcare professionals within the NHS Connecting for Health programme in order to access patient data is done via smartcards, issued by registration authorities. All organisations that need to access patient information within the NHS Care Records Service and other National Programmes set up Registration Authorities to manage this process. The Registration Authority is responsible for verifying the identity of healthcare professionals and workers who wish to register to use these services.

Once authorised, individuals are issued an NHS CRS Smartcard by the Registration Authority. Individuals use their NHS CRS Smartcard and their Smartcard Passcode each time they log on. NHS CRS Smartcards help control who accesses the NHS CRS and what level of access that they can have.

A user's Smartcard is printed with the person's name, photograph and unique user identity number. To register for a Smartcard, Registration Authorities are required to ask applicants for identification which satisfies the government recommended standard 'e-Gif Level 3', providing at least three forms of ID (photo and non-photo) and including a proof of address.

Healthcare professionals and other relevant employees are granted access to patient information based on the type of work they do, and their level of involvement in patient care. [54]

3.4.3 Standards

Standards are not only crucial to enable interoperable exchange of meaningful information in the healthcare system; they also ensure secure access to patient records by healthcare providers and citizens. This study aims to identify, among other usage, standards related to the domain of health informatics, such as the SNOMED Clinical Terms or the LOINC terminology. SNOMED CT (Systematized Nomenclature of Medicine-Clinical Terms) is considered to be the most comprehensive, multilingual clinical healthcare terminology in the world. The organisation developing SNOMED is called the International Health Terminology Standardisation Organisation (IHTSDO[55]).

Overall, the United Kingdom is a member of the IHTSDO. The Department of Health's Informatics Directorate (DHID) is the host of the IHTSDO United Kingdom Terminology Centre (UKTC).

NHS Data Standards & Products

In England, DHID has oversight of health informatics standards which are reflected in NHS Data Standards & Products[56] (NHS DS&P), which is the responsibility of the Technology Office in DHID; the Technology Office is responsible for the introduction, development and delivery of coding system products used in the patient records of the NHS Care Records Service, and for the phasing-out of dated systems. Principal activities are:

- The NHS Terminology Service[57] provides support and maintenance for SNOMED CT, Read codes and the Dictionary of Medicines and Devices; it also manages the IHTSDO United Kingdom Terminology Centre (UKTC).

[54] NHS Connecting for Health 2010

[55] International Health Terminology Standards Development Organisation (IHTSDO)

[56] NHS Connecting for Health 2010

- The NHS Classifications Service[58] provides support and maintenance for OPCS4 and ICD-10.
- The NHS Data Model and Dictionary Service[59] provides the development, maintenance and support of NHS data standards.
- The Standards Consulting Group[60] provides guidance and assistance to NHS Connecting for Health programmes in the development and implementation of standards in a consistent manner.
- The Information Governance Group[61] Information Governance ensures necessary safeguards for, and appropriate use of, patient and personal information.

Although it lies outside of the NHS Data Standards and Products group, a Health Informatics Service Benchmarking and Accreditation Scheme was developed and launched in 2008.[62]. Its aim is to help health informatics providers and Information, Management & Technology departments to develop services that are quality-assured and "fit for purpose".

The following standards are currently used in England (the list includes United Kingdom-developed standards):[63]

Standards used in England:

HL7 v3: This forms the basis of all clinical communication between Connecting for Health systems.

Clinical Document Architecture (CDA): is a document mark-up standard, based on HL7 v3, used when transferring clinical information as documents rather than messages.

SNOMED-CT.

ICD 10.

OPCS-4 Intervention Classification: Current version is OPCS-4.5

Read codes: Support provided for all versions of the Read Codes, including the Drug and Appliance Dictionary.

