

# A NEW IT STRATEGY FOR HEALTHCARE

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## 1 Introduction

The previous government had significant problems with healthcare IT. There were a number of serious scandals; some (like the problems with developing hospital systems) cost tens of millions of pounds of taxpayers' money; others (such as the London Ambulance Service fiasco) cost lives. Meanwhile, doctors have lost confidence in the Department of Health's Information Management and Technology (IM&T) Strategy and are vigorously opposing it on both safety and privacy grounds.

All this has compounded the National Health Service's morale and management problems, tackling which is a priority for the new Labour government. However, IT can both improve patient care, and improve the safety and privacy of patients' medical records — provided that it is deployed in a thoughtful way with the support of the medical and allied professions.

For these reasons, the Institute of Public Policy Research held a one day seminar on the 22nd July 1996 to discuss what could and should be done. The MPs present (Harriet Harman and Anne Campbell) asked for papers on the current state of play, the problems, and what might reasonably be achieved by an incoming Labour government after one, two and five years. The first draft of this paper was a response to that request; it has been updated following Labour's election victory to take account of the last nine months' developments.

## 2 Management Summary

The sensitivity of rationing access to healthcare led the previous government to disguise changes sought on economic grounds, often by presenting them as improvements to information systems. This enabled a large empire to be built by the NHS Executive's Information Management Group (IMG), which dominated central purchasing of IT systems in the health service. This approach guaranteed that systems would be oriented towards administrative rather than clinical needs.

They were therefore viewed with suspicion and resentment by clinicians, and this in turn contributed to their poor performance.

The IMG vigorously promoted an Information Management and Technology ('IM&T') Strategy, which attempted to yoke healthcare computing to the requirements of the internal market. It was explicitly driven by administrative rather than clinical concerns, and assumed that personal health information would be aggregated into large central databases in order to facilitate central control of provider activity.

One of its stated goals was an electronic patient record shared throughout the NHS, based on the assumption that this must be a self-evident advance. This was quite predictably opposed by the healthcare professions on ethical grounds: the General Medical Council takes the view that personal health information may not be shared without the patient's consent, and the positions of the other professional regulatory bodies are similar. The NHS Executive's response was to maintain that administrative 'need to know' was paramount; they tried to redefine 'consent' as informing the patient in general terms of the uses to which his information may be put, without giving the option of saying no.

An example of the strategy's effect became apparent in the Winchester constituency of Gerry Malone, the former health minister, where the strategy was implemented more quickly than elsewhere. Since the 6th of June 1996, his constituents have not been able to get confidential tests performed by their GPs. This is because all their tests are now entered into the local hospital's information system, where they are available to all staff on the wards and consultants in outpatients — even for highly sensitive matters such as HIV and pregnancy tests. (This made the Local Medical Committee extremely upset, and it surely had an effect on Mr. Malone's losing his seat at the election by two votes.)

In addition to the ethical and political problems, there are serious efficiency and safety issues with the IMG's approach of developing systems that are neither required nor designed by those who need to use them. It is well known that the likelihood that a large IT project will fail is inversely proportional to the degree of involvement that its future users have in its design. Yet systems were conceived in isolation by officials, put out to contract, and then introduced surreptitiously. Once they were in place, they were often found to be unworkable.

A number of spectacular system failures resulted, which cost tens of millions of pounds, and in some cases even human lives.

In addition to the direct harm, there was long lasting and pernicious harm done by the erosion of the clinical professions' confidence of in the competence of NHS top management, and by the suspicion with which new system developments were (in most cases rightly) treated. New computer systems were (in some cases correctly) perceived as an a means for administrators to influence more and more details of clinical practice. Doctors and other clinical professionals felt that their autonomy was being eroded, and that they were being turned into technicians who merely executed care protocols designed and ordered by people who did not practise medicine.

This was a destructive addition to the existing NHS problems of low morale and poor motivation due to capricious and occasionally conflicting demands from the NHS Executive. This has undoubtedly played its part in early retirements and severe staff shortages in both primary and secondary care. Tackling this low morale is a main priority of the new Labour government, and a new IT strategy will be an essential component of this.

In this document, we describe the main uses of computing in the NHS and what has gone wrong. We recommend that:

- the first priority of an incoming Labour government in healthcare IT should be to separate the management of the clinical and administrative aspects of IT, so that the latter can no longer dominate the agenda of the former;
- the proposed abolition of the internal market will remove the justification for most of the flagship projects currently being worked on by IMG;
- it would be desirable for the IMG to be abolished outright, and for two successor organisations to be created to cope with clinical and administrative computing respectively. Such radical action would enable large sums of money to be saved;
- IT strategy, policy and priorities should be set openly with wide consultation. This will minimise the number of unwanted or otherwise inappropriate systems that are developed, maximise buy-in by clinical staff and build public confidence.

As an initial contribution to this process, we suggest a framework for a future IT strategy for the NHS. We also provide some concrete suggestions of the tangible benefits we might achieve over a one year, two year and five year timescale.

