



Royal College
of Physicians

A photograph of a woman with blonde hair, wearing a light blue button-down shirt, sitting on a grey bench. She is looking down at a tablet computer she is holding with both hands. The background is a blurred grey wall with white horizontal lines.

Personal health record (PHR) case study

Patient access

This case study covers several topics of common interest relating to patients accessing their general practice records online. GP practices, patients and clinical commissioning groups (CCGs) may find it useful in implementing and using Patient Online. Hospitals and other health and social care providers may also find the case study useful as the issues discussed are relevant to providing online access to patient records in any setting.

Acknowledgements

The case study has been produced through discussions with Dr Richard Fitton, GP; and Dr Caroline Fitton, clinical fellow at Barts and the London School of Medicine and Dentistry. It is based on research and experience in practice of patient online access to GP records. Our thanks to them for their considerable help with the case study.

Patient and practice benefits

Patient benefits

An audit of online access was carried out in two GP practices in Manchester in 2011 with 226 patients. The aim was to identify why patients access their primary care records¹. The survey found that the main reasons could be categorised as follows:

- Making savings, for example looking at information such as test results, online, can mean that patients don't have to phone or visit the surgery to obtain their results. Some patients may be able to interpret their results and determine whether or not an appointment is necessary. This results in savings both to patients (eg time off work, petrol), the environment (eg through less travel) and to the practice (practice savings were estimated in a separate study – see below).
- Checking past activity. Patients found it easier to check online information that would have been possible previously but required contact with the practice (eg phoning the practice to check a child's vaccination status). Some patients also identified new types of checking, that would not have been easy to do in the past (eg checking the content or outcome of a consultation, spotting discrepancies in their record). Some patients reported printing out documents to share with others in hospital or to have available if needed in an emergency (eg to share with ambulance paramedics). Some also obtained information needed for insurance or benefits purposes.

- Preparing for future action. Some patients found that access to their record prompted them to find further information about their condition (from sources available via the online record). They used this information to support them in making decisions (eg whether an appointment was necessary) and in preparing for an appointment either with their GP or another healthcare professional. Monitoring the course of a condition was also valued by some (eg reviewing blood pressure results for trends over time).

The survey also identified that online access had raised patient expectations about what was possible in managing their own health and some frustrations (eg at perceived limitations in the content available to them), the speed at which it was made available and in understanding some of the information (eg abbreviations used in general practice).

Practice benefits

A research study was also carried out to identify the benefits to the same two practices². Those with patient access were asked whether their contact with the practice (both visits and phone calls) had reduced, increased or stayed the same in the last year. A total of 229 patients responded and identified a reduction of 187 clinical appointments and 290 phone calls. Practice cost data was used to extrapolate and assess changes that the reported changes in patient behaviour in staff and system would cost.

The study found that if 30% of patients accessed their records online at least twice a year, in a 10,000 patient practice, there would be a saving of 4,767 appointments and 8,020 phone calls per year (amounting to approximately 11% of appointments). The study noted that these findings were similar to a US study.

The study suggested that the reduction in patient contact with the practice would quite likely be due to people doing things for themselves (eg looking up test results online) rather than having to contact the practice. The study also found that costs to the practice could be minimised if patient registration for online access could be managed by trained administrative staff.

Limitations of the study were discussed, including the issue of patient recall, the nature of the practices as early adopters of patient access and of early adopter patients. The recommendation was made that a full scale study should be carried out to validate the findings.

Patients reviewing their records for inaccuracies

Patients expect their records to be an accurate reflection of their consultations and where they are not, expect to see them corrected. The Data Protection Act (DPA) 1998 (Section 14 DPA) requires rectification of inaccurate information, which may include backtracking to other records that include the incorrect data. The National Information Governance Board produced guidance in 2010 for both the public and healthcare professionals about how to go about amending health and social care records³. In the guidance, the following are distinguished:

- a) inaccuracies, where information needs to be corrected in the record (but retained in the audit trail).
- b) differences of opinion, where a note should be made in the record, but the information retained.