Dictionary of medicines + devices (dm+d): dm+d is a dictionary containing unique identifiers and associated textual descriptions for medicines and medical

[57] NHS Connecting for Health 2010
[58] NHS Connecting for Health 2010
[59] NHS Connecting for Health 2010
[60] NHS Connecting for Health 2010
[61] NHS Connecting for Health 2010
[62] NHS Connecting for Health 2010
[63] NHS Connecting for Health 2010

devices. It has been developed for use throughout the NHS (in both primary and secondary care) as a means of uniquely identifying the specific medicines or devices used in the diagnosis or treatment of patients. (Release 2 version 3.0, April 2010).

The main challenges related to standards development in the NHS England will be not only retaining the resources (both financial and professional) to deal with the diverse range of healthcare informatics services but also finding new money for future initiatives and investment. Continuing professional development of such staff is also important, and organisations such as the United Kingdom Council for Health Informatics Professions might help to achieve this.

3.5 Legal and regulatory facilitators

Legal and regulatory issues are among the most challenging aspects of eHealth: privacy and confidentiality, liability and data-protection all need to be addressed in order to make eHealth applications possible. Rarely does a country have a coherent set of laws specifically designed to address eHealth. Instead, the eHealth phenomenon has to be addressed within existing laws, such as on professional liability and data protection.

Most health legislation relating to England since 1977 was consolidated in two acts of parliament that came into effect on 1 March 2007.

Joint guidance on the use of IT equipment and access to patient data

On 25 April 2007, the Department of Health, the General Medical Council and the Office of the Information Commissioner issued "Joint guidance on the use of IT equipment and access to patient data"[64]. This document pointed out the need to comply with duties of confidentiality that are a part of the code of conduct of the regulatory bodies that govern registered health professionals. The document also draws attention to two other relevant guides issued by the Department of Health: Confidentiality: NHS Code of Conduct[65] (November 2003) and the Care Record Guarantee[66] (first published May 2005, and subsequently updated). Within those two documents, attention was drawn to people's access rights to their own records, controls on others' access, the options people have to further limit access, and access rights in case of an emergency.

The joint guidance on the use of IT equipment and access to patient data cited three specific legal standards:

- The Human Rights Act 1998, especially Article 8.
- The Data Protection Act 1998, especially the 1st and 7th Principles, and Section 55.
- The Common Law[67] of Confidentiality.

[64] Department of Health 25.04.2007

[65] Department of Health 2003

[66] Health Minister Lord Warner

[67] "Although not codified in an Act of Parliament, common law is built up from case law where practice has been established by individual judgements. The key principle is that information confided for the purpose of receiving care and treatment should not be processed for other purposes except in circumstances where the law permits or requires it."

The Department of Health has also issued guidance entitled Records Management: NHS Code of Practice Part 1 (April 2006) and Part 2 (January 2009). This "is a guide to the required standards of practice in the management of records for those who work within or under contract to NHS organisations in England. It is based on current legal requirements and professional best practice". The code makes, for example, recommendations on the minimum periods for which different forms of medical records should be retained.

NHS Connecting for Health has provided supplementary information, NHS Records Management: A clinicians' guide to record standards, which contains "a range of practical tools and guidance designed to support organisations in the implementation of an effective records management system in line with the principles of Records Management: NHS Code of Practice".

Digital, personal demographic, and health data are stored centrally on the NPfIT component known as the Spine. Direct access to the Spine or to services that access these data are controlled by the Access Control Framework. Organisations that need to access patient information within the NHS Care Records Service (NHS CRS) and other National Programmes set up Registration Authorities to manage this process. Once authorised, individuals are issued an NHS CRS Smartcard by the Registration Authority. Individuals use their NHS CRS Smartcard and their Smartcard Passcode each time they log on. Individual access is further restricted according to a Role-based Access Control that is assigned when a smartcard is issued.

With regard to ePrescription applications, some legislative changes were required in England. Traditionally prescriptions have been issued on approved paper forms and had to be signed with ink. The National Health Service Pharmaceutical Services Regulations of 2005 now provide that when prescribed to an Electronic Transfer of Prescription service and with the patient's consent healthcare providers may also issue their prescriptions electronically.

Telemedicine as a specific concept is not further regulated. Although, in a different context, the question of whether a doctor is obliged to physically attend a patient did arise in the United Kingdom, there does not seem to be any general principle requiring this.

