Explaining the Medical Record: a Research Agenda for Non-medical Practitioners

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Abstract - This paper proposes a research agenda exploring how Generative Artificial Intelligence (GAI) can help explain patient medical records, particularly to the patients of non-medical practitioners. While patient access to records is expanding globally, little is known about how this access supports care beyond primary care doctors, or how GAI tools like ChatGPT may assist in interpretation. We outline key research questions and argue for co-designed solutions that include nurses, midwives, and allied health professionals to ensure accessible, equitable, and scalable approaches to explainability in digital health.

Keywords- explainability; patient access to records; research agenda; non-medical practitioners.

I. INTRODUCTION

Medical records were originally developed in the 18th and 19th centuries, primarily as an aide-mémoire for clinicians to support diagnosis, monitor treatment, and facilitate communication between healthcare professionals, not as documents intended for patients themselves. During the 1960s and 1970s researchers and practitioners began to suggest that patients could benefit from access to their records or hold shared care records [1], for example, in diabetes or hypertension [2]. As technology developed opportunities arose to share computer-produced summaries, for example, a clinical system for diabetes that produced records for hospital, GP and patient [3][4]. Use of this problem-oriented record showed that doctors were not always ready to share all problem-list entries with their patients [5][6]. On the other hand, in some situations such as antenatal care [7], clinicians were prepared to ‘hand over’ a complete paper medical record for women to look after.

In the 1990s we saw attempts to explain medical records to patients including the development of ‘lay dictionaries’ to ‘translate’ medical problems [8][9] as well as AI approaches to construct explanations [10][11] and showed that explanations based on their medical record were preferred to more generic information [12][13]. Randomised trials in the 1990s and 2000s [12][14][15] showed that giving patients access to their record with some type of explanation was of benefit. For example, a computer-produced paper record of the medical record with quality relevant information was more likely to be shared by cancer patients with their family than just the general information. This helped reduce patient anxiety [12].

More recently, a 2020 systematic review of patient access to medical records found that sharing electronic records with patients improved medicine safety and often reduced healthcare use, including fewer hospital visits and appointments [16]. However, an editorial by Sarkar et al [17] argued that the impact of patient access depends heavily on implementation. Contextual factors such as digital literacy, language, and clinical workflows must be considered, or else the benefits may be offset by increased clinician burden and exacerbated inequalities [18].

In section 2 we describe current practice, in section 3 the changing health information landscape in the UK, in section 4 we describe research questions about explaining medical records to patients, in section 5 we focus on under-researched areas and draw conclusion in section 6.

II. CURRENT PRACTICE

Progress in this area had been slow until recently, but patients in at least 30 countries now have some level of access to their records. Online routine access to medical records has demonstrated benefits including patient empowerment, reducing inefficiencies, error correction, and better shared decision making [19-21].

However, the degree of routine implementation differs. In the UK, patients were expected to gain prospective access to new data in their primary care records, including letters and consultations, from October 2023. However, a recent study [22] of 400 GPs in England revealed that in 2023 only 33% supported patient access to records. Most GPs felt that patients would worry more (91%) or find records confusing (85%). While many acknowledged potential patient benefits, most believed that online record access would increase their workload. Qualitative analysis [23] echoed these concerns among other primary care staff. Clinicians are concerned that patients will not understand their records.

III. THE CHANGING UK HEALTH INFORMATION LANDSCAPE

The NHS 10-Year Plan sets out a vision for a digitally enabled, personalised, and prevention-focused health service, emphasising the shift of care closer to home and the importance of empowering individuals to manage their own health. Achieving this vision requires not only giving patients access to their health records, but also ensuring they can understand and use that information effectively [24].

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In the UK as elsewhere, the digital health landscape is evolving rapidly, both in terms of access to general health information and the development of personal health records. High-quality health information is widely available from trusted sources such as the NHS [26], Mayo Clinic [27], NICE [28], as well as peer-reviewed medical journals. This information is increasingly being accessed, summarised, and transformed by GAI tools such as ChatGPT.

