

**Computerising the Chinese Army - Information
Systems in the NHS**



Forward by Andrew Lansley M.P. Shadow Secretary of State for Health

"I welcome this report. Far too many Government IT projects have been costly failures. There are now more eggs in the NHS National Programme for IT (NPfIT) basket than in any previous project. IT in the NHS must catch up; it is absurd that we have the most integrated system of health care, but a lack of integrated communication and IT. A viable approach would have been to base the IT systems on common standards, but the Government chose central procurement. After the election NPfIT needs to be reviewed – we need to maximize competition, to involve users fully and effectively, simplify systems of patient choice, and ensure security and patient confidentiality are robust and meet patient expectations. I hope we can do so urgently after the General Election."



Andrew Lansley CBE M.P.

About this Paper

Dr Ellie Hopkins has prepared this paper on behalf of Aediles in conjunction with the Conservative Technology Forum.

About Aediles

Aediles is an independent open market think tank exploring market driven solutions in European Information Society policy.

About the Conservative Technology Forum

Information economy and information society issues now play an increasingly important part in plans for the economic success of the United Kingdom and the future of the European Economic Community. Led by Shadow Industry & Technology Minister Michael Fabricant M.P. and chaired by Malcolm Harbour M.E.P. (European Information Society spokesman for the Conservatives), the Conservative Technology Forum is actively contributing to Westminster Front Bench thinking, on Information Society matters. In conjunction with the independent policy and research unit Aediles, its objective is to enlist the creativity of those working with the new computing, communication and content industries in examining how society should be enabling constructive change, while handling the consequences of rapid technology evolution. Its home page is www.conservative-technology.org



Although published under the auspices of the Conservative Technology Forum, the contents are a contribution to policy debate and do not represent a statement of Conservative Party policy.

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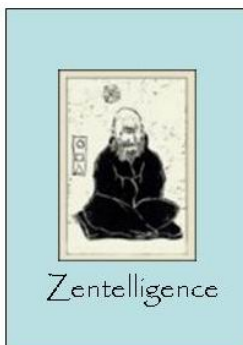


Independent Opinions

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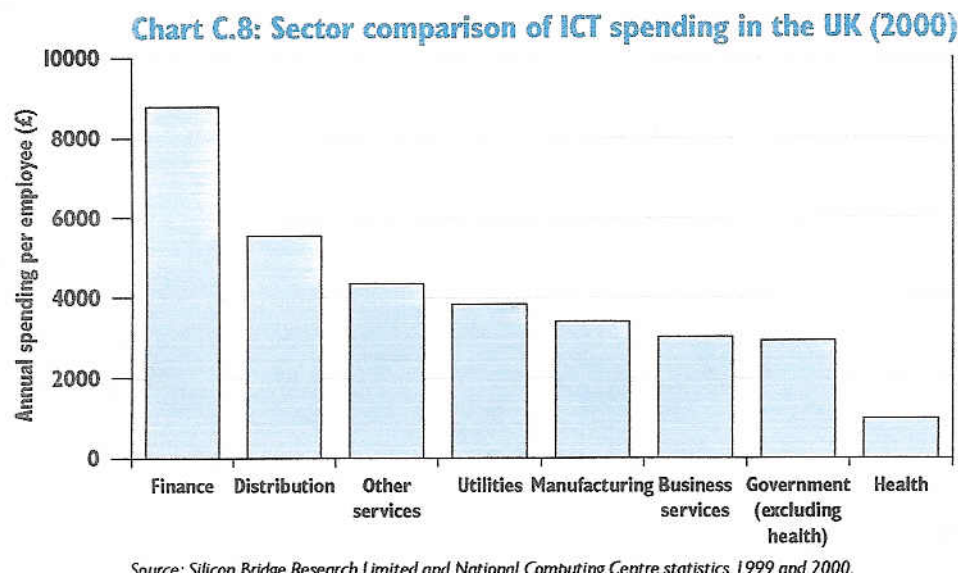
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Summary and Main Recommendations

The problem with healthcare IT

Healthcare IT has long been seriously under-funded in the UK. Most of the current installed base is locally chosen clinical systems whose output is transcribed onto paper for transmission between hospital departments and general practitioners with extracts or entry into local, regional or central administrative systems. In consequence, the lack of availability and accessibility of patient records and the cost of errors (estimated at over £500 million a year) have long had serious impact on the quality and availability of health care.

