Patients' access to their electronic record: proceed with caution

GPs have always been at the forefront of IT developments in the NHS. We were quick to see the benefits that computers could offer, helping to improve the quality and safety of clinical care and supporting the efficient delivery of primary care. While hospital colleagues have had to contend with the difficulties of providing care for patients using large patient paper records that could often go missing, for the nearly 20 years that I have been a GP, I have never worked without a computer on my surgery desk.

Initially it was the ease with which repeat prescriptions could be issued and the help offered in doing clinical audit and practice management, but soon GPs realised the benefit of developing a single comprehensive electronic patient record. Today it would be almost impossible to achieve the high standards of clinical care that GPs consistently deliver for patients with increasingly complex needs without the support of our clinical IT systems.

However as our systems develop, they bring new challenges, and rather than simply moving forward at speed because IT developments allow us to, it is important that we pause, think carefully, and deal with each challenge appropriately to avoid putting at risk the foundation on which our electronic records are built: patients' trust.

PROTECTING CONFIDENTIALITY

Patients trust us with their life stories. They trust us with information that they would not even tell their closest friend or life partner. We sit next to patients at some of the most difficult times of their lives. Patients know that our professionalism means we will retain that confidence, and only share it with others when it is in their interests to do so. Patients expect their GP to be on their side and to not let them down. It is why we are so highly respected in an increasingly cynical society. This means that we must do all we can to protect patient confidentiality.

It is already possible for patients to look at their records. The Data Protection Act provides legal force for something that few, if any, GPs have concerns about. Access to the record is done in a controlled way, usually printing off a paper copy or looking at their record on a screen in the surgery. Remote access to the patient's electronic record is a very different situation and raises far more concerns for clinicians because of

---

"Patients trust us with their life stories. They trust us with information that they would not even tell their closest friend or life partner."

---

fears that their patient's confidentiality will be breached.

Any patient requesting remote access to their medical record would need to first ask for it, their identity would be verified, and finally they would be given a password to ensure their access is secure. So far so good; this is a process that is no different from accessing a bank account or many other sites on the internet. However, unlike a bank account the electronic record may contain information about other people, not just the patient concerned.

Patients often talk about their relatives' or friends' illnesses or problems. Often this can be a cause for the patient's own illness and so GPs rightly record this information. Remote access to the retrospective record would have to provide an opportunity to remove this third party information, which is an almost impossible task. Even if access were only to the prospective record, to no longer record such information in a patient's record for fear that it may be remotely accessed would leave the record as a whole poorer, and the ability to treat the patient effectively would be undermined.

PROTECTING VULNERABLE PATIENTS

Much more of a concern would be the potential that vulnerable patients could be exploited by the possibility of remote electronic access to their record. It is quite likely that a person in an abusive relationship would be forced by their abuser to give access to their medical record, just to check what they told the GP when they attended with an injury or in distress. It is not good enough to say that the patient could not ask for a password from the

practice or ask that their record be blocked. Abusers are often clever and manipulative. They will know about these options and for the patient to choose them will only sow suspicion that secrets are being hidden and could leave the abused person even more exposed to future harm. The abused patient would therefore be faced with either allowing their abuser access to their record or simply not going to the GP in the first place, as seeking help from the GP will no longer be seen as a safe option.

A similar situation could happen to an employee with a difficult employer. It is quite likely that in the future an employer would want to see more than a fit note to explain a period of absence. They could request access to the employee's full medical record to quickly find out the full truth not only of their employee's illness but a lot more besides. Again there is a risk that patients would become much more guarded about what they tell their GP, or that GPs become much more limited in their recording of certain pieces of important information.

Easy access to the full electronic record could also become a rich goldmine for lawyers. It would be quite easy for legal firms to encourage people to give them complete access to their electronic record in the anticipation that somewhere in the past is an error that could form the basis of a medical claim.

SUPPORTING CLINICIANS

The electronic medical record is primarily for the use of clinicians to help them to manage the care of the patient. It contains many medical terms, abbreviations, and

---

"... vulnerable patients could be exploited by the possibility of remote electronic access to their record."

"Full access to the record will undoubtedly lead to an initial increase in GP workload as patients request consultations or time with their GP to help them understand what the record really means."

technical information that some patients would not understand or could misinterpret. Full access to the record will undoubtedly lead to an initial increase in GP workload as patients request consultations or time with their GP to help them understand what the record really means. In 2009, 33% of patients surveyed in a study into patient access reported difficulty understanding their medical record.¹

Records also contain notes to remind the clinician or differential diagnoses, which could potentially distress the patient unless handled carefully. GPs would be very guarded about including such information in the medical record in the future and the character and usefulness of the record may change as a result. Even if such information were to be recorded, patients may request that it be changed or amended. In the future, an openly accessible electronic record may be more useful and understandable for the patient but the risk is it won't be as helpful a clinical tool for the clinician and therefore the quality of care could suffer.

INCREASED WORKLOAD

It is often argued that patients accessing their record will save GPs' time. It is quite possible that an informed patient will access their results and clinic letters and so no longer need to make an appointment. However it is also possible that informed patients have more questions than the information answers and so could be more likely to seek further help. A study found that having online access to records and clinicians was associated with an increased use of clinical services compared with those patients that did not have such access.² This included an increased use of out-of-hours services, use of emergency departments, and hospital admission.

Finally there is little evidence that many patients want access to their medical record. Clearly a small and increasingly vocal few do but the UCL evaluation of HealthSpace³ found little patient demand for electronic record access and take-up of EMIS Access by practices has also been very low. Online access to electronic

records may well be a political priority but it doesn't appear to be one for patients. Therefore, is a wholesale change in the way that every patient record is kept worth the financial cost, the potential impact on patient care, and the risk to patients' trust in their GP in order to provide a potential, but still questionable, gain for a small number of patients? We should therefore make haste slowly and address the risks before we implement something we later seriously regret.

Richard Vautrey,

GP, Meanwood Group Practice, Leeds.

Provenance

Commissioned; not externally peer reviewed.

DOI: 10.3399/bjgp13X668393

ADDRESS FOR CORRESPONDENCE

Richard Vautrey

Meanwood Group Practice, 548 Meanwood Road, Leeds, LS6 4JN, UK.

E-mail: Richard.Vautrey@nhs.net

REFERENCES

1. Fisher B, Bhavnani V, Winfield M. How patients use access to their full health records: a qualitative study of patients in general practice. *J R Soc Med* 2009; **102**(12): 539–544.
2. Palen TE, Ross C, Powers JD, Xu S. Association of online patient access to clinicians and medical records with use of clinical services. *JAMA* 2012; **308**(19): 2012–2019.
3. Greenhalgh T, Stramer K, Bratan T, *et al*. *The devil's in the detail: final report of the independent evaluation of the Summary Care Record and HealthSpace programmes*. London: University College London, 2010. <http://www.ucl.ac.uk/news/scrsummary.pdf> [accessed 25 Apr 2013].