### **3 What is going on?**

There are four main uses of computing in the NHS:

1. In instrumentation, especially in imaging systems
2. In general practice
3. In hospitals and community care
4. In central administration

Applications that might become significant in time include telemedicine (everything from remote keyhole surgery to email consultation with patients) and interactive medical encyclopaedias (the first author is currently helping to develop such a system). However the four types of system listed above account for almost all of today's operational systems. We will look at each of them in turn and briefly describe the opportunities and problems.

### 3.1 Instrumentation

A wide variety of imaging systems (ultra-sound, CAT, MRI) rely heavily on computers to produce recognisable images. This is the high-tech end of health-care computing, and millions of pounds are being invested — not only by the government, but also by the EU and charities — in topics such as image guided surgery and the automatic monitoring of tumour growth. This research has great promise but has both political and technical obstacles.

The political obstacle is the NHS wide network. Not only are its charges so high as to inhibit the widespread sharing of image data, but its code of connection stifles communication between the clinical departments that generate images, and the research departments that use them in further system development. This is highly undesirable; indeed, it should be a priority to improve the generally poor communications between medical research and the rest of the university sector. Many academic disciplines, including most of the scientific and engineering ones, are potential contributors to medicine. It is ironic that as electronic communication is opening up many new avenues, the NHS's new network appears to be closing them down in medicine.

The technical problem is that imaging systems have few common standards for the presentation of images, or for exporting images to other systems. A key step in facilitating the growth of telemedicine would be the distribution of software to translate images into common formats so that they can be used, for example, in general practice to guide follow-up care.

Given a solution to the political problem (which would require no more than the stroke of a ministerial pen) we expect that standard interfaces based on worldwide web technology could bring significant progress within a short time frame (in fact, software to convert from proprietary medical image formats such as DICOM to PC-readable formats such as JPEG already exists; it merely needs polishing and distribution). These would also be associated with a significant reduction in costs to the taxpayer.

### 3.2 General Practice

The large majority of GPs — perhaps 90% — make regular use of IT systems in their practices. Their systems are primarily directed at helping them handle individual patient consultations: typical tasks are the structured storage of records and handling paperwork such as repeat prescriptions, item of service claims and patient registration. There is little use of decision support systems in diagnosis (as the current financial arrangements discourage this), and limited use of reference sources.

The systems come from a number of competing suppliers, whose products are incompatible. The main problems seem to be in exchanging data between GP systems when a patient moves, or with systems used in hospitals or the NHS centrally. As far as we are aware, there have been no multi-million pound disasters;

but development energies are now being redirected by the NHS executive into providing links to central administrative systems rather than on improvements that would improve the quality of patient care. During the last few years especially, GPs have come to feel that the agenda of patient care has been hijacked for self-serving bureaucratic ends.

If this trend can be reversed, then the main short term gains could come from the interchange of clinical data. The presently troubled GP-hospital links project could be rescued and within one year GPs could get pathology and radiology results electronically — saving much time spent retyping paper reports, and reducing the risk of life-threatening errors.

Once GP-hospital links are up and running, the next step will be systems to transmit referral and discharge letters, and exchange other notes, using secure electronic mail. The problem here is that most hospital consultants do not yet have PCs on their desks; so although the communications infrastructure could be set up quickly, most GPs would have nobody to talk to. So further progress will depend on investment in hospital systems.

### **3.3 Hospitals and community care**

The situation in NHS hospitals is chaotic. Where IT systems are in use they concentrate on the control and administration of resources; there is a near total absence of systems designed to provide support for doctors, nurses and other staff who actually treat patients. The recent National Audit Office report refers to this.

Central attempts to control the specification of hospital systems have led to a greater uniformity in hospital systems than overseas, but this regimentation has not brought any perceivable benefits of cost, quality or connectivity. There have been some widely publicised disasters, with large sums of public money spent on projects which have either not been delivered at all, or which when delivered have failed to match expectations.

Many hospitals have their own local area networks, but are rarely connected to any wider network. Current attempts to build an NHS wide network are being resisted by the profession on safety, privacy and cost grounds. Thus there are very few examples of successful systems which allow data to pass between hospitals and GPs' surgery systems; as noted above, aggravating factors include the lack of standards for medical images and the lack of PCs on consultants' desks.

There have been no large failures of which we are aware in community care, perhaps because these services were organised more recently and computers are in general only used for office tasks such as word processing. Considerable benefits might be gained from networking with GPs and hospitals in the local community, yet the problems with the NHS network have limited this to a few sites.

Overall there is much to criticise in this area, although there are some successful installations. Significant progress could be made given better management, although the time taken to build a team and start making the necessary changes might mean a realistic time scale of 3–4 years. Shorter term gains could come from specific initiatives such as getting PCs on hospital consultants' desks so that they could communicate with GPs.

### 3.4 In the NHS centrally

The applications of IT within the NHS centrally are driven by administrative rather than clinical demands, and appear to be aimed at two goals: facilitating the internal market, and the central collection of personal health information.

The systems involved include the following.

