Clarifying Research and Education Needed to Explain the Medical Record to Patients: Protocol for UK Survey of Non-medical Practitioners

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Abstract— **Online record access (ORA) is expanding across the British National Health Services and internationally, and patients increasingly use generative AI (GAI) tools to interpret clinical information. Despite this shift, research and curricula have focused largely on doctors, leaving a substantial gap in understanding the needs and perspectives of nurses, midwives, and allied health professionals. This paper presents a multi-level framework for explainability in AI-mediated patient record access and a detailed protocol for the first United Kingdom national survey of non-medical practitioners on the topic. The survey will identify research priorities and curriculum requirements related to ORA and patients' use of GAI using a novel design that embeds 30 minutes of Continuing Professional Development to engage busy clinical academics. Findings will inform co-designed approaches to explainability, support equitable implementation, and guide curriculum development for the future workforce. Although UK-based the work should be relevant to other countries.**

Keywords— explainability; patient access to records; research and education agenda; non-medical practitioners; survey protocol.

I. INTRODUCTION

Health systems internationally are undergoing a fundamental transformation in how clinical information is generated, stored, and shared. Patient online record access (ORA) is becoming widely implemented across primary and secondary care, enabling patients to view consultation notes, laboratory results, correspondence, and care plans in near real time. At the same time, generative artificial intelligence (GAI) tools such as ChatGPT, Copilot, and Gemini are increasingly used by patients to interpret, summarise, and query clinical information. Together, these developments create a new information environment in which patients are no longer passive recipients of professionally mediated explanations, but active users of algorithmically generated interpretations of their own health data.

This convergence of ORA and GAI fundamentally alters the conditions under which clinical meaning is produced, communicated, and acted upon. Explainability, the ability of a system to make information intelligible, usable, and trustworthy to its users, has traditionally been treated as a property of software systems or machine-learning models. In healthcare, however, explainability is not produced by algorithms alone. It emerges from interactions between digital records, AI systems, healthcare professionals, organisational workflows, and patients' and their families' own capabilities, experiences, and vulnerabilities. Explainability in this context is therefore a socio-technical property of healthcare systems rather than a purely technical feature of software.

Most research on ORA and clinical AI has focused on doctors, particularly in primary care, even though nurses, midwives, and allied health professionals (AHPs) deliver the majority of patient contacts and are often the clinicians who help patients interpret what they see in their records. Yet their perspectives on patient-accessible records, AI-mediated explanations, and the implications for professional practice, communication, and safety remain largely absent from the literature.

This omission matters for three reasons. First, non-medical practitioners routinely manage clinical information that is highly technical, longitudinal, and functionally oriented, including rehabilitation plans, mental-health notes, functional scores, and therapy goals. Second, they play a central role in helping patients and families make sense of clinical data, especially in long-term and community-based care. Third, emerging AI tools are increasingly capable of generating persuasive, empathetic, and apparently authoritative explanations, which patients may bring into clinical encounters, reshaping professional roles, responsibilities, and power dynamics.

At the same time, professional education and regulatory standards for nurses, midwives, and AHPs have not kept pace with these developments. While digital literacy and record-keeping are emphasised, there is little formal preparation for responding to patients who have continuous online access to their records or who use AI to interpret them. This creates a growing gap between the information environment patients inhabit and the training received by the workforce expected to support them.

This paper addresses that gap by advancing a conceptual and methodological framework for studying explainability in AI-enabled patient record access, grounded in the realities of non-medical clinical practice. We propose that meaningful explainability operates across multiple levels of the health system—individual, organisational, and systemic—and that research and curriculum development must be aligned across these levels. To operationalise this approach in the United Kingdom (UK), we present a protocol for a UK-wide study that uses a novel combination of bibliometric sampling and a CPD-embedded survey to identify research priorities and curriculum needs among academic nurses, midwives, and AHPs.

By integrating socio-technical theory, digital health informatics, and professional education, this work contributes a scalable framework for understanding and shaping how AI-mediated record access is explained, governed, and taught within contemporary healthcare systems.

This paper makes three contributions: (i) it conceptualises explainability in AI-mediated patient record access as a multi-level socio-technical property; (ii) it derives research and curriculum requirements from that framework for non-medical practitioners; and (iii) it presents a novel CPD-embedded survey design to operationalise this agenda at national scale.

II. CONCEPTUAL FRAMEWORK: EXPLAINABILITY AS A MULTI-LEVEL SOCIO-TECHNICAL PROPERTY

A. Explainability Beyond the Algorithm

In the artificial intelligence literature, explainability is typically framed as a property of models—how well a system can make its outputs transparent, interpretable, or justifiable to users. In healthcare, however, the outputs of AI are rarely consumed in isolation. They are embedded within electronic health records, patient portals, clinical workflows, professional judgement, and patient–clinician relationships. As a result, whether an explanation is meaningful, safe, or actionable depends not only on the algorithm, but on how it is situated within a wider socio-technical system.

When patients access their records through portals such as the National Health Service (NHS) App or hospital systems and then use GAI tools to interpret those records, explainability becomes distributed across at least three interacting components: the record itself, the AI that transforms it, and the clinician who contextualises it. This creates a triadic relationship between patient, practitioner, and AI, in which responsibility for meaning-making is shared and contested. Errors, misunderstandings, or misalignments can arise at any point in this triad and cannot be fully understood by examining any single component in isolation.

B. Three-Level Model of Explainability

To capture this complexity, we conceptualise explainability in AI-enabled patient record access as operating across three interdependent levels: micro, meso, and macro.

At the **micro level**, explainability concerns the interaction between an individual patient and their health information. At this personal level, this includes how clinical data are presented, how AI tools translate or summarise them, and how explanations are adapted to patients' literacy, cognitive capacity, emotional state, and cultural context. Micro-level explainability determines whether a particular patient can understand what is written in their record and what an AI-generated explanation means for the understanding their own health.

At the **meso level**, explainability is shaped by organisational and professional contexts. At this team or service level, this includes how clinicians document information when they know patients will read it, how teams integrate patient portals and AI tools into workflows, and how practitioners respond when patients bring AI-generated interpretations into consultations. Here, explainability becomes a property of clinical relationships, professional norms, and service design, rather than of individual technologies.

At the **macro level**, explainability is influenced by system-wide structures such as digital infrastructure, regulatory frameworks, workforce policies, and health-inequality dynamics. At this system-wide level, decisions about whether AI tools are integrated into patient portals, how data are governed, and how digital inclusion is addressed determine which populations benefit from AI-mediated explanations and which are left behind. Macro-level explainability therefore links technical design to equity, safety, and system performance.

These three levels are not independent. Changes at one level propagate to others: e.g. national policies to provide real-time access to records (macro) alter documentation practices (meso) and affect how individual patients encounter and interpret their data (micro). Conversely, patient experiences at the micro level can drive organisational change or policy reform.

C. Implications for Research and Education

This multi-level view implies that research on ORA and GAI cannot be confined to usability testing or algorithmic performance. It must also examine professional practice, organisational adaptation, and system-level consequences. Similarly, education for nurses, midwives, and AHPs cannot be limited to digital skills training; it must prepare practitioners to operate within a patient–AI–clinician triad, managing uncertainty, correcting errors, supporting vulnerable users, filling important gaps in understanding, and negotiating shared decision-making in an AI-mediated information environment.

The conceptual framework therefore links three domains: (i) the socio-technical dynamics of explainability, (ii) research priorities across micro, meso, and macro levels, and (iii) the competencies required of the future workforce. This alignment underpins the study design presented in the paper, which seeks to identify and prioritise research and curriculum needs among non-medical clinical academics who are uniquely positioned at the intersection of practice, education, and digital health innovation.

D. Co-design as structured socio-technical negotiation

Co-design in this context should not be understood simply as bringing technical developers and clinical practitioners together in workshops. The groups involved in AI-mediated record access are likely to hold different, and sometimes conflicting, priorities: developers may emphasise technical

performance, scalability and integration; clinicians may emphasise safety, professional accountability and workflow burden; educators may emphasise curriculum feasibility; and patients and carers may emphasise comprehensibility, trust, autonomy and equitable access. A useful co-design process therefore requires an explicit framework for surfacing and resolving these tensions.

