Special report editor
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SPECIAL REPORT

A NEW ERA

The revolution has started. How information is collected, and the technology employed to utilise it, is transforming. Now all clinicians have to do is embrace the changes and reap the rewards...

The information revolution is all around us – it's happening all across society and it can't be ignored. Expectations are shifting, the amount of information available to us each and every day is growing exponentially.

The government is committed to embracing this revolution and using it to transform the way public services are delivered, taking as much of the data collected on behalf of the taxpayer and making it available.

The government is also committed to changing the way citizens interact with public services, making them "digital by default" to make them more efficient and more convenient.

In health, we have started our journey with an information, rather than technology, strategy; information will persist far longer than the tools we use to manipulate it.

If we can gather and store information using standard definitions then we expect there to be many innovative ways to use it to benefit patients, including by patients themselves to shape service delivery and control their experience.

The consultation on the information strategy closed on 14 January 2011. It highlighted the need for patients to access and control their own records. This is a key building block in helping each of us take control of our own health and wellbeing.

> **'This approach is not intended as a substitute for face-to-face engagement'**

Other industries have shown that when consumers have access to information they take more control and provide feedback to services suppliers who use that information to improve their business.

As a patient I want to know how good my local hospital is, how often the clinical team I am seeing has done the procedure, how successful they have been compared to others and what waiting times look like. I want to understand the quality of the patient experience. I want to see all of this data in a format that suits me and at the time that I am making an appointment.

We take this kind of information for granted when we are researching other services. Managing your health is far more important than managing your holiday and yet most of us expect to spend more time researching that holiday.

Our aspiration goes beyond giving out information to helping patients "transact" with the health service online. If I can use my iPhone to find out that a bus is running late, why can't I be told that the clinic I expect to visit is running late?

For some the future may even include communicating with their clinician online. We already have examples where patients are emailing clinicians securely.

This approach is not intended as a substitute for face-to-face clinical engagement but rather to allow the face-to-face interaction to concentrate on the things that can best be delivered that way.

Clinicians, too, will see many benefits. We expect to improve the quality and availability of information by asking clinicians to capture it during the care episode. Comparative data will help clinicians compare effectiveness with those of other clinical teams.

We have seen with cardio-thoracic surgeons that this acts to drive up quality and performance, rather than create risk averse behaviour. We have started with an information strategy but we will also need to move forward with technology. If our previous technology strategy was characterised as "replacing" all systems in the health service, our current strategy is to "connect" all systems together.

This means, for example, that clinical teams will be able to use innovative tools to manipulate data and draw in data from core clinical systems, making decisions locally on systems that suit them best. Making this happen requires standards – both data and technical. The Health and Social Care Bill gives the power to set these standards for health to the National Commissioning Board. We have already started building tools to promote integration – the interoperability toolkit will be an important enabler to deliver a connected world of information in the most efficient way.

This is an exciting time to be working in health informatics. Nowhere else can the benefits of information and technology make a greater difference to the quality of our lives. ●

Christine Connelly
CIO for Health, England and director general for informatics, Department of Health.

Christine Connelly

BUILDING A RECORD OF TRUST

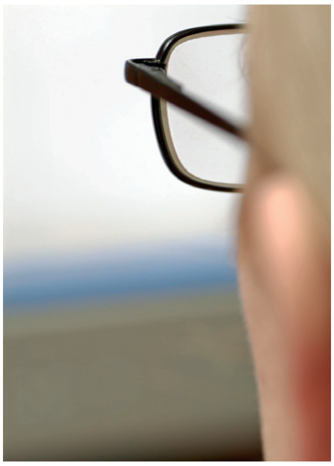
Allowing patients access to their own records has become easier thanks to the internet. It's obviously empowering for the patient but what are the pros and cons of opening the online door to clinical files?

Yvonne Bennett, 63, loves looking at her medical record. It is not that she is a hypochondriac, it just makes life much easier.

"I have an under-active thyroid," she says. "So I need regular blood tests in case my medication needs changing. Now I can look up the results online. If it needs increasing I get a message asking me to call the surgery or to pick up a prescription that will be waiting for me."

She also has osteoporosis and has been treated at several different hospitals for fractures. "Last time I went to the fracture clinic, I printed off the discharge letter from my physiotherapist and my osteoporosis scan. The nurse was absolutely knocked out by that. It saved her so much time." Mrs Bennett is a patient at Haughton Thornley Medical Centre in Hyde – which replaced the practice of convicted murderer Harold Shipman who killed an estimated 236 of his patients.