Meanwhile, personal health records, created through interactions with frontline systems in general practice and community care (e.g., EMIS [29] and SystmOne [30]), as well as hospital systems (e.g., Cerner [31] and Epic [32]), are being extracted into patient-facing platforms such as the NHS App [33]. These records may also feed into shared care records for care planning and potential future patient access (e.g., via systems like Orion [34] and Black Pear [35]). Patients may therefore engage with digital health in different ways: using public websites or AI tools independently or verifying their clinical data through patient portals, then exploring it via GAI. Some health IT providers are beginning to integrate, or plan to integrate, GAI directly into their patient portal platforms. For example, Epic is working with Microsoft/OpenAI to embed GAI into clinician workflows and patient portals and NHS England is exploring how GAI might be used in the NHS App and other digital services.

GAI tools offer new opportunities to make medical records more accessible by translating clinical jargon into lay language, providing context-specific explanations, supporting conversational queries, and generating personalised summaries. These tools may enhance patient understanding, engagement, and self-management, especially when integrated with voice interfaces or patient portals. However, public-facing GAI tools also carry significant risks. They may generate incorrect or misleading information ("hallucinations"), lack source traceability, pose privacy concerns if sensitive data is shared outside secure systems, and exacerbate inequalities among patients with low digital literacy or poor internet access. Without safeguards and careful integration into clinical workflows, GAI may increase anxiety or misunderstandings rather than empowering patients. Research is therefore needed to explore how GAI can be safely and effectively deployed in real-world health contexts, particularly for non-medical practitioners and the populations they support.

IV. RESEARCH QUESTIONS ABOUT EXPLAINING MEDICAL RECORDS TO PATIENTS.

We could divide research questions about medical records into three categories:

- ‘Micro’ level, the explainability of the record, exploring which types of explanation are preferred or are more useful.
- ‘Meso’ level, whether patients want to use portals and whether their use and GAI affects the practitioner-patient relationship, and
- ‘Macro’ level, how this transformation can affect patient outcomes and possible changes to care processes, such as the shift from acute to community care and the focus towards health promotion and disease prevention [36].

Micro questions might include: How much do patients need their medical record if they know enough to ask a GAI for explanation? Will software developers build in GAI to their systems? Will this be more secure than patients using information from their online records to query a GAI? If NHS App builds in GAI will patients use that or still use independent GAI? What about the digitally disadvantaged? How should GAI adapt explanations to the knowledge level of the patient? Should the priority be on giving voice AI access to medical records so that those with no internet access or lack of skills can use the telephone to find out more?

At the ‘Meso’ level, questions are focussed on how we develop the triad of patient-practitioner and AI? What staff training is needed? How can practitioners collaborate with patients who turn up with lists or cite papers or GAI? How can practitioners support patients who do not use the Internet? How can practitioners assess their patients’ IT abilities and knowledge? How might this approach need to be adapted for some categories of patients such as the cognitively impaired? How do practitioners feel about patients reading and interpreting their notes—especially sensitive or nuanced ones (e.g. mental health, pain, uncertainty)? Does transparency change clinical documentation practices (e.g., tone, completeness, candour)? What are the risks and benefits of giving access to records in real time versus following clinician review or filtering? How do we introduce this topic to the curriculum of doctors, nurses, and other health professionals?

At the Macro level, NHS level questions are concerned with the most scalable and cost-effective methods for explaining records (e.g., automated summaries vs clinician review vs chatbot support)? How can health systems measure ‘understanding’ as an outcome of record-sharing interventions? Will these developments increase or decrease health inequalities?

