

# THE CLINICAL INFORMATICS REVOLUTION

April 2015

Association of Surgeons of Great Britain and Ireland

**ISSUES IN PROFESSIONAL PRACTICE**

THE CLINICAL INFORMATICS REVOLUTION



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# THE CLINICAL INFORMATICS REVOLUTION

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**ISSUES IN PROFESSIONAL PRACTICE**  
THE CLINICAL INFORMATICS REVOLUTION

## SERIES FOREWORD

*Issues in Professional Practice* (IIPP) is an occasional series of booklets published by the Association of Surgeons of Great Britain and Ireland to offer guidance on a wide range of areas which impact on the daily professional lives of surgeons. Some topics focus on clinical issues, some cover management and service delivery, whilst others feature broader aspects of surgical working life such as education, leadership and the law.

This latest IIPP booklet on *The Clinical Informatics Revolution* represents a foray into subject matter which will profoundly influence the shape of professional practice throughout the NHS in years to come, and with which many members and readers may presently be relatively unfamiliar. This issue follows naturally from our recent survey of workplace attitudes among surgeons to the call by the Secretary of State to move to a Paperless NHS by 2018, published recently as an IIPP. We are grateful to the author for teasing out some of the principles and complexities in this national policy objective, and in pointing us to some possible solutions as we engage with a rapidly changing digital health economy.

The Association of Surgeons of Great Britain and Ireland, in common with many of the other surgical specialty associations and societies, is proud to represent members across the four devolved UK home nations, England, Scotland, Wales and Northern Ireland, as well as the Republic of Ireland. However, it would have been impractical to cross-reference the complexities of the clinical informatics revolution in all jurisdictions. This Issue in Professional Practice booklet necessarily draws heavily upon material published by the London-based Government Digital Service and by NHS England. Nevertheless, we very much hope that the guiding principles will be of value to surgeons and others working across the Four Nations of the United Kingdom; to our colleagues in Ireland; and to those working further afield.

The Association intends that this publication, and others in the series (all of which are accessible at: [www.asgbi.org.uk/publications](http://www.asgbi.org.uk/publications)), will provide concise advice and guidance on major current issues, and prove to be a helpful and accessible resource to support your professional practice. We welcome feedback on this and other booklets in the *Issues in Professional Practice* series, and proposals and contributions for future issues in the series.



**Mr John Moorehead**  
**President**  
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Association of Surgeons of Great Britain and Ireland

# *ISSUES IN PROFESSIONAL PRACTICE*

THE CLINICAL INFORMATICS REVOLUTION

## FOREWORD TO ‘THE CLINICAL INFORMATICS REVOLUTION’

Healthcare is on the brink - overwhelmed in the developed world by the burden of chronic disease, unsustainable cost, and the demand for less intrusive healthcare; and in the less developed world, by limitations in access to and availability of frugal models of care delivery. Healthcare systems are also on the brink of a technology influx that will revolutionise the unsustainable legacy delivery models that have served us well in a bygone era. The healthcare community joins as a laggard the list of well-evolved aspects of life that have been so dramatically transformed by mobile technologies. Clinical informatics is not really about the technologies themselves, however, but rather their role as tools for both empowering self-care and for generating incredibly valuable data on population health and wellness that will transform evidence-based medical practice.

There is substantial competition across Europe and throughout the world to capture a leading position in the rapidly expanding digital health space. The UK is ideally placed to lead in this revolution in healthcare delivery models. The NHS and its equivalents across the UK are viewed as effective, coordinated single-payer healthcare systems ideal for implementation of innovative healthcare solutions at scale. The Government continues to establish attractive programmes in support of innovation, investment and implementation. Public and private businesses continue to invest in new infrastructure, R&D, and centres of innovation that bring skilled and higher paying jobs to the UK. Cementing the UK's leadership role in the implementation of these transformational practices requires determination and coordination, both to empower existing digital health activity and to attract expertise and investment.

In this timely addition to the Association's *Issues in Professional Practice* series, David Rew highlights the specific areas of overlap and impact of technological advances in surgical practice. Given the critically important role the surgical community has in the delivery of healthcare, surgeons are well placed to drive and accelerate progress in the safe application and development of new technologies. Every aspect of care delivery will be affected by the fundamental disruption that is taking place in the healthcare ecosystem, and by improving our individual and collective understanding of the role technology plays, we can help to ensure that we evolve quickly enough to maximise the benefits for both our patients and our health economy.



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## INTRODUCTION

The UK Government has set an ambitious target for transition to a “digital by default” public sector economy in this decade. In simple terms, this envisages the transformation of public services through the application of the “best of class” strategies that have changed the commercial world through digital technology. It also empowers such change from the highest level of Government.

“Digital by Default” transformation of Government is more than about providing slick websites or a social media presence. It is about the re-engineering of the State, and its component services, using modern technology and informatics systems to transform the user and customer experience, rather than to meet the convenience of the service provider. In the process, it is already securing huge and measurable efficiencies in service design and delivery.

The UK Government strategy has proved to be so persuasive and effective to date that many other Governments are now adopting the same approach to public service design and delivery, including the US and Australian Governments.

### ASGBI AND CLINICAL INFORMATICS

ASGBI is the SAC-defined Surgical Specialty Association for General Surgery in Great Britain and Ireland, and exerts considerable influence in a wide range of issues relating to the professional lives and to the clinical effectiveness of General Surgeons in the workplace. Thus, the Association is well placed to take a leading role in informing professional debate and in promoting innovation in the progressive adoption of “digital by default” healthcare systems.

ASGBI has its own “digital by default” informatics strategy. 2014 saw the launch of the Association’s first paperless Congress and of digital publication for all ASGBI journals, publications and documents. There is also a flourishing website and an interactive ‘app’ for mobile devices. The speed of acceptance of these technologies has confirmed the technical maturity and “informatics adaptability” of the general surgical workforce.

In October 2014, the Association published a survey of workplace views and experiences of the Digital NHS in an **Issue In Professional Practice** booklet entitled *Operating within a digital NHS?*, which was widely viewed and well received. Surgeons have an important role in leadership and innovation within the professional workplace. It is, therefore, essential that surgeons are fully conversant with language and concepts of the “Digital by Default” health economy, and that we are individually and collectively able to articulate arguments and discussions on the strategy and detail of implementation.

# ISSUES IN PROFESSIONAL PRACTICE

## THE CLINICAL INFORMATICS REVOLUTION

This **IIPP** booklet seeks to build upon the Association's own educational strategy on the subject of Clinical Informatics for the Adaptable NHS Surgical Workforce. It also considers a wide range of issues which are relevant to the transition to the paper-light and paperless workplace, and the opportunities and constraints associated with that process.

For the purposes of this **Issues in Professional Practice** booklet, we will focus discussion to the clinical informatics revolution as it affects hospital practice, and surgical practice in particular, as these are the areas where we have most experience.

## PART 1: THE GOVERNMENT DIGITAL SERVICE AS AN EXEMPLAR

### A BRIEF HISTORY OF THE GOVERNMENT DIGITAL SERVICE (GDS)

In 2010, the UK Central Government set up a **Digital Public Services Unit** under the direction of the Cabinet Office. Its mandate was to transform the Government's use in informatics and web-based services in its interactions with the General Public. The Government recognised that the evolving information strategy was not fit for purpose in delivering services direct to the general public, and that it was not taking full advantages of the economies and efficiencies inherent in digital services.

Each of some 25 Departments of State, and each major and minor branch of government, had developed its own web systems with a provider focus rather than a user focus. This had led to waste, complexity, duplication and inefficiency throughout Government. By comparison, user (customer) focussed private sector informatics had surged ahead, as evidenced by the success of many household commercial names in delivering attractive web-based services; as in online bookings within the travel industry.

In 2010, a committee comprising many experts from digital commerce, and which was chaired by (subsequently Baroness) Martha Lane Fox, founder of *last-minute.com*, recommended sweeping changes to the UK's public sector approach to digital communications and transactions across the breadth of public services. The changes were not (yet) directed at the NHS, although they were influenced by experience with failing programmes such as *Connecting for Health*. Baroness Lane Fox recommended that the Government:

1. Make 'GOV.UK' (originally branded as **DirectGov**) the government front end for all departments' transactional online services to citizens and businesses, to set standards and to force departments to improve citizens' experience of key transactions.
2. Make GOV.UK a wholesaler, as well as the retail shop front for government services and content, by mandating the development and opening up of *Application Programme Interfaces* (APIs) to third parties.
3. Change the model of government online publishing, by putting a new central team in Cabinet Office in absolute control of the overall user experience across all digital channels.
4. Appoint a new CEO for Digital in the Cabinet Office with absolute authority over the user experience across all government online services, websites and *Application Programming Interfaces* (APIs); and the power to direct all government online spending.

See: [www.gov.uk/government/publications/directgov-2010-and-beyond-revolution-not-evolution-a-report-by-martha-lane-fox](http://www.gov.uk/government/publications/directgov-2010-and-beyond-revolution-not-evolution-a-report-by-martha-lane-fox)

These recommendations were accepted rapidly and in full. They led to the formation of the **Government Digital Service** (GDS). This was underpinned by a new team of internet savvy thinkers and developers, based in London's East End around "Silicon Roundabout", and charged with implementing these changes. More insights can be gleaned from:

<https://gds.blog.gov.uk/>

[http://en.wikipedia.org/wiki/Government\\_Digital\\_Service](http://en.wikipedia.org/wiki/Government_Digital_Service)

<https://www.gov.uk/government/organisations/government-digital-service>

The review process led to the consolidation of reforms under the Cabinet Office leadership of Francis Maude and under the logo of GOV.UK. The scale and breadth of the work involved is illustrated by the diversity of the seven departments which handle most government online transactions, being:

- HM Revenue and Customs (HMRC).
- Department for Transport (DFT).
- Department for Work and Pensions (DWP).
- Ministry of Justice (MOJ).
- Department for Business Innovation and Skills (BIS).
- Department for Environment Food and Rural Affairs (Defra).
- The Home Office.

The GDS identified a series of 25 high volume exemplar projects, which would benefit from the "simpler, clearer and faster to use" strategy. These included Voter registration (46M annual confirmations); 6M annual Driving Licence views; 3.2M Carer's Allowance applications; 10M Universal Credit transactions; tracking 41M PAYE employees, and so on. An early example of the success of this approach, with which many surgeons will be familiar, was the simplification of car tax renewal online.

The idea has been that success with these exemplars would establish momentum, experience and knowledge for transformation across the breadth of Government. In the course of such changes, huge savings are being achieved in transactional costs by moving previously complex user-driven processes online. In this process, employment patterns and skills would also change within the Civil Service and beyond.

Some forms of work would be improved or superseded by technology, particularly in the field of document and information processing. New categories of employment and skills requirements would emerge to implement and manage the new digital public sector, see: [www.gov.uk/government/publications/government-digital-strategy/government-digital-strategy](http://www.gov.uk/government/publications/government-digital-strategy/government-digital-strategy)

## A SUMMARY OF GOVERNMENT DIGITAL SERVICE DESIGN PRINCIPLES

The GDS digital design principles for the re-engineering of Government departmental services translate to the re-engineering of national health systems. These general principles are as follows:

1. Start with an assessment of the users' needs.
2. Aim to "Do Less".
3. Base the design upon data and research, rather than upon opinion and speculation.
4. Do the hard work to make it simple. In other words, design for simplicity.
5. Iterate (repeat the process), then iterate again as the development process proceeds.
6. Build for inclusion. In other words, aim to make the service accessible to the least technically literate potential user.
7. Understand context.
8. Build digital services, not websites. Digital usage is increasingly about access through mobile phones and other information tools.
9. Be consistent in the design principles, including details such as fonts, icons and presentational layouts.