We propose that subsequent co-design work should use the micro–meso–macro model as a structuring device. At the micro level, patient-facing explanations would be assessed for clarity, emotional impact, accessibility and risk of misinterpretation. At the meso level, proposed solutions would be assessed against clinical workflow, documentation practices, professional responsibility and the effect on practitioner–patient relationships. At the macro level, decisions would be assessed against governance, digital inclusion, data protection, scalability and system-level equity. In practical terms, co-design workshops would use patient scenarios, example record extracts, AI-generated explanations and service-use cases as shared "boundary objects" through which different stakeholders can identify benefits, risks and trade-offs.

Where priorities conflict, resolution should not rely on simple majority preference or technical feasibility alone. Instead, candidate solutions should be prioritised using explicit criteria: clinical safety, patient comprehensibility, equity, feasibility within workflow, professional accountability and governance acceptability. Safety, privacy and equity would be treated as minimum requirements rather than optional preferences. Disagreements would be documented as part of the design process, with unresolved tensions becoming research questions or implementation risks rather than being hidden. In this way, co-design becomes a deliberative socio-technical process for aligning patient needs, clinical practice, educational requirements and technical development, rather than a generic consultation exercise.

III. EMPIRICAL AND POLICY CONTEXT FOR EXPLAINABILITY

The conceptual framework outlined above builds on a long trajectory of research demonstrating that access to clinical information is beneficial to patients when it is accompanied by appropriate explanation. We previously articulated a research agenda for non-medical practitioners in explaining the medical record to patients, positioning explainability as a shared clinical responsibility rather than a purely technical function [1].

Early randomised controlled trials conducted over two decades ago demonstrated that providing patients with personalised explanations of their medical records improved understanding, reduced anxiety, and increased constructive use of information [2-4]. In cancer care, patients given computer-generated, clinically relevant summaries were more likely to share information with family members and reported lower anxiety than those given generic information alone [2]. Similar benefits were observed in patients with schizophrenia [3] and across a range of long-term conditions [4]. These studies established that access alone is insufficient: explanation is a necessary mediator of benefit.

More recently, large-scale evidence from electronic health records has confirmed and extended these findings. A 2020 systematic review and meta-analysis found that patient access to electronic records improved medication safety and was associated with reduced healthcare utilisation, including fewer hospital visits and appointments [5]. Subsequent studies have shown improvements in patient empowerment, error detection, and shared decision-making when online record access is implemented routinely [6–8]. However, these benefits are highly contingent on how systems are deployed. Differences in interface design, clinical workflows, and patient support produce widely varying outcomes, reinforcing the importance of meso- and macro-level explainability [9]. Without attention to digital literacy, language, and organisational practice, record access can increase clinician burden and exacerbate health inequalities [10].

These tensions are evident in current clinical attitudes. In England, although prospective access to primary care records became the default in October 2023, a national survey of general practitioners found that only one-third supported the policy in principle. Most anticipated increased patient anxiety and confusion and feared additional workload [11]. Qualitative research with primary care staff has echoed these concerns, highlighting uncertainty about how to document sensitive information and how to manage patient reactions [12]. These findings illustrate that explainability is not only a technical issue but a professional and organisational one.

At the system level, UK policy explicitly links digital access to patient empowerment. The NHS Long Term Plan and associated digital strategies emphasise prevention, self-management, and care closer to home, all of which depend on patients being able to understand and act on their health information [13]. England is exploring how GAI might be used in the NHS App and other digital services [14]. This policy environment has accelerated the integration of patient portals and record-sharing platforms across all levels of care.

In practice, patients now encounter a complex digital ecosystem. High-quality clinical information is available from authoritative sources such as the NHS, Mayo Clinic, and NICE [15–16], while personal health records generated in systems such as EMIS, SystmOne, Cerner, and EPIC [17–20] are increasingly made visible through patient portals and the NHS App [21]. At the same time, GAI is transforming how this information is consumed [22]. Patients commonly use tools such as ChatGPT or Copilot to translate medical jargon, summarise consultation notes, and explore possible meanings of test results. Health IT vendors are now embedding these capabilities directly into patient portals, with major platforms collaborating with AI providers and NHS England exploring similar functionality within the NHS App. This creates the conditions for an AI-mediated explainability layer operating between patients and their records.

These developments offer substantial opportunities. AI can provide personalised summaries, conversational explanations, and adaptive support that may enhance understanding and engagement, particularly for patients managing complex or long-term conditions. However, they also introduce new risks,

including hallucinated content, lack of provenance, data-privacy concerns, friction between patients and clinical staff, and the potential to widen digital inequalities [23]. Without careful integration into clinical workflows and professional practice, AI-mediated explanations may increase anxiety, misinterpretation, and mistrust rather than empowerment.

It is within this evolving empirical and policy context that the need for a multi-level approach to explainability becomes clear. Patients are already using AI to interpret their records; systems are already sharing those records by default; and clinicians, including nurses, midwives, and AHPs, are already being asked to manage the consequences. The remaining question is not whether AI-mediated explainability will occur, but how it should be governed, researched, and taught.

IV. RISKS OF UNMANAGED AI-MEDIATED EXPLAINABILITY

The rapid convergence of ORA and GAI creates not only opportunities for patient empowerment, but also new and under-recognised risks for clinical safety, professional practice, and health equity. Patients are already using public GAI tools to interpret laboratory results, consultation notes, and diagnostic reports, often outside secure clinical environments and without any professional mediation. Studies comparing AI chatbot responses to clinician advice have shown that AI can generate fluent and persuasive explanations that are sometimes inaccurate, incomplete, or clinically unsafe, particularly in complex or ambiguous cases [39,40]. When such outputs are applied to personal health records, the risk is not merely theoretical: patients may be reassured inappropriately, alarmed unnecessarily, or encouraged to take actions that conflict with clinical advice.

Nurses, midwives, and AHPs can be the first professionals patients consult when they are confused, distressed, or uncertain about what they have read in their records or generated through AI. In community and long-term care settings, they manage much of the relational, educational, and interpretive work that supports patient understanding. Yet they currently do so without formal guidance, training, or system-level support for dealing with AI-mediated explanations. This creates a growing mismatch between what patients can access and what the workforce has been prepared to manage.

At the organisational level, unmanaged AI use can also destabilise documentation practices and professional accountability. If clinicians know that their notes will be read, transformed, and potentially misinterpreted by AI systems, this may alter how they write, what they record, and how candidly they document uncertainty. At the system level, the unregulated spread of AI-mediated explainability risks exacerbating digital exclusion, as patients with higher digital literacy and access gain enhanced interpretive tools while others are left with opaque records and limited support.

Taken together, these dynamics mean that explainability is no longer a design choice but a patient-safety and workforce-preparedness issue. Without empirical evidence on how non-medical practitioners experience, manage, and prioritise these challenges, health systems risk embedding AI-mediated record access in ways that increase misunderstanding, workload, and inequality rather than reducing them. This makes a systematic investigation of research and curriculum priorities for this workforce not optional, but necessary for the safe and equitable evolution of digitally enabled care.

V. TARGET GROUPS FOR FURTHER STUDY

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 AHPs (healthcare professionals other than doctors and nurses) from 14 professions (such as physiotherapy, podiatry, dietetics) working across community, primary, and secondary care. Yet, 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 [25] identified 66 studies, with none addressing nursing or AHP attitudes or GAI use in those settings. Therefore, it is important to establish what needs to be researched and what should go into a research-informed curriculum for these non-medical practitioners (Figure 1).