By giving people access to the record electronically they are more likely to spot issues. A study carried out by Caroline Fitton, where 31 patients reviewed their primary care records to identify errors, indicated that patients felt empowered by doing so⁴. Thirty per cent of patients found at least one item which they considered to be an error in their records. Some of these were inaccuracies, for example, the notes having the wrong date transcribed from a hospital letter, whilst others were differences of opinion, for example the doctor had diagnosed a patient with asthma but the patient didn't think that they had asthma.

'The administrative and clinical staff dealing with patients discovered discrepancies agreeing to examine the noted errors, assessing them, correcting them if necessary, annotating them if in dispute or leaving them if there is no error and informing the patient of the outcome. It is generally a positive experience in a shared partnership of trust' – Richard Fitton, GP

Patients identifying what they would not want to share

Once patients can access their records online they can share them with whomever they want (eg family, carers, healthcare professionals) (Section 36 DPA). There may be information in records that some patients would not want to share.

Caroline Fitton carried out research with 31 patients who were provided with a copy of their primary care record and asked to identify the information that they would not want to be shared. Sixteen per cent identified some information that they did not want to share. The majority of entries related to lifetime events and behaviour which had strong moral and social significance or connotations – contraception, conception and pregnancy (eg emergency contraception prescription), sexual health (eg referral for erectile dysfunction, note of genital warts) and mental illness (eg record of anxiety, overdose attempt), drug and alcohol abuse and genetic information.

Currently, patients don't share information that they don't want to by simply not disclosing it. This suggests that personal health records will need to provide people with similar choices about which data to allow to be recorded and which data to withhold from sharing.

They may also wish to name which professionals not to share with (ie professionals who are relatives, neighbours, friends etc who have access to notes through their professional roles). It seems possible that digital role-based access control identifiers of professionals might be used to selectively block access by specific professional individuals to the records of patients who have identified them as not to have access. Access by the patient to the identity of the professionals who have accessed their record could also be a powerful deterrent to inappropriate viewers and be welcome to the privacy lobby.

Further research and development is needed to understand these requirements further.

Granting access to people with lasting powers of attorney

‘The Medical Defence Union (MDU) annual report 2015 directs professionals to candour of practice and mishaps and to the reduction of miscommunication. Complaints (around 30% that the MDU deal with are poor communication) are usually made after death by relatives and often, I suggest, they could have been avoided if the family and interested parties could have seen the contemporary record as care proceeded. (Junior staff are reluctant to give relatives details of patients’ progress and care lest they give the wrong information or the right information to the wrong person).

It is possible to for a patient to notify the hospital at admission that an interested party or attorney can see the record. Another positive step can be taken by the patient before admission if the patient donates health and welfare powers of attorney to friends or relatives. These powers of attorney allow attorneys to view the patient’s (donor of the power) records. This will entail real time access to LPAs and patient selected interested parties’ – Richard Fitton, GP

Patient access to their records is one way of improving communication with patients and their carers. Where an individual has lasting power of attorney (LPA) for health and welfare, they are able to access the patient’s record before and after their death.^{5,6} The Social Care Institute for Excellence has good online learning tools on this and indicates that being an LPA for health and welfare allows one to see the patient’s record. However, both the public and staff in NHS organisations are often unaware of this.

A clause can be inserted by a donor into an LPA for health and welfare to make this right explicit as follows:

- a) You may access all of my personal, medical and social care records
- b) You may apply for access to and/or copies of my health and social care records after my death if it is for the benefit of the health and welfare of my descendants and nearest of kin and not of detriment to my reputation
- c) You may register me with an accredited (by the Care Quality Commission) home care organisation and create an online information sharing tool with them and my attorneys to jointly manage my health and social welfare.

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- ³ National Information Governance Board. *Requesting amendments to health and social care records: Guidance for patients, service users and professionals*. 2010.
- ⁴ <http://webarchive.nationalarchives.gov.uk/20130513181011/http://www.nigb.nhs.uk/guidebooklet.pdf> [Accessed 17 May 2016]
- ⁵ Fitton R, Fitton C. Sharing electronic records: The patient view. *Informatics in Primary Care* 2006;14:55–7 BCS
- ⁶ Galvin, J For the record. *Law Society PS magazine*. May 2015.
- ⁷ <https://www.gov.uk/power-of-attorney/overview>

Further reading

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