

Caution urged over giving patients online access to their health records

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The image shows a hand holding a tablet that displays a 'Case History Form'. The form is a structured document with various sections for patient information and medical history.

Case History Form					
Patient Name - Last		First	Middle Initial	Date of birth	Age
Address - Number, Street		City, ZIP		State	
Ethnicity					
PRESENT ILLNESS					
Onset date		Hospitalized? <input type="checkbox"/> Yes <input type="checkbox"/> No		Admit date	
				Hospital Name	
Level of medical care (check all that apply):					
<input type="checkbox"/> Outpatient clinic <input type="checkbox"/> Emergency Room <input type="checkbox"/> Inpatient ward <input type="checkbox"/> Intensive Care Unit <input type="checkbox"/> None					
Symptoms that occurred during the current illness (check all that apply):					
<input type="checkbox"/> Fever (≥ 38 °C) <input type="checkbox"/> Seizures <input type="checkbox"/> Ataxia <input type="checkbox"/> Nausea <input type="checkbox"/> Vomiting <input type="checkbox"/> Altered consciousness <input type="checkbox"/> Lower respiratory (cough, wheezing, shortness of breath, bronchospasm) <input type="checkbox"/> Other: _____					
Complications that occurred during the acute illness					
Medicine received and why					
Significant past medical history:					
Cardiac disease					
Chronic pulmonary disorder (e.g. Asthma, cystic fibrosis)					
Infectious disease (e.g. Hepatitis, HIV)					
Immunosuppression (e.g. HIV, malignancy)					
Neuromuscular disorder					
Metabolic Disorder (e.g. diabetes mellitus, renal)					
Seizure disorder					
Folate seizures					
Hemoglobinopathy					
Long-term aspirin therapy					
Steroid therapy					
Cancer chemotherapy					
Radiation therapy					

The Government is aiming for all adults to have online access to their health and social care records by 2020, but researchers from the Institute of Child Health, QMUL and the University of Bristol are concerned about the potential for unintended harm.

In a *British Journal of General Practice* editorial the researchers

recommend that online access to the full [medical record](#) should be implemented slowly, in a staged process and with thorough evaluation.

While they agree that online access is likely to have a transformative effect on the content and use of [health records](#) and also on general practice itself, the researchers are particularly concerned about the potential for coercion: patients unwillingly giving others access to their online medical record.

Prof Gene Feder, a GP and Professor of Primary Care at Bristol's Centre for Academic Primary Care, said: "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."

Young people who live with their parents may also be discouraged from talking to their GP about sensitive problems, for fear of parental expectations to share the health record at home.

Dr Jenny Woodman, a researcher at the UCL Institute of Child Health, said: "Current proposals suggest that parents will not have automatic access to a child's record after they are 12-years old. However, teenagers may find it difficult to refuse parental requests for access if they are worried it may look like they have something to hide.

"As a result, there's a risk online access might deter young patients from seeking the help they need from their GP, whether that be anything from asking about contraception to discussing self-harm."

Feder and colleagues are also concerned that the clinician, worried about coercion or information leakage within households, may not record anything deemed to be sensitive, including early concerns about abuse or maltreatment. 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.

The authors highlight unanswered ethical questions in relation to giving patients online access to their health record. 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](#)? They say, "Now is the time to openly debate these questions in the context of potential harms, share experience, and find feasible and acceptable safeguards".

For those currently implementing online access, the researchers 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.

More information: "Online access to medical records: finding ways to minimise harms." bjgp.org/content/65/635/280

Provided by University of Bristol

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