## THE DIGITAL STRATEGY OF CENTRAL GOVERNMENT SINCE 2010

The *Government Service Design Manual* ([www.gov.uk/service-manual](http://www.gov.uk/service-manual)) sets out how these key principles of digital reform are translated into practical product. They emphasise:

- That the user needs and experience must be informed by market testing, rather than what the service provider thinks best.
- The importance of the evidence base, including internet transactional data (such as provided by **Google Analytics**), website optimisation techniques, and user evaluations.
- The importance of uniformity, clarity and simplicity of search functions and data presentation.
- The importance of "bottom-up" development of new online systems and services. This is based upon design-test-adjust principles and continual reinforcement of "good-enough" functionality, rather than "top-down" specification of "perfect" systems that may or may not work in practice, and which may or may not be what the user requires.

We may draw a parallel with the history of the motor car since its first inception. No one was able to specify a modern high performance vehicle in 1900. However, by continuous evolution

of all components over a century, the crude concept of the early and autonomous horseless carriage seamlessly evolved into the cars and road infrastructure which we enjoy today.

- The **Digital by Default Service Standard** ([www.gov.uk/service-manual/digital-by-default](http://www.gov.uk/service-manual/digital-by-default)). This seeks to make the online service of choice so practical and attractive that users will usually prefer to use the system to its slower transactional alternatives (eg. paper based communications), while recognising that some users will always require additional help.

The **Digital by Default Service Standard** sets out a series of 26 clear, attainable and auditable criteria by which the standard can be achieved. Individual services are evaluated as they are transformed, to ensure that they meet the standard and that they can function within the GOV.UK system.

- The use of **Open Software Standards**, providing flexibility and independence from individual systems and commercial suppliers.
- The Speed of Change. The Cabinet Office set a 400 day challenge in 2013 under the “Sprint” designation to establish the momentum and to secure the principal changes. The lexicon of change includes buzz words and phrases such as “Agile Development” and “Sprint Pathways”.
- The Utility of Data; the new government approach does not claim or seek ownership of data where alternative information sets and sources exist.
- Simplicity of communication; the language used will always be “Plain English”, and web design will be relentlessly focussed upon ease of use, ease of navigation and ease of visualisation.

The consequence of the strategy is intended to be that individual governmental departmental services are transformed in weeks and months, rather than years and decades. In the process, new uses are found for the presentation and dissemination of existing data. For example, the combination of government data on flood plains to public data from **Google Maps** helps developers, insurers and home buyers better to understand the risks of flooding in any one location.

## THE MECHANICS OF BUILDING A “DIGITAL BY DEFAULT” PUBLIC SERVICE

Self-evidently, organisations which seek to change and modernise their service delivery around digital informatics systems need to create a process by which change can be effected. Within the public sector, old hierarchies and “Ways of Doing Things” require a thorough overhaul. The necessary skills in digital technology and programming may be unfamiliar, but there are many well established precedents in the public and independent sectors for the successful management of complex projects.

The GDS has described the implementation of change around Agile Methodologies in a range of publications and blogs. For example, see: <https://www.gov.uk/service-manual/agile>

Organisations which seek to go down the digital transformation route need to build teams with the specialist skills in digital transformation management, user research and programming. They also need to identify space for these teams to work, with the requisite information technology infrastructure and a workspace which promotes teamworking and interaction. A key element is the creation of plenty of wall space on which to plot workstreams and progress, as illustrated in *Figure 1*.



*Figure 1: The Transition Programme Wall at Aviation House, Holborn, home of the GDS.*

See: <https://transition.blog.gov.uk/2013/11/12/transition-programme-stages-a-make-over/>

It may come as a surprise that such a digitally advanced organisation resorts to white boards and colour coded stationery notes to map complex processes. However, the effectiveness of

organisational tools is long established, and somewhat analogous to the RAF fighter control rooms of WWII.

In this particular visual example, the stages of the transformation programme are plotted out in a series of columns, from a 'To Do' list, through discovery, user needs analysis, content analysis, digital service design and construction, and so on. Information flows from left to right across the wall as projects progress.

Once the team has mapped out the workload, the team leader will prioritise the projects, which are then progressed as a series of Sprints. Each of these lasts one to two weeks, and each of which is based around "Scrum" software development methodology. Scrum is a process of close physical co-location of team members, which allows for flexibility and parallel working, in addressing the questions:

- What will we do?  
and
- How will we do it?

This recognises that project requirements change continuously as the project progresses, and that these cannot be anticipated, fully understood or planned sequentially in advance. The development team is self-organising under the direction of the Scrum Master, and holds a short stand up meeting on a daily basis around the project wall to coordinate its activities. A retrospective meeting to review lessons learned is a key element of each Sprint phase.

Continuous testing, and individual responsibility for every element of the process, are also key elements of Agile methodology. This minimises the risk of expensive and troublesome delays later in the acceptance process.

Testing also takes a number of forms, including:

- Technical performance at various user loads.
- Security and penetration testing to prevent malicious disruption or data theft.
- Accessibility testing for different intended users, for example those with visual, auditory or motor skills impairment, and for those using a range of different access tools, including keyboards, track pads, screen readers and voice recognition systems.
- Crowd sourcing testing, where systems in development are regularly put out to large numbers of friends and colleagues for testing and feedback.

## THE PHASES OF DESIGN, TESTING AND RELEASE OF “DIGITAL BY DEFAULT” SYSTEMS

There a series of stages in the implementation of each and every “Digital by Default” system, that includes five phases and a retirement plan. The key phases are:

- The Discovery Phase.
- The Alpha (Test) Phase.
- The Beta (Test) Phase, subdivided into Private and Public Test Phases.
- The Live Phase.
- The Retirement Plan.

### The Discovery Phase

This is the process by which user needs are researched. User needs analysis is based around creating a series of User Stories, focussed upon user research. User stories are an essential part of the agile design process. They comprise three elements:

- The person using the service - the actor - (eg. as a surgeon).
- What the user needs of the service - the narrative - (I need to be able to access and analyse my operative workload data).
- Why the user needs the service - the goal - (so as to inform my annual appraisal and job planning processes).

User stories help organise digital system development work into manageable chunks which create tangible value, and which can be discussed and prioritised independently, see:

<https://www.gov.uk/service-manual/user-centred-design/user-research/index.html>



**Figure 2: Example of a User Needs research board and workflow during the development of a digital system for the Carer’s Allowance**  
<https://userresearch.blog.gov.uk/2015/01/21/user-research-for-government-services-8-strategies-that-worked-for-us/>

Again, the stationery note wall is a valuable tool for mapping out needs and processes. Kate Towsey, of the **Carer's Allowance Development Team**, describes the importance of this process in a GDS blog:

*"A quick walk around our offices and you'll see that vertical surfaces, whether wall or not, are both covered and coveted. Project paraphernalia are our wallpaper. Sticky notes, images, screenshots, survey results, analytics and team photos name just a small selection of 'stuff that should be stuck up there' Our walls have purpose. They're vertical 'campfires'; places where teams connect, stakeholders gather quick insight, and passersby take inspiration and add to them. As user-researchers, our walls are an important and constant broadcast signal. A well-tended wall keeps research insights and user needs constant in the collective 'mind' of the project team."*

Ben Holliday, from the same team, states of the process that:

*"We try and post things up as they relate to each other and to understand relationships between insights, user needs and different parts of the transaction. Most importantly, everything is constantly discussed, pulled apart and updated by the project team, not just the user researchers".*

<https://gds.blog.gov.uk/2014/09/03/vertical-campfires-our-user-research-walls/>

Key Performance Indicators (KPIs) need to be identified for the proposed new service, so that once the software is developed and released for public testing, the digital service provider will have a clear understanding of its impact. KPIs include the cost per transaction, user satisfaction, the completion rate of transactions and digital take-up of the service.

### The Alpha Phase

This covers the construction of a working prototype of the system. This is used to test the design approach, to build a development team, and to understand the technology and the possible software and coding solutions. GDS sets a target to complete the Alpha phase within two months, using a small core team of designers, developers and stakeholders. The outputs for the alpha phase (see: [www.gov.uk/service-manual/phases/ideal-alfas](http://www.gov.uk/service-manual/phases/ideal-alfas)) are:

- High level story cards.
- Plan for beta testing and running the live service.
- A working system with limited functionality for user testing.
- Planning for replacement or integration with legacy data systems.
- A decision to progress (or not) to the beta phase.
- Final analysis on the research on user needs.
- Options for the support of users who are not digitally proficient or capable.

### **The Beta Phase**

This is the process of development to the production of a working prototype, and introduction of the system to the user, firstly to a selected group of users (the Private Beta) and then to a wider public audience (the Public Beta). The phase would be expected to take a few months.

The development team will now include Web operations engineers (also known as the systems administrators, operations engineers or site reliability engineers). They have expertise in infrastructure, configuration management, monitoring, deployment and operating systems (see: [www.gov.uk/service-manual/the-team/web-operations.html](http://www.gov.uk/service-manual/the-team/web-operations.html)). They will understand the new language of running the production systems and oversee the development of software which is easy to operate, scale and secure. This is also the point at which the particular service receives accreditation sign-off, so as to “Go Live”.

### **The Live Phase**

A GOV.UK web service will now be fully accredited for performance and security standards, with appropriate analytical tools in place to monitor the KPIs. The new service will be continuously monitored and subject to regular upgrades, with operational support, security testing and subsidiary developments, optimised hosting, technical and customer support, disaster recovery planning and so on.

### **The Retirement Phase**

The process also recognises that services come to an end because they are superseded or taken over by other bodies. The design process of any service also needs to take into account the many functions required to wind up, or transfer, a service at the end of its functional operational life.

## PART II: “DIGITAL BY DEFAULT” HEALTH SECTOR TRANSFORMATION

Why are the previous sections significant to health professionals? In the past, software sourcing and provision has been devolved to large providers who have worked to prior specifications - remote from the end user - to produce systems that then fail to deliver the goods.

Any health professional who has worked in the development of user-focussed clinical software will understand just how complex, iterative and unpredictable this process is, and how important the practical experience of the GDS design and implementation teams has become to those seeking to improve clinical informatics.

Unlike the authorship of a book or film script, any but the most basic software programmes require continuous engagement and iteration between the developers and the users. Excellence in software development is clearly critically important to the design and implementation of clinical systems which advance, rather than impede, the workplace efficiency of health professionals.

As purchasing decisions are devolved from central bodies to individual Trusts, and as any one healthcare provider will have a complex mix of legacy systems requiring different programming, so health professionals will need to understand and influence the processes of development and improvement of software systems which will rapidly and increasingly come to dominate their working lives.