The fragmentation of procurement and implementation responsibility, failure of attempts to install centralised health authority hospital administration systems and lack of prospect of larger future orders led the majority of large ICT suppliers to leave the UK Health Care market to specialist medical equipment suppliers and small firms, many founded with the support of clinicians who had developed or were seeking systems for their own use. The result was isolated pockets of excellence within a largely paper-based set of care communities. Many of the clinical systems in use however, have long had facilities for electronic transmission but these have not been used in the past, largely because of lack of central resource or authority to overcome problems with regard to local coding standards (clinical as well as ICT).



The National Health Service Information Authority was created to overcome these problems but had to advance by consensus because it lacked the power to impose solutions. Over the past five years its progress was, however, accelerating: activities like the creation of the Council for Health Informatics Professions were bringing together the Clinical and ICT communities and by the time the “National Programme for IT ” was announced, over half of all GPs (for example) used systems from one supplier. Many hospitals were similarly standardising and some of the major suppliers that had withdrawn from the UK Health Care market were beginning to regret that they had done so. Most importantly perhaps, the main

pre-condition for bringing computer systems together, the process of adopting common coding standards across the UK health care professions, was well under way.

Meanwhile, many doctors as well as patients were becoming impatient with the slow progress towards the more effective use of ICT to help improve patient care. Politicians were becoming similarly impatient to see results.

As a result the current government held a high level seminar, commissioned a central study and in 2002 embarked on the largest and most ambitious civilian IT project in the world, the National Programme for IT in the NHS, with a deadline for the first phase results in 2005.

An introduction to the National Programme for IT in the NHS (NPfIT)

The NHS National Plan is, however, not just about IT. It is what it says “The biggest change to healthcare in England since the NHS was formed in 1948”. It is part of an exercise to move control over patient care away from individual clinicians and into the hands of government - the business left unfinished by the Post War Labour Government. The mantra is “patient choice”. The last government had sought to put more authority into the hands of General Practitioners, seen as the “advisors” most commonly trusted by patients when they have a genuine choice and as a first step in a process of change driven from below. New Labour condemned this as “market forces” and has gone for the biggest centrally planned change programme since the original nationalisation programmes of the late 1940s.

Patient records are to be centralised (as well as put on-line), patients are to be allowed to choose between those options which NHS budget planners have agreed and integrated records are to be used to monitor the performance of all concerned.

The capital cost of the central and regional parts of the national plan were budgeted to cost £6 billion over the next 10 years. To this must be added any over-runs plus local spend on new equipment, software and support, estimated at up to £30 billion. There is a private sector rule of thumb that the ICT spend is commonly barely 10% (and rarely more than 20%) of the total cost of a major change programme. The rest includes matters like training staff to use the new systems and cleaning and loading data files.

Hence both the eagerness of those product and service suppliers who see major business opportunities and the concerns of clinicians who see an attempt to transform the NHS being driven and organised by those with no track record of consultation, understanding or success.

The cornerstones of the National Plan are a £64.5 million national system for electronic booking of hospital appointments, a £620 million care records service giving patients in England access to their electronic health records (the National Data Spine), an NHS broadband infrastructure and a full electronic prescriptions service. This has been put on a rigid implementation timetable by the government with punitive penalties for non-compliance.

Hence also the concerns of those who fear that failure will be used to tarnish the UK ICT industry and profession as a whole - because a massive, centrally planned, top down transformation programme is not only being imposed on users who have not been well consulted, but is being done at a speed which compounds the risks, with most of the conventional early stages of any information systems engineering programmes (such as feasibility studies and pilots) having been bypassed or truncated. Even if the systems do what

is contracted (and given the reputation of some of those concerned that is highly likely) they may well not serve to improve patient care without major change.

Aims of this paper

The aim of this paper is to explore the issues involved with the implementation of NPfIT and to provide a vision and direction on how to move towards systems that really will help our health care professionals make effective use of ICT, at all levels, to improve patient care at a price we can afford.

Chapter One: Where our Healthcare Information System Stands

Introduction

Twenty years ago the then Chief Executive of the National Health Services, (Sir Len Peach, previously personnel director of IBM UK) pointed out that the NHS was the third largest employer in the world, after the Chinese and Russian Armies and significantly larger than the fourth, the Indian State Railways. As such it was too large and complex to be centrally planned, directed and managed. His task should be to devolve authority to those in a position to know what they were doing. This was not a popular message and the Conservative Government had barely made a start before New Labour reversed the process.