- the NHS wide Clearing service. This aims to centralise all secondary care payments, which used to be handled locally. It will also provide information to health authorities on referral patterns, readmission rates and the like; yet such services are already available from commercial firms who work with de-identified data. Its main other function is to feed information on all secondary care episodes in the UK to:
- HES — the Hospital Episode Statistics database. This contains information on all secondary care episodes in the UK, and indexes patients by date of birth and postcode. This allows over 99% of all patients to be identified, and is a potentially serious privacy problem: many medical interventions of a confidential nature (including all pregnancy terminations and much treatment for AIDS) are carried out in the secondary sector and thus appear on this database. HES has thus become a point of ethical confrontation between the BMA and the NHS. This issue was 'kicked into touch' for the election by the appointment of the Caldicott and Bellingham commissions, but it will have to be tackled and preferably sooner rather than later.
- The NHS number and the Administrative Register. The NHS is allocating a number to each actual or potential patient, which can be looked up via the administrative registers. These provide a history of each patient's associations with healthcare providers, which clinicians also find objectionable; for example, visits to outpatient psychiatric clinics will become widely visible.
- The NHS wide network is meant to provide the backbone that will enable all these systems to work together. Unfortunately, its structure gives the appearance of offering a duopoly to BT and Mercury in clinical data networking; the prices charged are very high and users must undertake not to connect to any competing network service providers. Technologically it is obsolete, being based on the X.400 mail standard rather than the IP protocol suite that has prevailed in the marketplace. Its adherence to obsolete technology means that developments based on it will stand little chance in the export markets; it is also heavily criticised on safety and privacy grounds.

NHS IT systems are concerned solely with handling administrative data, and they do not even do that job well. They are almost totally isolated from clinical systems except, ironically, in the few aspects which clinicians find unethical. Where data can be exchanged, there seems to be an attitude that the data exists for the sole benefit of the managerial cadre within the NHS, and that this group should have rights of access to all manner of personal data which they do not actually need for their administrative tasks to be performed. Changes in format and presentation are made frequently and without consultation.

There have been a number of disasters in this area, with costs running into many tens of millions of pounds for systems which were not delivered, or did not perform when they were. Yet under the present arrangements, the administrative computing interest (and in particular the IMG) is steadily gaining control over computing in other sectors. They already control much of what goes on in hospital computing, and are extending their control to GP computing. This is doing serious harm.

### **3.5 The harm done by IMG**

The first aspect of IMG's increased control over GP and hospital computing is that clinicians in both primary and secondary care feel that they have less and less control over their work. Although responsible as ever for the wellbeing of their patients, the means to discharge this responsibility are felt to be slipping from their grasp, as they are directed to perform more non-clinical tasks. This has led to serious loss of morale. Senior consultants are looking to their pensions; jobs in general practice that drew hundreds of applicants in the 1980's now attract none; and despite a significant increase over the last ten years in medical student numbers, the staff shortage has got to the point of causing diplomatic incidents — the government of South Africa complained last year about NHS efforts to recruit doctors there.

The health of clinicians is also an issue. Both the level of serum fibrinogen and the incidence of coronary heart disease are known to be in inverse proportion to the level of control that people feel over their work. The drive towards central control can thus be expected to increase clinician morbidity and mortality, leading to a further decline in the quality of care afforded to other patients.

The next issue is the efficient use of public money. Well run companies delegate decision making as far down the structure as possible, and give workers as much control as possible, because they have found from experience that this is the most efficient way to make money for their shareholders. So for the NHS to centralise all information flows is contrary to best practice, as well as the EU principle of subsidiarity and the Labour concern for empowering local communities. It can also be expected to waste large amounts of taxpayers' cash.

The final issue arises from medical ethics, as we have mentioned above. If neither the privacy nor the safety of clinical information can be guaranteed to a reasonable level of confidence, then its utility is seriously impaired.

Clinicians are only now waking up to the harm that the strategy will do to the efficiency of the NHS, the working conditions of health care staff, and the confidentiality that has been a cornerstone of medical practice for millenia. The result is a rapidly accelerating loss of confidence in the IM&T strategy and in healthcare computing generally. If patients also start to lose confidence in the privacy of electronic medical records, as has happened over the last twenty years in the USA, then they will start to withhold information that may be important to their care<sup>1</sup>. The quality of care, and the level of public confidence in the NHS, will both be seriously affected.

Straightening out the mess will need a clear direction from ministers on how the NHS will develop. Will the internal market be scrapped, and replaced with GP commissioning? Will the NHS be a relatively decentralised service (as it was originally), or will control be tightly centralised, as the previous government wanted? Will an information management strategy be developed openly, with the participation and support of the labour force, or will government keep trying to sneak through politically delicate ‘reform’ by tinkering with computer systems?

## 4 How should we sort out the mess?

The view of most people involved in healthcare computing is that the IMG is hopelessly compromised by its history of past failure and by its visible lack of technical competence. Trust in it has simply collapsed, and with it has gone a lot of confidence in the government’s management of the health service. The quickest way to regain this confidence will be to abolish the IMG outright. But this will not be quite as straightforward as it seems.

