April 2014

Patient access

Digital and M-health

Are imaging professionals ready for the revolution?

Background
In 2012 the government launched its Information Strategy for the next 10 years, the title of which, *The power of information: Putting all of us in control of the health and care information we need* provides an important clue about why medical imaging professionals need to take its main ambitions very seriously. Indeed if we are to engage with the intentions of the strategy then it is clear radiographers and radiologists will have to make some important decisions about the role they will play in helping patients access and understand their clinical images and examination data. This paper will outline some of the more controversial aspects of the strategy and explore what these might mean for us.

The strategy, released in May 2012 (in standard and easy to read versions – try the easy to read version, it’s eminently more appealing!), identifies nine overarching ambitions.

Most of these will come as no surprise as these are related to efficient and safe use of technology to support integrated care and effective management of resources. There are three ambitions however, which will require a significant shift in the way we engage with patients. The following discussion will consider the first two together as these are inter-related and then move on to the third ambition related to patient information.

1. A change in culture and mindset, in which our health and care professionals, organisations and systems recognise that information in our own care records is fundamentally about us – so that it becomes normal for us to access our own records easily;

2. Anyone who needs it gets support to access and understand information about their health and care, so that they have an equal say and can be active in their own care (easy read version).

In these two ambitions, the strategy makes clear that by allowing patients to access, contribute to and choose to share health and care records, the NHS supports a culture of “no decision about me without me”. The target for open access to notes is for patients to be able to see GP records online by 2015 and the graphic on page 18 of the strategy shows a radiographic image as being one of the examples of information that can be accessed and shared.

There is evidence to show patient care is improved using such an approach. In the Open Notes project, 20,000 patients in Boston, rural Pennsylvania, and Seattle were given full access to their notes via an Internet portal over the period of one year. The results showed that 90% of patients were in favour of having been able to read their notes, citing improved adherence to medications, and better control and involvement in decisions about their (and their family’s) health.
A number of UK practices have also begun to provide patients with open access to their notes. One such example is Houghton Thornley Medical Centres, and it is worth visiting their website\(^3\) to read patient testimonials about how access to notes has positively influenced their care.

Patients are therefore already being given access to their notes and this has in fact been possible for more than a decade via the Data Protection Act (DPA) (1998)\(^4\). Principle 6 of the DPA refers to the right of individuals to request access to any information held about them by an organisation. However, it is worth bearing in mind that the DPA (1998) relates to all data both physical and digital, in all areas of our lives. Whilst this right can be exercised at any time, it tends to be used when problems occur.

The scope of the *The power of information: Putting all of us in control of the health and care information we need*, explicitly relates to the availability of a patient’s health information digitally via an online system. It is moving away from a right of access to an expectation of access to individual health records.

Therefore the rationale for access here is fundamentally different. Access in this context is not for the purpose of litigation, ie a retrospective view of ‘what went wrong’ but to help inform decisions about on-going care. Access therefore needs to be openly and freely given in a timely and non-bureaucratic manner in order to effectively support the clinical decision-making process.

What is not clear is how this will pan out in the imaging department. If patients are to become used to the notion of information on-the-go at the point of care, will they be expecting immediate access to their images? The Society of Radiographers’ Code of Professional Conduct\(^5\) supports such an approach. Statement 1.3 says: “Working in partnership with patients is more than just giving appropriate information before undertaking examinations or treatment. It means transferring the decision-making to them, respecting their autonomy to make decisions about their own care or treatment and advocating with others on their behalf even if you do not agree with their decision. Full and truthful answers must be given to any question reasonably asked by the patient”\(^5\)

The HCPC Standards of Performance\(^6\) similarly advocate empowering patients to make informed decisions. Yet anecdotal information suggests practice in many imaging departments is to avoid or deflect such requests, with the stock phrases, “I’m not allowed to tell you, I’m only the radiographer”. Whilst it is true that we must not work outside our scope of practice, the patient is not likely to be interested in a full report, but only access to their images with possibly a comment. For many examinations this should be in the remit of most radiographers, and a natural progression of the red dot system, according to the SoR’s statement on radiographer initial commenting\(^7\).