Some readers of this document will work in hospitals and healthcare units which have made their own investment in software systems development, and which are fortunate to have access to the skill sets to shape their informatics space.

However, most hospitals will not have access to such human resources. Many are dependent upon proprietary software systems which are imposed by commercial firms with little commitment to agile and continuous improvement or responsiveness to end-user feedback beyond the purchasing managers. We hope that this document will help shape and inform discussion and negotiation with previously intransigent suppliers, for whom continuous agile product development in the clinician end user workplace is as yet unfamiliar.

## TRANSLATION OF GOV.UK DIGITAL PRINCIPLES INTO THE “HEALTHCARE SPACE”

The informatics design revolution, as espoused by the GDS, has not yet explicitly and publicly extended to the NHS workplace. Nevertheless, self-evidently, “Digital by Default” principles have considerable implications for IT implementation in the UK Health System, and they have profound implications for the development of integrated healthcare over the coming decade.

They will inexorably lead to a transition from provider defined services (by hospitals, GPs and health service managers) to consumer, user and patient demand-led services, where health information is far more transparent than at present, and where the comfortable certainties of current service provision will be radically challenged.

It is also clear that, once the public realises how efficient public sector data management can be in the provision of commonly used services, the demand for change and the rate of change are likely to be dramatic. It is, thus, essential that clinicians are prepared to influence and to manage this change. We need to understand what is already out there in the “health informatics space”, and to understand where development energies need to be directed.

## A UK-WIDE STRATEGY FOR “DIGITAL BY DEFAULT” PUBLIC HEALTH CARE DELIVERY

The “Digital by Default” principles espoused by UK Central Government can also be applied to the huge challenges of modernisation and integration of the public health and social care services around user needs. While much of the material presented in this booklet is gleaned from NHS England resources, the principles apply equally to health services in all of the devolved nation health services, and indeed to public health service in other countries, as the principles are universal.

In November 2014, HM Government published a strategy document to capture the principles of GDS Transformation for Health Care, under the leadership of Tim Kelsey, Chair of the National (Health) Information Board, and Dr Will Cavendish, the Accountable Informatics Officer at the Department of Health. The paper *Personalised Health and Care 2020 - A Framework for Action* envisages the use of data to transform outcomes for all citizens.

Kelsey and Cavendish introduce the new **National Information Board** at the Department of Health, and describe its roots in the DoH *Power of Information* paper of 2012; the DoH *Digital Strategy: Leading the Culture Change in Health and Care* paper

of 2012; the Government *Digital Strategy* paper of 2013; and the ambitions of the **Care Act** of 2014. They set out a series of proposals to:

- Enable citizens to make the right health and care choices, with full access to personal care records and the information necessary to make those choices, in modern and accessible forms.
- Provide information to professionals and carers in real time to aid decision making on citizen-specific care.
- Make the quality of care transparent.
- Build and sustain public trust.
- Advance effective new treatments, innovation and growth.
- Support care professionals to make the best use of data and technology.
- Assure best value for the taxpayer in all settings.

Clearly, clinical informatics is now a high priority on the national health agenda. It therefore merits detailed appraisal and an understanding of its principles by healthcare professionals. The practical benefits of a “digital by default” health strategy may be far reaching. It should secure substantial efficiency gains in terms of the flow of information between social care agencies, primary and secondary healthcare providers, suppliers of materials, equipment, medicines and consumables, and risk management bodies such as the **Medicines and Healthcare Regulatory Agency** (MHRA) and the **NHS Litigation Authority** (NHS LA).

It may also cause a major upheaval in the way that health and social care is delivered, and in the working practices of many health professionals. How, for example, will General Practice change when individual citizens are substantially more empowered with health information and health records under personal control, such that individual health information flows around rather than being controlled through Primary Care Centres?

There are substantial practical and technical hurdles to be overcome if the high level ambitions for a fully digital health economy are to be realised, and there is considerable potential for service disruption, clinical and political risk if and when things go wrong. These hurdles include:

- The lack of the technical infrastructure to support a fully integrated digital service.
- The lack of an agreed design for a “cradle to grave” electronic patient record, and the software systems to support it.
- The lack of digital transformative skills within the healthcare workforce to secure the necessary changes.

## THE HISTORY OF CLINICAL INFORMATICS WITHIN THE NHS

The NHS has made major strides towards a digital health economy in the past two decades. Progress to computerisation from an informatics infrastructure based upon paper has been patchy and disjointed, but the workforce is now entirely technology-literate, and computers are the norm throughout the workplace.

Nevertheless, centrally directed national IT infrastructure projects have been plagued with similar problems to those which drove Central Government to establish the GDS. The large IT suppliers have been found wanting in their ability to address the complexity of problems and challenges within the health environment through grandiose and overambitious projects, upon which **NHS Connecting for Health Project** and the **NHS National Programme for Information Technology** (NPfIT), also founded between 2005 and 2013.

We now recognise that the complexity of the healthcare informatics environment defies top down command and control design of IT systems. Hard and expensive lessons have been learned about the complexity and impracticality of specifying a single project to transform healthcare informatics systems.

The citizenry of any country provides a highly complex social and biological ecosystem, with a huge diversity of individual health needs; each of which places different demands upon primary, secondary and tertiary healthcare services, and the related social services and support systems.

In turn, healthcare delivery is compartmentalised in a large number of delivery organisations, each of whom are “stakeholders” in the design process for an integrated healthcare informatics system. These include:

- Citizens, patients and their friends and families.
- Hospital Managers.
- General Practice Managers.
- Clinicians, Nurses and Allied Health Professionals.
- Local, regional and national health bodies.
- Public supervisory boards and private purchasing consortia and funding bodies.
- Ambulance and Patient Transport Services.
- Health educational bodies.
- Healthcare Charities.
- Health Information Technologists, and so on.

Despite the critical press that failings in the national health informatics programmes have attracted over several decades, there has nevertheless been considerable progress towards more effective

digital data systems in Health Services. The worldwide revolution in informatics provides a near universal digital infrastructure in hardware and software, from which healthcare can take advantage.

This infrastructure includes the internet, the personal computer and the mobile phone, and the tools to reach the entire citizenry in a very cost-effective way through cheap and efficient communications, underwritten by national fibre-optic and mobile communications networks.

The UK healthcare workforce has consequently become much more technically literate in the past two decades; the understanding and use of computers and mobile communications is virtually universal; and the national informatics and hardware infrastructure is continually improving, as the communication network providers roll out high capacity broadband systems down to the level of individual domestic properties.

While the overall ambitions of earlier NHS IT programmes have not been realised, there has been significant progress in a number of areas, including:

- The establishment of a national fibre-optic health communications infrastructure.
- The NHS Data Spine.
- The introduction of an NHS-wide email system.
- The NHS Care Record Service and the Summary Care Record (SCR).
- The Personal Demographics Service (PDS), based upon the universal NHS Number.
- The Secondary (data) Uses Service, (SUS).
- The Picture Archiving and Communications System (PACS).

### **THE NHS DATA SPINE**

Many clinicians will be unaware as to just how much activity data is already collected centrally for the Department of Health. The **NHS Data Spine** is:

*“a collection of national applications, services and directories that support the NHS in the exchange of information across national and local NHS systems. The Spine connects clinicians, patients and local service providers throughout England to essential national services, for example, the Electronic Prescription Service, Summary Care Record, Choose and Book and Demographics services”.*

See: <http://systems.hscic.gov.uk/spine>

The Spine services are delivered on a large scale. As of August 2014, it:

- Connected more than 21,000 organisations and linked over 27,000 ICT systems within these organisations.
- Provided a single consistent source of demographic data for 80 million patients. Information is requested and amended more than 2.6 billion times a year.
- Enabled over 42 million Summary Care Records to be created and stored.
- Was processing around 50 million records per month through the DBS (Demographic Batch Tracing Service).
- Had transmitted over 1.3 billion EPS prescription messages and 50 million EPS dispense notifications.
- Was registering some 2,500 new smartcard users per week.
- Was delivering some 77,000 GP to GP record transfers a month.

### THE SUMMARY CARE RECORD

The SCR master planning document stated in 2011 that the SCR is:

*“designed to provide a summary of clinical information which would be deemed useful in the event of urgent or emergency care for a patient, particularly when other sources of information may not be readily available. The aim is that the SCR will contain only significant aspects of a person’s care, those deemed to deliver benefit to a patient when receiving urgent and emergency care”.*

By September 2013, approximately 5,800 General Practices had participated in the creation of some 43 million such records, with a voluntary public opt out rate of only 1.4%. Nevertheless, the future use and the branding of the SCR as a component of the overall GP record is uncertain in the context of continuing evolution of the electronic patient record in general practice. See:

<http://systems.hscic.gov.uk/scr>

### THE PERSONAL DEMOGRAPHICS SERVICE

The **Personal Demographics Service** (PDS) is a key component of the *NHS Data Spine*. It is the national electronic database of NHS patient demographic details, including name, address, date of birth and the 10 digit NHS Number which is issued at birth for immediate identification purposes. Data in the PDS allows a patient to be identified quickly and accurately. See:

<http://systems.hscic.gov.uk/demographics>

## THE NHS SECONDARY USES SERVICE

The SUS has been the central repository of health data in England since 2006, under the control of the **Health and Social Care Information Centre (HSCIC)**. The data is used for a range of health planning purposes, service provision and commissioning, including “Payment by Results”. It is also available to applicants for research purposes in anonymised and pseudo-anonymised forms. SUS also supplies the **NHS Hospital Episodes Statistics (HES)** system. The history of HES is of interest, as recorded by HSCIC. HES emerged in 1987 from a report on collection and use of hospital activity information published under the leadership of Dame Edith Körner (1921-2000).

Prior to 1987, 10% sample of patient admission records were collected nationally. HES now aims to collect a detailed record for each ‘episode’ of admitted patient care delivered in England. This may be either by NHS hospitals or in the independent sector when commissioned by the NHS. Data was initially collected annually, then quarterly, and it is now collected monthly.

Such data is available for every financial year from 1989-90 onwards. HES data was collated by regional health authorities until 1996, when the **NHS-Wide Clearing Service (NWCS)** was set up. In 2006, this work was taken over by the SUS, within the HSCIC of the **NHS Programme for IT (NPfIT)**.

HES data also underpins the work of **Dr Foster Intelligence**, a company which was founded in 2000 by two journalists and in which the NHS bought a share in 2006. In turn, the company links with, and supports, the health statistical research work of Professor Sir Brian Jarman at Imperial College. See: <http://www.hscic.gov.uk/sus>

## THE NHS HOSPITAL EPISODES STATISTICS SYSTEM

HES stores a detailed record for each patient activity across every NHS hospital and contracted independent facility in England. This amounts to some 1.5 billion records, to which some 125 million new records are added every month.