Within nursing, midwifery and the allied health professions there is a varied history of patient access to their records and use of GAI. For example, antenatal care has a long history of providing patients with access to their records [26]. It continues to lead in shared record practices, with handheld notes and digital maternity apps now widely used. While, in physiotherapy, the largest of the allied health professions, routine access to clinical notes remains less common, and many departments still rely on paper records or standalone systems. This mix of promising developments and significant gaps offers both researchers and educators diverse range of environments in which to explore and evaluate innovative approaches.

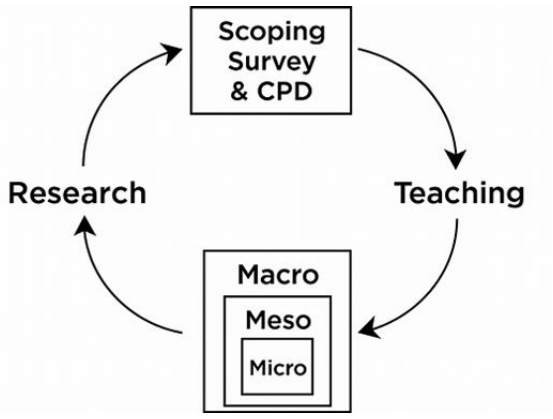

Figure 1. Multi-level socio-technical model linking explainability, research, and curriculum development for online record access and generative AI.

VI. RESEARCH QUESTIONS ABOUT EXPLAINING MEDICAL RECORDS TO PATIENTS.

Research questions about patient access to explained medical records can be grouped at three levels (Table 1):

'Micro' level, (personal level) the explainability of the record, exploring which types of explanation are preferred or are more useful.

'Meso' level, (service or team level) whether patients want to use portals and whether their use and GAI affects the practitioner-patient relationship, and

'Macro' level, (system-wide 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 [24].

VII. A RESEARCH INFORMED CURRICULUM FOR NON-MEDICAL PRACTITIONERS

Nursing and midwifery: Despite national policy commitments to digital transformation and patient empowerment, nursing education in England has not yet formally incorporated competencies related to ORA or patient use of GAI. The Nursing and Midwifery Council (NMC) standards for registered nurses and Health Education England's digital capability framework set out broad expectations for digital literacy and record keeping but make no reference to ORA or patients' use of GAI [27,28]. In nursing, professional risk guidance recommends local training for staff producing notes accessible to patients, but such training remains workplace-based and optional rather than embedded in educational standards [29]. We therefore need to consider integrating ORA-related competencies or related patient use of GAI into pre-registration curricula.

Table 1. Multi-level research agenda for explainability in online record access and generative AI.

Level	Explainability focus	Primary AI-related risks	Key research constructs	Implications for professional education
Micro (patient level)	How individual patients understand, trust, and use information from their clinical record when it is mediated by generative AI	Misinterpretation, hallucinated explanations, inappropriate reassurance or alarm, unequal access for digitally disadvantaged patients	Health literacy, cognitive load, trust in AI, comprehension of records, accuracy of AI explanations, patient self-efficacy	Teaching clinicians how to explain records in patient-centred language; recognising limits of AI-generated explanations; supporting vulnerable and low-literacy patients
Meso (service and professional level)	How clinical teams integrate ORA and AI explanations into documentation, communication, and consultations	Role confusion, defensive documentation, erosion of professional authority, increased workload, conflict over AI-generated interpretations	Workflow adaptation, documentation practices, clinician–patient–AI interaction, professional responsibility, communication quality	Preparing practitioners to manage AI-informed patients; ethical use of AI; handling disagreement between AI and professional judgement; maintaining therapeutic relationships
Macro (system level)	How health systems govern, scale, and regulate AI-mediated explainability in patient record access	Inequitable access, privacy breaches, unsafe automation, misaligned incentives, widening health inequalities	Digital infrastructure, governance frameworks, regulatory standards, cost-effectiveness, equity and inclusion	Policy literacy, digital governance, understanding system-level risks and benefits, preparing the workforce for AI-enabled care models
Cross cutting	What factors interplay at micro, meso and macro levels to impact the optimal deployment of ORA and GAI in practitioner-patient relationships?	Misalignment between policy, technology design, organisational practice, and patient capability; fragmented accountability; uneven implementation that benefits some groups while disadvantaging others	Implementation science; socio-technical alignment; co-design with patients and clinicians; digital inclusion; governance–practice feedback loops; learning health systems	Understand how implementation and optimal deployment of GAI/ORA is mediated through micro, meso and macro system factors

Allied Health Professions: Despite being responsible for over 200 million patient contacts annually across rehabilitation, diagnostics, therapy, and long-term condition management [24], AHPs have been almost entirely absent from the ORA and

patient-AI literature. Unlike the NMC, where professional standards reference documentation and patient communication explicitly, AHP regulation via the Health and Care Professions Council (HCPC) emphasises record keeping, informed consent, and communication, but does not address patient online access or the implications of patients using GAI to interpret therapy notes, imaging reports, or rehabilitation plans. This omission is particularly consequential because AHP records often contain highly technical, functional, and prognostic information (e.g., radiology reports or therapy progress notes) that patients are increasingly able to view via portals such as the NHS App. Without explicit curricular preparation, AHPs are left to navigate how to respond when patients arrive with AI-generated interpretations of scan findings, therapy goals, or outcome measures. Integrating ORA- and GAI-related competencies into AHP education is therefore essential not only for patient understanding, but also for preserving professional accountability, managing risk, and supporting shared decision-making across rehabilitation and diagnostic pathways.

To clarify the link between research priorities and educational needs, Table 2 maps the three levels of inquiry, micro, meso, and macro, onto corresponding curriculum implications. This alignment illustrates how findings from future research can directly inform pre-registration training for nurses, midwives, and AHPs. By presenting these connections visually, the table reinforces the argument that curriculum development should be evidence-based and responsive to emerging digital health trends, including ORA and GAI.

VIII. PROTOCOL FOR A CROSS-SECTIONAL SURVEY, CPD AND NETWORKING

It is important to ask nursing, midwifery and AHP researchers, as an expert group, for their views as to (i) research priorities and (ii) what goes into the curriculum regarding patient ORA and related use of GAI to explain them. This is a rapidly evolving field, and non-medical health academics themselves may struggle to keep pace with advances in digital and AI technologies, given their competing clinical, teaching, and administrative commitments [30,31].

Table 2. Curriculum requirements derived from the multi-level explainability framework

Level	Explainability failure mode	What graduates must be able to do	What must be taught	What should be assessed
Micro (patient–AI interaction)	Patients misinterpret records or AI explanations, leading to anxiety, false reassurance, or unsafe decisions	Recognise misunderstanding; explain record content in patient-centred language; correct misleading AI output; support digitally vulnerable patients	Principles of explainability; health literacy; limitations and hallucinations of GAI; communicating uncertainty; adapting explanations to patient context	Ability to interpret AI-mediated patient queries; simulated consultations involving AI-generated explanations; recognition of unsafe or misleading outputs
Meso (clinical teams and workflows)	AI and ORA disrupt professional roles, documentation practices, or therapeutic relationships	Integrate ORA and AI into safe documentation and consultations; manage disagreement between AI and professional judgement; maintain trust and accountability	Professional responsibilities in AI-mediated care; documentation for patient visibility; ethics of transparency; managing digitally informed patients	Case-based assessments involving AI-informed patients; documentation exercises; ethical reasoning about AI use in clinical encounters
Macro (health system and equity)	AI-mediated explainability increases inequity, undermines governance, or creates unsafe system-level effects	Understand how digital policy, regulation, and infrastructure shape patient experience; recognise system-level risks and inequalities	Digital health governance; data protection; equity and inclusion in digital systems; NHS digital strategy and regulation	Policy analysis tasks; evaluation of digital health interventions for equity and safety; understanding regulatory and governance frameworks

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To encourage respondents to complete, the survey will be paired with a learning opportunity on the topic, and a Continuing Professional Development (CPD) certificate upon completion (Figure 1). In doing so, this study uses a structured knowledge-exchange design, in which participants receive curated evidence and contribute expert judgement. To have further impact the survey will aim to set up a Smart Patient Academic Network for further collaboration on empowering patients by addressing research and teaching on ORA and GAI.

