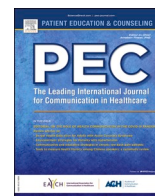





Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.journals.elsevier.com/patient-education-and-counseling

‘Getting it write’ in an era of online electronic health records access in primary care: A qualitative study exploring the needs and requirements of underserved patients and carers

Gail Davidge^a , Charlotte Blease^b, Lindsey Brown^a , Goran Nenadic^c, Caroline Sanders^a, Brian McMillan^{a,*} 

^a Centre for Primary Care and Health Services Research, University of Manchester, Manchester, UK

^b Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden

^c School of Computer Science, University of Manchester, Manchester, UK

ABSTRACT

Objectives: Most adult patients in England now have access to their primary care electronic health record (EHR), including free-text consultation notes, via the NHS App or other online services. As EHRs were not designed for patient audiences, this study aimed to explore patients' and carers' perspectives and understanding of simulated consultation notes.

Methods: One interview and five focus groups were conducted with 26 patients and carers from a purposive sample of underserved communities in England between April and May 2023. Participants' understanding and views were elicited regarding five vignettes about patient consultation scenarios and corresponding simulated primary care EHR entries. Verbatim transcripts were analysed inductively using thematic analysis.

Results: Most participants struggled to fully understand the simulated consultation notes, particularly medical acronyms, clinician shorthand and non-clinical abbreviations. Participants also identified issues which may cause unintended offence or anxiety, and made suggestions about how EHRs may be improved to meet the needs of patient audiences and maintain positive patient-clinician relationships.

Conclusions: Opening up online record access to include patient audiences necessitates a significant cultural shift in the way that consultation notes are written and used. Participants proposed technological and documentation adaptations to enhance understanding, support diverse patient needs and maintain positive patient-clinician relationships.

Practice implications: To fully realise the benefits of patient online records access, it is important for consultation notes to be written in a way that patients find meaningful, while maintaining their clinical integrity. To optimise NHS England's investment in this policy and avoid exacerbating health inequalities, it is essential to ensure all patients can access the benefits of online access to their EHR. Healthcare professionals need to be supported to manage the challenges of writing consultation notes for patient audiences, while continuing to maintain effective clinical care.

1. Introduction

Research highlights potential benefits of patient online access to electronic health records (EHRs), including improved patient engagement, safety, and care [1–5]. The commitment by G7 health ministers to provide digital access to personal health information emphasises the significance of this innovation [6]. In England, following revisions to the 2023/2024 General Practice (GP) contract [7], GPs are now mandated to make all new health information added to their EHR available to all adult patients unless restricted by safeguarding concerns, data protection regulations, or patient requests. As of April 2024, 84.1 % of GP practices in England had enabled their patients with prospective records

access to their EHR [8], and three quarters of adults in England have signed up to the National Health Service (NHS) App [9]. Such services enable online access to any new ‘free text’ written by clinicians in a patient's EHR about a consultation at their GP surgery.

Online records access (ORA) has potential to enhance patient health literacy and engagement and may particularly benefit marginalised populations [10]. However, it could also exacerbate inequalities for those lacking the skills and resources to utilise digital health support [11]. Additionally, language used in EHRs may contribute to stigmatisation toward certain patient groups [12–17]. Addressing these disparities is essential to maximise patient benefit from ORA [18].

Patient trust in healthcare professionals (HCPs) is crucial for

* Correspondence to: Centre for Primary Care and Health Services Research, University of Manchester, Manchester M13 9PL, UK.

E-mail addresses: gail.davidge@manchester.ac.uk (G. Davidge), charlotte.blease@uu.se (C. Blease), lindseybrown.work@gmail.com (L. Brown), gnenadic@manchester.ac.uk (G. Nenadic), caroline.sanders@manchester.ac.uk (C. Sanders), brian.mcmillan@manchester.ac.uk (B. McMillan).

<https://doi.org/10.1016/j.pec.2025.109192>

Received 17 February 2025; Received in revised form 22 May 2025; Accepted 25 May 2025

Available online 27 May 2025

0738-3991/© 2025 The Author(s). Published by Elsevier B.V. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

maintaining effective clinical care [19]. However, ORA has potential to both build and diminish trust. Higher levels of patient trust correlate with beneficial health behaviours, fewer symptoms, and higher quality of life [20]. Conversely, patient evaluations of ORA in the United States (US) indicate that inaccuracies or poor understanding can lead to reduced confidence in clinicians [21]. Additionally, failure to communicate appropriately with marginalised patients can fuel stigmatisation, negatively affecting trust and quality of care [13].

The introduction of ORA necessitates a cultural shift in healthcare [22]. Studies in countries with established policies show that patients with ORA better understand their health and more actively participate in decision-making [4]. However, increased openness can sometimes result in unintended consequences [11,20,22,23]. HCPs may become less candid in documentation [24], and patients may struggle to comprehend [25] or feel dismissed or offended by EHR content [12–14, 17]. For example, a recent focus group study highlighted a range of ways in which patients wished healthcare professionals would adapt their clinical notes to make them clearer, more empathetic, and less likely to cause offence [26]. Fig. 1

HCPs express concerns about effectively communicating with patients while upholding the clinical integrity of the EHR in the era of ORA [22,27,28]. These concerns include patients' ability to accurately interpret clinical terminology, as well as apprehensions about how ORA might affect their relationships with patients [22]. Currently, healthcare training in England and internationally lacks sufficient support for clinicians in documenting consultation entries for patient audiences [29].