In terms of telemedicine applications in England, there is no specific accreditation for health professionals who are involved in the provision of telemedicine services to patients. However, all medical doctors undergo continuing education and upgrade their skills in a wide range of different fields. Continuing education is strongly promoted by all of the regulatory bodies in the United Kingdom that govern health professionals in England. Furthermore, the British Medical Association has made its own recommendations with regard to the need for training in the field of supporting self care on the part of patients (however, there is no direct correlation made in the text between self care and home care in an electronic sense). These recommendations are:

- "Education on facilitating self care should be included in the medical curriculum including awareness of the fragility of self care and how it can be strengthened. Training should also be provided for practising doctors on the appropriate consultation techniques for patients with long term conditions."[68]
- "Healthcare professionals should be rewarded for undertaking learning and skills development for long term support of self management."

[68] British Medical Association 2007

Patient rights

"Your health information and the NHS Care Records Service"

Patients' rights with regard to their personal data are comprehensively set out in various sources in England. They are described in "Your health information, confidentiality and the NHS Care Records Service"[69] (April 2008) and in the "NHS Care Record Guarantee"[70] (July 2009) and under the Data Protection and Access to Health Records Acts. A patient/person has the right to apply for access to his/her data or request a copy of the data based on payment of an administrative fee. A patient can ask to see information about who has had access to his/her Summary Care Record. If any item of information is not readily intelligible to the patient, further explanation must accompany the record.

In England, the concepts of patient confidentiality and consent are significant for the provision of care. Legislation, such as the Data Protection Act, and common law do not define these concepts but provide frameworks for processing information on a patient's care.

An example is the summary care record. Policy makers have opted for an implied consent model. Patients are notified in writing that a summary care record will be created for them unless they opt out within a limited period (between two to three months).

A patient can add or change some demographic information and other non-clinical information on the electronic patient record: see Your health information, confidentiality and the NHS Care Records Service (April 2008, pp.11-12). This facility is provided through a web-based service called NHS HealthSpace although it is also possible for such changes to be made via a patient's GP.

Furthermore, patients cannot change information that other people write to the record; however, they can ask staff to correct mistakes. If the staff member thinks that the information is correct, a patient can add a statement to say that s/he disagrees. The National Information Governance Board has produced Guidance on Requesting amendments to health and social care records[71].

In the future, a patient will be able to ask for certain information to be hidden. This may be done through a "patient's sealed envelope" although the final details are still under consideration. Using this feature, if a patient "seals" some information, no-one outside of the care team that sealed the information will able to see what has been hidden. However, a flag associated with the patient record will indicate that some information has been hidden. If information is "sealed and locked" by a care team, it will be completely invisible to anyone outside of that care team.

Procedures to allow access to the summary care records are defined

Procedures to allow access to certain people other than the patient are also described in "Your health information, confidentiality and the NHS Care Records Service"[72] and in the "NHS Care Record Guarantee"[73]. The patient is advised to speak to a healthcare professional to decide which information to make available, to whom, and in what circumstances. Furthermore, at present, parents or guardians of children under 16 have

[69] NHS Connecting for Health 2008

[70] Health Minister Lord Warner

[71] National Governance Board for Health and Social Care 2010

[72] NHS Connecting for Health 2008, p.12-16

[73] NHS Connecting for Health 2009, p.6 and p.12-13

the right to access their child's records. Although a child can ask that the parents or guardians not be given access, this request might be overruled if the reasons given for access are more important than the requirement to keep child's information confidential. The Access to Medical Records Act (1990) provides an explicit right of access to medical records of deceased persons.

There are circumstances in which the NHS can use patient data for purposes than the provision of healthcare. In some cases, such as an application for medical insurance, the patient must give explicit consent to allow the insurer to see the patient record. The patient can also limit which information can be accessed (Confidentiality, p.14). In other cases, such as anonymised research or to protect public health, the information can be used without patient consent (Confidentiality, p.4, Guarantee p.1, pp.5-7). In limited circumstances, the Secretary of State for Health can give permission to the use patient of information without asking for permission (Confidentiality, p.5), for example, in the conduct of important health research where it is not practical to contact all of the patients.