### 4.1 The structure problem

At present, the effectiveness of healthcare computer systems appears to be in direct proportion to the level of clinical involvement in their design. Systems such as scanners and GP computer systems are generally designed with very significant medical input, and generally work well; but the administrative and hospital systems are generally ineffective.

We will discuss below why this is the case, but for the meantime we will remark that successful systems — such as GP computing — attract the envy of the administrators, who attempt to capture them in various ways. At present, for example, much of the development effort of the GP suppliers is directed towards implementing the NHS number and Item-of-Service links, for which they receive handsome payments from IMG. The result is that clinically useful

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<sup>1</sup> Three recent patient surveys show that only about 20% of UK patients are prepared to trust health administrators with personal information — a figure similar to that for social workers and government statisticians



developments get crowded out, and systems that were initially useful and well regarded are turned by degrees into systems that are more a source of frustration and resentment.

An example is given by Read codes. These were initially developed by a medical practitioner but have now spawned a bureaucracy that has been linked in the press with allegations of incompetence and financial corruption. There is much dissatisfaction among GPs with the system, and real concern about the way in which the next generation of Read codes is being developed.

Scandals of this kind may be inevitable so long as IT strategy is centralised in a body that is part of the NHS Executive and is therefore driven by their agenda. Simply abolishing the IMG and replacing it with a successor with a similar place in the organisational structure would not solve the problem. So it appears essential that a separate IT body be set up with responsibility for clinical computing and a separate reporting line to the Secretary of State.

#### **4.2 Splitting clinical from administrative computing**

As mentioned above, there are two options for splitting the clinical aspects of healthcare computing from the administrative. The first would be to abolish the IMG outright and replace it with two bodies, one responsible for instrumentation based computing, GP computing, hospital clinical computing and research activities such as telemedicine, while the latter would take care of administrative matters such as stores and payroll. (In fact, the IMG's origins lie in stores and payroll and there is a strong case for it never to have advanced beyond that.)

If this option were to run into serious opposition in Whitehall and ministers did not care to force it through, then the alternative would be to set up a separate clinical IT directorate and transfer the relevant responsibilities to it.

The personnel in the new clinical computing body should have little (preferably no) overlap with those currently employed in IMG. This is not simply a matter of competence, but of the culture that is needed to develop safety-critical systems successfully.

#### **4.3 Managing clinical computing**

At present, NHS systems are conceived in isolation from the healthcare professionals who will have to use them, contracts are let for their construction, and they are fielded in an almost surreptitious manner. This not only erodes the confidence of staff, but also results in poor designs that ignore the reality on the ground and are dangerous to patients. The systems' objectives are never clearly thought through; and although there are mechanisms for liaison between interested groups as to what services are required, these seem to be grudgingly offered, and in most cases the work of these groups is either ignored or relegated to a low priority.

Propagating this culture would negate much of the potential benefit of any reform. So it is vital that the new body have fresh top management — probably recruited from the better firms in the healthcare IT industry — and with a management board on which clinicians and patients' groups are represented effectively. It should act as a channel for funding developments of clinical merit. It should operate with wide consultation, and evaluate project proposals using the criteria of evidence based medicine. Indeed, its own performance should in turn be evaluated using these principles.

It is by now obvious that we need an open and public mechanism for identifying requirements and setting priorities. But we also need ministers and senior staff to participate in this objective setting process.

#### **4.4 Managing administrative computing**

Assuming that the internal market is to be replaced with other control mechanisms such as commissioning, there will also be a rare opportunity to move towards openness in setting administrative goals and interfaces whilst reducing costs. In fact, this is a strong argument for the abolition of IMG and its replacement by a new organisation with a different culture.

The logic of the internal market has in many ways shouldered aside the primary goal of the NHS, which is the diagnosis and treatment of patients, and the maintenance of the health of the population. Its successor should not be permitted to do that. Systems — whether primarily clinical, primarily scientific or primarily administrative — should be evaluated for their contribution to the overall mission.

#### **4.5 Keeping systems open**

Originally GP computer systems were modified 'off the peg' systems. The peculiar reimbursement structure imposed by the previous government has led to dedicated providers producing systems at horrendous prices. But there is no reason why so much has to be constructed especially for the medical profession, when many of the applications are common with other systems. Off-the-shelf products should be used wherever possible. We would not think of designing a special word processor or spreadsheet program for doctors — so why a special network? It would be much more economical (and lead to much faster system deployment) if NHS bodies simply used the best local network service providers. Universities often find that their cheapest network service provider is the local cable company; hospitals should also be free to go down this route.

Making an open computing environment work will require more attention to the detail of functional standards than is paid at present, and less to the detail of design and implementation. However this is necessary in any case and requires the attention of only a few capable people.

The political imperative is to keep open standards, and thus open competition, at the heart of healthcare computing. For this reason, it is essential that standards should fall within the jurisdiction of the clinical rather than the administrative computing body. The actual work can largely be subcontracted to universities, as is already the case with Britain's contribution to many IT standards committees.

