

## IT and Healthcare

There is still much uncertainty on how IT can help deliver better healthcare. There have been many articles in the press, on the radio and television and even in parliament on whether the route being taken by the NHS is one that is worthwhile and cost effective or not. Although there may be changes at the top, IT is here to stay and the likelihood is that the main thrust of the NHS IT programme (NPFIT) is likely to remain. We are after all moving into a digital world and we need to understand how to best evolve with this and manage the resources we have as effectively as possible. Even if we dislike IT (or perhaps distrust it?), there is a very challenging agenda of change in the way healthcare is delivered. Increasingly patients who were traditionally seen by doctors are now being seen by nurses and allied health professionals. Also there is a shift of patients from secondary care to primary care and more emphasis is being placed on patients to self-manage. The epidemic of obesity, diabetes, heart disease, osteoporosis, mental health etc is placing ever increasing burdens on a healthcare system that is struggling to keep pace. Continuing to do what we have always done will not do – we have to change the way we do things just to keep pace with the demands of society and to help deliver improved care.

There will be winners and there may be losers too. But it is important to try to recognise the paradigm shift that is inevitably happening and attempt to identify how we can best take advantage of this for patients and their carers, the clinicians and the systems supporting healthcare including medical institutions and pharmaceutical companies. IT could help but the case is yet to be made to convince others that this is what is needed now. Simply having more doctors or nurses is not the answer – we have to look at how we can make them more productive. Part of the solution lies in enabling patients to take more responsibility for their own health safely.

Having a joined up approach that involves the different stakeholders from amongst patients, clinicians, system suppliers, those regulating the health-care system, those involved in academia and research and pharmaceutical companies may well help to deliver a solution that is beneficial to all. Each stakeholder will have their own particular reason for getting involved in Records Access but it must be clear that the overall aim is to help deliver better care to the patient: in this new world, it is the patient who we are trying to support and which links all these different stakeholders together. But we must also recognise that pharmaceutical companies need to make a profit for their shareholders and clinicians have a duty of care to all patients – not just those who are interested in their own health and are willing to gain the benefits of records access. Similarly patients and their carers may well wish to have nothing to do with pharmaceutical companies and yet they wish to benefit from the advances pharmaceutical companies have made by investing in drugs and bringing them to the market. Research academia may be interested in demonstrating how records access helps deliver better care and may already have good relationships with all the stakeholders but they need to understand the key pressures that exist in the real world of medicine so that lessons learned can be fed back to the healthcare system to help move it forwards rather than being in some sort of ideal world that does not really exist.

### **Where can we go from here and what can we do to help support the change?**

There needs to be a recognition that change is needed and that there will be some pain to go through this change. I have helped develop some of these thoughts in articles I have written (eg [Be patient with IT and your patients will see the benefit JPG.doc](#)) or the presentation I did with Professor Mike Pringle as part of the GP engagement with CfH last year (<http://www.connectingforhealth.nhs.uk/newsroom/news/gp-engagement-forums-autumn-2006> see [16th November Manchester](#) and click on [Amir Hannan](#)). Furthermore, the recent joint BMA / CfH conference in Birmingham gave a further opportunity for us to share ideas with the wider clinical community and show case some of my patients and their views about the agenda ([www.connectingforhealth.nhs.uk/engagement/clinical/whatsinitforme](http://www.connectingforhealth.nhs.uk/engagement/clinical/whatsinitforme) see workshop 4 [It's about the patient, stupid](#) as well as the [report for the workshop](#) showing the Q & A session afterwards).

Patients have also risen to the challenge and have begun to develop a web-site / resource to help fellow patients make more sense of this new shift in thinking and how they can help themselves. [www.usercare.info](http://www.usercare.info) goes from “e-health and information”, through “Life and Death” and helps patients to understand how they can reach “health”, “long life” and “happiness” by being at one with their health. This is the beginning of a voyage of discovery that we are beginning to make as we understand what tools patients will need as they navigate through life and interact with the medical profession along the way.