HES sub-serves a number of functions, including the reconciliation of payments to NHS hospitals and affiliated units for services provided. It also generates substantial analytical data of use for planning, benchmarking, and academic research. HES also illustrates the benefits of the new strategy of outsourcing the “Digital by Default” programme to innovative Small and Medium Enterprises (SMEs), see: <http://www.hscic.gov.uk/hes>

The infrastructure of HES was fully modernised in 2014 by a Leeds based IT consultancy firm, **BJSS Ltd**, whose team reported that:

*“As HES grew, it became increasingly resource-intensive. It lacked adequate testing and staging facilities and required significant manual processing. It had become unwieldy and expensive to maintain. An external third party retained all of its process knowledge.*

*In line with Government IT policy, the NHS decided to bring HES in-house. Within six months, a small team of developers had completely re-written the HES system for one instead of six computers, and had produced a rationalised, maintainable code base.*

*The original 3.5 million lines of SQL code and 500 step manual process which ran on six machines has been reduced to just 100,000 lines of SQL code and a two-step automated process running on a single machine. BJSS completed a comprehensive knowledge transfer by supplying fully documented code and operational procedures and a detailed software architecture and design document”.*

In September 2013, BJSS was also engaged to design and build an NHS-wide e-referral service to supersede Choose and Book, see:

<http://www.bjss.com/>

## **THE HEALTH AND SOCIAL CARE INFORMATION CENTRE**

The **Health and Social Care Information Centre** (HSCIC) is the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care. It is an executive non-departmental public body, set up in April 2013 and sponsored by the Department of Health. Its employs 2,500 staff, including IT specialists, programme and project managers, statisticians, analysts and information security experts. It is responsible for:

- Collecting, analysing and presenting national health and social care data.
- Publishing a register of this information.
- Setting up and managing national IT systems.
- Setting standards and guidelines in the fields of data collection and reporting.
- Publishing rules on the management of personal confidential information.
- Creating indicators of the quality of health and care services.
- Helping health and care organisations to improve the quality of data collection.

<https://www.gov.uk/government/organisations/health-and-social-care-information-centre/about>

<http://www.hscic.gov.uk/about-us>

More information on HSCIC functions is listed in *Appendices A to C*.

### **THE MOVE FROM “TOP DOWN” TO “BOTTOM UP” NHS SOFTWARE SYSTEMS DEVELOPMENT**

In 2013, the Department of Health also pulled the plug on the increasingly expensive and unproductive strategy of support for large “top down” commercial IT projects in favour of a bottom-up, evolutionary approach using local initiatives and innovative SMEs to solve local problems and to drive national solutions.

Top down “Command Informatics” has thus been replaced by a better understanding of the value of development of effective IT systems from the end user upwards, and by the recognition of the benefits of locally purchased systems and solutions within a framework of common data and communications standards. Such systems can be progressively networked and integrated into the wider health data economy as they are improved and refined.

### **THE INFORMATICS NEEDS OF NHS CLINICIANS**

Within any one clinical unit, different users have different data needs in different places and at different times. All hospitals have complex data requirements for diverse users, who include:

- Managers and administrators, who must optimise the allocation and safe use of resources including beds, outpatient clinics, staff, material logistics, and estate maintenance.
- Clinicians and allied health professionals engaged in inpatient and outpatient service provision.

At present, data about patients is severely disjointed and incomplete at any point of need. Primary care, hospitals and social services keep different data in different formats. For example, individual NHS hospitals, independent hospitals, NHS funded and independently managed Treatment Centres and private hospitals maintain their own data in locked “silos”. Any future system that seeks to integrate all clinically useful data on any one patient, will thus have to overcome a series of very significant institutional and organisational barriers.

### **HEALTH INFORMATION SECURITY AND PRESENTATION**

There are two particular elements which need to be addressed if healthcare information is to flow freely around the healthcare informatics space, to the benefit of all citizens at any and all points of need.

The first is a secure identity system, to underwrite confidentiality, so that each and every citizen and healthcare worker can be clearly and confidently identified at every point of contact with digital clinical data.

The second is a simple, understandable and elegantly structured electronic patient record.

### Secure Personal Identity Online

Many transactions between individual citizens and Government agencies require reliable and trusted identification of the individual, to prevent fraud and identity theft. Until similar reliability is built into online transactions involving health data, it will prove difficult to realise the full potential of health informatics.

The Government is undertaking a range of experiments in the development of a nationally acceptable system of clinical identity verification.

**Government Gateway** is a system of registration to obtain a secure online identity for individuals, organisations and agents (ie. those who act on behalf of individuals and organisations). It is a relatively cumbersome process, which requires the individual to register for identity check and to wait for the receipt of confirmation several days later.

**GOV.UK Verify** is the new system to establish and prove personal identity online, in a much more efficient and responsive manner. Instead of a single government database, individual commercial and credit identification companies such as **Verizon**, **Experian** and the major banks, are licensed to provide the information. Individuals can select their nominated and designated “identity provider”, and check the information held. This also reduces the government holding of data regarding individuals that it does not otherwise need.

The designated company then provides identity checks in real time in support of any particular transaction. Using “Two-Factor” Authentication, which is now widely used in online transactions, a “one time” code is then sent to the individual by mobile phone, email or by landline telephone. GOV.UK states that the benefit of this system, which is presently under development, is that:

*“Working with certified companies means your information and transactions with government are safer, simpler and faster than any other method. This is because:*

- *there is no central storage of information so your personal data is more secure*
- *it's completely online*
- *the company you choose can't use or share your data without your permission”*

Once the system is set up, subsequent use by registrants is rapid and is believed to be safe and reliable. Time and experience will tell if this proves to be the case.

GOV.UK is also committed to working with the **Open Identity Exchange** (OIX, see: <http://oixuk.org/>). OIXUK is a not-for-profit organisation which works with industry and government to develop reliable on line identity systems.

### THE ELECTRONIC PATIENT RECORD

A consistent framework and “*Highway Code*” for The *Electronic Patient Record* (EPR) is key to the development of an efficient digital health economy. Unfortunately, the concept of the EPR presently means different things to different people, and no one definition or operational standard has yet been achieved.

In general terms, we can define an EPR as a continuing electronic collection of health-related information on any one patient. The EPR may contain a wide variety of notes, documents, letters, reports and test results, based around a framework, central to which is the patient’s demographic data and unique identifiers.

In its most basic format, the component data are held in a variety of different computer systems which are accessed independently by the user. Such an EPR is a list of documents, results and reports about a patient, held in a list form by the computer of an agent or institution, which might be a General Practitioner, a health centre or a hospital. Anyone who has worked with such records will recognise that any but the shortest of such records becomes tiring, tiresome and time consuming to search and read.

In more sophisticated systems, all relevant data are “pulled in” (linked directly) to the master EPR, so that the user moves seamlessly from one document to another through a single EPR interface. An example of such an interface is set out in Exemplar 1 at the end of this booklet.

Development of the EPR should be seen as evolutionary, rather than a single “top-down” specification. With time, an optimal functional design should emerge, much as the domestic motor vehicle has evolved around what is now a standard core design .

Moreover, personal records are invariably fragmented between primary care centres, across any number of hospitals, and across a variety of care agencies; each of which uses a range of different bespoke and proprietary software systems, often working in isolation.

## THE DESIGN OF THE “IDEAL” EPR FOR AN INDIVIDUAL PATIENT

A set of criteria that would describe an ideal EPR, would:

- Integrate clinical and administrative information in practical ways.
- Bring together all of the diverse information that impacts upon an individual’s health into an integrated, single information system:
  - in a secure manner, both in terms of the reliability of the data entered and stored in the record, and in terms of control of access and addition or amendment to that data;
  - have lifelong resilience and reliability;
  - which optimised the individual’s healthcare and outcomes, through clarity, accuracy of data content, and through context-sensitive linkage to relevant evidence based information;
  - optimise the use of human and material resources to secure such outcomes;
  - collate, display and distribute information in the individual EPR in the most efficient form of access and content visualisation for users.

However, rather than setting out “top down” to define the software coding for a single overarching EPR, we would do much better by finding out:

- who needs to use the EPR
- where and when this need arises, and critically
- what are the specific needs of the users in a range of different circumstances

We can then cut loose the programmers do the development work in a competitive market of small, medium and large independent sector firms, and public sector agencies.

Again, the evolution of the motor industry may be instructive in this regard. It has developed from a cottage industry of small-scale producers a century ago, to a sophisticated modern industry, adding new features to the fundamentally stable design. In the process, many different vehicle designs and a host of incremental improvements to individual components were trialled in a competitive international marketplace.

From the products of this process, we can select the “best in class” designs and software tools to serve the EPR function from a rolling conveyor belt of innovation. These products can then be subjected to rigorous usability testing in a variety of settings and by a range of users.

## THE COLLECTIVE BENEFITS OF THE “IDEAL” EPR

Just as the *Highway Code* allows drivers of a diverse range of motor vehicles to share a common highway, so the collective framework of rules for a standard or ideal EPR would allow healthcare information on individual patients to flow freely around the “Collective Health Space” of primary, secondary and social care.

The standard EPR would work in a wide variety of different health care settings, and in a wide range of different circumstances, subject to appropriate controls on user access and confidential data protection.

Standardisation would allow suitably anonymised data and metadata from a wide variety of health providers to be put to effective collective uses. These would include the better use of resources and a better understanding of the healthcare of populations, whether locally, regionally, nationally or internationally.

Standardised EPR data should also bring a wide range of clinical benefits from the simplified longitudinal study of the patterns and relationships between diseases and health interventions in individuals and in complex populations of patients.

The evolving EPR will thus contain a mix of administrative information about any one patient - the Who? Where? and When? - and the clinically significant information – the What? And the Which? (test results, decisions and clinical actions).

EPR data will also advance clinical research, by allowing the “How” and “Why?” questions to be asked in relation to treatment inputs and clinical outcomes.

### Timelines and the design of the ideal EPR

The passage of time and its measurement is a central feature of an EPR. The Timeline is the key to the graphical representation of time-structured data. Conventionally, it runs from left to right across the printed page, screen or graph. It permits the layout and orientation of records, reports and results in a logical linear format. This allows the user to understand the content, and the relationship of events.

The timeline of any one patient may be comprehensive, in that it describes the whole of his or her life from birth to death, or to the present time, across a wide range of health parameters, including, for example, immunisation and medicinal history, primary and secondary health care contacts and interventions (see Exemplar A at the end of this booklet).

The Timeline structured EPR may also be Episode or Diagnosis based, following the course of a particular illness or sequence of interest (see Exemplar 2 at the end of this booklet).

In all circumstances, the content of the EPR will be determined by the availability of records in a useable electronic format. Where the information exists only in paper or non-digital image form, as in archival medical records, the content must either be re-entered in electronic format, or it must be captured as digital images (usually in PDF format). A number of companies now provide high capacity **Electronic Document Management System (EDMS)** to organisations which process large volumes of paper, including NHS hospitals.

### **Parallel Timelines**

Human lives can be described by a series of parallel timelines, which may include professional, social and domestic events. Personal health histories can also be represented by a parallel series of timelines that may represent a variety of activities, including vaccinations and travel history, medications, General Practitioner visits, hospital visits and so on.

**Granularity** describes the data density or the level of detail in the data record. A timeline with low granularity may give an overview only of occasional events over a lifetime. A timeline with high granularity may show data which changes over seconds, minutes and hours, such as arises with continuous monitoring by an anaesthetic machine or within an intensive care unit.

In general terms, a patient's personal medical timeline will include periods where there is relatively little activity on the GP and hospital timeline. Contact with a GP or with the local hospital may be limited to the occasional outpatient referral or investigations.