#### **4.6 Legislative support**

Too much of what is proposed at present involves serious erosion of the rights of patients to have their medical records kept private, with access only where there either consent or an overwhelming public interest (such as preventing others from direct harm). A number of recent surveys make clear that patients have real concerns about the extent to which their records may be accessed by administrative staff, with no clinical requirement, or made available to commercial interests.

Thus the privacy and safety of clinical information should be considered at the outset of each project and the necessary mechanisms integrated into all systems, rather than being grafted on as a late addition. This could not be done effectively under the previous government, which created an environment where there were many competing pressures, most of which positively demanded the removal of privacy safeguards.

The BMA in particular was driven to the conclusion that patients' rights needed to be enshrined in legislation, and sponsored the 'Walton bill' which was blocked by the previous government. But legislation is required anyway under the EU Directive on Data Protection, and the Government has promised to work towards this. This presents a great opportunity for ministers and the healthcare professions to settle the medical privacy issue for a generation; professions and government should collaborate to ensure that appropriate safeguards are incorporated into the forthcoming law.

## **5 What might we achieve in 1, 2 and 5 years?**

### **5.1 One Year:**

The considerable savings that will accrue from abandoning the projects oriented to the internal market can be used to start new projects without seeking new funding from the Treasury.

This new investment must not be spent through the old structures, or the familiar problems will just recur in new forms. For this reason, we should split healthcare computing into separate clinical and administrative structures.

The confidence of the medical and allied professions should be regained by a decisive move from secret to open specification of healthcare IT systems, and a shift in emphasis from systems that enhance the power and control of administrators to systems that improve patient care.

As a part of this process, political structures need to be built to facilitate consultation at both local and national levels. At national level, we could have not just clinical unions and Royal Colleges but also patients' groups and special interest groups (such as the sufferers from blindness, diabetes, AIDS, and other chronic diseases). Suppliers, some of whom are both competent and well motivated, have a role to play in this activity, but for obvious reasons their role needs to be carefully defined and properly monitored.

A number of low profile but useful projects could be completed that would build confidence and start to reap the immediately achievable gains from health data networking. Links between GPs and hospitals would be high priority, and the lab links project could be rescued and fielded within a year or so. More capital intensive projects such as putting PCs (or at least network terminals) on every consultant's desk can be piloted in a number of districts.

In order to support the planned privacy legislation in a medical context, there will have to be guidelines on issues such as the use of anonymous records to facilitate clinical audit and research. The necessary mechanisms are available, having been developed in other countries, and are surprisingly inexpensive. The effects of this will include resolving the debate between the British Diabetic Association and the Department of Health over whether diabetes registers should be de-identified: by adopting the well-tested Diabcare standards from Europe, we could safeguard the essential interests of both patients and researchers.

Finally, a number of research projects can be initiated such as the delivery of medical records over the world wide web and the construction of regional research databases aimed at improving clinical care.

## **5.2 Two Years:**

Links between GPs and hospitals could extend to large-scale use of computer networks for appointment booking, referrals and discharge letters. This has the potential to eliminate a fair amount of the inefficiency in the current system. Waiting lists might not shorten by much, but confusion and frustration could be substantially reduced.

Web-based medical records could be piloted in a number of areas. These will give much better record access to clinical staff and also enable patients to view their own casenotes, X-rays etc., thus empowering them to take more interest in, and responsibility for, their condition.

The widespread use of email in the NHS will improve communications and enable administrative structures to be flattened.

If the diabetes register issue has by now been solved to the satisfaction of all parties, then it can be used as a model for the management of other chronic diseases. The obvious next step would be to develop a standard approach to cancer registries (where at present there is uneven provision across the UK). De-identified data can also be used to support GP commissioning, without the fierce ethical rows provoked, for example, by the centralisation of fully identifiable data in the internal market's Clearing service.

### **5.3 Five Years:**

Based on the experience of the pilots conducted in the first two years, systems have now been rolled out to the whole of the UK that tackle all the problems described in the above sections:

- The output from instrumentation and imaging systems will be captured and entered in web-based records that are available to GP systems, in wards, on the patient's home computer, and wherever the patient gives his or her consent. There would be only a small investment in equipment here, as many GP systems are already of a standard that they could display images that are adequate for follow-up care (if not necessarily for diagnosis), and the process of bringing all GP systems up to standard has already been assumed in the NHS's forward budgeting
- Hospital systems will be starting to give the same level of support to clinical practice that is available in the best GP systems today
- De-identified records will be available for research under suitable controls to prevent inferences being drawn about individuals. As well as providing evidence on the effectiveness of interventions, they will support local decision making about healthcare priorities, whether via GP commissioning or whatever other consultative structures emerge

This is our vision: open standards enabling an open information architecture that enables clinical information to flow to where it is needed while providing the necessary privacy and safety controls. This architecture will also encourage outcome measures, using qualitative as well as quantitative methodologies, and support decision making based on units that look after sensible numbers of patients, thus saving the enormous expense of accounting for individual patient episodes.

## **6 Principles for a Better Strategy**

The current modus operandi, of conceiving IT strategy in secret as a cover for organisational changes that could not in themselves be publicly defended, is not the way forward. The details of the successor strategy should be worked out in

a process of public consultation with the clinical professions, patients' groups, system suppliers and other interested parties.