What might be the outcome if patients are enabled through legislation and/or policy to access their images, but radiographers are reluctant or refuse to engage in such interactions? It is possible that this mantle will be adopted by another profession and radiographers may be relegated to a role in which they produce ‘test data’ to support someone else’s clinical dialogue with patients. Are we potentially at another pivotal point in defining the radiographic profession of the future?

Empowering patients to be more involved in the decision making process is, however, complex and requires careful consideration beyond merely allowing patients access to information. It requires a cultural shift in the way we manage and view patient interactions, demanding an open and honest approach, and being prepared to manage potentially difficult encounters. This was evident in the Open Notes project previously described where 30% of the physicians involved in the study admitted to having to take more care in wording the notes because patients were viewing them\(^2\).

We also need to be comfortable with relinquishing our ‘control’ which can be difficult. In the Open Notes...
project, a third of patients wanted to be able to ‘approve’ notes whereas around 90% of physicians disagreed with such a move. Furthermore, a study at the University of Salford, which looked at health professionals as service users of the NHS breast screening service, showed that it is not only health professionals who struggle with the notion of patient empowerment. In this study, a group of ‘professionally-educated patients’ said they would be reluctant to question mammographers regarding compression used during the examination because “the expert knows best”. This suggests that some patients may choose to remain disempowered, finding the cultural shift required to bring about a change in the patient-clinician relationship too difficult to make.

There are many issues that will need to be considered, such as the impact on the length of time per examination, changes in the number or skills mix of staff that will be required, appropriate physical equipment, out of hours access to assistance and ensuring confidentiality, amongst others.

So where does all this leave us? As professionals are we prepared for how open access to information might influence our relationship with patients, and if we really are signed up to the notion of shared decision-making, how do we help patients develop the confidence to make such decisions? Education providers have a role to play in ensuring their curricula prepare graduates with the necessary leadership skills to understand the value of, embrace and manage such a change in the balance of power.

As well as educating and preparing health care professionals for such a change, another solution must be better education of patients and this is the third aim articulated in the information strategy worthy of consideration.

3. “The widespread use of modern technology to make health and care services more convenient, accessible and efficient”.

Through the Internet, patients today have access to a wide range of online sources of information regarding conditions and interventions which should help them to arrive for their examination more informed and ready to engage in a more fruitful discussion about the procedure and its outcomes.

However, critical analysis of available information suggests imaging departments in the UK have perhaps not fully exploited this technology for the purposes of effective patient communication. Online patient information about imaging in the UK is still fairly well embedded within web 1.0 technology. In other words, patients can access static information but not so easily engage with it through, for example, user forums or networks. This ‘paternalistic’ top-down approach to communication with patients is contrary to the notion of empowering patients. Static information can also be dull. Although videos offer a more visual approach to informing patients, the plethora of such media about imaging examinations, for example on YouTube, tends to be either: commercially produced, with the potential bias this confers; created by Americans for the US market; or of poor quality. However, other countries, in particular the USA, appear to have embraced web 2.0 for patient information, see for instance the excellent Patients-Like-Me. Web 2.0 technology means that user-generated information has turned communication from monologue, ie a unidirectional flow of information from health professional to patient, into dialogue. This dialogue may involve information flowing back from patient to health professional or may manifest as communication between patients themselves.

The implication of web 2.0 for imaging practitioners is two-fold:

Firstly because it is now possible for our patients to communicate with us online such facilities need to be carefully thought through in terms of how they are facilitated. For instance, some sites in the UK do offer patients the option of posting queries however they are not always ‘managed’ so patients are left with misconceptions or unanswered questions. One poor postee asked: “Do you have to
have radioactive stuff injected into your body before a CT scan in April 2013 and was apparently never answered. One wonders if they ever turned up for their scan!

Who best to help such patients than radiographers? Preparing patients, psychologically and physically, for their examination has always been a fundamental role for radiographers. The shift in technology merely repositions this interaction to a different time and virtual space. Resources invested in this way are likely to reap dividends in improved patient care and attendance rates, but must be considered in service design. This will require staff to be trained and given the time to develop this area.

