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Empowering Patients through Universal Access to Electronic Health Records

Richard Fitton

Venkatesh Karthikeyan

A rigorous appreciation of why patients require access to their records must begin with precision regarding what those records contain and what epistemic value they hold. Clinical documentation, in its raw form, constitutes data – discrete, decontextualised biomedical facts. These data points, when organised and presented in a form comprehensible to a non-specialist reader, become information. The distinction is not trivial: a patient who receives a printed laboratory result but cannot interpret its clinical significance has acquired data, not information, and the therapeutic utility of that transaction remains minimal.

Knowledge emerges when two or more informational inputs are synthesised in relation to a known reference. For instance, a patient should understand that an elevated hemoglobin A1c (HbA1c) in the context of a high-carbohydrate diet and physical inactivity is not an isolated laboratory anomaly, but rather the expression of poorly controlled glycaemia with implications for nephropathy and retinopathy. Understanding, a further cognitive layer, arises when the patient applies accumulated knowledge to their own specific longitudinal experience, producing a personalised interpretative framework. This patient-derived understanding, while idiosyncratic and at times partially incorrect, represents an irreplaceable epistemological resource that differs from, and adds to, the clinician's view.

The World Health Organization (WHO) defines health literacy as *"representing the personal knowledge and competencies that accumulate through daily activities, social interactions and across generations. Personal knowledge and competencies are mediated by the organizational structures and availability of resources that enable people to access, understand, appraise, and use information and services in ways that promote and maintain good health and well-being for themselves and those around them"* [1]. Without access to their own records, patients cannot achieve the full potential benefit. Data remain sequestered within systems that, however sophisticated, cannot substitute for the individual's capacity to self-monitor, self-interpret, and self-advocate.

Clinical Safety, Quality, and the Patient Avatar

Electronic health records (EHRs) function not merely as administrative repositories but as dynamic digital representations of the patient – which can be described as the "patient avatar." This conceptualisation carries profound implications. Just as a detailed anatomical model must be accurate to be clinically useful, the EHR must be complete, current, and validated by the most informed possible source: patients themselves. The systematic exclusion of patients from the co-authorship and ongoing verification of their own records introduces a structural vulnerability into the safety architecture of clinical care.

Peer-reviewed evidence demonstrates the magnitude of this vulnerability. Studies have identified that a significant percentage of clinical records contain errors or omissions of potential clinical significance – that would be deemed unacceptable in any other safety-critical industry [2,3]. The aviation sector, widely cited as a comparator for its systemic approach to failure prevention, has developed layered inspection protocols premised on the recognition that individual expertise, however excellent, is an insufficient safeguard against the accumulation of small errors. The parallel with patient co-inspection of health records is direct: patients reviewing their own records have been shown to identify inaccuracies in documented diagnoses, allergies, medication lists, and procedural histories. These corrections prevent adverse drug reactions, diagnostic misattributions, and the perpetuation of clinical errors

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across institutional boundaries.

The temporal reality of chronic disease management renders this co-inspection as structurally necessary. In typical outpatient practice, a physician may interact with a patient for approximately 15 minutes, with even shorter consultation times in resource-limited settings [4]. In contrast, the patient lives with their condition for approximately 525,600 minutes annually – every conscious moment spent negotiating symptoms, managing medications, observing responses to treatment, and navigating daily functional limitations. During this vast interval of unsupervised self-management, the EHR functions as a "Memory Palace": a structured repository of clinical history that the patient can consult, study, and annotate, transforming passive data storage into an active instrument of self-knowledge. Research examining the OpenNotes initiative – which enabled patients in the United States to read their physicians' clinical notes – has demonstrated that access to records improves treatment adherence, increases patient preparedness for clinical encounters, and reduces emergency department utilisation, particularly among patients managing complex, multi-system chronic disease [5,6].

The safety imperative is not hypothetical. The case of Harold Shipman – a British physician subsequently convicted of the murder of about 250 patients through illicit opioid administration, with deaths obscured by falsified records – illustrates an extreme instance of what can occur when patients have no independent access to the documentation purporting to represent their clinical history [7]. Patients and families who possessed copies of their own records would have been positioned to detect alterations in clinical entries, thereby providing an independent audit trail. While it would be reductive to frame the case for universal record access around the prevention of criminal conduct, the case nonetheless crystallises the epistemic argument: a record that cannot be independently verified by its subject is a record that cannot be fully trusted.

Systemic Barriers

The desirability of universal patient access to EHRs is largely uncontested. Those working in health informatics and digital health governance frequently command sophisticated technical competencies while underestimating or misapplying the sociological, anthropological, and other dimensions of implementation. The introduction of digital records into clinical practice requires the simultaneous transformation of consultation habits, professional identities, institutional cultures, and patient expectations. Its implementation is constrained by infrastructural, policy, and structural constraints.

- *Infrastructural challenges:* Economies characterised by pronounced urban-rural disparities in digital access and healthcare provision face the greatest infrastructural challenges. The frameworks articulated by the Black Report and subsequently the Acheson Report demonstrated that health outcomes are substantially determined by socioeconomic position, and that the systematic under-resourcing of primary care in deprived communities perpetuates these differentials [8,9]. The absence of robust, accessible digital health records in these communities with the highest clinical complexity and the greatest need for coordinated care constitutes a contemporary manifestation of this historical pattern.