When Dr Amir Hannan took over the practice he started opening up GP records to patients. "Trust had completely broken down when I arrived here," he says. "People needed to check the information in their records. But I also felt it was a way to improve care."



'We do monitor for the obsessive compulsive. Most people check once and that indicates healthy behaviour'

Over time this has evolved to online access. Now more than 1,000 of his 12,000 patients have signed up to browse their entire records as well as make or cancel appointments, request repeat prescriptions and view test results online. In December 2010, 136 of them looked at their record. "We do monitor for the obsessive compulsive patient who is constantly checking their record but so far we have not seen this behaviour," says Dr Hannan. "Most people check once and that indicates healthy behaviour."

He is keener to talk about the positive impact. "This is all about working with the patient and building a partnership of trust," he says.

He cites one patient with kidney disease who recently reached the point of needing dialysis and, beyond that, a possible transplant. So Dr Hannan referred him to the hospital.

"But first he looked at his medical records, where I had added some links to credible information sources," says Dr Hannan.

"I got a letter back from the kidney specialist saying it was the best consultation he had ever had as the patient was informed and had all his questions ready."

Enabling

Online access by patients to their own health records is a cornerstone of the government's *NHS Information Revolution*; indeed the operating framework for 2011-12 contains an indicator for primary care trusts to measure just how many practices are enabling it within primary care.

The answer is not many. Dr Hannan reckons the number is 50 so far, of which 15 are in the north west. It is even rarer in the acute sector, where clinical systems and electronic health records are typically much less well developed. The Renal Patient View system now

PATIENT ACCESS IN THE ACUTE S

If you are a kidney patient being treated in a hospital, the chances are you will be offered a chance to sign up to Renal Patient View.

Through its website, you can view your diagnosis, your test results and find out more about your condition. It's currently used by more than 6,000 patients in two thirds of UK renal units.

"Patients are tremendously positive about it," says Neil Turner, professor of nephrology at The University of Edinburgh who set up the site with colleague Keith Simpson.

"Clinicians are often nervous at first and worried that giving patients information will make them anxious. What they are forgetting is that illness is worrying and uncertainty makes that worse. Patients who sign up to Renal Patient View take the risk of receiving bad news and for them it is better to know."

Clinicians soon change their minds with experience, he adds.

An issue of trust? Sharing records with patients can have many benefits

ALAMY

ECTOR

"They say that the quality of consultations lifts. Patients are informed already and instead of giving them bad news, the consultant can spend more time talking about how they are going to deal with it." Departments report taking fewer telephone calls to chase results.

Part of the success of the site is that it was build jointly by clinicians and patients who helped inform and test it every step of the way. Another part has been a good database – in this case and the UK Renal Registry.

The technical piece was relatively straightforward but the information governance was, says Professor Turner, very fraught. "There were lots of people who could tell us no, but no one who could say yes, you have this right." Renal Patient View is certainly a model for others, he says, and he has had discussions with colleagues in diabetes, heamatology and cancer about setting up something similar.

Renal Patient View is not the only example of patients accessing their own records in the acute sector. In some places, pathology patients can now view lab results online alongside informative data. The idea is also built into plans to develop electronic health records in forward-thinking centres such as University Hospitals Bristol and Rotherham General Hospital. In all cases, good IT systems are a pre-requisite.

But many remain cautious. Bibhas Roy, consultant orthopaedic surgeon at Trafford Healthcare Trust and a member of North West's healthcare informatics clinical advisory team, says: "It raises concerns in the clinical environment. First, clinicians think there is nothing in it for them, when there is. They say it is technically difficult and they worry about giving patients information that they cannot understand.

"Certainly we need to be very careful about all of this but really this is all about the doctor-patient relationship and how this has to change."

'While the principles of patients controlling aspects of their record is a good one, there must be safeguards to reduce the risks'

installed in two thirds of NHS renal units is an exception (see box).

It is not, however, universally supported. The most common concern – expressed by everyone from the BMA to the King's Fund to the Medical Protection Society – is that information sharing on the scale envisaged by the government could endanger patient confidentiality.

Dr Chaand Nagpaul, a GP and member of the BMA's working party on IT, has this to say: "While the principle of patients controlling aspects of their records is a good one, there must be safeguards to reduce the risks involved in sharing such sensitive data.

"Even if a patient validly decides to share part of their records, for example via an online support forum, they will effectively lose control once posting it."

New ways

Dr Hannan is alive to this – and in guidance he and a colleague wrote for the Royal College of GPs in September 2010 he noted: "It is important that all health professionals understand that new ways of working with patients become possible with electronic records. However, it is essential to apply these new ways safely and effectively."

