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PRIMARY COLOUR

Helen Salisbury: Unintended consequences of open access to medical notes

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Patients now have access to their own medical notes, which is surely progress. More patients are now taking advantage of the ability to view all of the coded information in their GP record online—and this November they'll have access to all of the free text written in the consultation from that date onwards.[1]

Leaving aside the question of ownership (is it the patient's record? Is it my record of an encounter with the patient?), if we want people to be active partners in improving their health rather than passive recipients of healthcare, sharing information is a first step.

But there are unintended consequences. One is the increased demand for explanations. In an ideal world every test is explained to the patient, and consent is taken before blood is drawn. Even when I manage to do this there may be a need for more explanations when the results arrive. Among the dozens of laboratory results I file each day, many are just outside the normal range: a very slightly low sodium level or a subset of white blood cells just above the cut-off for normal. These I mark as satisfactory, but patients who are anxious, or simply pay attention to detail, often ask for further explanation and reassurance. A conversation about probability, normal distributions, and the clinical irrelevance of the technical abnormalities sometimes follows, and I have no problems with sharing my knowledge—but I just don't have time.[2]

As junior doctors, we learn that everything we write in a patient's notes may potentially be read by them and that we should be polite and objective, backing up opinions with evidence. I may note mismatches between symptoms and signs when my patient who says that she's fine has nevertheless objectively lost weight, or when the child with dreadful tummy ache clambers energetically onto my couch to be examined. In the past only a handful of patients ever asked to read their notes, but many GPs will have experienced protracted conversations with patients who were unhappy with the contents. In the future, when patients have routine access to everything we write, I fear that I may have to spend more time explaining my record of the consultation.

Of course, it will be possible to hide some entries electronically, which is vital if they contain third party information, but a human decision about this will need to be made for each consultation, clinic letter, or result. The rollout of full patient access has been delayed because of concerns about safeguarding: how do we protect the confidentiality of patients who may be in coercive controlling relationships? Do parents of a 14 year old have access to her record, and, if so, what implication does that have for access to contraception? More fundamentally, if there's a high likelihood that all notes will be viewed online, will GPs stop noting their "soft concerns" that are so vital in both child and adult safeguarding?

The Royal College of General Practitioners has yet to update its toolkit to cover these areas, but even with its advice I fear that mistakes will be made in the pressured world of primary care.[3]

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1 NHS Digital. Access to patient records through the NHS App. Updated 13 Jun 2022. https://digital.nhs.uk/services/nhs-app/nhs-app-guidance-for-gp-practices/guidance-on-nhs-app-features/accelerating-patient-access-to-their-record

2 O'Kane MJ, Lopez B. Explaining laboratory test results to patients: what the clinician needs to know. *BMJ* 2015;351:h5552. doi: 10.1136/bmj.h5552. pmid: 26634382

3 Royal College of General Practitioners. Patient online toolkit. https://elearning.rcgp.org.uk/mod/book/view.php?id=12893&chapterid=511

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