The failure of the public sector and its suppliers to deliver large IT programmes

The NHS is still the third largest employer in the world (the Russian Army has shrunk but the Indian State Railways has grown). The current National Plan is the largest civilian computer project in the world, ever. As the Public Accounts Committee Reports of the past decade, not just the recent Select Committee Reports into the Child Support Agency and the Department of Work and Pensions, point out: *the UK public sector and many of its suppliers have serious credibility problems with the delivery of large programmes.*

The reasons are the scale of outsourcing over the past decade or more (leading to a dearth of in-house skills); the neglect of the UK professional and technical ICT skills base over the same period (especially with regard to information systems engineering as opposed to “mere” technical skills); and the cycle of bad practice leading to top-down commitment to contract driven programmes before any serious feasibility study or user consultation. There has been widespread neglect of the people disciplines necessary for success: beginning with clarity of objectives, priorities and responsibilities.

According to a series of articles in Computer Weekly *the National Plan for IT in the Health Service* fits that cycle: having begun as a top down exercise (supposedly after a Number 10 seminar chaired by the Prime Minister), having bypassed the Gateway review of the business plan and with the Director General recruited after the event, with a massive budget to “reverse engineer” already published implementation commitments. There is little evidence of consultation with the users: who-ever these may be or however they might have been defined. *The process has been described as “classic NHS management: name a principle of good practice and the politicians will mandate the opposite”.*

The other reason is the sheer scale of UK public ICT projects. All other nations with populations approaching that of the United Kingdom are decentralised. Many, perhaps most, of the functions that are handled by Whitehall under legislation passed by Westminster, are commonly devolved to State Legislatures, Regional Administrations or Local Government. No other governments even try to organise centralised programmes of the size of the NHS Plan for IT. But in 2002 the current government embarked on the largest and most ambitious civilian IT project in the world, the National Programme for IT in the NHS, with a deadline for first phase results in 2005.

The death of the small supplier

The UK private sector, like most other governments, has moved away from large integrated projects to programmes of structured and phased evolutionary change. Some of these may be large and ambitious, such as the current rollout of chip and pin cards across the banking system, but they are phased over much longer timescales than that for the NHS National Plan.

None of the current lead NHS suppliers has experience of bringing in any comparable project to time and budget. *The side effect of concentrating on a limited number of large, often US suppliers, has been to damage the UK market for smaller suppliers.*

Small and medium-sized enterprises currently support most of the clinical ICT systems used by the NHS and for over twenty years have the main focal point for innovation in health care systems, including the funding and organisation of UK contributions to relevant international standards activities. Policy in other areas has been to encourage British enterprise and the use of international standards. The NHS is doing neither.

Chapter Two: The impact of the National Programme for IT in the NHS (NPfIT)

The GP IT System

Most General Practitioners use systems from a handful of suppliers who won their market dominance by reliably delivering what doctors wanted at prices they were willing to pay. As a *result UK GP systems are more advanced than anywhere else in the world*

The current systems have been criticised on the basis that:

- systems do not do not talk to each other, so when a patient moves from one practice to another all the electronic records are printed out, forwarded to the next practice, then typed in again
- they do not send prescriptions electronically to pharmacies which again forces retyping of the data

The necessary facilities have been developed many times in the past. It is DoH inertia that has prevented their introduction. *Used, trusted, reliable systems appear about to be replaced with less functional new systems from new suppliers over which doctors do not feel they have been as well consulted by as their previous suppliers.*

This is a consequent risk to patient care because many GPs have built practice services around their IT. There will be significant disruption to these by the imposition of new and possibly less useful systems. There is also a risk that if the new systems are accepted as fit for purpose by NHS ICT staff with inadequate input from the GPs who are to use them, suppliers may not be motivated to listen to their users and swiftly introduce any changes requested. If the users do not control the budgets, how will we ensure that suppliers have the necessary incentives to respond to their needs?

At the time of writing NPfIT or Connecting for Health as it is now called has agreed that GPs can have choice of any recognised system. This means they can continue to use EMIS via a CSC contract but they have varied the terms so a GP can have a system of any of the GP systems suppliers that has a contract with any LSP i.e. any GP anywhere in England can now use EMIS.

Hospital systems, procurement issues and legal liability associated with NPfIT

The UK market for hospital systems was, by comparison, until recently fragmented and immature because most reputable suppliers had walked away after the failure of a series of over-ambitious projects and an overly bureaucratic, cumbersome and fragmented procurement process.

Those running the National Plan deserve praise for the professionalism of their central negotiations with large ICT suppliers, but the attempt to move rapidly towards integrated national systems, delivered by suppliers with little or no recent in-house practical experience in this market, involved high risk even before consultation processes were truncated in order to meet delivery deadlines.