One argument against giving patients access to their records is whether they could be disturbed to read that their doctor suspects cancer, for example, or whether it would allow them to see test results before the doctor. Think HIV in this context.

Dr Hannan disagrees. "There is a proviso in the Data Protection Act that talks about harmful data," he points out.

"But who decides what harm is? It may be more harmful to make you wait for data. I would argue that we should not be doing tests until patients are properly informed."

What about the patient with a mental health diagnosis who is under the care of a consultant psychiatrist but receiving care in the community from the GP?

Dr Hannan has experience of just this. "There are rules for record access," he stresses. "When we have a patient under secondary mental health care, we ask for the consultant's approval for record access." So far, they have been very supportive and in Dr Hannan's albeit anecdotal experience, it has reassured anxious and depressed patients.

There is also the question of access; not everyone has a computer or is able to use one. Dr Hannan and Mrs Bennett have worked with local libraries to set up computing for beginners to solve this.

"I have a friend who is 83, did the course and went to buy a computer," says Mrs Bennett. "She regularly uses her records online and is now in Facebook contact with her son in the army in Afghanistan as a result."

"I would say 80 per cent of patients can do it," adds Dr Hannan.

Mrs Bennett says her care has dramatically improved as a result of access to her own records. For the future, she says: "I may at some stage have to go into a nursing home and I want them to be able to see my records."

She intends to bequeath them to her children so that they can be sure about the family medical history too.

Dr Hannan, meanwhile, would like to see patients pester their own GP for access.

"There is a question of whose data this is," he says. "Even if GPs say no to start with at least it will get the conversation started." ●

CLINICAL PORTALS

Installing a whole new electronic health record system is a costly business. But with the use of an information portal access to patient data could be both a cost effective and speedy tool

With money too tight to mention, very few NHS trusts are looking to replace their entire IT system. Instead, they are looking to get a few more years out of the existing kit by integrating the individual software applications and adding a clinical portal that lets clinicians see all the information the hospital holds about a patient in one view.

Portals are a bit like Google, says Wayne Parslow, general manager of Carefx. "They trawl the information you hold in any of your applications and databases without copying that information into a warehouse," he says. "You can personalise how you want the information presented."

It's relatively cheap – think six figures versus a multi-million pound project for a new patient administration system with electronic health record. It's relatively easy – think weeks and months rather than years. And it seems, on current experience, to work rather well.

James Norman, director of IM&T at Royal Liverpool and Broadgreen University Hospitals is unremittingly positive about his new portal, built on the Carefx Fusionfx platform and designed to bring clinical data about individuals into one place and do away with paper notes.

A proof of concept last year found that consultants who used it saved an average 30 minutes per clinic. It drastically cut the amount of time nurses and ward clerks spent looking for notes. Doctors said it improved consultations as they could see all the information in one place and share that view with the patient rather than having to leaf through reams of notes.

'In my own practice [as an A&E consultant] I never have to call for paper records'

Full implementation

The trust signed on the dotted line for full implementation in December and expected the roll out to be completed by the end of March, including to GPs in Liverpool who will be able to see information about the care their patients receive. A new PAS and EHR would have cost millions (that the trust does not have) and taken years.

"It's fantastic the way it has been adopted," says Mr Norman. "I have consultants knocking at my door wanting to be first. We have 220 consultants in the trust and nearly 220 pilots waiting to start."

Suppliers indicate that demand is growing. Colin Henderson, managing director of Orion Health, told *HSJ*: "We have never been busier. On one day in January we gave five demonstrations to trusts." The crucial fact, he says, is that "clinicians like this technology and they are using it".

Take NHS Greater Glasgow and Clyde which implemented Orion's clinical portal in 2008-09, giving clinicians across the massive health board single sign-on access information about their patients including letters, pre-op assessments, operation notes, lab results and radiology results.

In one week in November 2010, more than 3,000 authorised staff logged in 27,000 times to examine in excess of 205,000 documents – treble the figures for a year previously.

"The rate of uptake has been exponential," says Malcolm Gordon, clinical director of IM&T at the health board. "It provides what clinicians need rather than what is easy for IT to provide. In my own practice [as an A&E consultant] I never have to call for paper records."

The devolved governments in Scotland and Wales have committed to developing clinical portals across the NHS and in Wales work is underway on the Welsh clinical portal. Not only will it give clinicians information about patients but allow them to access pathways and clinical evidence, help them to plan care and transfer information between care settings. It is now being rolled out across Hywel Dda Health Board and tested in three others.

Local developments

England has no such great plans. Instead, individual organisations such as Cambridge University Hospitals, Royal Liverpool and Broadgreen University Hospitals, West Hertfordshire Hospitals and Ashton, Leigh and Wigan PCT have led the way with their own local developments.