3.6 Financing and reimbursement issues

In England, the Department of Health funds the vast majority of the eHealth infrastructure. It is possible though that some county councils and local authorities, through their social services budget, fund part of the operational costs of local telecare and telehealth services.

More precisely, the Department of Health has an overall annual budget of approximately £100 billion. The projected costs of the National Programme for IT[74] from 2003/04 to 2013/14 were £12.7 billion at 2004/05 prices. To 31 March 2009, £4.5 billion had been spent. Some detail is provided in ***Table 1*** which is taken from Public Expenditure on Health and Personal Social Services 2009, written evidence to the Health Committee of the House of Commons (January 2010).

The table below summarises the English expenditure on health and personal social services. All figures in the table are in GBP millions.

[74] National Audit Office 2008

Table 1[75]: Public Expenditure on Health and Personal Social Services in England[76]

	Category	Projected lifetime costs	Expenditure to 31 March 2009
Core Contracts			
	London	1,021	326
	South	1,104	133
	North East	1,035	276
	East	930	237
	North West & West Midlands	1,042	271
	Spine	889	791
	N3 Network	554	554
	Choose and Book	144	133
	Amount retained by Accenture[77]	110	-52
Total core contracts		6,829	
	Products added to scope	666	420
	Other central costs	1,599	615
Total central costs		9,094	
	Local costs (estimated)[78]	3,562	772
Total		**12,656**	**4,476**

[75] **Notes related to the table:** The figures shown in the last two columns are not directly comparable, as the projected lifetime costs are shown at 2004/05 prices and final outturn will be higher due to inflation in subsequent years. Those for expenditure to 31 March 2009 are resource outturn figures.

As for London, South, North East, North West & West Midlands, these geographical areas correspond to contracts with major suppliers (Local Service Providers) who work with the NHS to deliver the National Programme for IT systems and services at the local level, including the NHS Care Records Service. The **Spine** is a group of eight applications which underpins the NHS Care Records Service – three applications hold care record data; four are security applications to restrict access to only accredited users; and one is a messaging service, providing interfaces between Spine data and other services. The New **NHS Network** (N3) provides IT infrastructure, network services and broadband connectivity linking every NHS site in England including hospitals and general practitioner surgeries, and non-NHS sites providing NHS care.

Further, **Choose and Book** is the national electronic referral service which gives patients a choice of time and place for their first outpatient appointment, and allows the appointment to be booked using the Internet, a telephone booking service or a general practitioner's IT system. **Products added to scope** are applications and services that have been added during the course of the programme. These include GP Systems Choice which allows general practitioners to choose an approved clinical IT system other than the one offered by the Local Service Provider. An NHS e-mail system, NHSmail was also added.

Additionally, **local costs** are the costs incurred by local NHS bodies to implement the systems (principally the new Care Records Service and the Picture Archiving and Communications Systems), for example in training staff and upgrading computer hardware. These estimates have not been revised since the original business cases were submitted in 2003/04.

[76] Health Committee 2010

[77] In 2006, Accenture made arrangements to voluntarily novate [assign] the company's contract to another existing supplier under the programme. Of the £179 million Accenture had received to that point the company retained £110 million for work completed. £52 million represents the value, for accounting purposes, of moneys repaid as at 31 March 2009.

[78] No figures have been received to date for local costs for period 2008-09 and therefore the figure is retained as per 2008 return.

Connecting for Health has regularly been criticised in the United Kingdom press for the relative size and volume of its initiative, and the generous allocation of financing to it. Its approach has at times been compared unfavourably to more incremental, smaller initiatives in countries with much smaller populations (e.g., those of Scotland and/or Wales).