To operationalise this multi-level explainability framework, we have designed a national study that aims to identify and prioritise research priorities and curriculum content for incorporating ORA and related GAI into non-medical health education in the UK and to test the strategy of combined research investigation with CPD for the respondents.

The study design is a cross-sectional survey of non-medical clinical university staff who have experience of research and teaching. The survey conducted online simultaneously offers CPD and a CPD certificate to respondents on patients' ORA and use of GAI. The survey will include structured ratings and rankings and open-ended qualitative questions. The survey will not be anonymous if respondents wish to be awarded a CPD certificate for their completion of the learning aspects of the survey.

IX. RECRUITMENT STRATEGY

We aim to recruit UK university-based nursing, midwifery and AHP clinical academics. These will have a "360-degree view" (as researchers, teachers, and patients or confidants to patients) of ORA and GAI. We considered (but discounted) recruiting via professional bodies such as Royal College of Midwives, Chartered Society of Physiotherapy, and the British Dietetic Association, but (a) this may have resulted in many non-university contacts (so ineligible for the survey, and (b) we wanted to explore a non-NHS method requiring only University ethical approval, to optimise feasibility.

Participants will be recruited using a snowball method starting with university academics who have published. The survey therefore will be a structured expert consultation rather than a prevalence survey of representative academics. We will 'seed' the snowball with a large (n=400) quota sample of authors, identified via Web of Science. These authors are likely to be eligible, will be invited to complete it themselves, and will also be asked to forward it to colleagues who they think may be interested. First, we identified relevant publications in 2023-2025. Second, we extracted the email addresses of the authors where they were employed by a UK university. This returned a large sample of 2087 authors, many of whom are medical, dental, or non-clinical researchers. Internet searches were used to identify a quota sample of 400 (20%) within the 2087 people that appear to be qualified as nurses, midwives or AHPs. Appendix 1 gives a detailed description of how the 'snowball seeds' were identified and the invitation email.

We estimate that with 400 snowball seeds, we may recruit a sample of 200 (an estimated 100 from the seeds and a further 100 from a forwarded email). This would give sufficient precision on proportions estimated from closed questions and sufficient breadth of recruitment for the thematic analysis of open questions. For example, if the proportion of clinical non-medical academics who (Q17 (Appendix 2)) think it is important or essential to include ORA and GAI in the curriculum is 60%, the 95% confidence interval would be 53.2% to 66.8%. For an exploratory survey, we propose that this provides sufficient precision.

X. ELIGIBILITY AND INCLUSION

Respondents are eligible if they are (i) registered as a nurse, midwife or AHP; (ii) employed by a UK university; and (iii) engaged in both teaching and research. Eligibility will be confirmed through screening questions at the start of the online survey.

XI. SURVEY INSTRUMENT

The online questionnaire (Appendix 2) developed using JISC Survey consists of four main sections. We first present the participant information, check eligibility and ask about their role as an academic, patient and confidant. Second, we present information about ORA and GAI and seek their views on research priorities. Third we focus on ORA and present three papers and ask what should be included in the undergraduate curriculum. We also ask about their own personal experience of using ORA. From our previous study of retired doctors [34] we found that personal use of ORA was a strong predictor of respondents' attitudes to all patients having online access to their records. Section 4 takes the same approach for GAI. Sections 3 and 4 include summaries of six relevant publications as learning materials [35-40] which will be reviewed to ensure they are up-to-date before releasing the survey when starting the survey. Section 5 is about implementation in the curriculum and asks about whether ORA and GAI should have any priority given the pressure of required elements of the existing curricula. Section 6 ask respondents to choose anonymity or to give their email if they want to receive a CPD certificate. CPD certification is granted for engagement with the learning materials and completion of the survey, regardless of the views expressed. Section 7 asks about the methods of the survey: (i) whether they think the combination of a survey with CPD 'works' and (ii) asks how they received the invitation (directly from the principal investigator or forwarded from a colleague).

XII. DATA ANALYSIS, GOVERNANCE, DISSEMINATION

Quantitative data will be analysed descriptively using frequencies, crosstabs and possibly multiple logistic regression using SPSS. Anonymous qualitative free-text responses will undergo rapid thematic analysis to identify recurring themes, merged and analysed using a quantitised approach [41]. Ethics will be sought from the Faculty Research and Integrity Committee, University of Plymouth. Data management will be via JISC Survey with a single researcher (RJ) handling data. There are no collaborators external to University of Plymouth. Findings will be shared with respondents along with CPD certificates. Peer review papers will be submitted and executive

summaries shared with nursing and AHP education leads, national nursing, midwifery, and AHP bodies, and NHS England digital leadership groups.

XIII. LIMITATIONS OF THIS APPROACH

This approach of course has limitations. (i) Any such survey will have self-selection bias – only those with some interest in the topic are likely to respond. We try to address this by offering a CPD certificate but such bias is unavoidable. (ii) The speed of technological change is very fast. Generative AI moves faster than traditional curriculum redesign but if we do not try to ascertain academics' views we will be 'running blind'. The survey results may be somewhat outdated but they will at least give some indication of academics' views. (iii) Our proposed sample and survey is UK-Centric and so there are limitations of how well it can be used to generalize to other countries particularly those with greater use of private medicine. (iv) Once we have the views of academics, implementing them will face barriers due to the systemic lack of time/resources in both the university sector and in the NHS where nurses and AHPs may be prevented from actually performing this new core clinical function. (v) Our sample identification via publication will give a view biased towards research active academics; it is possible that an additional complementary sample of less research active academics needs to be included.

XIV. CONCLUSION

As AI increasingly mediates patient understanding, explainability becomes a core clinical function rather than a technical feature. This shifts professional boundaries for nurses, midwives and AHPs, who are often the primary human interpreters of algorithmic medicine. Patient access to their medical records, combined with the rapid emergence of generative AI, creates both new opportunities and new risks for patient understanding, safety, and equity. Yet the perspectives of nurses, midwives, and AHPs remain largely absent from the literature, despite their central role in patient communication and the volume of contacts they deliver.

This protocol sets out the first UK study to identify research priorities and curriculum needs for non-medical practitioners concerning online record access and patients' use of generative AI. By embedding a short CPD component within the survey, the study will also test a scalable model for engaging busy clinical academics with fast-moving digital health topics.

Findings will inform a structured socio-technical co-design agenda in which patients, carers, practitioners, educators, system leaders and developers use the micro–meso–macro framework to identify conflicts between technical feasibility, clinical safety, workflow, professional accountability, educational feasibility and patient understanding. Rather than assuming consensus, this approach treats such tensions as explicit design and governance problems to be surfaced, prioritised and, where necessary, carried forward as research questions or implementation risks. To unlock the benefits of digitally accessible records and generative AI, while avoiding widening inequalities, research and education must now extend beyond medicine to include the wider healthcare workforce and the diverse communities they serve.

REFERENCES

[1] R. B. Jones et al., "Explaining the medical record: a research agenda for non-medical practitioners," presented at EXPLAINABILITY 2025: The Second International Conference on Systems Explainability, Barcelona, Spain, 2025. [Online]. Available from: https://www.thinkmind.org/library/EXPLAINABILITY/EXPLAINABILITY_2025/explainability_2025_1_60_10044.html

[2] R. Jones et al., "Randomised trial of personalised computer based information for cancer patients," BMJ, vol. 319, no. 7219, pp. 1241–1247, Nov. 1999, doi: 10.1136/bmj.319.7219.1241.

[3] R. B. Jones et al., "Randomised trial of personalised computer based information for patients with schizophrenia," BMJ, vol. 322, no. 7290, pp. 835–840, Apr. 2001, doi: 10.1136/bmj.322.7290.835.

[4] R. B. Jones et al., "Effect of different forms of information produced for cancer patients on their use of the information, social support, and anxiety: randomised trial," BMJ, vol. 332, no. 7547, pp. 942–946A, Apr. 2006, doi: 10.1136/bmj.38807.571042.68.