When a patient is admitted to hospital, the clinical activity and hence the frequency and volume of data generation increases substantially. Additional services come into play, including Nursing, Physiotherapy, and Pharmacy systems, and the clinical, logistic and administrative aspects of care (food, consumables and so on) must also be carefully coordinated. In some cases, care may be necessarily intensive and prolonged, generating very large quantities of data in series over weeks and months.

To account for such fluctuations in data density over time, the EPR design needs to have an adaptable and adjustable timeline, wherein the scaling changes from weeks, months and years to minutes, hours and days, according to the prevailing activity.

## PART III: THE DIGITAL NHS HOSPITAL

In July 2013, the Government and NHS England published a guidance document entitled *Safer Hospitals, Safer Wards* that set out the goal of achieving an integrated care record in all hospitals, as an enabling step towards integrated care records across the health and care system. The paper foresaw progression through paper-light to paperless record keeping, for which financial support was made available from a **Safer Hospitals, Safer Wards Technology Fund**.

The *Safer Hospitals, Safer Wards* strategy has major implications for all hospital employees, but particularly for surgeons, both in the delivery of care in Outpatients and within the hospital.

The *Safer Hospitals, Safer Wards* paper acknowledged the varying maturity of digital hospital systems across the NHS, and emphasised the criticality of having clinicians at the heart of decision making and implementation.

The *Safer Hospitals, Safer Wards* paper also gives priority to recommendation 244 of *The Mid Staffordshire NHS Foundation Trust Public Inquiry*, also known as the *Francis Inquiry Report*, of 2013, which stated that:

- There is a need for all to accept common information practices, and to feed performance information into shared databases for monitoring purposes. The following principles should be applied in considering the introduction of electronic patient information systems:
  - Patients need to be granted user friendly, real time and retrospective access to read their records, and a facility to enter comments. They should be enabled to have a copy of records in a form useable by them, if they wish to have one. If possible, the summary care record should be made accessible in this way.
  - Systems should be designed to include prompts and defaults where these will contribute to safe and effective care, and to accurate recording of information on first entry.
  - Systems should include a facility to alert supervisors where actions which might be expected have not occurred, or where likely inaccuracies have been entered.
  - Systems must be designed by healthcare professionals in partnership with patient groups to secure maximum professional and patient engagement in ensuring accuracy, utility and relevance, both to the needs of the individual patients and collective professional, managerial and regulatory requirements.

The paper sets out the ambition to develop an ***Integrated Digital Care Record***. This implies the creation of a Record that extends beyond local and institutional EPRs; which would allow the coordination of all forms of information held in primary, secondary and social care organisations about any one patient; and that would be available to that patient inter alia. The paper also recognised the need for the interface to be intuitive, adaptable and widely accessible.

### **THE CLINICAL DIGITAL MATURITY INDEX**

The paper also set out the intention to classify every hospital and mental health provider with a measure of organisational maturity in digital systems. This ***Clinical Digital Maturity Index*** (CDMI) would be based upon a range of factors, which include:

- Hardware and software infrastructure.
- The current level of clinical digital capability.
- The current level of clinical digital usage.
- The current use of key information standards.
- The level of interoperability within and external to an organisation.
- The capability for business change.
- Clinical and managerial leadership and buy-in.

The self-evident ambition of this programme is to assist all organisations to move progressively up the ladder of digital capability, under a variety of headings.

### **HOSPITAL DIGITAL ARCHITECTURE AND DIGITAL STANDARDS**

The ***Safer Hospitals-Safer Wards*** strategy is not prescriptive of systems and technologies, so long as they conform to the principles that have already been set out by the **Government Digital Service** and the new and overarching national public digital strategy, being:

***Open Application Programming Interfaces*** must be used to secure and ensure the flow of information in and out of the system. The use of the NHS Number (rather than local identifiers) as the primary patient identifier, and central coordination of the Patient Identity through the **Personal Demographics Service**. Engagement with Small and Medium Enterprise suppliers to secure “best of breed” technologies and digital services. Effective and efficient Digital Data Capture.

### **Storage and Indexing**

In response to the top level drive to digitisation, many hospitals have moved towards the acquisition of ***Electronic Document Management Systems*** (EDMS). An effective EDMS tracks all documents and their metadata in any one patient record. These

include letters, discharge summaries, operation records and so on. This metadata includes the date and time of production of each document; the author, context (eg. clinical discipline, outpatient or inpatient) and other information that subsequently allows the document to be plugged into the EPR framework. These documents may include PDF images for archiving of handwritten documents.

The *Safer Hospitals-Safer Wards* paper states the following:

*Once information is captured, it needs to be held electronically in a repository so that it can be accessed by those who need it. Information held electronically needs to be properly structured so that it can be categorised, indexed, linked and searched. This will allow clinicians to access the specific information they need to make decisions.*

*An EDMS can provide a shared repository for clinical documentation. It can be linked with scanning solutions to support moving away from paper records. It can also hold electronically generated documents from the various systems in the organisation.*

*It is important to consider what historic information needs to be captured electronically. For example, very old, paper based historic records required solely for medico-legal purposes may be better stored on paper indefinitely. It is often cheaper than scanning, provided storage space is available. For files of ongoing patients, Trusts need to decide, with clinical input, the level of indexation required.*

*When paper records are scanned, consideration should be given to the use of Natural Language Processing and the Automatic SNOMED-Encoding of Free Text.*

### **Patient Access to Records**

This is a challenge for information governance. The *Safer Hospitals-Safer Wards* paper states that:

*The process used to register the patient should be robust and proportionate to the information that will be made available when the service is accessed. The following key activities are required:*

- *Registration: the act of establishing the identity of a subject.*
- *Service access: the process by which a registered user's entitlement to access a particular service is confirmed and authorisation is then granted.*
- *Authentication: The process by which the electronic identity of a user is validated using a credential issued following a successful registration.*

- *The need to maintain privacy in the handling of personal and/or commercially sensitive information.*
- *Capability for layered access (i.e. separation of access to the record from transactions) and the capacity to provide a parental/carer view to enable appointment booking and prescriptions requests without sight of other transactions.*

More details relating to these technical capabilities can be found at:  
<http://www.technologystrategy.england.nhs.uk>  
<http://systems.hscic.gov.uk/qipp/library/identityfs.pdf>  
<http://systems.hscic.gov.uk/infogov>

### **Standards of descriptive coding and Semantic Harmonisation**

Clinical information must be recorded consistently to improve communication and to minimise risk of error. The meaning of words, terms and phrases must thus be standardised using agreed definitions and reference works. The *Safer Hospitals-Safer Wards* paper lists the sources of the key standards to which local organisations should adhere; see *Appendix A*.

### **Plain English**

Whatever digital systems are introduced, there remains a critical requirement for Plain English in digital communication and expression. An absolute emphasis upon simplicity, readability and comprehension of content helps reduce risk. It will also become a critical factor in reducing misunderstanding as medical records are made more widely available to patients.

There are many examples of ill-conceived, badly implemented and sometimes incomprehensible language that are met in daily life, and which arise from thoughtless adherence to rigidities of computer coding. For example, in Read Code, the otherwise clear description of “*simple mastectomy, sentinel node biopsy and auxiliary clearance*” becomes translated, in computer speak, on one local system to the impenetrable and superfluous description of a “*(primary operation) (secondary operation) (secondary operation) NEC (not otherwise specified)*”.

### **PAPERLESS AND PAPER-LIGHT CLINICAL INFORMATION SYSTEMS IN HOSPITALS**

The direction of travel is now clear. Nevertheless, all surgeons will be familiar with the paradoxical explosion in paperwork, forms and form-filling that has accompanied and paralleled the introduction of computers into the workplace. Many more senior readers will remember with wry cynicism the misplaced optimism of the gurus of office computerisation two decades ago, in extolling the ill-considered myth that the end of paper was nigh. Such optimism was an excellent signal to buy shares in office printer paper suppliers.

There is a need to work through the challenge of what amounts to a fundamental re-engineering of information flow in the professional workplace; to discover what works and what does not, and to change the all encompassing form mentality of the present era.

### DEFINITIONS OF PAPER-LIGHT AND PAPERLESS

**Paper-light:** In the context of medical records, paper-light implies the minimisation of paper-based activity within a conventional paper-based records infrastructure.

**Paper-less:** This implies a system in which paper-based documents are eliminated completely, and all information is stored electronically.

### THE THEORETICAL ADVANTAGES OF PAPERLESS MEDICAL RECORDS

Many customer-facing businesses have made a very successful transition to paper-light systems, whereby all processes that can be digitised are digitised, and paper documents are immediately captured and disseminated as electronic (primarily PDF) images.

The potential efficiency gains from information transactions by paperless and paper-light health systems are considerable. Such processes will need to be implemented throughout public and private health systems, including:

- Within primary care services.
- At the interface of these services with secondary care; including public and private providers of hospital, mental health and social care.
- Many different types of clinical transaction, including referrals, discharges and the movement of patients across provider boundaries.
- Within hospitals, and between hospitals.
- Within social, community nursing, rehabilitation, prison, palliative, veterans, charitable and voluntary services.
- Between primary, secondary and tertiary health care providers and central information collaters (eg government, insurers, statistical agencies, risk management agencies).
- Between health care providers and the supply chain.

Within secondary care services, a large hospital and/or a busy surgical unit will generate many thousands of new documents and clinical records every year. Hospital- wide, there may be half a million or more paper based record folder movements between clinics, secretaries, admissions offices and records stores.

Within this data ecosystem, there are many millions of information transactions recording temporal (time-stamped and sometimes time-critical) events. Paper folders and document wallets often fail to move as fast as patients, so records are not always where they need to be at the point of use. This generates additional costs, duplicate records and unnecessary transactions, which - in turn - waste time and resources. Inefficiency also creates additional clinical risk from the absence of useful or critical clinical information at the point of need.

It is therefore self-evident that well designed IT systems will have the capability to transform healthcare delivery as useful information flows in a timely and appropriate manner between all parties in primary, secondary and social care. However, there is many a slip twixt cup and lip.

Association of Surgeons of Great Britain and Ireland

# ISSUES IN PROFESSIONAL PRACTICE

THE CLINICAL INFORMATICS REVOLUTION

## PART IV: PAPERLESS AND PAPER-LIGHT CHANGES IN THE SURGICAL WORKPLACE

Surgeons will be primarily concerned about the drive to paperless and paper-light information transactions within their immediate clinical environment. These include the computerisation of:

- Outpatient letters and referrals.
- Inpatient activity (ward based clinical notes and operation records.
- Consent forms, procedure records and operation notes.
- Discharge summaries.
- Nursing and governance documentation of patient episodes.
- Physiological records such as TPR measurements, fluid balance and prescription charts.

There are many other practical applications for the data generated by such activity, including data for appraisals, revalidation, job-planning and multidisciplinary meetings.

The key element in this process of transformation is an intuitive framework EPR, to which digital transformation can be added incrementally through “Design, Test and Adjust” principles.

### CHALLENGES IN THE IMPLEMENTATION OF PAPERLESS AND PAPERLIGHT SYSTEMS

There are a number of significant constraints to the efficient uptake of paperless working practices in surgical units. These include:

#### 1. The lack of agreement as to what constitutes a standard patient record

The information to be recorded and retained needs to be agreed:

- In the record maintained by clinicians.
- In the records maintained by allied health professionals.
- In the “charts” record.
- In the “ancillary” documents (for example, the check lists which are now a major component of every hospital record).