We will suggest some principles as input to this public discussion. Following the best commercial models, we assume that:

1. Information should be collected once only, in order to cut costs and keyboarding errors. Where possible it should be collected by the treating clinician;
2. Information should be kept at the user level;
3. The information collected should be the minimum necessary to allow the collecting NHS worker to perform her work most effectively;
4. Persons requesting information from other levels and organisations must make an ethical case and must commit resources to cover the collection of that information;
5. Decisions should be taken at the appropriate level in the service;
6. Patients should be empowered through greater understanding of both their condition and their options.

In the following pages, we will expand on these somewhat.

## **6.1 Data collection by clinicians**

Firstly, the collection of appropriate information by the treating clinician should be a priority. This already happens in primary care; most GPs have personal computers and use them during (or immediately after) each consultation to enter casenotes. Most hospital doctors have still to catch up; they make paper notes which are typed up later (often months later) by a coding clerk. The problems with this system are well known and have been described by the Audit Commission; paper notes get lost, and even when they do not, coding errors are commonplace. These difficulties have helped wreck major initiatives such as KORNER and HAA in the past.

In any case, there is usually a backlog (of six weeks in a typical hospital) which means that discharge letters get back to GPs too late for effective aftercare. Many trusts have now tacitly acknowledged this by providing a minimal information letter which satisfies the auditor's requirements for purchasing, but can hardly be described as contributing to patient care. This mess seriously hinders current attempts to get GPs to take more follow-up treatment over from the secondary sector.

The main impediment to clinical computing at present is that only GPs have computers and access to electronic messaging services. This prevents the introduction of the three applications that by common agreement could bring most benefit, namely pathology lab reports, referrals and discharge letters. Changing these from paper to electronic form would save the average GP about an hour a day that is currently spent in typing data into the system, while manually

verifying that there is nothing requiring urgent attention. Of course mistakes sometimes get made, and there is scope for these to be reduced provided that systems are designed carefully.

The safety and security aspects have been discussed in the BMA policy and guidelines; essentially, personal health information should be signed and encrypted when sent between clinicians, both to ensure its integrity and to ensure that access controls are propagated in such a way as to enforce the principle of patient consent. The use of signed, encrypted electronic mail will also reduce the amount and the effect of lost mail, something many trusts and GP surgeries recognise as a constant problem. Finally, the universal availability of secure electronic mail would block the ‘social engineering’ techniques used by private detective agencies to obtain personal health information unlawfully (they typically phone up the patient’s GP or Health Authority pretending to be a hospital doctor involved in the patient’s emergency care).

## **6.2 Keeping the information where it is used**

Secondly, the debate on who owns the record, and what structure the electronic patient record will have, must be unambiguously and courageously resolved — preferably, in the view of the medical profession, by the primary legislation proposed in the recent Queen’s Speech. At present, the debate on these topics is not conducted in the interests of the patient as patient, or even of the patient as taxpayer; it is rather a cover for attempts by three separate groups (administrators, hospitals, and public health officials) to wrest control of the primary lifelong record from the general practitioner. The solution we suggest is in line with the EU directive on data protection and the BMA security policy: that the patient should control access to the record.

In practice, each clinician who is responsible for his care will keep an appropriate part of it as his agent. In most cases, there will be a lifelong record kept by the general practitioner; and where the patient is referred to hospital, another record will be kept there that will normally be opened with the referral letter from the GP and closed by the discharge letter to the GP. (The discharge letter might in principle consist of the whole record, but in practice a summary will be better in most cases.)

## **6.3 There should be enough information but no more**

This leads naturally to the third point, that information should be just sufficient. Providing more information than is required is a major reason for the growth of bureaucratic empires. It hinders effective decision making, whether clinical or administrative; data that could conceivably be relevant, but are not, will in most cases simply cloud the issue and prevent the really relevant and useful facts from coming to the attention of the decision maker.

In medicine there are also ethical considerations. For example, the established guidelines of the GMSC/RCGP Joint Computer Group laid down in 1988 that when a general practice sends clinical information to any external organisation, then either the patients affected must give their consent, or the data must be de-identified effectively.

These guidelines were ignored by the developers of the IM&T strategy, and this is one of the sources of the current conflict. There is no reason for patients to be identified in contract data (or for that matter in commissioning data). Even if the current internal market were to be retained, identifiers can be replaced with pseudonyms without preventing either clinical or financial audits. (De-identified, aggregated claims data have been used successfully for years in Germany.)

An example of pointlessly collected information is the GP's claim for contraceptive payment. This was based on a paper form originated by Barbara Castle when it was anticipated that there would be few claims. The following years have seen an almost total shift in provision of the service to GPs, who now supply most women with contraception at some point in their lives. Yet a claim still has to be submitted for each woman every year, and processing these claims occupies many staff at FHSAs.

