Providing patients online access to their primary care computerised medical records: a case study of sharing and caring

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ABSTRACT

Background Healthcare systems are struggling to deliver high quality care and constrain costs as more people live longer with a greater burden of disease. Providing patients with access to their records and with practice specific health information may improve the quality of care.

Objective To describe one practice’s experience of providing patients with access to their primary care records.

Subjects and setting Approximately 12 200 patients, registered with a semi-rural practice based on two sites, have been offered online access to their records.

Method A description of strategies used to encourage patients to sign up for access to their records. This includes the development of a practice-based web portal regularly updated with health advice.

Results Six percent of the patients in the practice now have access to their records via an explicit consent process. There are over 100 000 viewings of the practice web portal. There have been no problems as a result of providing access. Further developments include developing a new process for patients unable to provide consent in nursing homes.

Conclusions This case study provides a model of how to set up patient access to electronic records.

Keywords: computerised medical records systems, confidentiality, medical informatics, patient access to records, personal health records

Introduction

Our work as clinicians is becoming more challenging, with greater demands on our time, a greater need to demonstrate quality and an increased risk of litigation if things go wrong. More people are living longer with a greater burden of disease and increasing financial pressures on the system to deliver. Healthcare systems seek to deliver high quality care, control costs and balance patient expectations and experience. The General Medical Council advises UK doctors in Good Medical Practice (2006): 'Patients must be able to trust doctors with their lives and health'.

It is incumbent upon the medical profession to practice safely and effectively, and continually improve the patient experience. However, as Sir Cyril Chantler states: 'Medicine used to be simple, ineffective and relatively safe. It is now complex, effective and potentially dangerous'.

The benefits that good information technology (IT) implementation has brought to health care are improvements in quality and safety as well as the opportunity to provide patients access to improved health information and to their records. In the UK, healthcare organisations are now being challenged to focus on quality, innovation, productivity and prevention (QIPP), and to achieve improvement through IT, including patient access to their records. Developments in primary care IT systems mean that it is now possible for at least two electronic patient record (EPR) systems in the UK to enable patients to access their full GP electronic health records – EMIS and
The EMIS Patient Access to Electronic Record Systems (PAERS) solution enables patients to see a summary of their problem list, details of their consultation, current and past prescribed medication, the results of any tests and investigations and copies of letters and other documentation. Currently the majority of general practices in England use EMIS and at the beginning of 2010 over 40 practices were offering this service to patients.

This is a case study describing how one practice, Haughton Thornley Medical Centres, has enabled its patients to sign up for access to their records.

**Method**

**Process of providing consent and guidance for access to the GP electronic health records**

*Identifying a method for enabling explicit consent from the patient to gain access to their records*

Patients expressing an interest were invited to a meeting where a structured discussion took place describing what a medical record was and how to view records. The unresolved issues are: access to children’s records; psychiatric problems; potential difficulties around third parties; and harmful data that may exist in some records (or that may be added to the records after the patient has been granted access). Later, a DVD of the structured discussion was produced and the videos were then put on YouTube. This had the added advantage of being accessible at any time and from any place where the internet was available.

**Encouragement by clinicians for patients to get access to their records**

Although there are numerous waiting room posters and videos playing on the plasma screens, as well as articles in newspapers and magazines and on radio and TV, clinicians asking patients during consultations to sign up for patient records access has had the greatest impact. Box 1 describes the characteristics of the patients who have signed up for records access. Two simple questions are asked:

1. Do you have access to the internet?
2. Would you like access to your records online?

An affirmative answer to both questions often leads to the patient signing up for access to their records.

**The need for a practice-based web portal to support patients with access to their records**

Some patients who had access to their records did not necessarily understand how this could help them. This led to the development of the Practice-based Web Portal www.htmc.co.uk, which facilitates access to records and other online services as well as explaining what the benefits are and providing up-to-date, trustworthy information about healthcare matters that patients can refer to.

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**Box 1** Types of patients wanting access to their GP electronic health records

1. Patients who join the practice at the new patient check
2. Patients who have been diagnosed with a long-term condition needing regular monitoring, e.g. diabetes or rheumatoid arthritis, and on disease modifying drugs requiring regular blood tests
3. Patients who have recently been discharged from hospital following an acute medical problem, e.g. myocardial infarction
4. Patients who are referred to the hospital for further tests and investigations
5. Patients who are already online and do most other things on the internet, e.g. booking holidays, shopping or finances
6. Patients who find out they are pregnant and want to know and do everything they can
7. Patients who have started ordering prescriptions and booking appointments online and want to go to the next level
8. Patients who realise they can save an immense amount of time or realise they can speed things up by being more involved in their care, perhaps because information was not available previously for those that needed it
9. Patients who have been persuaded by other family members, patients or other health professionals to give it a go
Patients, students and clinicians learning from each other and sharing this information widely

The bedrock of the approach we have taken is the ‘Partnership of Trust’ between patients and the practice. For example: a patient is now teaching medical students about the benefits patient records access brings; another patient has recommended that all medical students should be given access to their own medical records, as a way of teaching them the rights and responsibilities of patients’ access to their medical records and the need to uphold privacy and confidentiality. Patients have presented at a large number of national and international conferences on their experiences to date.