It is invariably argued that every scrap of information in the clinical record should be retained for “medico-legal purposes”. However, those familiar with medico-legal report writing will recognise that the vast majority of information in any individual record is quite irrelevant to causation, case evolution and case resolution. This produces substantial

costs in records storage. There needs to be a rationalisation on the principles and practice of record keeping, informed by the experience of organisations such as the NHSLA, in discussion with the legal authorities.

## **2. The lack of common standards for document storage and retrieval**

PDF documents are very data intensive. Form based and structured data entry systems (enter once - use often) offer significant advantages for paper-light records, but standards have yet to be set and agreed as to optimised form design.

## **3. The lack of access to electronic information throughout the workplace**

It seems likely that current hard-wired desktop systems will be largely supplemented and superseded by wireless networks, tablet computers and other mobile devices. However, the assumed superiority and durability of these systems over historic, paper-based recording systems has yet to be proven.

## **4. Data security**

It is reasonable to assume that all electronic data is vulnerable to unauthorised use, hacking, misuse and corruption, if individuals or organisations are sufficiently determined, skilled and resourced to access and manipulate it. While paper records are also open to theft or unauthorised access, digital abuse is characterised by its scale and speed. Health system security procedures are strong, but they have the unfortunate and paradoxical side effect of slowing information transactions and creating user and security fatigue through the incessant need to log-in and log-out of disparate hospital systems with different access codes and passwords.

Data security also covers the long-term preservation of data, system redundancy, back-up and data warehousing. This raises questions as to how much digital data to retain, of what type, in what format and for how long?

One of the great advantages of paper is its integrity as an information storage medium over generations, subject to preservation and conservation. A major advantage of electronic data is the ability to conduct powerful analyses and to extract clinical intelligence from the mass of raw data.

As yet, there is no assurance of the ultimate reliability and integrity of long-term electronic data storage. However, the usefulness of electronic data increases with time, as sophisticated longitudinal studies on large populations and on long-term outcomes are conducted over decades, compared to the impracticality of using paper based records.

## 5. Disparate information requirements

There is a challenge in meeting the conflicting information requirements of different information users in hospitals. To date, most IT investments have been directed to administrative functions in hospitals. The design requirements of systems which produce actionable clinical intelligence and clinical insight are somewhat different.

## 6. Speed of access and operation of digital systems

Current hospital computer systems are often slow in booting up and in loading relevant software and documents. It is essential for workforce efficiency that all systems are optimised for speed of use and that they are robustly tested with users to optimise screen and content formats.

## NEW WAYS OF LOOKING AT OLD PROCESSES: THE OUTPATIENT LETTER

There are many component processes in hospital practice which are highly inefficient, but which are presently taken for granted. They are suitable targets for stepwise modernisation as “exemplar” test models during digital transformation. The outpatient letter is a prime example. It is worth considering in detail the natural history of such a document in typical conventional hospital practice, from the point of consultation in the outpatient clinic, where the clinician will typically dictate a letter into an analogue or digital Dictaphone. Voice recognition systems remain largely error prone and un-adopted.

Outpatient dictation of content is generally highly permissive. Clinic letters and their content are rarely formally structured other than by the most general of linguistic conventions. There can be a very substantial variation in the “information delivery” from any one letter and any one clinician to another, even within a single service which is treating large numbers of patients with similar problems in similar workflows.

A standard, structured and significantly automated letter could readily be optimised for information delivery rather than social discourse, although this would challenge much accepted outpatient practice and perceived “clinical freedom”.

Once dictated, the collection of letters from that day’s clinic is typically passed on to a secretary/PA/typing pool, who/which may be local to the hospital or remote in a “call centre”, possibly as far away as another continent, where the cultural and linguistic nuances of many letters and regional UK accents may be misunderstood, misconstrued or mistyped.

On return from the typing pool, the letter may need corrections or other processing, before the final document is cleared for sending on paper through the “snail mail” postal system to the intended GP recipient.

On receipt of the letter at the GP surgery, it is usually scanned and converted into “PDF” format for electronic archiving. The entire

process can, at best, take a few days, and sometimes it can take up to six weeks, by which time events will often have moved way beyond the original clinical decision.

It is clear that this is an archaic and inefficient method of communication. It would be significantly circumvented if most letters were created and posted electronically during, or immediately after, the clinic. This could readily be achieved by intelligent design and modest changes to working practice.

An improved electronic outpatient letter is but one element of a more seamless and automated communication system between the GP consultation and the computer screen of the hospital clinician. This has been made possible by the national Choose and Book system, but it has yet to be widely implemented in surgical units.

### **DIGITAL TRANSFORMATION AND TEACHING, TRAINING AND EDUCATION**

A move to a digital health economy requires a major adaptation of core skills by the entire work force, which has been trained to use paper systems for centuries, and for which the human eye and brain are well adapted. It also requires a rethinking of all aspects of professional practice.

There is therefore a need to educate and adapt the workforce to different ways of thinking about information flows, and the use of health informatics. Most health professionals are now very familiar with the workings and benefits of digital technology. Nevertheless, full realisation of the potential will require “cradle to grave” changes in workforce education, and in particular within the University medical and nursing schools.

### **THE IMPLICATIONS OF DIGITAL TRANSFORMATION FOR PROFESSIONAL PRACTICE**

Implementation of the Integrated Digital Care Record may ultimately have a profound impact on professional working practices for clinicians, allied health professionals and for many other professionals working in health and social care.

For example, the General Practitioner is presently the gatekeeper to much clinical information. Once the IDCR is implemented, and once open access to personal health data becomes the norm, patients will be able to access results and reports directly, and to relate them to “best practice” healthcare delivered through health information internet portals.

The rapid growth of personal physiological micro-sensors, such as for cardiac rhythms and diabetic monitoring, are now being pioneered for and by the “iPhone generation”, and will further change the dependency upon GPs. The implications of such technological advances for the hospital workforce have yet fully to be thought through.

## PART V: THE BIGGER PICTURE

*“The variation in the quality of health and adult social care is too wide. This unacceptable variation in quality needs to be widely acknowledged and addressed. That care can be delivered in different ways, does not justify poor quality for some people, settings or locations. Everyone should receive good quality care, no matter how or where it is being delivered. This means improving the care that is inadequate or requires improvement, while leaving others to flourish to develop their good and outstanding care”.*

***The state of healthcare and adult social care in England 2013/14***

Care Quality Commission Report, October 2014

In February 2014, Jeremy Hunt, Secretary of State for Health, commissioned Sir David Dalton, Chief Executive Officer of Salford Royal NHS Foundation Trust, to examine new options and opportunities for providers of NHS care, along with an Expert Panel of very senior and experienced NHS Executive Officers. The report is published at: <http://www.gov.uk/government/publications/dalton-review-options-for-providers-of-nhs-care>

This review focussed on organisational structures and exemplars. Inter alia, Sir David and his Expert Panel considered that:

*“The gap between required and actual standards manifests itself in variation of standards across the country; reducing this variation and ensuring uniformly high standards of care across the provider sector is vitally important.*

*As demand and complexity continue to increase, it has become increasingly difficult for providers of all types to navigate the challenges that the NHS faces.*

*The NHS Five Year Forward View identifies that the NHS needs better ways of delivering care at greater scale. It identifies that:*

- a.** *care should be personal, whilst based on population health needs;*
- b.** *there should be a new focus on co-ordinated care systems and networks;*
- c.** *a greater emphasis should be given to redesigning out-of-hospital care;*
- d.** *centralisation should be supported where it demonstrably delivers improvements in quality and safety; and,*
- e.** *to achieve greater productivity, new approaches should adopt greater standardisation of processes, use of technology and shared information.*

*The new approaches to developing care models proposed by the NHS Five Year Forward View help to address some of the key challenges faced by providers:*

- i. There are more people living with long term conditions: the number of people with three or more conditions is expected to rise from 1.9 million in 2008 to 2.9 million by 2018.*
- ii. Patients with chronic disease have complex and varied needs, often accessing services across a spectrum of care;*
- iii. Between 2011/12 and 2012/13 the number of emergency admissions increased by 1.8%; outpatient appointments by 3.9% and day case episodes by 2.3% and this demand pattern further increased in 2013/14*

*Overall demand is predicted to rise to 7% per annum. This is coupled with an aging demographic where the number of patients over the age of 85 is expected to double by 2030, many of whom will have one or more chronic conditions.*

*Establishing models and systems of care which meet the needs of individuals and communities is essential, and it is crucial for local leaders to determine what will work best for their locality. It is for provider organisations and their leadership, governance, structures and workforce to deliver the required transformational change. New models of care require new organisational responses”.*

It is clear that excellence in clinical informatics will make a major contribution to these worthy objectives.

## PART VI: SUMMARY

The purpose of this booklet in the ASGBI **Issues in Professional Practice** series has been to stimulate awareness and interest in clinical informatics among surgeons, at a time of rapid technical and organisational change within the public services.

Change driven by technological advance is inevitable, and it will be as disruptive to the health service as it has been to many other industries and services in recent times.

Overly optimistic or overly rapid introduction of digital technology into the healthcare sector nevertheless carries the potential for unwanted operational disruption at a time of severe overstretch of the public health service.

It is therefore essential that surgeons, as professional leaders, have the knowledge and skills both to advance change where it is clear that the new technologies are appropriate and properly tested; to provide informed advice where the risks exceed the gains; and to experiment with new systems and technologies in all areas of their clinical practice.

Above all, we hope that this booklet will promote debate, ideas exchange and communication between surgeons and more widely on all facets of the implementation of digital technology in the workplace.

## EXEMPLAR 1: DEVELOPMENT OF A TIMELINE STRUCTURED DYNAMIC EPR IN THE UNIVERSITY HOSPITAL SOUTHAMPTON CLINICAL DATA ENVIRONMENT

### THE MARYLAND LIFELINES TIMELINE EPR CONCEPT MODEL (1996-97)

Various attempts have been made to develop a practical structure for an informative EPR. The presentation of data using graphical techniques, colour and icons allows patterns within complex data to be readily and rapidly visualised.

An effective and useful visualisation tool should conform to the mantra of “Overview > Zoom > Filter”, which has been promoted by Professor Schneiderman of the **Human Computer Interaction Laboratory** (HCIL) at the University of Maryland as a key concept in the design of visualisation tools for the study of complex and heterogenous data. The design of any such tool should:

- Allow for an Overview of the Data.
- Allow the user to Zoom in on any feature of interest (such as the content of an individual document).
- Allow the user to Filter out unwanted information.

In the 1990s, a HCIL team under the direction of Professor Schneiderman created a model health record which they termed **Lifelines** (see: *Figure 3*). This contained a number of innovative design features which are particularly attractive as a basis for a clinically useful EPR, in that:

- The model was Windows based.
- It was structured along a timeline along the X axis and by subject matter. Immunisations, hospital visits, medications prescribed, test results and so on were allocated separate timelines with origins on the Y axis.
- By selecting individual icons, the user could drill down into content, and call up individual letters, reports and images.