They are variously using clinical portals not just to bring together information about a single patient – and thus do away with paper notes – but also to access software applications such as test ordering and clinical decision support systems.

Mr Norman, meanwhile, has his eye on the future. Next steps include integrating digital dictation and developing a patient view. His only word of caution is this: "We are investing in our infrastructure to make sure we can support this. It is very important that once we start delivering the portal, we do not see systems start to drop in terms of their performance." ●

FOTOLIA

TAKE THE LEAD

The implementation of nationally-led schemes has resulted in a lack of expertise in project managing. Now IT leaders are being challenged to step up to the plate, says Alison Moore

FOTOLIA

The NHS is facing an information revolution that will affect every part of its internal organisation and how it interacts with increasingly IT-savvy patients. The quality of data will be crucial as organisations are judged and benchmarked against their peers. IT and informatics professionals will play an important part in bringing about this revolution – but do they have the skills to lead the revolution in their own organisations?

The signs are not good. Not only are there very few chief executives who come from an IT background, relatively few directors of IT have seats on boards. Typically, they report through the director of finance and depend on them to get support for projects and to explain their importance.

Difficult step

Rotherham Foundation Trust chief executive Brian James, who has spent much of his working life in IT, says it can be a struggle to find good examples of successful IT implementations for boards to follow.

His own trust is planning a £30m investment in an electronic patient record that will revolutionise the way many staff work and potentially deliver huge efficiencies and productivity gains. But even with his expertise and vision, it has been a challenging and difficult step to get agreement.

He warns that the preponderance of nationally-led IT schemes over the last few years means that most trusts now have little expertise in project managing such big investments. The National Programme for IT, he says, failed to provide a mechanism for bringing forward IT leaders in local organisations.

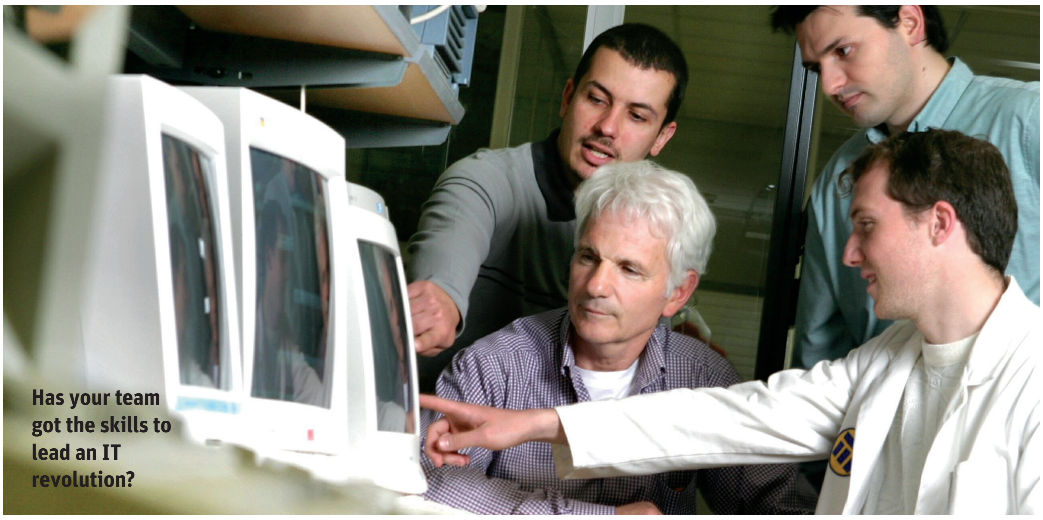
Those who are in positions of leadership now believe there is a lot of work to be done to develop the strong cadre that will be needed over the next decade or so – and they have some clear ideas about what exactly that should be. The cornerstones are developing leadership skills, developing career pathways, delivering the goods and engaging clinicians.

> **‘It’s not about people who can do the technical stuff; leadership is about having the vision’**

Martin Bell, director of assurance, information and technology at North Bristol Trust and one of a handful of IT directors on the NHS top leadership scheme, says leadership is not about people who can do the technical stuff; it is about having the vision of what difference information can make to an organisation and delivering effective patient care.

IT leaders need to stop focusing on IT and start concentrating on their influencing skills to gain board-level support, he suggests.

There is nothing like a few easy wins where the use of IT has improved patient care or saved money, adds Mike Denis,



Has your team got the skills to lead an IT revolution?