The NHS is already implementing a move from paper to electronic item of service claims; but this will not improve the situation, as the information flow will not change. Indeed, from the patient's point of view things are getting worse. Under the old system, under-age women could and often did get treatment under false names, and for perfectly sound personal reasons. But the introduction of computer links between GPs and health authorities has meant that pseudonymous item of service claims are now rejected. The GP is coopted as a policeman; if he cannot find out the girl's name and supply it to the government, he does not get paid. This is in clear conflict with the objective of reducing the huge social and welfare costs of unwanted teenage pregnancies, and is also a form of blackmail of clinical staff.

A more efficient solution would be for a doctor to simply claim that 'on 22nd January 1996 I administered contraceptive treatment to one female aged 10-19 and two females aged 30-39'. Such bulk claiming can easily be audited against the practice's clinical database by the health authority's independent medical adviser, and could also be implemented using paper claim forms for those practices that prefer to maintain manual records.

#### **6.4 Information flows must be ethical and must be paid for**

Some points of contention have both ethical and financial aspects, and a good example is the wish of public health doctors to access the information held on GPs' computer systems. The approach favoured by the NHS Executive is to appropriate this valuable information to the centre, and this may be influenced by the fact that a single database containing all of Britain's medical records could



be worth two to three billion pounds. Comparable large aggregates of personal health information in the USA are valued at about \$75 per person; for example, Eli Lilly bought a prescription database on 56 million Americans for \$4 billion. This figure appears not to depend strongly on whether the data are used for research, drug marketing or credit reference purposes.

But the existence of such a large aggregate of valuable information will bring with it irresistible political pressure for legitimised access — and not just by researchers but also by banks, credit reference agencies, insurance companies, the police and security services, private detectives and others with less than altruistic motives. For that reason it will be solidly opposed by the clinical professions and the public, and this opposition will impede public health research.

But there is no need to prevent legitimate research involving the clinical information held in GPs' computer systems. It is already possible using the Miquet system for a research question such as 'what is the correlation between smoking and a first report of psoriasis among women aged 15-24' to be sent by email to GPs, and for answers to be returned that do not identify any patient. The main problem is the lack of motivation for GPs to assist researchers, and for administrators to act ethically.

Therefore, we propose the abolition of the present rule that GPs may not charge for extracting public health and other statistical information from their systems. As the record is, in our proposal, the patient's property, the GP would act as his agent, retaining a fee for this service; the patient might receive a discount on prescription charges, or even be paid directly in cash. An ethics body would monitor the trade in health information for abuse, set standards and regulate fees.

The effect will be that both patients and GPs will have clear incentives to collaborate with legitimate research. As many researchers work for commercial firms such as drug companies, there should be a net financial gain to the NHS; and in any case a market mechanism subject to patient consent is vastly preferable to the previous Conservative Government's attempt to nationalise the nation's medical records without consultation or compensation.

## **6.5 Decisions should be taken at the appropriate level**

At present there is confusion about the intended flows of control within the NHS. The idea behind fundholding is that GPs decide where their patients are treated and at what price. It is therefore illogical to duplicate control structures regionally, with HAs, and centrally, with the NHS Clearing system.

Much of the confusion seems to spring from the previous Government's lack of political courage; it clearly wanted the benefits of both centrally directed and market based healthcare without the disadvantages of either, and so naturally ended up getting the disadvantages of both without any visible benefits at all. This experience is also shared by other governments, such as that of Queensland,

which has moved since 1989 from a centrally funded hospital system to one based on contracts.

The confusion means that administrators at all levels seek to have all possible information flows available to them, so as to avoid either being accused of negligence, or being excluded on structural grounds when the political wind next shifts.

In the old system (in which clinicians were paid by the government on fixed rates and costs are contained by controlling entry to medical school), the state had no need for access to all or even most clinical records; a small sample was sufficient for government statisticians to predict trends and allocate priorities in so far as this can practicably be done. On the other hand, in an insured fee-for-service scheme where the GP was the insurer (as originally proposed for fundholding in the mid 1980s), the GP has both the money and the records, so he is under no pressure at all to share data other than with professional suppliers such as hospital consultants. The experience of other countries provides a number of other options; all of them require significantly smaller central information flows than the present strategy.

But whatever the course of action chosen by the new Labour government, ministers should bear in mind that substantial information flows to the centre are inextricably linked to the business case for employing large numbers of bureaucrats. Regardless of whether Parliament favours a traditional or fee-for-service funding structure, both the information flows and the number of bureaucrats can be greatly reduced — and indeed they can only be reduced — by local decision making. This is, we believe, squarely in line with Labour Party thinking on health.

## **6.6 Empower patients**

The excuse most often used by administrators in the course of building their empires is that the practice of medicine is inefficient, and that it can be made less so by using computers to ‘target achievable health gains’. Given the level of knowledge of actual medical practice shown by the documents emanating from the NHS Executive’s computer people, and given that ‘targeting achievable health gains’ is a standard euphemism for hiring more administrators, this claim need not be treated too seriously. However, we shall answer it for the sake of completeness.