However, the model was focussed upon primary care, and it was not further developed or implemented in practice.

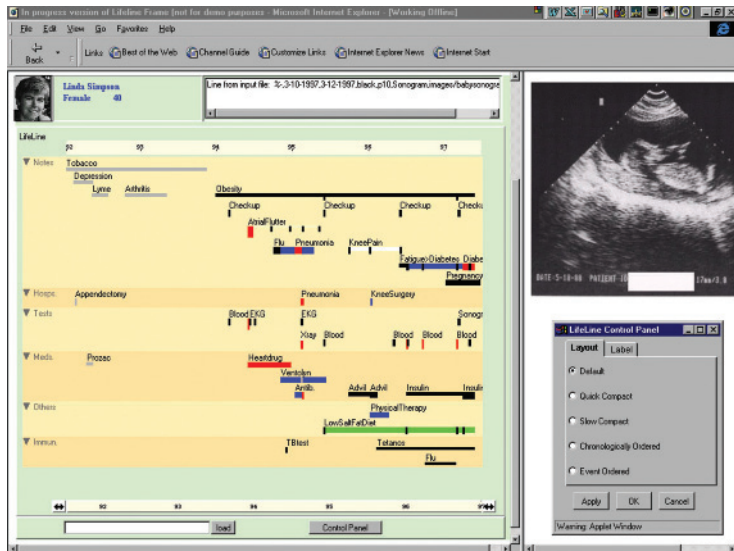


Figure 3: Basic format of the clinical LifeLine prototype developed by HCIL at the University of Maryland

### THE UNIVERSITY HOSPITAL SOUTHAMPTON EXEMPLAR OF AN INTEGRATED EPR

It was recently decided to build a practical EPR using the design principles in Lifelines future EPR concept within the *University Hospital Southampton Clinical Data Environment (UHS CDE)*. The Discovery and Alpha Phase design team comprised one surgeon; one systems design specialist with detailed knowledge of the local hardware and software architecture; and the leader of the Trust's **Information Management Directorate**.

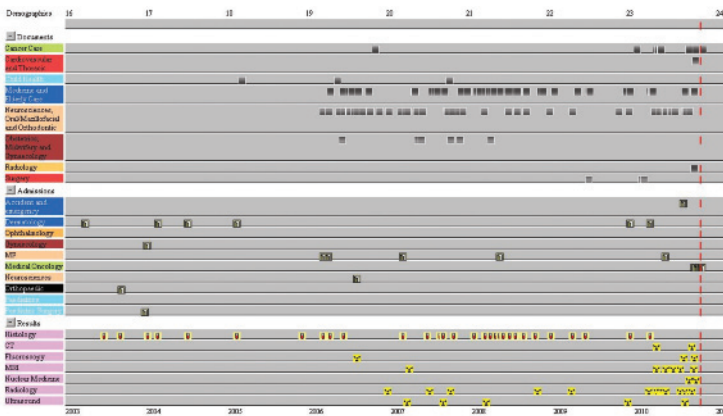
The Southampton CDE has been in progressive and incremental development since the early 1990's with a mix of legacy, nationally specified and locally developed systems. This is a challenge which is common to all hospitals in the UK. Specifically, all documents and clinical results are accessible on a common digital platform. It was aimed to build a system and a patient-specific EPR which:

- Was highly intuitive and easy to use by clinical and administrative staff, to the point at which the model would ultimately become the preferred route of entry into the UHS CDE for the majority of data transactions.
- Automatically loaded and was accessible in real time.
- Was timeline structured and continuously updated.
- Gave an Overview of all data (documents, results, reports) on a single screen.

- Allowed individual documents, reports and result to be selected out and called up (expanded) individually, thus addressing the Filter and Zoom functions.

The resulting prototype (“Alpha”) tool (see *Figure 4*) was produced in a few months at minimal cost through an iterative, design-test-adjust process. It provided an intuitive and continuously adaptable EPR interface that is now being rewritten and updated in modern code.

The screenshot in *Figure 4* is taken from the records of a young patient with a complex clinical condition (spina bifida) involving multiple specialities. Each icon indicates a document, test result or report. Hovering over any icon reveals the metadata describing when and where it was generated, and by whom. Clicking on the icon brings up the full document / record / report. The subject colour coding reflects an established coding of paper records which has been in use in UHS for around 50 years, and is therefore familiar to all staff.



*Figure 4: The prototype Southampton Electronic Patient Record (2010)*

This particular model is coded to work within the UHS CDE. Unfortunately, it cannot be “shrink wrapped” and imported directly into any other hospital computer system in its present form without specialist programming skills, because it is taking data feeds from a variety of different software systems.

The interface will thus need to be separately coded into each hospital system, given the substantial variation in hardware and software architecture from hospital to hospital. Nevertheless, it seems highly likely that this will become an attractive and practical design for developers of the next generation of clinical informatics systems.

The direct and indirect benefits of such an EPR are readily apparent. They include:

- Simplification of access to diverse documents and data types.
- Simple and instant visualisation of relationships between activity and documents in different clinical disciplines and treatment streams.
- A comprehensive overview of all clinical records relating to any patient at any time, rather than a narrow focus on one discipline or treatment stream.
- A breadth and depth of focus on a patient's entire clinical history, whether lifelong or within a single institution.
- An expandable and scalable record along both X and Y axes.
- Reduced costs of duplication of effort and tests.

This model has been developed within a controlled hospital data environment, but it is easy to see how it could be readily applied in primary care to generate a "whole of life" overview of an individual patient history.

## EXEMPLAR 2: TIMELINE STRUCTURED, DISEASE- SPECIFIC RESEARCH DATA BASES: AN EXEMPLAR OF A DATA SYSTEM FOR BREAST CANCER

The extraction of knowledge and actionable clinical intelligence from electronic information and documents is a particular intellectual and software design challenge.

Timeline based data visualisation opens a range of creative opportunities for the display and analysis of clinical data. The concepts of the Lifelines EPR have been extended to the development of an integrated data system within the **Southampton Clinical Data Environment** using breast cancer as an exemplar.

This model can be used as a generic tool with applications in the study of all chronic diseases of childhood and adulthood, and as a framework for other forms of clinical research. It also has applications as a clinical *Decision Assistance Tool* in specialist practice and for multidisciplinary teams.

The **Southampton Breast Cancer Data System** has evolved on a “design, test and adjust” basis over three years of local development. It currently holds some 12,000+ records on all patients diagnosed and treated locally and a further 4,000+ cases referred for chemotherapy and radiotherapy from other regional hospitals, since the records began in 1949. The framework records are continuous since 1979, and supported by complete pathology records since 1990.

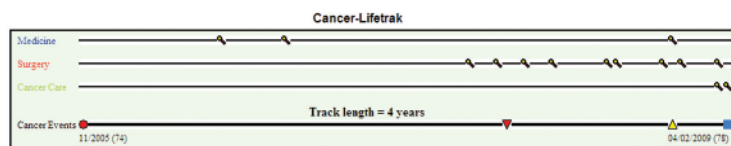
This data system is structured using conventional Microsoft Windows tools, drop down menus, check boxes and so on, for ease of use and data population. It incorporates a number of original features, which include:

- Intrinsic timelines supporting documents generated within selected sub-specialities, including Surgery, Cancer Care, Medicine (for co-morbidities) and Histopathology.
- Direct linkage to all document and report files, allowing dynamic and continual updating of all records and timelines for living patients.
- A LifeTrak timeline, modelled on the railway marker on Ordnance Survey maps. This highlights the month of onset of key episodes of breast cancer progression; Diagnosis, Local Recurrence, Metastasis and Death (in the case of breast cancer) are represented as stations on the LifeTrak, with a simple colour code for laterality (red = right; green = left).

starboard = right). The LifeTrak permits measurement of intervals between episodes, and the correlation of these intervals with pathology and treatments.

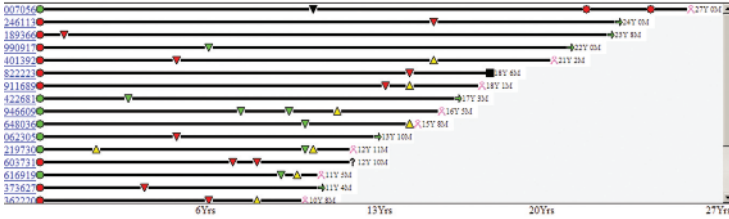
- A “cause of death” menu for deceased patients, which can often be populated with accurate information from those documents relating to end of life admissions which are held within the UHS CDE.
- Semi-automation of data loading. The hospital servers are trawled at midnight every 24 hours, and new skeletal records are created for all new patients with a breast cancer diagnosis. Further population of records is primarily manual at present, because of the range and complexity of legacy data resources (for example, hand written card indices). However, it lends itself to future automation.
- A Data Mining tool which permits the selection and analysis of cohorts of patients by a wide range of demographic, pathological and treatment criteria, as well as by the year of treatment. This function allows the direct comparison of outcomes between cohorts treated in different years and eras.

The following images illustrate the key components of the “whole time course of the disease” structure and function of the *Southampton Breast Cancer Data System*, as an exemplar of applied clinical informatics.



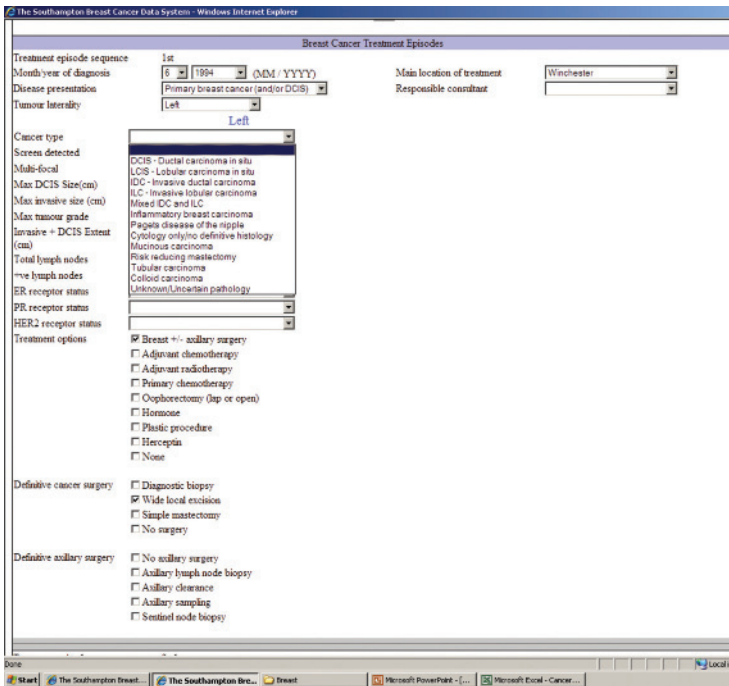
*Figure 5: The Cancer Lifetrak records the month of Primary Diagnosis (circle); local recurrence (inverse triangle) and metastasis (yellow triangle).*

The terminal icon indicates the cause of death, which in this particular patient was from late onset oesophageal cancer rather than progressive breast cancer, as evidenced in the supporting documents, indicated by the microscope icons.