Secondly, through social networking web 2.0 technology also enables patients to access one another. Providing a platform for anxious patients to access others online could similarly prove effective in preparing them for their examinations. This is because the experienced patient is best placed to understand how another will be feeling. It has also been shown that the ‘novice’ patient can feel less intimidated asking questions of other patients than health care practitioners. With this in mind, radiography academics at the University of Salford are working with clinical colleagues in the breast screening service to design a digital social network for women attending for their first breast screening mammogram. Again, there remains the question of how, and indeed whether, such networks should be managed, for instance to address extreme views and avoid scare-mongering, and the work at Salford intends to explore these issues with both practitioners and users alike.

Nevertheless, the social networking phenomenon is massive and it is unlikely that health professionals will be able to control or stem this tide. Quite simply, Facebook and Twitter allow people to talk to each other anyway, regardless of whether specially managed sites are provided. Perhaps radiographers need to put themselves ‘out there’ more in order to present a stronger digitally networked ‘voice’ to the world. In this way we will be able to take every opportunity to promote the profession and defend misrepresentation of what we do. Attempting to develop a PLN (professional learning network) amongst radiographers on Twitter is a little disappointing as it appears very few are Twitter-active.

Having argued, that there is a need for high quality multi-function patient interaction software, which not only provides information about examinations, but enables user-professional and user-user communication options, how best to present this? The Food and Drugs Agency suggests that by 2018, half of the estimated 3.4 billion smart phone and tablet users will have downloaded at least one medical or health app. It would therefore seem sensible for radiology-specific patient software to be provided as an app. The NHS appears to be moving towards this notion with its NHS App Store. It would therefore seem sensible for radiology-specific patient software to be provided as an app. The NHS appears to be moving towards this notion with its NHS App Store. It would therefore seem sensible for radiology-specific patient software to be provided as an app. The NHS appears to be moving towards this notion with its NHS App Store. It would therefore seem sensible for radiology-specific patient software to be provided as an app.

How to use this article for CPD

Consider whether there are any aspects of communication you undertake on a daily basis which might be better delivered in a digital format. How might you develop an action plan to transform an aspect of your service this way? There are funds which are available to support you in this endeavour. Visit http://www.ehi.co.uk/news/EHI/8878/nurse-tech-fund-open-soon


Reflecting on your practice, do you feel you empower your patients/clients to make decisions about their examinations? In what ways do you do this?

Set up a Twitter account and make a professional connection with other radiographers. Share some interesting information with them about your practice. Ensure your communication complies with the HCPC guidance on the use of social networking available at http://www.hpc-uk.org/mediaandevents/socialmedia
date and pertinent, would be able to support most clinical departments at a local level.

Summary
The Information Strategy advises health care professionals that, “You will recognise that it is your duty to ensure people can access their records online if they wish and have the support they need to understand information in their records”1.

The strategy is therefore clear about our duty in fulfilling its aims, however it also presents medical imaging professionals with the potential for some exciting opportunities, but unless we embrace these new ways of working with patients there is a real danger that we will become seen as ‘data gatherers’, servicing the needs of other professions.

We all have a role to play in making a difference. Firstly, we need to examine our own attitudes to patient empowerment and reflect on how we will respond to patient requests for information. Managers will have to consider how resources are managed to facilitate new ways of communicating with patients both face-to-face and online, and we should make sure we are using digital health technologies to maximum effect, ensuring our patients are well-informed and prepared for their examinations.

We should also think about our individual responsibilities for contributing to a stronger networked professional voice. Finally, educators must ensure their graduates are prepared for practice which is digitally informed to support the best quality of patient care.

The Society of Radiographers’ Information Management and Technology group is working to establish what the views and needs of the radiography workforce are in the light of The power of information: Putting all of us in control of the health and care information we need1. This will include understanding the readiness of the workforce for the changes that may be required. The first step will be a series of focus groups that will establish a basic understanding of the level of knowledge that currently exists. The results of the focus groups will be used to inform a national online survey of the Society of Radiographers’ membership base.

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