Under all this, lies a profound feeling that we need to learn to trust each other. *Trust* is a very difficult idea to build and yet is fundamental to all that we are trying to do – whether it is trust in the IT systems that contain our personal (health) information, whether it is in the doctor or nurse who will help us with our illnesses or whether it is in the hospital that we enter for an operation hoping we do not contract MRSA or clostridium difficile or whether we should work with pharmaceutical companies in an ethical manner. There is no magical formula that tells us how to gain trust or what ingredients make this up and yet we inherently seem to know who to trust or who not to. Today, perhaps more than ever before, this issue of “Trust” has become fundamental in understanding the relationship that exists between patients, clinicians, the medical system, the underpinning IT system and perhaps even the pharmaceutical industry. Recognising this as a fact, I have written a paper with a patient for the *International Council for Medical Care & Compunetics* to further understand these issues on a global level. (*Towards a Partnership of Trust* <http://2007.icmcc.org/php/show.php?p=2007hannan>). Its purpose is to understand the nature of the relationship and to discuss and debate what the implications are for people at a global level who may be developing strategies in different markets. Trust is a central pillar that we all need to recognise and appreciate as we move forwards. The world is becoming much smaller as a result of developments in IT and communication such that an idea that is generated in one part of the world can now be shared throughout all corners in a matter of seconds. Trust can take many years to gradually build but unfortunately can be broken in a moment if issues are not handled appropriately. Other forces can be at work too including politics, market forces, competition, insurance schemes, advertising and of course inertia in a system resistant to change. This can create tension which may help support change or hinder it. This is further discussed as part of a paper at the ICMCC conference (<http://2007.icmcc.org>) to be sent to the World Health Organisation saying every single person on the planet should have the right to access their medical records. It will then be up to member countries to implement this within their boundaries. This will be further discussed at the 6<sup>th</sup> *International Conference for Urban Health* in Baltimore ([www.icuh2007.com/abstracts.html](http://www.icuh2007.com/abstracts.html)) as well as at the *Primary Health Care Specialist Group* summer conference in June ([www.phcsg.org](http://www.phcsg.org))

#### **Things to consider / see**

1. Most importantly consider the issues raised here and what they mean for you and your organisation
2. Consider where you are now and where you think you need to be and whether you have the necessary expertise to advise you on how to get there
3. The most likely scenario is that we are going to need each other and bring us all together. But only part of the resource may be available to achieve this. This resource is not just in terms of money but also in terms of who can participate, the time they have, where they meet and how they learn about this. To date, we have attempted to ensure as much of the learning can be shared throughout the world as soon as the educational need is identified.
4. If you wish to know about Records Access and point someone to one place, then go to [www.icmcc.org](http://www.icmcc.org) and click on “Records Access”. Also click on “Blog” to see the world’s first blog for members of the public, patients, clinicians, people in the system and system suppliers to share ideas and learn about what this means for them. Click on “introduction” on the right side of the page and then slide the page down to the bottom to see the start of the blog.
5. If you want to know about my consent process and how I actually recruit patients then see [Records Access – an introduction for patients and clinicians.doc](#) . This includes what

it is, what the issues are and what safeguards have been put in place. There is also information to help patients to understand their medical records better and what to do if they do not understand something. In order to gain access to their own records, they have to fill out a questionnaire enclosed in the document and then the consent form – true informed consent.

#### **What are the main problems at the moment**

1. Only a small number of patients have signed up for Records Access even though it is completely free for them
2. GPs are either sceptical or do not know or understand what the initiative is about. Clinicians in the NHS are generally angry with the IT
3. As patients learn about the initiative, they are increasingly wanting it themselves potentially putting themselves and their GPs at conflict.
4. The initiative is likely to grow beyond England very quickly because of the global nature of healthcare delivery. This has implications for all markets including those in America, Europe, the Far East, Australia and even Africa and other Third World countries. The implication for each market however is different – hence those operating in the different markets will need to consider its implications for them.

#### **What can you do to help?**

1. Give us further ideas on how we can help further develop this agenda so that it can reach out to more people. The more people we involve in this, the more likely we are to flush out the issues and reach a more equitable solution that fulfils most people's needs. Posting comments on the [www.icmcc.org](http://www.icmcc.org) blog enables people all over the world to benefit from your ideas.
2. Support us in recruiting more patients to access their records over the internet. We have produced some basic support material but this needs further rationalisation and perhaps made up into a more professional booklet that can be handed out to patients rather than simply e-mailed. There may be other ways in communicating these messages too. In particular patients are an important group but understanding how we can enable the voice of patients to be heard throughout the world remains an elusive problem.
3. Support us in encouraging practices to sign up for Records Access. It is free for practices to offer the service and we would also provide support for them from the experience we have had to date. At the moment we think those practices who are already providing an excellent service but wish to excel further may well wish to come forwards and provide this extra service and learn about how to work with "patients of the future". People may not be interested in giving Records Access per se but they may be interested in providing excellent asthma care or diabetes care. Patients who understand their health better are likely to do better. This may be a better approach rather than simply asking practices to offer Records Access.
4. We encourage you to go the ICMCC conference in June as well as the Primary Healthcare Specialist Group conference to get further insight into the issues raised here and feel the energy that is now being generated and how this will develop into a movement throughout the world.

We are in discussions with a number of people in America including the American Medical Informatics Association and Kaiser Permanente as well as people from as far afield as Canada, Australia, India and the Netherlands. This is a field where there is rapid growth and great interest far and wide. The Kaiser Permanente Institute for Health policy document on "realising the transformative potential for personal health records" demonstrates how close we are with others as we each try to move forwards. Please feel free to contact me if you would like to know more or if you would like to get in touch with others from the Records Access Collaborative.

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