- *Policy challenges:* The integration of digital health infrastructure confronts a structural and policy paradox that is replicated across multiple national contexts. In many low- and middle-income countries, the agencies responsible for health system governance and information technology investment operate as entirely independent governmental entities, with separate legislative mandates. Achieving the degree of inter-ministerial coordination necessary to develop, procure, and implement a nationally standardised EHR system demands sustained political will across governmental silos that are not structurally incentivised to collaborate.

- *Structural challenges:* Standardisation and data portability represent the technical prerequisites for the vision of universal record access to be realised. A patient who moves between healthcare providers, regions, or countries must be able to carry a complete, machine-readable health history whose integrity is preserved across institutional boundaries. The current global landscape is characterised by non-interoperable systems and commercial arrangements that impede data flow across institutions and geographies. The consolidation of health data within commercial cloud infrastructure – including the storage of the United Kingdom's National Health Service (NHS)

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patient data within major technology corporation servers – introduces further questions regarding data governance, sovereignty, and the financial architecture under which personal health information is processed and potentially commercialised [10]. Dynamic consent, whereby patients retain ongoing, revisable control over data and use, is an essential safeguard for patient-centred digital health systems, though its implementation at scale remains challenging [11].

The Ethics of Shared Records

A persistent concern raised by clinicians considering the expansion of patient record access is the risk of professional responsibility being transferred to or claimed by, the patient. The physician who enables a patient to read, understand, and contribute to their own clinical record does not thereby surrender the professional and ethical obligations of clinical stewardship. The physician retains responsibility for the accuracy of clinical judgement, the appropriateness of therapeutic interventions, the timeliness of referrals, and the overall architecture of the care plan. Information (not responsibility) is shared, enhancing the patient's ability to contribute meaningfully to the clinical encounter, monitor their own progress, and advocate effectively for themselves in interactions with healthcare providers who do not know their medical history.

This framing is consistent with the broader trajectory of international health policy. The WHO's Patient Safety Charter, revised in 2023, explicitly articulates a patient's right to access their own records as the eighth right within its framework – a recognition that transparency in clinical documentation is integral to the safety and dignity of the therapeutic relationship [12]. Although incorporating this right into an internationally recognised charter does not resolve the structural barriers to its implementation, it establishes a standard for evaluating national health systems.

Towards a Global Standard

The transition from paternalistic medicine to genuine patient partnership requires more than attitudinal reform at the level of the individual clinician. It warrants the systematic redesign of health information infrastructure to place patients at the centre of their own clinical documentation. Rather than remaining passive recipients of information about themselves, patients should be recognised as active co-producers and validators of the records that shape their care. Universal patient access to EHRs is the necessary technical and ethical precondition for this transformation.

The evidence base is robust: patients with access to their records demonstrate superior treatment adherence, enhanced self-management competency, and reduced acute care utilisation. The patient safety case is clear: a significant rate of errors in clinical documentation constitutes a structural failure that patient review is uniquely positioned to address. The equity argument is urgent: in the absence of deliberate policy intervention, the benefits of digital health will accrue disproportionately to those with the existing resources, literacy, and digital access to exploit them, while the populations with the greatest clinical need are left furthest behind.

This analysis gives rise to actionable recommendations at both structural and grassroots levels. Structurally, health ministries should implement mandatory interoperability standards, dynamic consent frameworks, and data portability architectures that enable patients to access their complete health records regardless of provider or institutional context. At the inter-governmental level, coordinated investment across health and information technology portfolios is essential, with shared strategic planning replacing fragmented ministerial mandates. At the clinical level, the most durable driver of change is the cultivation of genuine partnership with patients, including their representation on clinical excellence and patient safety governance boards.

Conclusion

The patient who can read, annotate, and contribute to their own problem-oriented record is not a threat to the clinical enterprise; they are its most reliable collaborator. By bridging the gap between passive data storage and active therapeutic partnership, universal access to EHRs acts as a foundational intervention that promotes health equity, literacy, and safety. As the technological infrastructure for universal access matures – and as the policy architecture supporting data portability, standardisation, and dynamic consent is progressively constructed – the fundamental obligation of healthcare providers and health systems is to resist the inertia of historical paternalism and embrace the empirically demonstrated, ethically mandated reality. After all, the patient is not merely the subject of the health record but, in every meaningful sense, its author.

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Author Contribution Statement

RF and VK conceptualised the design and prepared the original manuscript draft. All authors critically reviewed and revised the manuscript and approved the final version for publication.

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Authors

Richard Fitton,
MBBS, MRCGP, DCH, DRCOG
Family physician
Manchester, England
richardpeterfitton7@gmail.com

Venkatesh Karthikeyan,
MBBS, MD
Senior Resident, Community & Family Medicine,
All India Institute of Medical Sciences
Publications Director, WMA
Junior Doctors Network
Patna, India
4852012@gmail.com

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