It is found from time to time that certain treatments that had been used by generations of practitioners actually bring little or no clinical benefit when the outcomes are studied over large numbers of patients. Examples that have recently been in the news include ECT and D&C treatments for depression and menorrhagia respectively. Bureaucrats seize on such examples and argue that it takes a long time for medical research to be absorbed into practice. Should we not therefore use compulsion? Should expensive treatments of doubtful efficacy,

such as ECT, not simply be outlawed, or else relegated to specialist centres or to private sector healthcare providers?

However, public (and medical) confidence in such arguments is not increased by the recent behaviour of the NHS Executive in starting a scare about expensive contraceptive pills. Although some slightly negative findings had been published, they were controversial; both the clinical professions and the public got the impression that the real motive was saving money rather than improving care. Any reform that led to administrators taking decisions about what treatments were acceptable, on the basis of research findings that they were not qualified to assess, would turn out to be a political minefield.

In any case, the way in which alternative treatments are assessed may be about to change radically, as a result of the empowerment of patients by the Internet. Even if the NHS Executive manages to prevent doctors connecting to the Internet, they cannot prevent patients from accessing its resources, and the likely effects are not appreciated yet — whether by administrators, or for that matter by most clinicians.

In the old days, a patient might go to his GP and complain of a skin rash. The GP might say, ‘that’s just psoriasis, here is a prescription for some ointment’, and the patient would gratefully tug his forelock on the way out. But nowadays he can go to his PC and hit a web search engine such as Altavista; within seconds, a search on the keywords ‘psoriasis support’ finds a thousand relevant articles and displays their abstracts ten at a time. He can follow hypertext links to pictures from the University of Iowa College of Medicine’s Department of Dermatology, read the Mayo clinic on calcipotriene and Boston University researchers on calcitriol, and then read a bulletin board on which Californian GPs discuss the relative merits of efudix, temovate, mandelic acid, methotrexate, etretinate, intralesional steroids and azulfadine. Contrary views are there too; he will see the bleak assessment on UCLA’s student health service that ‘No medication which consistently reduces psoriasis has been identified’.

Eventually he will get to the US National Psoriasis Foundation<sup>2</sup> and within a short space of time he will have read far more about his disease than his GP ever did.

This may be the most significant change in the environment in which health care professionals have to work. Together with the death of deference and paternalism, and the growing belief in a therapeutic partnership between the patient and the clinician, it will radically change the practice of medicine. One aspect of this change will be to wrongfoot administrators who insist that patients get cheap treatments rather than good ones. However, patients will still need someone to listen to them; IT is unlikely to replace the GP’s ‘bedside manner’ (at least in the near future).

In any case, the assumption that information technology will cut costs has been disproved in many if not most industries. So current cost control strate-

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<sup>2</sup> <http://www.psoriasis.org/>

gies need reappraisal. They are based on centralising and controlling the flow of information in both directions, and while they could function in the more deferential environment of a previous generation in which doctors were trusted completely and ‘the man from Whitehall knows best’, they cannot be expected to function at all well in an environment in which patients are empowered and the flow of information about health is no longer under even professional control, let alone the control of any national government. This will mean that hard political choices will have to be taken in a much more transparent manner than previously.

The astute political approach may be to have rationing decisions debated in public rather than in Whitehall. This course of action has already been taken in Oregon and developments in this direction bear close monitoring.

## 7 Conclusion

The information management and technology strategy of the NHS is a failure. It was designed to help administrators build bureaucratic empires, and while it has been highly successful at this, its side effects are intolerable. These include a manpower crisis in the NHS, the destruction of patient privacy, and the entrenchment of cost control mechanisms that have no chance of working. The combination of crumbling standards of care and escalating costs can no longer be supported and a new strategy is urgently needed.

We have pointed out in this note what the new information strategy should do. It must be clinically oriented rather than driven by administrative agendas; a board in which medical doctors and other healthcare professionals outnumber computer scientists by about two to one should be about right.

However, the new clinical computing directorate must not wield the oppressive financial and coercive power of the current IMG. Systems should be developed from the bottom up rather than the top down. Hospital doctors should be allowed to purchase systems where they can make a business case, as GPs have been; the nature of these systems should be a matter of contract between the doctors as buyers and the systems houses as sellers, with minimal interference from the centre.

Only in that way is there a reasonable expectation that most of the features will be real advantages, proven at or originating from the coal-face. The role of the new directorate should be primarily that of a facilitator — helping to establish priorities through public discussion, funding research, and above all setting standards. But it must have the political clout to resist the inevitable encroachment by bureaucratic interests.

The flows of information to the centre will be greatly reduced, thus enabling large numbers of the health service managers hired by the previous government to be retrenched. Most care decisions will be taken by clinical professionals;

this empowerment will help reverse the slump in morale with its associated recruitment problems.

Civil servants may say that such a strategy will not work. This is nonsense: the last twenty years' experience of healthcare computing teaches one lesson above all others, that computer systems that have been developed by clinical professionals or under their supervision and control usually work and bring real benefits. On the other hand, systems developed by bureaucrats have a long history of failure.

The time has come to end administrative control of clinical computing, thus improving the quality of patient care and saving the taxpayer huge sums of money.

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