[5] A. L. Neves et al., "Impact of providing patients access to electronic health records on quality and safety of care: a systematic review and meta-analysis," BMJ Quality & Safety, vol. 29, no. 12, pp. 1019–1032, 2020, doi: 10.1136/bmjqs-2019-010581.

[6] C. Blease et al., "The benefits and harms of open notes in mental health: a Delphi survey of international experts," PLoS ONE, vol. 16, no. 10, e0258056, Oct. 2021, doi: 10.1371/journal.pone.0258056.

[7] C. Blease, I. G. Cohen, and S. Hoffman, "Sharing clinical notes: potential medical-legal benefits and risks," JAMA, vol. 327, no. 8, pp. 717–718, Feb. 2022, doi: 10.1001/jama.2021.23179.

[8] A. Hannan and F. Webber, "Towards a partnership of trust," in Medical and Care Compunetics 4, L. Bos and B. Blobel, Eds. Amsterdam: IOS Press, 2007, pp. 108–116.

[9] U. Sarkar and C. Lyles, "Devil in the details: understanding the effects of providing electronic health record access to patients and families," BMJ Quality & Safety, vol. 29, no. 12, pp. 965–967, 2020, doi: 10.1136/bmjqs-2020-011185.

[10] A. Turner et al., "Unintended consequences of patient online access to health records: a qualitative study in UK primary care,"

British Journal of General Practice, vol. 73, no. 726, pp. e67–e74, Jan. 2023, doi: 10.3399/BJGP.2021.0720.
[11] C. R. Blease et al., "Experiences and opinions of general practitioners with patient online record access: an online survey in England," BMJ Open, vol. 14, no. 1, e078158, 2024, doi: 10.1136/bmjopen-2023-078158.
[12] C. Blease et al., "Patient online record access in English primary care: qualitative survey study of general practitioners' views," Journal of Medical Internet Research, vol. 25, e43496, 2023, doi: 10.2196/43496.
[13] S. Asthana, R. Jones, and R. Sheaff, "Why does the NHS struggle to adopt eHealth innovations? A review of macro, meso and micro factors," BMC Health Services Research, vol. 19, no. 1, pp. 1–7, 2019.
[14] NHS England, "AI knowledge repository." [Online]. Available from: https://digital.nhs.uk/services/ai-knowledge-repository. Accessed: 16-Jan-2026.
[15] Mayo Clinic, "Diseases and conditions." [Online]. Available from: https://www.mayoclinic.org/diseases-conditions. Accessed: 28-Aug-2025.
[16] National Institute for Health and Care Excellence, "Evidence summaries." [Online]. Available from: https://www.nice.org.uk/what-nice-does/our-guidance/about-evidence-summaries. Accessed: 09-May-2026.
[17] EMIS, "EMIS Web." [Online]. Available from: https://www.emishealth.com/emis-web. Accessed: 09-May-2026.
[18] TPP, "SystmOne." [Online]. Available from: https://tpp-uk.com/products/. Accessed: 09-May-2026.
[19] Oracle, "Oracle access governance." [Online]. Available from: https://docs.oracle.com/en/cloud/paas/access-governance/ocoir/. Accessed: 09-May-2026
[20] Epic, "Epic." [Online]. Available from: https://www.epic.com/. Accessed: 09-May-2026.
[21] NHS, "NHS App login." [Online]. Available from: https://www.nhsapp.service.nhs.uk/login. Accessed: 09-May-2026.
[22] A. Bracken et al., "Artificial intelligence (AI)-powered documentation systems in healthcare: a systematic review," Journal of Medical Systems, vol. 49, article 28, 2025, doi: 10.1007/s10916-025-02157-4.
[23] Z. L. Teo et al., "Generative artificial intelligence in medicine," Nature Medicine, vol. 31, no. 10, pp. 3270–3282, Oct. 2025.
[24] NHS England, "The allied health professions strategy for England: AHPs deliver, 2022–2027," 2022. [Online]. Available from: https://www.england.nhs.uk/ahp/allied-health-professions-strategy-for-england/. Accessed: 09-May-2026.
[25] T. Kariotis, M. Prictor, K. Gray, and S. Chang, "Patient-accessible electronic health records and information practices in mental health care contexts: scoping review," Journal of Medical Internet Research, vol. 27, e54973, 2025, doi: 10.2196/54973.
[26] D. Elbourne, M. Richardson, I. Chalmers, L. Waterhouse, and E. Holt, "The Newbury maternity care study: a randomized controlled trial to assess a policy of women holding their own obstetric records," British Journal of Obstetrics and Gynaecology, vol. 94, no. 7, pp. 612–619, 1987.
[27] Nursing and Midwifery Council, "Standards of proficiency for registered nurses," NMC, 2018, updated 2023. [Online]. Available from: https://www.nmc.org.uk/standards/standards-for-nurses/. Accessed: 09-May-2026.
[28] Health Education England, "The digital literacy framework for the health and social care workforce," HEE, 2018, updated NHS England 2022. [Online]. Available from: https://www.hee.nhs.uk/our-work/digital-literacy. Accessed: 09-May-2026.
[29] NHS England, "Record keeping and patient online access: guidance for clinicians," NHS England, 2023.
[30] C. Buchanan et al., "Predicted influences of artificial intelligence on nursing education: scoping review," JMIR Nursing, vol. 4, no. 1, e23933, 2021, doi: 10.2196/23933.
[31] G. Glauberman, A. Ito-Fujita, S. Katz, and J. Callahan, "Artificial intelligence in nursing education: opportunities and challenges," Hawaii Journal of Health & Social Welfare, vol. 82, no. 12, pp. 302–305, Dec. 2023.
[32] Wikipedia, "List of universities in the United Kingdom." [Online]. Available from: https://en.wikipedia.org/wiki/List_of_universities_in_the_United_Kingdom. Accessed: 09-May-2026.
[33] uniRank, "A-Z universities in the United Kingdom by alphabetical order." [Online]. Available from: https://www.unirank.org/gb/a-z/. Accessed: 09-May-2026.
[34] R. B. Jones et al., "Retired doctors' views on patients having access to their health records: cross-sectional mixed-methods survey in UK and Spain," as yet unpublished available from ray.jones@plymouth.ac.uk.
[35] S. N. D'Costa, I. L. Kuhn, and Z. Fritz, "A systematic review of patient access to medical records in the acute setting: practicalities, perspectives and ethical consequences," BMC Medical Ethics, vol. 21, article 18, 2020, doi: 10.1186/s12910-020-0459-6.
[36] K. De Groot, E. B. Sneep, W. Paans, and A. L. Francke, "Patient participation in electronic nursing documentation: an interview study among community nurses," BMC Nursing, vol. 20, article 72, 2021, doi: 10.1186/s12912-021-00590-7.
[37] S. O'Connor, P. Hanlon, C. A. O'Donnell, S. Garcia, J. Glanville, and F. S. Mair, "Understanding factors affecting patient and public engagement and recruitment to digital health interventions: a systematic review of qualitative studies," BMC Medical Informatics and Decision Making, vol. 16, article 120, 2016, doi: 10.1186/s12911-016-0359-3.
[38] J. W. Ayers et al., "Comparing physician and artificial intelligence chatbot responses to patient questions posted to a public social media forum," JAMA Internal Medicine, vol. 183, no. 6, pp. 589–596, 2023, doi: 10.1001/jamainternmed.2023.1838.
[39] C. Chen et al., "Comparison of an AI chatbot with a nurse hotline in reducing anxiety and depression levels in the general population: pilot randomized controlled trial," JMIR Human Factors, vol. 12, e65785, 2025, doi: 10.2196/65785.
[40] E. Reinhart, "What we lose when we surrender care to algorithms," The Guardian, 9-Nov-2025. [Online]. Available from: https://www.theguardian.com/us-news/ng-interactive/2025/nov/09/healthcare-artificial-intelligence-ai. Accessed: 16-Jan-2026.
[41] A. Tashakkori and C. Teddlie, Mixed Methodology: Combining Qualitative and Quantitative Approaches. Thousand Oaks, CA: Sage Publications, 1998.