The need to identify patients who have access to their records

Two years after enabling patient access to records, we created two local clinical codes entitled ‘Patient access to e-health record’ and ‘Carer access to e-health record’ to identify those patients whose records are accessible over the internet. Patients who want access to their records wish to do so because they want to become much more active partners in their own care. They want to feel enabled, involved and empowered to make decisions, based on information in their records that they can learn more about in their own time but then discuss with their clinician when decisions need to be made. Coding the record helps to identify these patients during a consultation.

The development of a guideline for clinicians, patients, systems suppliers and others on sharing electronic health records with patients

Members of the practice including patients with access, PAERS, the local NHS, the Medical Defence organisations, the Information Commissioner’s office, the General Medical Council, NHS Connecting for Health, the Information Standards Board for Health and Social Care and a number of patient support groups have jointly supported the development of guidance in order that patient records access may become a reality. The guidance is a combination of the author’s and others’ experience of enabling patients to access their records, as well as appropriate rules and regulations. The guidance is being quality assured by the Royal College of General Practitioners and a draft version has been available since 2008.

Results

Around 7% (800/12 164) of the practice have taken up access to their records; 6% (n = 730) are coded ‘Patient access to e-health record’. Figure 1 shows the age–sex distribution of those coded as having access, and Table 1 compares this with the practice population denominator.

Patients in all age groups are signing up for access to their records; interest is currently greatest amongst the 45 to 74 years age group. Whilst the proportion of patients remains low, more patients are registering to have access to their records.

Figure 1 Percentage of patients with access to their GP electronic health records according to age
Support for patients

We provide the following support for patients requesting sign-up:

A standardised process for patients signing up for the service

Back office staff have been trained to check medical records and identify whether it is ‘safe’ for the patient to have access. If there is doubt (for example, if the patient is suffering with severe mental illness) the notes are passed to the general practitioner (GP) for review. Patients collect their personal identification number (PIN) from the receptionist and provide their mobile telephone number and email address. A text message and email is then sent to prompt them to review follow-up information giving more details about how they can access their records. Patients can then look at the material online, fill out an online questionnaire and print and sign a consent form. Those patients that do not have a printer are given a consent form at the time that they ask for their PIN.

Online web access to information

An essential part of building the ‘online’ relationship with patients has been the provision of a Practice-based Web Portal (Figure 2) with material the practice has generated itself and with links to national as well as local health information embedded within it. For example, we provided ‘Swine Flu’ (H1N1) information to inform patients and carers, and video in Bengali provided by a local pharmacist for patients to watch. We have added talks on dementia services, breast cancer awareness and ischaemic heart disease. Patients are also producing their own content for the benefit of other patients (and other caregivers/providers). These include out of hours advice and a questionnaire looking at the health-seeking behaviour of teenagers—what websites they go to and what issues they are interested in. The practice services section shows patients how to manage their own care by developing a greater understanding of their own health. The ‘patient control panel’ allows patients to book appointments in the practice, order repeat prescriptions, access their records and learn to self-manage by looking at other trusted websites to which we have linked. Use of the portal has consistently increased with over 100,000 page views of the website per year and countless visits to other resources signposted from the portal.

Encouragement for patients

Clinicians regularly discuss how they are encouraging patients to get access to their records. Nurses in the vaccination clinic remind mothers to get access to the records for themselves and their children at the same time. Doctors are encouraged to ask patients whenever they order a blood test, X-ray or refer the patient to hospital for further care. We know patients do not often sign up immediately, however, and even those who could derive the most benefit may have to be reminded several times. It is not immediately clear why this might be, although the novel nature of patient records access, ‘the unknown’, may be the major reason. We have not reached the ‘tipping point’ where patient records access is spontaneously requested as a result of routine interactions. However, once patients have gained access they are very positive about the site. We have not had a single problem resulting from patients having gained access, though errors in records have been found and corrected.