In terms of international funding opportunities, England received financing by the European Commission through a variety of Framework Programmes, the European Regional Fund, the European Social Fund and other programmes. England has especially been an active participant in the large-scale pilot on eHealth interoperability called epSOS[79], and its accompanying thematic network which is known as CALLIOPE[80].

Challenges for eHealth financing

Future challenges will particularly lie in the capacity to continue to pour funding into NHS England as a whole (a difficulty raised by all England's political parties prior to the May 2010 election, but which it is fully anticipated that the government of the day will emphasise and a challenge that it will attempt to resolve). It is perhaps expected that 2010 and ensuing years will see both a reduction in NHS England budget, and the budget of Connecting for Health.

3.7 Evaluation results, plans and activities

From a public policy perspective, evaluation is a key activity in the policy-cycle. It provides insights into the success or failure of a policy or project and leads to new policy goals and new methods of implementation. The need for evaluation of eHealth policies and projects has been emphasised time and again by the EC, not least in order to further the spread of eHealth in the process of healthcare delivery.

Different evaluations completed and ongoing in cooperation with research groups

Since 2006, two eHealth evaluations in England have been completed and six further evaluations are ongoing. All of these evaluations have been or are undertaken by staff and researchers from one or more United Kingdom universities. The research group is selected on the basis of research submissions that were submitted in response to a call for proposals (issued by the University of Birmingham on behalf of the NHS Connecting for Health Evaluation Programme[81]).

The NHS Connecting for Health Evaluation Programme[82] was commissioned by NHS Connecting for Health (NHS CFH) through the Research and Development Directorate of the Department of Health. It was set up at the end of April 2006 to evaluate certain elements of the NPfIT delivery. It aims to inform subsequent deployments of technologies and to provide high quality, objective, third-party insights into the lessons learned as a result of such large-scale projects.

The Public Health, Epidemiology and Biostatistics Unit of the School of Health & Population Sciences at the University of Birmingham have been commissioned by NHS CFH to manage the evaluation programme on its behalf. This management of the programme includes two aspects: the independent procurement ("commissioning") of

[79] Smart Open Services for European Patients

[80] Calliope Network

[81] University of Birmingham

[82] NHS Connecting for Health 2010

evaluation services, and the day-to-day management of the independent organisations which actually conduct the evaluations.

Evaluation projects of eHealth activities[83]:

Completed:

NHS CFHEP 001: The Impact of eHealth on the Quality and Safety of Healthcare

NHS CFHEP 002: Evaluating the 'Early Adopter' implementation of the NHS Summary Care Record

Ongoing:

NHS CFHEP 001: Extension to The Impact of eHealth on the Quality and Safety of Healthcare

NHS CFHEP 003: Evaluation of the pilot implementation of an IT specification for a blood tracking systems

NHS CFHEP 004: Evaluation of the Electronic Prescription Service in Primary Care. This project has set up a web site to provide users and designers of the Electronic Prescription Service a forum to exchange their experiences, lessons and views of the EPS.

NHS CFHEP 005: Evaluation of the adoption of the NHS Care Record Service in secondary care

NHS CFHEP 007: Summary Care Record Independent Evaluation (SCRIE) Extension Programme

NHS CFHEP 009: Evaluation of different levels of structuring within the clinical record

NHS CFHEP 010: Evaluation of the effect of IT on interactions between healthcare workers and patients

The National Audit Office[84] has conducted two reviews of the National Programme. It published a document entitled “Department of Health: The National Programme for IT in the NHS”[85] (on June 16 2006). This was an assessment of the programme which took place around two years after its inception. The conclusions and recommendations in the report addressed challenges in three key areas:

- Ensuring that the IT suppliers continue to deliver systems that meet the needs of the NHS, and to agreed timescales without further slippage.

