

Devil in the details: understanding the effects of providing electronic health record access to patients and families

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Patient advocates have long called for patients to have access to all of their healthcare data, including electronic health records (EHRs).¹ In parallel, experts have suggested that providing patients with access to EHRs will improve patient engagement, care quality, and, by extension, health/healthcare outcomes.² Prior observational studies have supported some of these claims—for example, documenting that patients are overwhelmingly interested in and satisfied with receiving their healthcare data electronically,³ to finding that patients do identify errors when they read physician notes in the EHR.⁴ Because studies of EHR access for patients have been conducted and disseminated across disparate clinical conditions and settings and often using varied methodologies, the systematic review by Neves *et al* in this issue of *BMJ Quality & Safety* provides a valuable contribution in assessing the impact of patients' EHR access specifically within the randomised controlled trial (RCT) literature.⁵ Their meta-analysis demonstrates some significant but potentially limited benefits within these 20 RCTs that involved sharing EHR data/access with patients.

Overall, Neves *et al* found a few clear trends. First, there was a consistent, modest improvement in glycaemic control in RCTs targeting patients with diabetes, reinforcing the observational research focused on portal use for diabetes care.⁶ In addition, patient access to EHRs seemed to support safety of care in facilitating medication adherence and identification of medication discrepancies. These results are similar to observational studies,⁷ as well as a recent scoping review of patient engagement interventions to

promote the safety of care and to improve short-term and intermediate-term clinical outcomes.⁸ Finally, for patient-reported outcomes ranging from self-efficacy to patient activation to patient satisfaction, results were mixed, with about half of included studies showing some improvement. Thus, this review highlighted a wide variation and potential lack of consensus about what patient-centred outcome to include in studying EHR-enabled interventions, given the diffuse set of behaviours that could be targeted. More importantly, this review highlights that none of the included studies, many of which are older, focused on equity as a primary objective of the work (and very few even included data on racial/ethnic, educational attainment, digital literacy and/or health literacy differences^{9 10})—even though there are known barriers to digital health interventions by these characteristics.

Despite the modest benefits seen in these 20 randomised trials of EHR-facilitated complex care interventions, we still believe in the clinical value and potential improvement in patient-reported outcomes in this space. A more careful examination of the 20 included studies in this review actually sheds important light on delivering *complex* interventions to improve quality of care, during which patient access to EHRs was implemented in varied ways that might have led to more muddled results. For example, many of the included studies tested evidence-based practices that are known to independently enhance the quality of care, such as patient outreach and reminders for healthcare tasks, self-management training



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and increased healthcare provider communication access. Therefore, without detailed behavioural pathways for the targeted intervention components surrounding EHR data access, it is challenging to interpret observed trial effects. In our opinion and in our previous work,¹¹ one-time action by systems or clinics granting patient access to EHRs is unlikely to replicate the effect of these interventions. In particular, access versus training to use EHRs should likely be considered separately, as well as the study of specific features within the EHR. For example, passive provision of medical information from the EHR via online portals (eg, after-visit summaries or list of immunisations) differs substantially from active communication or completion of healthcare tasks via EHR-linked websites (eg, secure messaging exchanges between patients and providers about medical concerns or medication refill requests).

Therefore, we hope that this review can push the field beyond RCTs of patient access to EHR data and into specific mechanisms for patient uptake/use that could be more generalisable. First and foremost, it is now generally accepted that patients have the right to view their own health data, both because of their ownership of that information and the convenience it may offer. This indicates that it will likely be impossible to randomise patients to either receive or not receive EHR data in the future, and interventions surrounding universal EHR data access could be more specific to targeted behaviours. For example, now that patient electronic access to data is here to stay, future attention to research methods that tailor interventions, tease apart core implementation strategies, and engage patients and providers in codesign will be important next steps to ensure efficiency and relevance. Finally, and perhaps most importantly, RCT participants often differ significantly from target populations, with volunteers often exhibiting higher educational attainment and less racial/ethnic diversity.¹² Given known disparities in patient EHR access by race/ethnicity, socioeconomic status and health literacy mentioned previously, these trials are not likely to generalise to more diverse populations.

Moving forward, the results of this review highlight several principles for future studies of technology-facilitated healthcare delivery. First, all studies need to both include diverse participants and report on race, ethnicity, educational attainment, and health and digital literacy.¹³ Second, future work must focus on both internal and external validity of patient access/use of EHR data. The review by Neves *et al* gives us some clearer understanding of the internal validity of studies on clinical and patient-reported outcomes, but it remains unclear what impact these types of interventions will have on health outcomes across an entire healthcare system or region outside of RCT samples. Studies of patient EHR access/use can move into the external validity space (even

while conducting RCTs)¹⁴ by including implementation outcomes, such as the proportion of individuals offered EHR access who take it up, the extent of use over time, the type/features used, and costs for providers and staff, in addition to effectiveness in promoting health outcomes and differences across socioeconomic status, racial/ethnic groups and literacy levels.

Like patient advocates and experts for many years, we absolutely agree that patient records belong to patients and should be readily available in structured, electronic form for patients and families.¹⁵ Given the complexity of the information provided and the specific context for interacting or supporting patients in completing tasks via online patient portals/platforms, we should not expect access alone to ameliorate current gaps in care or significantly improve morbidity and mortality. As more care becomes digital-first (ie, with virtual care and telemedicine), there are real concerns about widening healthcare disparities for low-income, racial-ethnic minority and linguistically diverse populations. Our specific recommendations to avoid such undesirable developments moving forward include

- ▶ Wider measurement of patient interest and access/skills to using technology-based health platforms and tools.
- ▶ Tailoring of interventions to match patient preferences and needs, such as by digital literacy skills as well as inclusion of caregivers/families to support use.
- ▶ Use of mixed method and implementation science studies to understand use, usability, and uptake alongside clinical impact and effectiveness.

Attention to these points will allow us to understand the ways in which patient portals and other forms of EHR access for patients may produce different impacts across distinct patient groups. This understanding will not only mitigate potential adverse effects for vulnerable groups but also achieve the intended goal of improving healthcare quality for all patients through freer access to information about their care.

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