It is also noteworthy that several of those with practical experience of doing this in the UK (e.g. recent NHS “flagship projects”) or in other parts of Europe failed to win the contracts on offer, sometimes because their parent companies were unwilling to underwrite acceptance of liability for problems over which they had no control, sometimes because those who won were not willing to subcontract to those who already had operational systems.

One of the pre-conditions for success in any project (large or small) is continuity among the management team, on the user as well as the supplier side.

The NHS National Plan is about to have its second change of “Senior Responsible Owner” inside 18 months: John Bacon replacing the joint SRO’s Aidan Halligan and Richard Granger. Further major staff changes took place on March 31st when the National Health Service Information Authority was abolished with its infrastructure tasks transferred when the National Programme for IT became an executive agency of the Department of Health and assumes a new title, Connecting for Health. Likewise the Health and Social Care Information Centre becomes a Special Health Centre National. There are allegations of staffing problems with regard to the new centres, both on the part of the NHS and its suppliers, with staff at the existing locations unwilling to transfer and difficulties in recruiting the skills needed as the ICT skills market recovers.

A national Audit Office investigation is under way and a number of lawsuits are now in process (believed to include some from existing suppliers to the NHS who have been excluded by the new lead suppliers, who may also give evidence to the new OFT investigation into public procurement processes).

Issues of consultation

NPfIT has apparently moved ahead very rapidly under strong political pressure from the top without consultation of either the eventual users of the systems or of those people with practical experience of implementing health information systems. There is a large body of such experience and skill within and in other parts of the world. Very little of this has been used in building the NPfIT solutions. ***The imposition of one-size-suits-all solutions is also destroying those parts of the NHS that have in the past been described as “centres of excellence” in their use of information*** because their systems, from medical imaging through integrated on-line hospital records to local and regional care networks (linking patients, GPs, Practice Nurses and Consultants with regard to ongoing treatment as for Diabetes).

The proposed National Data Spine

Currently the model is to have a central National Data Spine containing all the information collected by local services. With the exception of some (detailed) hospital admission data every system will have to send details of every patient encounter to the Spine. ***This will result in one central repository of patient data with all the risks of security and confidentiality that imposes.***

It is technically very challenging and there is no evidence it can be constructed in a usable manner. Recent problems at the DWP and the Police Fingerprint Database indicate the vulnerability of centrally controlled on-line networks and the problems are not confined to the public sector. A fire in a communications tunnel under Manchester took out much of the communications of the North West for hours on end. A JCB operator working on the M11 managed to similarly sever much of the communications of the East of England, although the standby routings of the main operators meant that many users noticed no more than a blip in

service. Many hospitals however, let alone GP surgeries and local health care services, still have most or all of their communications routed through local single points of vulnerability without such alternative routings.

The alternative of a “thin” Spine that just serves as a directory for local systems to communicate with each other when necessary has been dismissed. But such a “thin” Spine would leave the sensitive data on local systems under the control of those who entered it on behalf of their patients, is less vulnerable to unauthorised access or central system failure and appears to be much more acceptable to both professionals and patients.

The task of the opposition should be to provide constructive and helpful comment and put forward a strategy for remedial action when a misconceived plan falls apart in lawsuits and acrimony.

Recruitment Problems in Public Sector IT

NPfIT suppliers have been grouped into four local service providers serving five “clusters” which in turn serve twenty-eight strategic health authorities.

Given the current number of large public IT projects and the recovery in the private sector market ***there are rapid shortages of information systems engineering and management skills, although not of those technology skills which can be outsourced to the far side of the world.*** The UK IT industry and professions have neglected such skills since before Y2K and dotcom boom and bust, focussing on technology training rather than developing analysis, application and implementation experience. Those seeking to recruit them on the open market therefore face rapidly increasing difficulties.

There are no rapid solutions to this problem but it appears that rather than tackling the underlying long term issues and tailoring short term plans to the skills available, government seems to be more concerned with a stick and carrot approach: penalise suppliers for non-delivery while offering cash incentives to users to implement elements of NPfIT e.g. the use of “choose and book”, whether or not it improves patient care, to rigid targets and schedules.

The need is to greatly reduce the risk of failure or resistance by focussing on that which can be delivered reliably, given the resources currently available, (people and time not just money) which directly helps those seeking to improve the care they provide to their patients.

Chapter Three: The Vision of Optimal Digital Health Information System

Access to patient information

The provision of optimal modern medical care is increasingly dependent on the rapid availability to health care professionals of accurate information on the treatments that a patient is (or has been) receiving from a variety of sources.