COLOURBOX

‘Skilled and strong IT leadership across the NHS holds the key to achieving our vision of improved outcomes’

director of IT strategy at South London and Maudsley Foundation Trust. An electronic patient record system – later linked to a research and information system – has successfully raised the profile of IT at his trust.

“I would point to the board itself, its culture and its interest rather than whether someone has access at that level,” he says. “We have a board that is highly enthusiastic about IT.”

With the decline in NPfIT, he expects to see a shift to more tactical solutions to individual problems – which may deliver the much-needed easy wins and boost confidence in further investments.

Career structure

But IT leaders need to feel there is a career structure they can access. Matt Swindells, head of the health section of the British Computer Society, says there are many competent IT managers in the NHS who lack the opportunity to move upwards.

Mr Swindells – who is now vice president of global consulting at Cerner and was previously chief information officer for the NHS – contrasts their position with that of nurses who have well-defined pathways of progression to director of nursing posts. There is no such well-trodden pathway for IT professionals. IT managers tend to have technical expertise rather than strategic expertise – and that strategic view is important if IT managers are to rise through the organisation into board positions.

Brian James says IT professionals need to widen their experience if they want to get a chief executive’s chair. He moved from being an IT director in charge of 70 people to director of business development with a part-time secretary to ensure he got that wider perspective. “You have to take the step sideways and get some real operational experience,” he says.

Mr Bell says potential IT leaders need investment – not necessarily money but coaching, mentoring and developmental support.

They need to be able to cut their teeth on progressively bigger projects.

However, as the NHS fragments with new community service providers and hundreds of commissioning consortia, the demand for talented IT professionals who are also leaders may outstrip supply. Mr Bell suggests that a shared service approach may help to spread these leadership skills around.

Christine Connelly, director general for informatics at the Department of Health, is alive to this debate. “IT professionals working at a senior level with their clinical and service management colleagues are pivotal to the successful delivery of our information strategy, which is due to be published shortly,” she says.

Improved outcomes

“Skilled and strong IT leadership across the NHS holds the key to achieving our vision of improved outcomes and shared decision making through the transforming power of information. We want to create a culture in the NHS where informatics is seen as a key part of a multi-disciplinary team and we will be working with regulatory bodies, professional organisations and training bodies to embed informatics skills into the workforce, attracting and retaining the best people from both the public and private sector.”

What Mr Swindells finds encouraging is that attitudes to informatics in the NHS are rapidly evolving.

“The last 12 months have seen a sea change in senior managers’ and chief executives’ views of information and the role of IT,” he says.

“They are looking at the size of the challenge they face going forward. Can you find any industry which has reinvented itself and cut 20 per cent out of its running costs and not used information to do it?” ●

WORKING WITH CLINICIANS

IT has the potential to transform the way clinical staff work – but spreading the IT gospel among busy doctors and nurses can be hard. There is a need to harness their enthusiasm for better patient care and meet their needs for information.

One idea is chief clinical information officers – senior clinicians with an interest in IT who could report to the medical director. They would be key to implementation of IT projects in clinical areas. Such posts are common in the US and becoming more so here.

Mr Swindells says they would drive forward IT in the clinical environment rather than IT being something that was “done to” clinicians. Candidates for such roles don’t have to be IT specialists or spend all their spare time playing with computers; it is more than they are interested in evidence based practice and want to use information to bring about change.

Mr Swindells believes numerate and IT literate clinicians would be candidates for such posts but “the issue would be making the post worth doing”. Empowerment is vital.

In the north west, a cadre of clinical health informatics leaders has arisen through engagement and involvement on IT projects.

Dr Andrew Coley, who leads on clinical engagement in NHS North West, says that the key has been not talking about “the kit” but about how information can help clinicians deliver the things they want for patients. The clinicians who are involved in the clinical health informatics network then influence their colleagues in local health economies.

At South London and Maudsley there is already a clinical lead for IT and an enthusiastic caucus of clinicians who see the value of IT. Mr Denis argues for a move from a model where the IT department dictated what was being developed to one in which it works with clinicians and others to decide and deliver what is needed. His own team was “shocked by this idea”, he says.

At the University Hospitals Birmingham Foundation Trust director of informatics and patient administration Daniel Ray reports to the executive medical director and has daily contact with clinicians. He says this structure gives a different focus to informatics around supporting clinicians with the information they need in a format they prefer.

For example, a nurses’ dashboard has been developed to give nurses a traffic light system on aspects of patient care. “Our role is very much as brokers, linkers and packagers of data,” he says. He has also found he has had to talk the language of clinicians to understand their needs better.

His boss – a technology enthusiast – is an effective voice for informatics at board level but Mr Ray concedes this might not be the case with all medical directors.