Appendix 1: Bibliometric methods and invitation email

Purpose of the bibliometric analysis

The purpose of the bibliometric analysis was to identify UK university clinical but non-medical researchers to act as seeds for a snowball sample.

Bibliometric search strategy

A structured search of the Web of Science (WoS) was conducted to identify UK-based publications related to ORA, patient portals and GAI and researchers from 164 UK Universities [33, 34]. Searches were performed in 20 batches using combinations of affiliation fields containing UK university names, geographic fields (UK, England, Wales, Scotland, Northern Ireland), a time-period of 2023–2025, and topic terms including online record access, patient portal, electronic health record, digital health, education, curriculum, student, artificial intelligence and generative AI.

Extraction of UK academics

All retrieved WoS records were downloaded and merged into a single dataset (approximately 6,000 publications). Authors with .ac.uk email addresses were extracted, producing 2,129 unique contacts. Authors were assigned to a university based on their email domain. After removing duplicates, non-university and student addresses, a list of 2,087 UK university-based authors remained (Table A1).

Focus on nursing, midwifery and AHPs

Because bibliometric data cannot reliably identify professional background, we searched the Internet to try to verify whether the authors were from our target population. For this stage we explored the use of AI tools (ChatGPT and Microsoft copilot) alongside simple 'Google searches'. Use of AI, with obfuscation and multiple hallucination was not found to be useful. Nevertheless, we have identified 20% quota samples for the largest and a sample of smaller universities to have confidence that we can do so for the complete sample. We will exclude students and research assistants likely to be on short term contracts and so no longer available and with little influence on the curriculum. We also excluded VERY senior academics (Deans, Vice Principals etc) who may be more likely to delete such an email invitation.

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Kings College London	196
University College London	131
Birmingham University	85
Northumbria University	84
Newcastle University	81
Imperial College London	79
Queens University Belfast	79
Cardiff University	69
Manchester Metropolitan University	58
Manchester University	57
London School of Hygiene & Tropical M	52
Oxford University	51
Queen Mary London	47
Keele University	43
Liverpool John Moores University	39
Plymouth University	36
Kingston University	35
Nottingham Trent University	35
Bournemouth University	31
Edinburgh University	29
Anglia Ruskin University	26
Liverpool University	26
City University	25
Glasgow Caledonian University	23
Exeter University	21
Oxford Brookes University	21
Bristol University	20
De Montford University	20
Glasgow University	20
Edinburgh Napier University	19
Leeds Beckett University	19
Cambridge University	18
Robert Gordon University	18
Lancashire University	17
Leeds University	17
Southampton Universiity	17
Coventry University	16
London South Bank University	16
Ulster University	16
Bradford University	15
Cardiff Metropolitan University	15
Sheffield University	15
70 Universities with fewer than 15 people	398

Table A1. 2087 people from 112 universities identified with relevant publications.

Personal emails (Figure A1) will be sent by the principal investigator to these researchers.

FIGURE A1. Draft Example invitation email to 'snowball seeds'

Dear <author title and name>, I am writing to you as an established health researcher. I got your email address from Web of Science and checking on the Internet I think that this is relevant to you and colleagues. I hope that you will consider this survey and Continuing Professional Development (CPD) opportunity yourself, also to forward to colleagues that you think will be interested and eligible to participate in

We aim to recruit ***non-medical clinical UK university staff involved in research and education*** *seeking their views both on research priorities on patient access to their records and their use of generative AI, and research-informed teaching in the curriculum for the same topic. We fully realise the pressure on their time, so we are offering an approach that combines half an hour's CPD with a certificate from the University of Plymouth Centre for Health Technology alongside completing our survey. If you or your colleagues decide to participate you will (i) have the option of being named in an Appendix to any publication as one of the consulted experts as well as (ii) having the opportunity for CPD.*

To find out more join the link at <URL> where there is more information for potential participants. If you continue, we think it will take about 30-35 minutes to complete. Participants can of course drop out at any time or remain anonymous (the URL survey is not linked to this email in any way).

Yours sincerely,
Ray Jones on behalf of study team.

Appendix 2 – Online Survey

UK non-medical researchers' views on research and teaching of patient online record access and use of AI

SECTION 1 of 7: Participant Information 1

Thank you for considering this study on patient use of online record access and generative AI.

Although patients increasingly have online access to their medical records, not enough is known about how non-medical practitioners—nurses, midwives, and allied health professionals (AHPs)—can help patients understand what they read. Most existing RESEARCH focuses on doctors, even though non-medical practitioners make up most of the NHS.

Early studies found that giving patients explanations tailored to them can reduce anxiety and make care safer. However, this is not done consistently across the NHS, and many clinicians still worry that too much information might confuse or worry patients. But patients already turn to websites and AI tools such as ChatGPT to help make sense of health information. Some healthcare systems are starting to build these tools directly into their services. These technologies could help turn medical jargon into plain language and providing personalised summaries, but they also carry risks, including incorrect information, privacy concerns, and the possibility of increasing existing inequalities.

RESEARCH is needed at:

(i) 'Micro' (personal) level

(ii) 'Meso' (service or team) level

(iii) 'Macro' (system-wide) level

EDUCATION is needed on how to address patient online record access and use of AI but while the undergraduate or preregistration curricula may include general digital literacy it rarely includes online record access or patient use of AI, so we need to know what research-based education should be included in the curricula.

This survey, CPD and networking opportunity seek the views of non-medical practitioners on RESEARCH and research-based EDUCATION.

SECTION 1 OF 7: Participant Information 2

This survey includes:

1. A short, structured learning component
2. Your responses to questions
3. The opportunity to receive a 30-minute CPD certificate and follow up papers issued by the University of Plymouth
4. The opportunity to join a six-month network (the Smart Patient Academic Network) of like-minded UK academics to facilitate collaboration for research and teaching.

Participation is voluntary. Estimated time: 30-35 minutes.

The purpose of this survey is to (i) get your views on the priorities for research (ii) identify what knowledge and skills students need on this topic. Lastly we will explore whether embedding a short CPD activity for respondents within a survey is useful.

The study team from the University of Plymouth is led by Professor Ray Jones. If you have any queries about this study please contact ray.jones@plymouth.ac.uk

A paper with the background and protocol for this study has been published in the Journal of xxxxxxxxx (2026).

The study has ethical approval from the University of Plymouth Faculty of Health Research Ethics Committee (date/time).

If you wish to complain about the study in the first instance please contact Ray Jones or then contact the Research Administrator on <email>

SECTION 1 OF 7: Eligibility and Consent

To continue please confirm that you:

(i) are qualified as a nurse, midwife, or allied health professional
(ii) are employed by a UK university
(iii) have been involved in teaching and research at some stage of your career
(iv) have read the participant information
(v) are willing for your responses to be included in the analysis of this survey
(vi) understand that you are able to choose (at the end) to be anonymous or named if you want a CPD certificate, further papers, or to join the Smart Patient Academic Network

Q1. I confirm that I meet the six inclusion criteria above (Yes/No)

SECTION 1 OF 7: About you

Q2. What is your role? Research Assistant / Fellow; Lecturer / Senior Lecturer / Reader / Associate Professor / Professor; Clinical Educator / Practice Learning Lead; Other

Q3. What is your discipline? (Open question)

Q4. (We ask this question as we are interested to know if personal experience affects views on patient information). Have you 'been a patient' in the last two years at any level of care (eg GP or hospital), or been the carer or confidant for a family member who has been a patient? I have been a patient; I have been a carer or confidant; Neither of the above

SECTION 2 OF 7: Research into patient online record access and use of AI – CPD1

Patients in 30 or more countries now have at least some access to online medical records. In England, the NHS 10-Year Plan sets out a vision for a digitally enabled, personalized service that focuses on preventing illness, supporting care closer to home, and helping people to take an active role in managing their own health. The other UK countries have similar policies. To make this work, it is not enough to simply give patients online access to their records; people also need support to understand and use the information effectively.