That information is commonly fragmented over a variety of records, many using different (often incompatible) data types, file formats, coding conventions and coding structures, with different levels of accuracy and confidentiality, let alone different computer systems or technologies. It is said that the consequent cost of delay and incompatibility, let alone inaccuracy, can be counted in unnecessary suffering and death, not just wasted time or money - although the evidence for this appears to be anecdotal rather than statistical.

To achieve the goal of accurate and relevant information available, when and where it is needed to improve patient care, information has to be collected and checked at the point of patient contact. There is much evidence that collecting data afterwards leads to delay, error and unusable (or even dangerous) information. But clinicians will not use computer systems that render their work difficult or interfere with the time they can spend on patient care. The systems must be seen not only to provide added value in patient care, but also to save the time of those whose skills are the *raison d'être* of the NHS, otherwise they will not be used and will fail.

Proposed strategy

The strategy most likely to succeed is to enlist the informed support of healthcare professionals, patients and would be suppliers of systems and services, in setting realistic and trusted frameworks within which practical progress can be made.

Once that consent has been gained *the need is then to ensure step by step progress within those frameworks, avoiding both the pursuit of grandiose “national” projects of the type which have previously failed so expensively and the concentration of scarce resources on prestige centres of excellence whose systems can neither be replicated nor joined up.* This is not easy because it requires the co-operation of a wide range of professionals in the application of programme and system development and application disciplines which they regard as a mundane distraction from their “real” job, patient care.

The position is complicated by current contractual arrangements with major suppliers, many of whose staff are convinced that because they understand ICT, they know best. It is becoming increasingly likely, however, that the suppliers will wish to see changes rather than take the blame, perhaps very expensively, for another set of high profile disasters.

Use of National Audit Office

The solution is probably to use the National Audit Office review to identify the changes necessary to ensure that suppliers can and do consult and work direct with the various interest groups, nationally and locally, to improve the prospects of success. The key is probably to move away from centralised, standardised, one-size-fits-all, solutions and towards the adoption (at all levels) of common frameworks for sharing that information which is already available, and to build on these, step by step, over time.

Use of open source software

This is software whose source code is openly published, usually available at no charge and has a licence allowing the recipient to develop, modify and use this code.

Closed code software (commonly protected by copyright, patent and confidentiality agreements) has problems of incompatibility, inflexibility, lack of customised support and unresponsiveness to user needs by dominant suppliers. It leaves little room for the evolutionary modification and development of software, in the light of experience from every day usage that lies at the heart of, for example, the development of the Internet.

In consequence we can see a common trend among major suppliers to meld open source and closed code in customised solutions for their major customers and for large customers, such as governments, to demand the right to re-use solutions for which they have paid and/or to multi-source maintenance and support.

Few NHS organisations have the in-house IT expertise to develop, implement and maintain their own information systems. Many would, however, benefit from being able to multi-source installation, training, on-going maintenance and other support across local suppliers competent to work with the systems of major suppliers, without having to wait for replies from the centralised help desks and support centres of large suppliers.

Objectives

If the objective is seen to be the improvement of patient care, including by making better use of the budgets and resources available, with open and accountable ways for reconciling conflicting priorities, then the process of moving from confrontation to co-operation should begin. Talk of using ICT to enable the introduction of choice and market forces should also be in the context of GPs or hospital clinicians being able to help patients to make informed choices; with nurses, who commonly spend more time with patients with chronic conditions and who use proportionately more resources, being motivated and able to keep them informed about progress: another dimension to “putting the patient at the centre”. Key to this process are credible and reliable frameworks and processes, not just technologies, for data sharing.

Approaches to system design and implementation

There are three main approaches to system design and implementation: -

- Big Bang – Rebuild the Universe

- Delayed Big Bang – Plan very carefully for the next four or five years then rebuild the Universe to a precise specification.
- Evolution – Piecemeal step-by-step improvement within an overall strategy but without total initial commitment.

Although the National Plan will be rolled out in stages across the country, there are still many similarities with the “Big Bang” approach of which it was said (in 1991) “has led to too many expensive fiascos to retain any credibility”. Most computer companies have switched to an evolutionary process for their internal computer systems and for package or operating system development, but do not recommend it to their customers because it gives little opportunity for spectacular promotion-earning sales campaigns.

Thus we have the popularity (especially among consultants) of “Delayed Big Bang”; which twenty years ago was known as “Bay of Pigs” because the CIA spent many years planning that operation in meticulous, secretive detail before going ahead. This approach gives many opportunities for lucrative business and evaluation exercises with much enjoyable intellectual exercise and wining and dining, plus the near certainty that the “high-flyers” will have flown on before the implementation is due and the chickens come home to roost.