[83] List of the evaluation projects on this website: University of Birmingham , http://www.haps.bham.ac.uk/publichealth/cfhep/research.shtml

[84] The NAO (http://www.nao.org.uk/) has the job of auditing the accounts of all government departments and agencies as well as a wide range of other public bodies. The Office reports to Parliament on the economy, efficiency, and effectiveness with which these bodies have used public money. Its head, the Comptroller and Auditor General, is an Officer of the House of Commons, appointed by the Queen, proposed by the Prime Minister with the agreement of the Chairman of the Committee of Public Accounts, and approved by the House of Commons. The role is an independent one; his/her staff carries out these auditing task on his/her behalf. The NAO undertakes around sixty value-for-money studies each year. This forms part of its overall aim to enable Parliament and government to drive through lasting improvements in public services. The reports are presented to Parliament, and most are considered by (i.e., reviewed by) the Public Accounts Committee of the House of Commons (PAC).

[85] National Audit Office 2006

- Ensuring that NHS organisations can and do fully play their part in implementing the Programme's systems.
- Winning the support of NHS staff and the public in making the best use of the systems to improve services.

Two years later, in 2008, the National Audit Office published a document entitled "The National Programme for IT in the NHS: Progress since 2006"[86] (May 16 2008). Although this was largely a value-for-money review, it did consider technical issues, and it examined how the implementation of new technology affected organisations, staff and patients.

By 2008, with more parts of the NHS involved in activities related to the National Programme for IT, the conclusions and recommendations addressed a similar set of challenges to the three problems outlined above:

Recommendations outlined by the National Audit Office

Achieving strong leadership and governance [within the Strategic Health Authorities and NHS Trusts]

Maintaining the confidence of patients that their records will be secure

Securing the support and involvement of clinicians and other NHS staff

Managing suppliers effectively

Deploying and using systems effectively at local level.

4 Outlook

The NHS has created or has started to create different eHealth applications in England, including the Summary Care Record or locally-organised telemedicine services. The NHS Connecting for Health was established in order to supervise and deliver the National Programme for IT. Connecting for Health is also the link between the Department of Health, stakeholders, healthcare professionals, and the patient. It provides a variety of information websites which clarify new developments or applications for the patient.

Overall, England pursues a transparent development and implementation of eHealth services. Future obstacles might involve the content of the Summary Care Record or the validation of a professional identifier. Nevertheless, England is heading towards a more patient-empowered approach, as the introduction of a "patient's sealed envelope" indicates.

Following elections in the UK in May 2010, the set-up of the NHS is under important review. The policy changes at hand will impact on the eHealth policy in NHS England. These changes are taken into account in this report to the extent that they are already discernible today in October 2010. However, much of this report focuses on the organisational conditions that prevailed in the NHS at the time that the first draft of this report was finalised (in early May, 2010).

[86] National Audit Office 2006

5 List of abbreviations

DHID	Department for Health Informatics Directorate
DRG	Diagnosis Related Group
EC	European Commission
EEA	European Economic Area
EHR	Electronic Health Record
EMR	Electronic Medical Record
EPS	Electronic Prescription Service
ERA	European Research Area
EU	European Union
FAST	Foundation for Assistive Technology
GDP	Gross Domestic Product
GP	General Practitioner
HCP	Healthcare Provider
HPC	Health Professional Card
ICT	Information and Communication Technology
ID	Identification (e.g. number, card or code)
IHTSDO	International Health Terminology Standards Development Organisation
ISB	Information Standards Board
IT	Information Technology
LIN	Telecare Living and Improving Network
NHS	National Heath Service
NHS CFH	National Health Service Connecting for Health
NHS CFHEP	National Health Service Connecting for Health Evaluation Programme
NHS CRS	National Health Service Care Records Service
NHS DS&P	National Health Service Data Standards and Products
NPfIT	National Programme for Information Technology
OECD	Organisation for Economic Co-operation and Development
PCTs	Primary Care Trusts
PDS	Personal Demographics Service
PHS	Personal Health System

PMIP	Pathology Messaging Implementation Programme
PSIs	Personal Spine Information Service
R&D	Research and Development
SCR	Summary Care Record
SCRIE	Summary Care Record Independent Evaluation
SHAs	Strategic Health Authorities
UKTC	United Kingdom Terminology Centre
WHO	World Health Organization
WSD	Whole System Demonstrator

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