V. UNDER RESEARCHED AREAS

In the English NHS, there are approximately 172,000 doctors (134,000 hospital doctors and 38,000 full-time equivalent GPs). However, there are some 372,000 nurses and midwives, and over 200,000 Allied Health Professionals (AHPs) (healthcare professionals other than doctors and nurses) from 14 professions (such as physiotherapy, podiatry, dietetics) working across community, primary, and secondary care. AHPs deliver over 208 million patient contacts annually [36]. Yet, most research into patient online access to their records has been in primary care and with GPs. Very little is known about nursing or AHPs’ or patients’ attitudes to patient access to their records or the use of GAI in non-medical clinical situations. For example, a recent scoping review of patient-accessible electronic health records [37] identified 66 studies, with none addressing nursing or AHP attitudes or GAI use in those settings.

We propose that the research questions outlined above regarding the most effective ways to explain medical records, could be more widely explored at micro, meso and macro levels, through co-design with patients and practitioners in non-medical disciplines. These include antenatal care, nurse-led pain clinics, physiotherapy, podiatry, and dietetics.

- Antenatal care has the longest history of providing patients with access to their records [7]. It continues to lead in shared record practices, with handheld notes and digital maternity apps now widely used.
- Pain clinics, particularly those led by nurses, are more cautious. While some services have begun to share care plans and symptom-tracking tools through patient portals, concerns remain about the risk of patients misinterpreting complex pharmacological or psychological data.
- Podiatry, especially within diabetes care, is seeing a growing use of digital platforms. These integrate podiatry notes into diabetes pathways and offer patients access to wound images, self-care advice, and foot health monitoring. However, access remains inconsistent.
- Dietetics is at a transitional stage. Patients are increasingly using digital tools to track dietary intake and receive tailored plans. There are also new digital platforms evolving such as MyRenalCare where clinicians including dietitians support the patient. Yet access to dietetic records is still limited, and documentation is not routinely shared or integrated across systems.
- Physiotherapy shows similar variability. Some integrated musculoskeletal pathways allow patients to access structured exercise plans and outcome data via apps like getUBetter or PhysiApp. However, routine access to clinical notes is uncommon, and many departments still rely on paper records or standalone systems.

Overall, progress toward shared records and digital self-management tools across these disciplines is uneven. There is a mix of promising developments and significant gaps. However, this inconsistency presents an opportunity: it offers researchers a diverse range of environments in which to explore and evaluate innovative approaches.

VI. CONCLUSION

Now is the time for a major change towards using AI to explain and interpret the content of a patient's medical record to the patient themselves. But we need (i) to switch attention to the under-researched areas of nursing and AHPs and (ii) to work with both practitioners and patients to co-design the convergence of patient access and GAI to empower patients to self-manage their condition and get what they need from their clinical consultation. Co-design is the only approach which identifies the needs and concerns of both groups (HCPs and patients) and enables them to work together in developing and sharing an optimum approach

We now need collaborative design between patients and practitioners to adapt these technologies effectively within clinical workflows. Without such work, we risk missing opportunities for improvement and compounding access disparities. This research proposes co-design approaches, including the development of solutions such as voiceAI telephone interfaces, to ensure these tools are usable, equitable, and aligned with NHS real-world needs.

Improvements in technology such as patient portals and GAI, may make it possible to improve patient autonomy, accelerate the switch from acute to community care, focus on health promotion and disease prevention. and reduce practitioner workloads. However, practitioners are concerned that the integration of AI and the potential need for deeper conversations with patients will add additional time pressures and create inefficiencies as conversations are misdirected to discuss strong preconceptions and conflicting advice, with some patient groups feeling empowered (but perhaps misinformed) while the more digitally excluded suffer even greater disadvantage.

To realise the benefits of patient access to records, particularly in community-based care, approaches must be co-designed by patients and practitioners and focus on inequalities. Despite extensive research in primary care and some in hospital settings, there has been virtually no exploration of patient access in collaboration with non-medical practitioners, apart from longstanding antenatal care research [7]. To unlock the full potential of patient-accessible records and generative AI, we must expand our research lens beyond doctors and engage the full breadth of the healthcare workforce and the patients they serve.

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