“Delayed Big Bang is based on false premise that that given enough study, one can design a fully workable and stable system to meet user requirements in a cost-effective manner. The reality is that hardly any users know what they want in sufficient detail to do a sensible specification and, if they do, they wouldn’t have wanted it at the resulting cost.”

The long preferred approach of both experienced ICT professionals and information systems engineers, is structured evolution - trial systems with a responsive computer department or supplier to enable users to quickly sort out from the options offered what they don’t want, what they can afford and what they are prepared to pay for. Over a couple of weeks or months of use their views change: new functions will be requested and can be dropped. The systems are then refined and rewritten for scalability and ease of maintenance and documented. This approach has had various titles over the past twenty years, including “Rapid Application Development” and “Dynamic Systems Development” but the main change has been that timescales have shortened from years to months and sometimes even weeks, as methodologies have been refined.

Chapter Four: Balancing Patient Care and Data Protection

Problems with information exchange and duplication

An increasingly common patient complaint is the need to give the same basic information at each stage of their treatment, because, all too often, essential information has not been passed on or because staff have no confidence in the accuracy of what they have been given. Even if a patient is admitted to a hospital that has treated them before, it is rare for the accident and emergency department to have early access to their records, while GPs rarely have good access to hospital information on their patients and vice versa. Meanwhile vast amounts of treatment, prescription and reaction reporting information, routinely logged over nearly twenty years by GP and Hospital systems is still not available for use in epidemiological research.

Much is said on the need to protect patient data from abuse but little actual data on patient views is advanced beyond anecdotal evidence of abuse and lack of trust. Three years ago the NHSIA commissioned MORI to collect views and the results showed widespread support for the open sharing of information between health care professionals (98% happy for their GP to see their record and over 80% for Hospital Clinicians concerned with their treatment), significantly less support for information being made available for medical research (about the same as for it being available to those managing the health service) and 43% against their medical information being available to practice administrative staff and 36% against access by social workers. Given the amount of information that is routinely passed to administrative staff to enter or which they are asked to look up and pass to the Health Care professional this means that multiple levels of confidentiality regarding the content of medical records are essential for expectations are to be met.

Protection of privacy

Many of the systems commonly used by GPs and specialist clinics have long had facilities for “sealed envelope” information available to named practitioners only for when patients may not wish some parts of their medical records to be available to their GP (e.g. young girl on the pill, who does not want her family doctor to share this with her parents or an individual with a sexually transmitted disease who may be sensitive about any other than their contact in a specialist clinic being aware). There are also some well recognized conditions (for example psychiatric or with diminishing frequency oncological) or combinations of conditions and individual patient requirements in which it may not be recommended by clinicians or desired by patients or relatives that they have access to all components of their clinical record.

The best protection of privacy is that health care professionals are responsible for their own conduct. They have confidentiality built into their professional codes of conduct and patients trust them. Some data protection professionals argue that that this should be backed up by logs of patient record accesses so that staff know that any abuse would be detected. Not only could the system overheads from such an approach be substantial, but also the logs might be

even more susceptible to abuse. More importantly, the task is to ensure that the routine and secure use of patient information systems by those entering or accessing data that they need for the treatment of the patient is easy and that *non-routine* accesses are properly authorised and recorded.

A particular need is for practical facilities, routines and guidance for non-medical staff that may have access to subsets of information for whatever purpose or are asked to provide assistance to clinical staff.

Chapter Five: The Problems of Data Accuracy and Compatibility

Recent exercises to check the accuracy of data entered by clerical staff into public sector systems where accuracy is supposedly important (from health care to police and criminal records) have commonly shown errors rates from 10 - 30%. Experience from the private sector has long been that only data entered at the time and place of transaction by those with a direct interest in its accuracy is likely to be reliable.

One of the biggest problems in the health service is to move towards direct data entry by health care professionals without increasing their net workload. Another, equally important, is to move towards standard and compatible terminologies from a situation where not merely many different terms be used but the same term may mean different things to different people in different systems.

The coding structures used in secondary care are often different between specialties or hospital practices - this can be a particular (and occasionally catastrophic) problem for those who may be called on to work long hours shortly after changing hospital or department (such as junior doctors). *The utility and compatibility of clinical coding systems has been an ongoing and significant problem for many years.*

Chapter Six: The issues of Consent and Data Protection

Patient consent

There is confusion as to the requirements for patient consent to data transfer under current Data Protection Act legislation. This is compounded by various items of legislation requiring the sharing of information with regard to, for example, law enforcement, child protection and human rights.

