Implications of the changes to patient online records access in English primary care

BACKGROUND

This year, NHS England (NHSE) announced that from November, most patients in England registered for online services such as the NHS App will be able to see all new entries in their primary care record by default.[1] This includes free text, hospital letters, test results, and new data added to the detailed coded record (DCR). Historic information in the record has not become visible as a result of the November change, but there are plans to enable requests to access the historic DCR via the NHS App in 2023.[1]

Since April 2019, the GP contract committed GPs in England to offer patients prospective online records access (ORA).[2] Prior to November, GP surgeries could grant access to patients on a case-by-case basis, determine the level of access (such as Summary Care Record only, DCR only, or full record), and set the date from which data was visible. This resulted in inconsistent levels of access, something that patients reported as frustrating.[3] NHS Digital's data highlight these inconsistencies; in August 2022, although 48.1% of adult patients in England could order repeat prescriptions online, only 13.9% were able to view their DCR.[4] Despite documented benefits of ORA,[3,5,6] primary care staff have raised concerns[7–9] that can be grouped into issues around workload, safeguarding, patient confusion or distress, and health inequities.

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WORKLOAD

One recent small qualitative study found that ORA could or did increase workload by requiring preparation of records prior to granting access, managing access queries, safeguarding, and handling queries about content.[7] This study was conducted before NHSE's announcement, but after this, practices still needed to ascertain which patients required a SNOMED-CT code to delay access and enable an enhanced review.[1] Staff writing in the record now need to consider if entries should be hidden from the patient view, and be able to justify why. Despite workload concerns, there is tentative evidence that the impact may not be as great as some fear. Neves *et al* found 80% of the studies they reviewed reported either no change or a reduction of healthcare usage following enablement of ORA.[6] NHSE explored the experiences of 16 'early adopter' sites who enabled full prospective access before November,[1] and found most sites did not see noticeable increases in workload, with some reporting reductions due to fewer subject access requests and test result queries. Concerns about workload related to complaints or litigation arising from ORA have also been raised;[8,9] however, findings from the US, where ORA has been the default since April 2021, have found no clear evidence for increased risk of litigation.[10]

SAFEGUARDING

The impact of ORA on safeguarding is a common concern.[7–9] There is potential for patients to be put at risk through unauthorised or coercive access. Clinicians are concerned that it is now more difficult to alert their colleagues by documenting suspicions about possible child/domestic abuse or issues such as drug use, as they cannot be sure who might view the record.[7–9] Staff who enter information into the record must now consider when to hide such entries from the patient online view, and NHS Digital have provided guidance regarding why, when, and how to do this.[1] It is not currently possible to redact parts of a consultation entry, only the entire consultation. One workaround is to record two separate consultation entries, one of which contains safeguarding concerns and is hidden from the patient view. Consultations containing information disclosed by third parties that the patient is unaware of should also be hidden from the online view.[1]

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PATIENT CONFUSION OR DISTRESS

Most GPs write free-text entries containing medical acronyms and terminology that a lay person may find confusing or even distressing. We may 'think aloud' in the record using terms such as '?Ca', even if this is far down our list of differentials. Other terms such as 'obese', while used factually, may come across as judgemental to a non-medical readership. Unless we adapt how we write in the record there is a risk of ORA causing confusion or distress, which could increase the number of patient queries or negatively impact on our relationships with patients. We could mitigate this risk by verbalising what we write while a patient is in the room, explaining our perceptions of the likelihood of our differential diagnoses, involving patients when writing entries, and using system tools that convert abbreviations to full text. Although test results are not visible in the patient view until filed, they are another potential source of confusion or distress.[11] If we are to reduce the risk of these being misunderstood, we need to involve patients at the point when tests are being requested, and file them alongside comments that patients will be able to understand. While there is an increasing trend for secondary care letters to be copied to patients and written in plain English,

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ORA adds new impetus for adoption of this practice by secondary care.

HEALTH INEQUITIES

Records access has the potential to exacerbate health inequities,[7–9] further disadvantaging those whose first language is not English, or who have lower literacy levels, poor digital skills, sensory needs, learning disabilities, or limited IT access.[7–9] Evidence from the US shows that age, education, ethnicity, and language do impact on online records access, but when individuals from disadvantaged groups use these services they report even greater benefits than other users.[5] We must ensure that groups who could be disadvantaged by ORA have supportive options available, such as translation services, patient advocates, or alternative formats. There are some beacons of good practice, such as the Bridges Medical Centre in Dorset, who have drop-in centres with 'digital volunteers' helping patients get online and explaining the benefits of records access (www.thebridgesmedicalcentre.co.uk). Online services such as the NHS App have taken steps to try to increase accessibility, but the NHS have acknowledged that *'some parts of the NHS App are not fully accessible'*.[12] Further patient-centred work is required not only to address accessibility features of online services, but also to present information in the record in a way that patients can interact with to aid understanding.

THE FUTURE

Electronic records access for patients has been around for almost 20 years,[13] yet is still in its infancy. Health records were not designed for a patient audience, and will need to evolve to meet their needs. In the future, patients and carers may routinely be able to flag errors, upload data from wearable devices, or add text to the record. The electronic health record may become less of a tool for healthcare providers to record information, and more of a shared space where patients, carers, and healthcare providers can collaborate. We may see the emergence of interactive features enabling patients to explore and understand the data within their record. The magnitude of these changes has parallels with the transition from paper to electronic records in the 1980s.[13] That change was fraught with challenges, yet it also opened up a new world of possibilities. ORA has the potential to do the same, but there is an urgent need for robust research using objective measures to ascertain its impact on issues such as workload and quality of care.

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