Since October 31st, 2023, all General Practice (GP) surgeries in England have been required to provide adult patients with online access to new information added to their primary care medical records by default. In practice, this means that patients should usually be able to see updates to their GP record through online services, such as the NHS App, without having to ask their GP for permission. This access includes most information added to the record, such as letters and notes from consultations. Only internal staff tasks are hidden from patients.

Information from hospital systems such as Cerner and EPIC is also being shared with patients, either through hospital patient portals or by feeding it into the NHS App. Patients may use digital health indifferent ways. Some look up information on public websites or use Generative AI tools on their own. Others check their medical records through patient portals and then use AI tools to help explore or explain what they see.

Some health IT providers are beginning to integrate, or plan to integrate, AI directly into patient portals. For example, EPIC is working with Microsoft/OpenAI to include AI tools in systems used by clinicians and patients. At the same time NHS England is exploring how generative AI might be used within the NHS App and other digital health services.

SECTION 2 OF 7: Research into patient online record access and use of AI – CPD2

Nurses, midwives and allied health professionals are frequently the clinicians who support patients, families or confidants understand what is written in their medical records and deal with questions or worries about it. In the future, AI will play a bigger role in explaining these records. This mayhappen through tools built into patient portals, such as the NHS App or hospital Electronic Record Systems, or through stand-alone tools such as ChatGPT, Google Gemini or Microsoft Copilot. However, more RESEARCH is needed, ideally designed with patients and professionals.

At a ‘Micro’(individual) level, it could explore which types of explanations are preferred by patients. At a ‘Meso’(service) level, it could examine whether patients want to use online portals, how they use them, and whether AI tools affect the practitioner-patient relationship. At a ‘Macro’(system-wide)level, it could look at how these changes affect patient outcomes and whether there are changes to care processes. We would like to know what you think the most important research priorities are.

Despite national policy commitments to digital transformation and patient empowerment, non-medical professions have not yet formally incorporated competencies related to online record access or patient’s use of generative AI. For example, in England, standards set by the Nursing and Midwifery Council and the digital capability framework from Health Education England set out broad expectations for digital literacy and record keeping, but do not mention patients accessing their records online or using AI tools to understand them. Perhaps patients accessing their records online or using AI tools should be in the pre-registration training curricula? Perhaps it is not needed?

We seek your views on whether online record access or patient use of AI should be included in the curriculum for your discipline, and how this could be best taught.

SECTION 2 OF 7: Your views about research

Q5. For your discipline now, where do you think the priority should be? Micro (personal) level; Meso (service or team) level; Macro (system-wide) level; I don't know

Q6. What are the research questions that you think we need to address on these topics? (Open question)

SECTION 3 OF 7: Patient online record access in the curriculum (CPD3)

Here are summaries of three papers that give a 'taste' of research on patient online record access. Then we will ask for your views about this topic in the undergraduate curriculum for your discipline.

PAPER 1 (of three): D'Costa et al conducted a systematic review exploring the practical, ethical and professional consequences of patient access to medical records in acute hospital settings. From nearly 8,900 studies screened, 18 met inclusion criteria (12 empirical, 6 ethical). Overall, the review found that letting patients see their records while they are in hospital can enhance understanding, engagement and trust, but evidence for measurable improvements in clinical outcomes was limited. Clinicians expressed concern that patients reading their records on their own might cause anxiety or confusion, and that staff might change how they write their notes if they know patients might read them.

The ethical discussion highlighted tensions between patient autonomy and potential harm, differences in people's digital skills, and the possibility that records could become less accurate or of less educational value if they are written mainly with patients in mind. The authors conclude that giving patients access to medical records is feasible and generally welcomed, but it needs to be carefully designed, with good patient support, and appropriate training for staff to avoid unintended consequences. They called for further research that includes different professional perspectives and looks at long-term effects.

The review shows that patient access to records changes how clinicians communicate, write notes and professional boundaries. These are core aspects of nursing and AHP practice. For this reason, this paper highlights the need for nurses and AHPs to be educated and supported in sharing information openly and in a patient-centred way, making it directly relevant to developing online record access skills and competencies in nursing education and professional development.

SECTION 3 OF 7: Patient online record access in the curriculum (CPD4)

PAPER 2 (of three): De Groot et al carried out qualitative interviews with 19 community nurses in the Netherlands about how they engage patients in electronic nursing documentation. Nurses considered patient participation important but described challenges relating to systems (technical issues), work environment (time pressures) and patients (digital skills, health status) when making documentation visible and participatory. Findings highlight that even when electronic patient portals and online access exist, meaningful participation depends on nurses' practice and the context — not just the technology.

SECTION 3 OF 7: Patient online record access in the curriculum (CPD5)

PAPER 3 (of 3): O'Connor et al conducted a systematic review of 83 qualitative studies examining how patients and health professionals use digital health interventions. These included patient portals, tele-rehabilitation systems, and patient-held electronic records. The studies mainly focused on long-term conditions and community care. Many involved allied health professionals such as physiotherapists, occupational therapists, speech and language therapists, and rehabilitation teams supporting patients in self-management and recovery.

The review found that digital records and patient-facing systems can help patient autonomy, improve continuity of care, and support shared goal setting, particularly in rehabilitation and chronic disease management. However, these benefits depended heavily on how clinicians introduced, explained, and used these tools in everyday practice.

Patients often struggled to understand clinical data, progress measures, or treatment plans without help from a professional. Clinicians reported concerns about patients misunderstanding information, increased workload, and some people being excluded because they lack digital access or skills.

A key finding was that AHPs play an important role in explaining and coaching patients when they use digital records and portals. They helping them make sense of functional scores, exercise plans, and progress notes. The authors concluded that technology alone does not empower patients. Instead, it works best when supported

by strong professional relationships and workflows, good communication, and shared decision-making.

SECTION 3 OF 7: Patient online record access – learning from experience

We ask this as it's a good way for you to learn what is on offer for your patients.

Q7. Have you seen all or part of your records, or those of someone you care for or are confidant for, online anywhere in the last 3 years, for example, your primary care record via the NHS App, or your hospital record through a 'patient portal', or received copies of letters from hospital to your GP? Yes NHS App; Yes Hospital portal; Had copies of letters from hospital to GP; Not seen any records or letters, but I haven't looked; Not seen any records or letters, didn't know I could; Not seen any records, despite wanting to; Not had any contact with NHS over last three years

SECTION 3 OF 7: Your views on patient online record access in the undergraduate curriculum for your discipline

Q8. How important is it to include something on patient online record access related competencies in the undergraduate (pre-registration) curriculum for your discipline? Not important; Useful; Quite important; Essential

Q9. Would you cite or use any of the three publications presented just now? Are they relevant as source materials for undergraduate or pre-registration students in your discipline? Or would you take a more personal approach related to their own use of' patient access?

The papers were:

(a) D'Costa, S.N., I.L. Kuhn, and Z. Fritz, A systematic review of patient access to medical records in the acute setting: practicalities, perspectives and ethical consequences. BMC Medical Ethics, 2020. 21(1).
(b) De Groot K, Sneep EB, Paans W, Francke AL. Patient participation in electronic nursing documentation: an interview study among community nurses. BMC Nursing.2021;20:72.
(c) O'Connor S, Hanlon P, O'Donnell CA, Garcia S, Glanville J, Mair FS. Understanding factors affecting patient and public engagement and recruitment to digital health interventions: a systematic review of qualitative studies. BMC Medical Informatics 2016;16:120.