Local support

The local Care Record Development Board, consisting of clinicians, managers and patients from the primary care trust, the acute hospital, the local mental health trust, social services and the local out-of-hours service has been very instrumental in supporting records access and encouraging other local practices to offer the service too. There are now three practices locally

| Table 1 Age-sex profile of people coded as having access to their medical records, compared with the age-sex profile of the practice (correct 12 March 2010) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Age range | 0–4 | 5–16 | 17–24 | 25–34 | 35–44 | 45–54 | 55–64 | 65–74 | 75–84 | 85–89 | 90+ | Totals |
| Males | 15 | 18 | 6 | 30 | 48 | 55 | 80 | 50 | 17 | 1 | 0 | 299 |
| Base | 450 | 951 | 704 | 775 | 944 | 836 | 672 | 448 | 250 | 42 | 12 | 6064 |
| Percentage | 3 | 21 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 | 7 |
| Females | 16 | 10 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 384 |
| Base | 432 | 914 | 644 | 858 | 833 | 777 | 649 | 498 | 339 | 95 | 71 | 6100 |
| Percentage | 4 | 1 | 3 | 7 | 10 | 12 | 12 | 7 | 4 | 1 | 4 | 7 |
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Patients’ views of record access

This patient describes how she does most things online and that managing her own health online just seems a natural extension to what she is doing anyway.

‘I am thirty something working mum looking after a small child, a part-time job, a husband, a house ... the list goes on and on. I also have Diabetes, an under-active thyroid, fertility problems, suffer with depression, asthma and recently started medication to protect my kidneys! I don’t have time to be ill! In 2007 I was introduced to my electronic medical records access. I now order my prescriptions, book my appointments to see the doctor, check my test results and sometimes I even go over the conversation I had in my consultation with the Doctor when I feel I need to clarify issues to understand my medical needs better. I feel I am taking a positive step towards maintaining a healthy life, understanding my medical

that are also enabling patients to access their records and a further four practices are about to start. The Caldicott Guardian is holding a series of meetings with the public, including the local press, to explain his very important role but also to explain the patients’ role in accessing their own health information.

Local library has set up a six-week IT course (two hours once a week) teaching patients – many of whom are novices – how to use the internet, create an email address, go to trusted websites to learn about their health, order repeat prescriptions and access their health records. This has been developed as a partnership between the NHS and the local council and helps to bridge the ‘digital divide’.

Figure 2. The practice website
needs and doing it all on MY time, when it’s CONVENIENT for me.

I shop online, I communicate online, I educate myself online, I control my finances online. In 2007, it’s only right that I look after myself ONLINE’ (capitals typed by patient)

This patient travels abroad a lot but recognises the need to monitor her own health and be an active partner in her care.

‘I am a patient at Haughton Thornley surgeries and am a passionate advocate of online access for those who wish to participate. I have a chronic disease and feel a real partner in the management of my health. Whether I am at home or abroad I can monitor information and share it with any other health professional involved in my care. I would be lost without it now!’

This patient feels record access has led to a reduction in visits to the surgery and that every GP should offer the same service too.

‘I’m one of the 3% (2008) in Dr Hannan’s surgery who chose to be able to access my medical records online. For me it was a no-brainer because:

1 I can easily order a repeat prescription any time I want?
2 I can make an appointment to see one of the GPs when it suits me.
3 I can view my medical history and access helpful links to other web sites that help me understand medical issues.

Overall, it has helped me engage with the surgery and my own medical condition (high blood pressure) since I can easily check up on my condition and monitor its progress online and now that I’m more engaged, I actually visit my GP (less) than I did in the past for routine check-ups.

For me, it’s just my local GP doing what everyone else is doing (giving me web access to my own personal details so that I can be better informed – in the same way that my bank, and other online accounts do).

Every GP should offer this service.’

This patient recognises the value of the links from her medical records as well as other sources of information pertinent to her health. She is also using her knowledge of how to access high quality information to become a source of information for other members of her family:

‘I love to use the www.htmc.co.uk website to manage my own health. It may be I want to access my health records to print information when I am going to the hospital. By following the various links I was able to look up information about an operation I needed to have. The information was very easy to understand and there was even a diagram. I found the information very useful. I was not anxious when I went for the operation as I knew exactly what to expect. I have even used the site to look up information for friends and family. The up to date information on Swine Flu is very good.’

One patient whose baby was unwell signed up for access to her records so that she could check the records prior to going to see the consultant for a private consultation after the weekend. Here is a copy of the email she sent, having just got access:

‘Just a quick e-mail to let you know that I have managed to access (child’s name)’s records. I will now access my own.