The Act does not of itself require the consent of patients to the processing of data for medical purposes. However, because there is a general requirement that all processing of personal data is lawful and because in many cases the general law (including medical confidentiality) requires that patient consent is obtained for the processing of personal data, then consent becomes an implied requirement of the Act.

There is a requirement for “data controllers” to advise patients of the data controller’s identity, the purpose or purposes for which the data is intended to be processed and any further information which is necessary, having regard to the specific circumstances in which the data are to be processed, to enable processing in respect of the patient to be fair.

Issues surrounding data matching

Any matching exercise needs to be lawful, which requires not only compliance with the Common Law duty of confidence but also with other Statute Law determining the functions and powers of organisations intended to be part of the data-matching exercise.

The patient must be given information as to whether the proposed uses or disclosures of data would be mandatory or optional. Failure to provide this information might result in personal data being unfairly collected.

In deciding whether to offer an opt-out, data controllers should attempt to distinguish between those uses and disclosures of data which are essential in order to treat patients within the health service and those which are not.

The term “essential” is meant for those uses and disclosures without which treatment could not be given and those uses or disclosures which the law makes mandatory.

In effect, such uses and disclosures are necessary elements of the medical purposes for which it is proposed that patients’ data are processed. Since it is unlikely to make good administrative sense to offer patients the opportunity to object to the processing of their data for any “essential” elements, it would make little sense to provide an opt-out in this area.

Optimal model for patient consent

The means of ensuring meaningful patient consent must not be so onerous that medical care becomes too time consuming. This has happened in other countries. *The mechanism must be capable of giving a patient some control, not necessarily routinely, and not so restrictive that important information is not available to treat that patient when required.*

Patients unilaterally declining consent for the reasonable and justifiable collection and holding of clinical data or simple administrative data must expect to experience degradation in the range, quality, promptness, accuracy and suitability of the medical care that they receive.

There are circumstances in which such behaviour could additionally infringe the rights of other patients who would otherwise benefit from epidemiological research, and when such behaviour could be argued also to infringe the 'rights' claimed, often with misguided understanding or motivation, by those who demand accurate detailed information on the performance and experience of clinical services and individual professional healthcare staff.

Use of anonymised data

It is proposed that NPfIT will provide anonymised patient data for research purposes. This is data with all personal identifiers or codes removed and therefore, not subject to the Data Protection Act for its processing. There is an issue if health information is combined with associated non-identifying data e.g. age, NHS Trust or diagnosis date, it may be possible to deduce the identity of the patient. The likelihood is increased with the use of large interlinked databases or powerful search engines.

Chapter Seven: Availability of Data

Information officers v Data Protection officers

The split of roles between information officers who make information available and data protection officers who prevent abuse (with the consequent risk of adversarial approaches) is considered to be counter-productive. The priority should be the accessibility of shared medical data when needed to the clinician. Since there is a risk of information overload where an individual has a complex medical history, it will be necessary for critical medical information to be brought to the forefront of data presentation, so that it is not hidden in a morass of less important data

In order to ensure that information remains controlled, the current adversarial structure in which Caldicott Guardians' work to a set of principles focussed on protection should be replaced so that an Information Officer would have a Caldicott Guardian to deal with the clinical data, with accountability through an external monitor.

Paper records v electronic records – the issues

Traditional routines for handling of medical records on paper are regarded by many systems professionals as less secure than most electronic record systems. From the viewpoint of any individual there may be a trade-off between the current lack of security for paper records and the potential for improved security from casual or unauthorized enquiry that electronic systems *can* offer.

The status quo does however offer a different form of security by virtue of the difficulty that paper records pose for anyone wishing to collate all of “your” data, in contrast to the ease of collation, which in principle would be readily achieved across the many disparate databases that might be connected electronically.

By contrast, electronic records are potentially much more readily collated and more strongly protected. Once electronic security is compromised, commonly by human failure, the dangers of abuse are very much greater.

In large organisations, with multi-levels and circles of confidentiality and trust, the provision of effective security over electronic networks can become very complex. In order to address these concerns, any wide spread sharing of data across the Health Service needs to be accompanied by clear guidance as to who should have what access to which data under what circumstances, including how to check authorisation and resolve queries and conflicts when emergency access is supposedly required by someone previously unknown.