I would use paper (a) only; I would use paper (b) only; I would use paper (c) only; I would use all of the papers; I would not use any of the papers; I would take a personal approach; I have other ideas

Q10. What specific knowledge and skills should students develop related to patient online record access? (Open question)

Q11. Have you already taught patient online record access content in your programme? Yes (at least one session focussed on ORA); Yes (mentioned in passing in other sessions); No, but planning to; No, and currently not planning to; Unsure

SECTION 4 OF 7: Patients' use of AI in the curriculum (CPD6)

We will now present summaries of three publications then ask whether you think AI use by patients is relevant and should be included for undergraduates in your discipline

PAPER 1 OF 3: Armbruster et al conducted a cross-sectional study published in JAMA Internal Medicine that compared patients' perceptions of responses to real medical questions when written either by physicians or by OpenAI's ChatGPT. The researchers selected 195 publicly posted patient–physician interactions from Reddit's r/AskDocs forum and generated corresponding ChatGPT replies to the same questions. A panel of licensed healthcare professionals rated the quality and empathy of each answer, while patient participants evaluated helpfulness, clarity, and trustworthiness.

ChatGPT's responses were rated significantly higher for both quality and empathy—about tenfold more likely to be rated "good" or "very good"—than physicians' original answers. However, the study cautioned that ChatGPT occasionally produced inaccurate or misleading content, highlighting risks of over-trust. The authors concluded that AI could be a valuable communication adjunct to improve patient understanding and satisfaction, provided there is clinical oversight to ensure safety and accuracy. The findings demonstrate that patients are already using AI to interpret diagnoses and treatments, valuing its clarity and tone. For nurses and AHPs, this underscores an urgent need to understand how patients use such tools and to develop strategies for guiding, correcting, and contextualising AI-generated health explanations in everyday practice.

SECTION 4 OF 7: Patients' use of AI in the curriculum (CPD7)

PAPER 2 OF 3: Chen et al, in a pilot RCT (Hong Kong) compared a patient-facing AI mental-health chatbot with a traditional nurse hotline. Adults from the general population were randomized to receive on-demand support from either the chatbot or nurses by phone. Primary outcomes were changes in depression and anxiety symptoms; satisfaction and perceived usefulness were secondary measures. Both groups improved after using the service; the AI chatbot's effects were comparable to the nurse hotline for short-term reductions in anxiety and depression. Service satisfaction did not differ significantly between groups. The authors conclude that an AI option can provide accessible support at scale but call for larger trials and careful safeguards. This is one of the clearest head-to-head tests of patients using AI versus interacting with non-medical practitioners. It suggests AI may handle some low-acuity support without worse short-term outcomes, but it also spotlights the need for practitioner oversight, triage protocols, and escalation pathways so that AI augments—rather than replaces—practitioners' relational, interpretive, and safety-critical roles.

SECTION 4 OF 7: Patients' use of AI in the curriculum (CPD8)

PAPER 3 OF 3: Bennett et al conducted a systematic review of how artificial intelligence is being used in physiotherapy and rehabilitation, including patient-facing applications such as exercise apps, virtual coaches, motion-tracking systems, and AI-supported feedback tools. The review covered 94 studies across musculoskeletal, neurological, and cardiorespiratory rehabilitation, many of which involved patients using digital platforms to monitor their progress, receive personalised guidance, and interpret performance data.

The authors found that AI-enabled systems could improve patient engagement, adherence to exercise programmes, and the accuracy of functional assessment, particularly when used to provide tailored feedback and real-time coaching. However, the review also highlighted important risks, including over-reliance on automated advice, misinterpretation of data by patients, and the exclusion of people with low digital literacy or complex needs. Clinicians reported that AI systems worked best when they supported—rather than replaced—professional judgement, communication, and shared goal setting. Importantly, for allied health professions, the review emphasised that physiotherapists and other rehabilitation professionals play a crucial role in interpreting AI-generated data, contextualising progress measures, and helping patients make sense of what the technology reports. The authors concluded that AI has strong potential to enhance rehabilitation and self-management, but only if professionals are trained to integrate these tools into therapeutic relationships, safety monitoring, and personalised care planning. This paper is directly relevant to teaching about patient use of AI because it shows how AI-generated information shapes patient understanding, expectations, and behaviour in AHP-led care

SECTION 4 OF 7: Using AI for personal health – learning from experience

Patients are increasingly using tools like ChatGPT and Microsoft Copilot to explain medical terms, summarise clinical notes, or translate technical language into everyday wording. First we ask a personal question (as it's a good way of learning about GAI)...

Q12. Have you used ChatGPT, Google Gemini, Microsoft Copilot or any other AI platform to explain anything to do with your own health or that of a family member or friend? Yes, I use it frequently; Yes, I have used it at least once; No, I have used it for other things but never used it for this purpose; No, never used these AI tools

SECTION 4 OF 7: Your views on patients' use of AI in the undergraduate curriculum for your discipline

Q13. In your view, how important is it to include something on AI use by patients in undergraduate (pre-registration) curriculum for your discipline? Not important; Useful; Quite important; Essential

Q14. Would you use any or all of the publications presented just now or would you take a more personal approach for undergraduate (pre-registration) students in your discipline?

The papers were

(a) Armbruster, W., Wong, A., Gallagher, T.H., Shen, N., et al. (2024) Comparing Physician and Artificial Intelligence Chatbot Responses to Patient Questions Posted to a Public Social Media Forum. JAMA Internal Medicine, 184(5), pp. 513–520.
(b) Chen C, Lam KT, Yip KM, et al. "Comparison of an AI Chatbot With a Nurse Hotline in Reducing

Anxiety and Depression Levels in the General Population: Pilot Randomized Controlled Trial." JMIR Human Factors. 2025;12:e65785.

(c) Bennett M, King D, Marshall S. Artificial intelligence in physiotherapy: A systematic review of current and emerging applications. Physiotherapy. 2022;114:1–12.

I would use paper (a) only; I would use paper (b) only; I would use paper (c) only; I would use all of the papers; I would use none of the papers; I would take a more personal approach; I have other ideas.

Q15. What specific knowledge and skills should students develop related to AI use by patients? (Open question).

Q16. Have you already taught patients' AI use content in your programme? Yes at least one session on AI use by patients; Yes mentioned in passing other sessions; No but planning to; No, and not currently planning to; Unsure

SECTION 5 OF 7: Implementation in the curriculum

Q17. The curriculum is crowded. Given the other priorities of topics and competencies for inclusion, how important is patient online to records and their use of AI? Of minor importance – include only if there is time/space; Quite important – need to find time/space by trimming other subjects; Essential – need to find time/space even if means dropping something else.

Q18. Use this space to comment on if these topics should be taught, if so what should be taught, and how it should be implemented. Please make sure the answer does not reveal your institution. Answers to this question will be thematically analysed with assistance from AI. Free text answers will be checked for anonymity, randomised, uploaded to get provisional themes. These will be checked and agreed by the researchers. AI will then be asked to classify each answer with multiple themes. These will be checked by the PI. A quantitised approach to reporting the themes will be used. (Open question).

SECTION 6 OF 7: ANONYMITY VS NAMED CONTRIBUTIONS

CPD Certificate and Paper Acknowledgement: If you wish to remain anonymous we cannot send you a CPD certificate or acknowledge your contribution in any publication.

Q19. Would you like to receive a CPD certificate and further papers as pdfs, and/or to be added to the Smart Patient Academic Network? (This will require leaving your email address). Yes I wish to give my email; No I wish to remain anonymous.

Q20. Your email address

Q21. Do you want to receive the CPD certificate and further papers? Yes; No

Q22. If we publish findings, may we list your name among an Appendix of contributors? Yes, include name; No, remain anonymous

Q23. What is your name for acknowledgement? (Open question)

Q24. Would you like your name and email added to the Smart Patient Academic Network? This will be a time-limited network in which the principal investigator (Ray Jones) will attempt to 'join up' like-minded researchers and educators on explainable health information for patients. All information on the network will be deleted by March 2027. Yes include me; No I am not interested.

SECTION 7 OF 7: REVIEW OF METHODS OF THIS STUDY

We realise that academics are busy and can also be overloaded with requests to complete surveys. We have tried to make participating in this survey useful – information exchange rather than just questionnaire.

Q25. As a method, do you think this works? Yes definitely; To some extent; No, not really; No, definitely not