The service is really excellent and will be invaluable during tomorrow’s consultation.

Many thanks for your assistance.’

Discussion

Principal findings

This case study reports the experience of one practice that has embraced the opportunity of enabling patients to access their general practice electronic health record. It describes a method of enabling patients in all age groups to access their electronic health records through an explicit consent process that has led to a number of patient benefits. To date there have not been any significant problems.

The experience of the first set of patients accessing their records is encouraging. The majority of those signing up are between 45 and 74 – a group of patients who often begin to develop long-term conditions necessitating frequent visits to medical establishments, tests and investigations and ongoing long-term treatment with associated side effects.

Implications of the findings

Whilst a number of concerns have been raised regarding the risks of electronic health records,26–28 this has not been our experience. If patients can get a better understanding of their health as well as any diagnosis and treatments then their compliance and concordance may improve.29

Comparison with the literature

The latest statistics suggest 70% of all households in the UK now have access to the internet,30 although 21% have no internet access anywhere. A number of IT systems have been deployed that allow sharing of patient information in other care settings:

1 the NHS Summary Care Record (SCR) shares summary information between professionals
2 HealthSpace allows patients to view their SCR as well as other health information online
3 some general practice EPR system vendors (EMIS, The Phoenix Partnership and vendors of the Scottish system GPASS) have vendor specific approaches to sharing data
4 Renal Patient View provides niche access to health data for renal patients.

EMIS Web, has been developed which allows parts of the GP electronic health record to be viewed outside the practice, whilst SystmOne allows information sharing across the community, the general practice and now community hospitals too, but does not yet include the patient. Renal Patient View has probably been most successful and now has over 10,000 patients who can access their renal records online. A HealthSpace advanced account enables patients to access the summary care record, but the process of getting an account has been cumbersome and very few patients have actually taken up the service. However, a recent survey suggests there is support for its further development. The latest figures show that 6,672 people could have a HealthSpace advanced account; of those, 1,416 people have actually completed the tasks necessary to open such an account. The NHS in Scotland has deployed the Emergency Care Summary and Wales is launching My Health Online.

Limitations
We still have a relatively low uptake of this service and now need to find ways to further encourage take-up. The library course teaches patients and the public how to learn about their health and introduces the internet, though it is too soon to judge its potential impact or that of other strategies yet to be discovered.

Call for further research
Further research is needed to see how the gap between those who have access to the internet and those that access their electronic health records can be reduced. There are some patients, however, who may not be able to give explicit consent and for whom another process may be necessary to enable their records to be accessible by those looking after them. Patients in residential and nursing homes or being cared for at home in the community by other family members may also benefit from records access, but presently have little or no way of benefiting from the service. The General Medical Council has recently published new guidance on confidentiality stating: 'Confidentiality is an important duty, but it is not absolute'.

As doctors, we 'must make sure that any personal information about patients that (we) hold or control is effectively protected at all times against improper disclosure'. However, in situations where there is a need for disclosure for patients who lack capacity to consent we must 'make the care of the patient our first concern ... respect the patient’s dignity and privacy ... (and) support and encourage the patient to be involved, as far as they want and are able, in decisions about disclosure of their personal information'.

Barber et al state that 69.9% of care home patients studied had experienced one or more medication errors, suggesting an urgent need for us to re-evaluate whether staff in such homes should be able to access patients’ records to see what medication they are supposed to be taking and why. Carers may also be better supported. We need better guidance as to how to balance the rights of individuals to privacy with understanding of what the technology could offer and how it might help to improve care for some of the most vulnerable in society who are unable to look after themselves. We also need further studies to evaluate the differences between the different offerings from EPR vendors, and between the NHS in England and the devolved nations (Wales and Scotland). Identifying tools for patients to make choices and manage their care better once they have easier access to their health records, hence improving their ‘life and health experience’, may be important future developments which will encourage patients and providers of services to engage in records access activity. Examples of this may include decision aids once a patient has access to their records and knows their personal ‘Map of Medicine’ pathway, or perhaps pre-consultation care – allowing patients to gather their thoughts prior to a consultation in a semi-formal manner.

Conclusions
We are moving into a new era where patients are fast becoming the centre of their own care. IT systems should recognise this and ‘the provision of patient-level operational data should form the foundation of NHS IT’. This is the first report describing how one practice in England is able to support patients to access their electronic health records. A programme based on these findings may help to support the change necessary. With an increasing number of practices now offering patient records access, the acceleration of take-up should enable better sharing of information to help deliver better care for many patients.

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REFERENCES

CONFLICTS OF INTEREST

None.

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