

Online access to medical records:

finding ways to minimise harms

ONLINE ACCESS IS COMING BUT THERE REMAIN MANY UNANSWERED QUESTIONS

Currently, GP practices in England should be offering their adult patients online access to a brief summary of their general practice medical record, to be followed as soon as possible by access to the full record. This mandate came into effect in April 2015.¹ The vision is that all adults will have online access to all their health and social care records by 2020.¹

Potentially, online access is more convenient for patients, empowers and enables patients to take better control of their health and health behaviour, helps patients navigate a complex system, and may make services more efficient, thereby reducing costs.^{2,3} The policy is also underpinned by ethical arguments about autonomy and individual rights: the health information in the record belongs to the patient who has at least equal rights of access as healthcare providers.²

A recent systematic review found that patients reported benefits of online access in terms of experience, satisfaction, and feeling able to take control of their own health care, with possible advantages to patient safety when patients have online access to medication lists.^{4,5} However, the same review concluded that we do not know whether online access translates into better health or health care for patients or whether it improves service efficiency.^{4,5}

POTENTIAL HARMS TO RECOGNISE, DISCUSS, AND SAFEGUARD AGAINST

Like any policy, there is also potential for unintended harm and this is our focus here, particularly those harms related to privacy and confidentiality. There has been no study on this topic as yet.^{4,5}

Online patient access is in the process of being rolled out across the country. As doctors and managers contemplate giving patients easier access to their records, they face time-consuming decisions that have a significant ethical dimension. Should access be limited to certain types of information, such as test results or prescriptions? Should online records extend back to birth? Should free text entries be available? What steps should be taken to prevent sensitive information about a patient becoming visible to carers and family or household members? Now is the time to openly

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debate these questions in the context of potential harms, share experience, and find feasible and acceptable safeguards.

The most obvious potential harm related to privacy and confidentiality is coercion: patients unwillingly giving others access to their online medical record.^{2,3,5} Coercion may result from overt threats or physical force in an abusive relationship or may appear under the guise of helping a vulnerable relative, especially older people or those with learning disabilities. References to abuse or maltreatment in the medical record seen by household members may lead to escalation of the abuse, restricted access to health care for victims, or pressure or aggression directed at health staff to change the record. These harms also affect abused and neglected children, whose parents may have authorised access to their record. The 27% of women and 15% of men who experience domestic violence in their lifetime and the 24% of children who experience abuse or neglect over childhood^{6,7} will be affected by these issues.

More recently, discussion has turned to issues of privacy and confidentiality more generally, issues that arise from the ease and likelihood with which people other than the patient may see records.^{4,8} This makes online access different from the existing legal entitlement to see one's full general practice record. Could there be harms associated with any one being reminded of forgotten things which happened years ago or uncovering unknown information about their childhood? Would an older person

want carers to know their past medical history, for example, sexually-transmitted infections or terminations? Will adults not reveal suicidal thoughts because they fear upsetting the people close to them? Will a teenager ask for contraception or discuss self-harm if they think that parents will look at their online records? For this last scenario, it is proposed that parents will not have automatic access to a child's record after they are 12 years old,³ but teenagers may find it difficult to refuse parental requests for access without implying they have something to hide. Without assured confidentiality, how can we expect patients to seek help from their GP for the full range of physical, emotional, sexual, and social problems that affect their health and wellbeing? This concern has recently been voiced by those providing and researching adolescent health in American healthcare settings.⁸

Equally important, the clinician, worried about coercion or information leakage within households, may not record anything deemed to be sensitive,^{4,5} including early concerns about abuse or maltreatment, contrary to recent guidance from the General Medical Council,⁹ National Institute for Health and Care Excellence,¹⁰ and the Royal College of General Practitioners (RCGP).¹¹ This may impact on care of the patient: recording can allow a cumulative picture of concern and judgement about how far action needs to be taken to support families or protect children. None of the guidelines about responding to child maltreatment in healthcare settings offer

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advice about how to mitigate these potential harms of online access to records.

SAFEGUARDS PROPOSED TO DATE

Three ways of minimising harm from online access have been proposed. First, informing patients and professionals. The RCGP recommends that patients be informed about the dangers of sharing login details when they register for online access, that patients be signposted to abuse support services, and that GPs be informed about coercion, remain vigilant for it, and withdraw online access if coercion is suspected or known.³ This solution does not account for the complexity of coercion, much of which will be hidden, or for the potential for health records to ‘leak’ within households. Second, we could design technical solutions to exclude certain parts of the record from patient-facing services; for example, restricting to recent records or test results only. We may also be able to find technical solutions to filter out obviously sensitive codes while providing online access to the full medical record or for patients to hide certain data in an electronic ‘walled garden’. There are as yet no easy methods for doing this.² We would have to minimise the opportunity for human error in any such fixes and think about whether vulnerable patients would be able to use any technical solutions operated by the patient. Third, GPs could systematically change the way they record sensitive information, such as abuse and neglect. Such an approach will require training and risks losing the benefits of a complete and cumulative health record. In addition, this solution only deals with information which is obviously sensitive. Even where pilot sites report success and benefit, there remain unresolved issues regarding online access for children, those reliant on carers or those in abusive relationships.¹²

CONCLUDING REMARKS

As others have concluded, online access is likely to have a transformative effect on the content and use of the health record and also on general practice itself.⁵ In the absence of robust evidence about effectiveness and safety, we suggest that

implementation be discussed and potential harms and safeguards openly debated. As the juggernaut of online access rolls forward, the least harmful way is to implement it slowly, in a staged process as the RCGP recommends,³ and with thorough evaluation. We encourage those at pilot sites and beyond to respond to this editorial and share their efforts to address the potential harms of online access. For those currently implementing online access, we suggest keeping it simple and limiting online access to recent information which has clear medical utility; such as test results, referral letters, clinic letters, current medication, and allergies.

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Provenance

Commissioned; not externally peer reviewed.

Acknowledgements

We thank Janice Allister, Susan Bewley, Sarah Blake, Simon de Lusignan and Brian Fisher for their comments on a draft of this editorial. The views expressed in this editorial reflect those of the authors: not all of those who commented were supportive of the views expressed here.

DOI: 10.3399/bjgp15X685129

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