The Department of Constitutional Affairs is looking at the provision of such guidance at a generic level but it is almost certain that many parts of the NHS will need specific guidance and protocols that can be followed routinely, not just statements of principle. We know that the care records system has an audit trail but the details have yet to be published.

Chapter Eight: The US Approach to Digital Health Information Technology

The US is taking a different approach to establishing a digital health system.

In a recent report to the US government, eight of the largest technology companies have stated that technology standards need to be agreed for sending health data across the network and sharing information between hospitals, doctors, insurers and researchers. The arbiter of such standards should be a non-for profit company.

In contrast with NPfIT it has been recommended that a national network should not include a centralised database. Patients should control their own health records and decide whether to agree to use of their information in drug effectiveness studies and treatment.

The government's role should be to provide seed financing and incentives to help doctors the computer software and hardware to participate in the network.

Open non-proprietary technology standards should be adopted as the software building blocks for a national health information network.

Chapter Nine: Recommendations

As part of a programme of “constructive criticism” to enlist the support of all parties in making NHS ICT work in practice, the Conservative Party should call for:

- Non-financial details of all NHS ICT contracts, including performance monitoring and change control processes, to be placed in the public domain. Lack of public confidence means that any case for confidentiality must be balanced against the need to avoid allegations that it serves to conceal incompetence, inefficiency and corruption. The Freedom of Information Act provides the necessary framework and guidance has already been drafted by the Office of the Information Commissioner.
- “Time and motion” studies to check that new systems really are quick and easy for clinicians and/or others to enter and/or confirm data at the point of treatment/decision/transaction. This is crucial to the acceptance of new systems since there is widespread concern over increasing the clinical workload to generate data that does not benefit patient care.
- NHS Information Officers to have responsibility both for ensuring that accurate information is passed, when needed, to those authorised to receive it AND for ensuring that any abuse results in corrective action - and also judged on their ability to manage the conflicting priorities that will arise.
- Central indices of permissions for data sharing to be collected from patients at a convenient time (e.g. registration) with facilities for refinement and updating as circumstances and views change. Thus some-one reluctant to have their data used for unspecified “research” may be willing to take part in a specific clinical trial.
- Those patients who wish (and/or are able) to check and/or manage the use of their patient records should be given opportunities to do so as part of their involvement in their own health improvement: within reasonable and practical limits. Amendments made by patients should be clearly marked as such and not be seen to disrupt the legality of the medical record. Except for specific category restrictions, patients should be able to see their data at little or no cost and to request a review with clinicians or administrators, at realistic cost, refundable if significant error or any malpractice were identified.
- All involved in medical records should be given clear guidance as to what information can and should be made available to whom, under what circumstances and what should not. “All” should include subcontractors et al (where-ever they are located). The provision of that guidance should have explicit inputs from the relevant clinical and other professional disciplines.
- The concept of the Data Spine should be reviewed. Consideration should be given to making the Data Spine a directory for communication with all NHS local systems plus a limited summary of patient information.
- The software produced by the Local Service and Application providers should have the ability for other software to interface with it. This means publishing the

messaging standards and Application Programmer Interfaces (APIs): the means of allowing programmes to communicate effectively.

- Establish an Accreditation Process for all NHS computer systems, separately from NPfIT. This will ensure systems are monitored and controlled, both as regards functionality and adherence to standards for security, confidentiality and `data sharing.
- Promote use of open source software.

The delays in fulfilling the contracts are beginning to trigger non -compliance penalties on the part of the Service Providers. This gives an opportunity to renegotiate the contracts.

Chapter Ten: Proposed Action Plan

- All NHS ICT contracts, including performance monitoring and change control processes, to be placed in the public domain.
- Announce series of high-level round table workshops, involving ICT suppliers and clinicians as well as a cross section of Health Service Management, to discuss consultation and co-operation mechanisms with the National Audit Office.
- Extend National Audit Office terms of reference to include recommendations on how best to structure consultation processes with clinicians of all types (both hospital and general practice) and patient care groups to help ensure that systems also meet their needs
- Follow this by a proper analysis of the business processes in health care. This will ensure that the software solutions will solve the real problems not those deemed to be important by people who do not understand the environment.
- Announce timetable for production of practical guidance on information sharing with regard to health care information across the National Health Service and with those with whom external exchange may be required (including where it is not in patients benefit: benefit fraud, criminal offences etc.) This needs to include a review of Section 60 of the Health and Social Care Act 2001, which gives the Secretary of State authority to obtain data from medical records even if the patient has not consented, under penalty to the record holder of a fine of up to £5,000. There are concerns now about some of the orders made under this act.

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