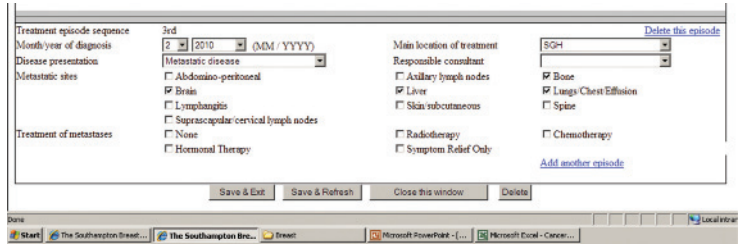


**Figure 6:** This prototype Data Entry screen for the primary diagnostic and treatment episode illustrates the use of drop down menus for ease of data entry

The screen contains a section for entering the disease pathology (for left, right or bilateral cancers), and the primary and adjuvant treatments. The data entry screen for Local Recurrence is similar.



**Figure 7:** This prototype screen allows recording of the fact and timing of diagnosis and treatment of tumour metastasis



*Figure 8: A test model data mining tool within the Southampton Breast Cancer Data System, which allows cohorts of patients to be selected by a range of criteria*

The ability to display and read the LifeTraks of the patients in the cohort, and to link them back directly to the source data, opens the door to a range of further studies based upon the “survival analysis” of intervals between episodes in relation to pathology and treatments.

## APPENDIX A: CUTTING THROUGH THE JARGON: STANDARDS AND SEMANTIC HARMONISATION

Medicine provides a rich and complex language of unique terms, eponyms, acronyms and abbreviations, which vary from region to region and hospital to hospital. A standard national terminology is essential to underpin developments in clinical informatics, and to ensure that all diseases, conditions and procedures are referenced in the simplest, most accurate and most efficient manner. The following notes may help the confused and bewildered to hack their way through the terminological jungle.

The **NHS Classifications Service**, a division of the **Health and Social Care Information Centre**, is responsible for the development and/or maintenance and implementation of the clinical classifications and the associated standards in support of this objective. The following resources are used and available to help standardise medical terminology in the move towards an integrated care record.

### 1. Read codes

Read codes are the standard clinical terminology system for General Practice in the UK. It supports diagnostic coding, along with many other factors, including occupation, social circumstances, ethnicity and religion, clinical signs, symptoms and observations; laboratory tests and results; therapeutic and surgical procedures performed; and a range of administrative factors.

The first version was developed in the early 1980s by Dr James Read, a Loughborough GP. It had a four character code structure, and was more commonly known as 4-Byte READ. The final official release of 4-Byte READ occurred in April 2009.

In order to cross-map to **ICD-9-CM** and **OPCS-4**, a new READ schema was devised with a code structure of five Bytes. This was known as READ2, or 5-Byte READ, which was first released in 1990. The October 2010 release contained 82,967 discrete 5-byte codes.

A third version of the READ code was devised through the 1990s, to address technical limitations of the earlier designs. This was known as Clinical terms Version 3, or CTV3.

The first release of CTV 3 occurred in the late 1990s. The October 2010 release contained 298,102 discrete concept codes of which 55,829 were marked as inactive, and 58,130 were pharmaceutical products or devices.

The two active versions of the READ codes (READ-2 and CTV3) are now maintained by the UK Terminology Centre.

## 2. SNOMED CT

SNOMED CT is the internationally recognised **Systematised Nomenclature of Medicine Clinical Terms** and has been adopted as the standard clinical terminology for the NHS in England. See: <http://systems.hscic.gov.uk/data/uktc>

SNOMED CT is a computer processable collection of medical terms providing codes, terms, synonyms and definitions used in clinical documentation and reporting. It is considered to be the most comprehensive, multilingual clinical healthcare terminology worldwide.

The primary purpose of SNOMED CT is to support the effective recording of clinical data. It provides the core general terminology for electronic health records. Its coverage includes: clinical findings, symptoms, diagnoses, procedures, body structures, organisms and other aetiologies, substances, pharmaceuticals, devices and specimens.

SNOMED CT is maintained and distributed by the **International Health Terminology Standards Development Organisation (IHTSDO)**, an international non-profit standards development organisation, based in Copenhagen.

SNOMED CT permits consistent information interchange and provides a consistent way to index, store, retrieve, and aggregate clinical data across specialties and sites of care. It also provides the user with a number of linkages to clinical care pathways, shared care plans and other knowledge resources.

SNOMED CT can cross-map to other international standards and classifications. Specific language editions are available which contain translations, and additional national terms.

UK SNOMED CT releases, both UK Clinical Extension and UK Drug Extension, are now available in the **UK SNOMED CT** download area of the HSCIC web site.

A complete UK Edition of SNOMED CT requires the International Release; the UK Clinical Extension and the UK Drug Extension. (information from Wikipedia)

### **The relationship between READ and SNOMED Coding**

SNOMED CT was created in 2001 out of a technical, editorial and content merger of CTV3 and SNOMED RT, an American system. A significant part of the International Core content of SNOMED CT derives directly from CTV3.

CTV3 continues to be released biannually by the NHS independently of SNOMED CT, but maintenance of both systems occurs in parallel.

The NHS in England is committed to move to **SNOMED CT**, and systems using SNOMED are now being deployed within the

NHS primary and secondary care estates. READ versions 2 and 3 were still the core clinical terminology used in UK primary care in 2010, with some 90% of the primary care estate still using READ version 2. (information from Wikipedia)

### 3. The OPCS Classification of Interventions and Procedures OPCS4

The first NHS procedural classification was published in 1987, by the **Office of Population Censuses and Surveys (OPCS)** as the *Classification of Surgical Operations*. In 1992 the 4<sup>th</sup> revision was released as the *OPCS Classification of Surgical Operations and Procedures (4th revision)*, (OPCS-4.2).

Responsibility for the OPCS classifications passed to the **NHS Information Authority** in 1999. (information from Wikipedia)

By 2003, OPCS-4.2 no longer accurately reflected many of the procedures being performed. A project to replace OPCS-4 with a more robust method of procedure coding was proposed, using a sequence of alphanumeric code up to 15 characters long.

A programme of annual revisions to OPCS-4 was implemented in 2005. Since the implementation of OPCS-4.3 in April 2006, there have been various further revisions to OPCS-4, each becoming mandated on 1st April in the year of publication.

### 4. The International Statistical Classification of Diseases and Related Health Problems (ICD10)

ICD-10 is the 10<sup>th</sup> revision of the *International Statistical Classification of Diseases and Related Health Problems (ICD)*, of the **World Health Organisation (WHO)**. It contains more than 14,400 different codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury.

The International version of ICD can be confused with *National Clinical Modifications (CM)* of ICD that frequently include much more detail, including procedures. The US ICD-10 Clinical Modification (ICD-10-CM) has some 70,000 codes. Work on ICD-10 began in 1983 and was completed in 1992. (information from Wikipedia)

<http://systems.hscic.gov.uk/data/clinicalcoding/codingstandards/>

### 5. The Dictionary of Medicines and Devices

The *Dictionary of Medicines and Devices (dm+d)* is the NHS dictionary which contains unique identifiers (codes) and associated textual descriptions for representing medicines and medical devices in information systems and electronic communications. It is linked to SNOMED CT and supports the national electronic prescriptions service, see:

<http://systems.hscic.gov.uk/data/uktc>

“dm+d” has been developed jointly by the **Health and Social Care Information Centre** and the **NHS Business Services Authority**. It provides consistency in how medicines and medical devices are described through a robust Editorial Policy.

**6. The Unified Code for Units of Measure (UCUM)**

The *Unified Code for Units of Measure* (UCUM) is a code system intended to include all units of measures currently used in international science, engineering, and business, see:

<http://unitsofmeasure.org>

## APPENDIX B: NHS INFORMATICS ORGANISATIONS AND RESOURCES

### **The NHS Data Dictionary**

The NHS Data Model and Dictionary provides a reference point for assured information standards to support healthcare activities within the NHS in England. <http://www.datadictionary.nhs.uk/>

### **The Organisational Data Service (ODS)**

This provides codes for organisations, sites, wards and individuals across UK health and social care.

<http://systems.hscic.gov.uk/data/ods>

### **The Information Standards Board (ISB)**

This provides support, appraisal and approval services for the development of standards for the NHS and social care.

<http://www.isb.nhs.uk/>

### **The Professional Records Standards Body (PRSB)**

This body has been set up to consider the development and use of record keeping standards.

<http://www.theprsb.org.uk/>

### **The Academy of Medical Royal Colleges Record Keeping Standards and Core Data Model**

This is a set of core information relating to clinical documentation.

<http://systems.hscic.gov.uk/clinrecords>

### **The NHS Technology Reference data Update Distribution Service (TRUD)**

TRUD is hosted by the **Health and Social Care Information Centre**. It provides a range of reference resources for information technology developers.

<http://isd.hscic.gov.uk/trud3/user/guest/group/0/home>

### **The UK Terminology Centre (UKTC)**

The UKTC at the HSCIC is responsible for the UK management of SNOMED CT, Read codes and other healthcare terminology products and Clinical Classifications. The UKTC maintains the *NHS Dictionary of Medicines and Devices* (dm+d) in partnership with the **NHS Business Service Authority**.

<http://isd.hscic.gov.uk/trud3/user/guest/group/2/home>

### **The Clinical Classifications Service (CCS)**

This is the definitive source of clinical coding guidance and sets the national standards used by the NHS in coding clinical data.

<http://systems.hscic.gov.uk/data/clinicalcoding>

### **The NHS Interoperability Framework**

This is a collection of software interoperability products intended for use by care system providers in England. They are classified into a number of categories, including:

- Architectural specifications for transport and infrastructural requirements.
- Domain Message Specifications for the interoperability payloads.
- Reference Data to assist in the creation of payloads.
- Tools and guidance to assist developers in implementing the specifications and payloads.

<https://isd.hscic.gov.uk/trud3/user/guest/group/41/home>

## APPENDIX C: STANDARDS FOR DIGITAL COMMUNICATIONS IN HEALTHCARE

### **Clinical Document Architecture (CDA)**

The CDA Release 2.0 provides an exchange model for clinical documents such as discharge summaries and progress notes.

### **eXtensible Mark up Language (XML)**

XML is a **World Wide Web Consortium** (W3C) standard specifying a syntactic format for conveying information.

### **The NHS Message Implementation Manual (MIM)**

NHS organisations have many different computer systems used for many different purposes, from pathology results to patient tracking. Health Level 7 (HL7) specifies a number of flexible standards, guidelines, and methodologies by which various healthcare systems can communicate with each other.

### **Domain Message Specification (DMS)**

This is the replacement system for the *Message Implementation Manual*. The first version was released in 2012.

### **Standards for Secure Information Transmission**

*Transport Layer Security* (TLS) is a protocol that ensures privacy between communicating applications and their users on the Internet. When a server and client communicate, TLS ensures that no third party may eavesdrop or tamper with any message. TLS is the successor to the *Secure Sockets Layer* (SSL). It is the approved *Cryptographic Standard* for NHS communications.

### **The Common User Interface toolkit**

The *Common User Interface toolkit* ([www.cui.nhs.uk](http://www.cui.nhs.uk)) provides a set of standards and specifications governing presentation or graphical user interface components of electronic health record systems.



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