The primary aim of the study was to explore elements of consultation notes that patients and carers from underserved groups may find difficult to understand, or which may unintentionally cause offence or increase anxiety. To achieve this, the study explored patient and carer responses to reading simulated consultation notes, in order to generate insights into their needs and requirements regarding ORA. For the purpose of this study, we sought to include patients and carers that may face additional barriers to research participation, focusing recruitment efforts on patient groups identified in the literature as particularly vulnerable to health inequities which may create additional barriers concerning ORA [30]. Findings have the potential to inform the development of resources and support for HCPs to align their EHR documentation with the needs of diverse patient audiences.

2. Methods

2.1. Study design and procedure

Qualitative study design was informed by discussions with nine members of PRIMER (Primary Care Research in Manchester Engagement Resource) comprising patients and carers. The patient and public involvement (PPI) lead (LB), worked closely with the research team, making substantial contributions throughout. The methodological framework was guided by the objective of identifying and understanding aspects of consultation notes that patients, especially those from underserved communities, may find either helpful or challenging. Participants received an information sheet (Multimedia Appendix 1), seven

days before taking part, and written consent was obtained. Three focus groups were held in-person at community venues, two were held online and one interview was conducted (at the participant's request) online. Focus groups comprised between 4 and 6 participants, were conducted in English, and led by GD, with LB co-facilitating. Participants were asked to consider the needs of fictional patients from vignettes and to highlight any potential comprehension challenges, offensive content, or anxiety triggers. Discussions lasting between 90 and 120 minutes were audio recorded and transcribed by a university-approved service. Audio files were encrypted and securely stored within the University Research Data Management Storage (RDS) facility, accessible only to the research team. Participants received £ 50 shopping vouchers as compensation. Ethical approval was granted by the University of Manchester Proportionate Research Ethics Committee (UREC) on 24th February 2023 (Ref:2023–15851–27453).

2.2. Participants

Purposive sampling was employed to include underserved patient populations [31], focusing on groups identified as particularly vulnerable to health inequities [30]. Study advertisements were promoted by gatekeepers of organisations supporting people identifying as LGBTQ+ (Focus Group (FG) 1), young individuals (aged 16–25) with experience of mental health issues (FG2), carers and older patients (FG3), individuals with English as an additional language (FG4) and residents of socially deprived areas (FG5). Twenty-six participants took part during April and May 2023. The sample size was guided by the exploratory nature of the study and the aim of including a range of perspectives across diverse groups. This approach is consistent with established principles of qualitative research, where sample adequacy is shaped by the depth and diversity of insight rather than numerical thresholds [32]. Demographic details are reported in Table 1.

2.2.1. Study materials

Vignettes, informed by the work of Tremblay et al. [33], were designed to position participants as knowledgeable contributors, capable of offering insights, identifying issues, and proposing solutions. Five fictional patient scenarios and simulated consultation notes,

Table 1
Participant characteristics (N = 26).

		N (%)
Ethnicity (Self-reported)	Arab	2 (7.7)
	Asian White	1 (3.8)
	Black American	1 (3.8)
	Black British	4 (15.4)
	Chinese	2 (7.7)
	Jamaican	1 (3.8)
	Mixed race	3 (11.5)
	Pakistani	3 (11.5)
	White British	9 (34.6)
	First language	Arabic
Cantonese		1 (3.8)
English		19 (73.1)
French		1 (3.8)
Urdu		2 (7.7)
Education	Postgraduate (level 7–8)	1 (3.8)
	Degree (level 6)	8 (30.8)
	Level 2–5	10 (38.5)
	No formal education	4 (15.4)
	Not stated	3 (11.5)
Index of Multiple Deprivation	Deciles 1–3 (most deprived)	11 (42.3)
	Deciles 4–7	10 (38.5)
	Deciles 8–10 (least deprived)	4 (15.4)
	Not stated	1 (3.8)

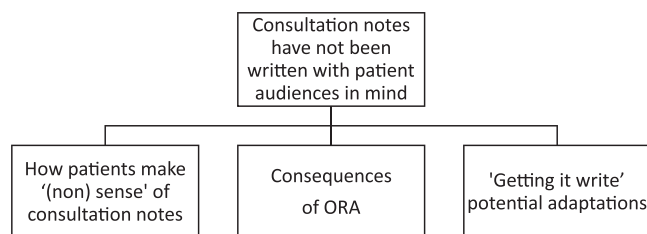


Fig. 1. Qualitative Themes*. Themes were derived using reflexive thematic analysis and are described in detail in 3.2.

written by a practising GP (BM) along with a semi-structured topic guide (Multimedia Appendix 2), enabled reflection on the diverse needs of patient audiences when reading free-text consultation entries. Participants were not shown their own medical records. This decision was made to ensure consistency across the sample, avoid any risk of distress or privacy concerns, and focus discussion on language issues and general rather than personal experiences.

2.3. Analysis

A reflexive thematic analysis approach, guided by the work of Braun and Clarke [32] was employed. Data were analysed inductively, following a process that included familiarisation with the data, generating codes, developing initial candidate themes, reviewing and refining these themes, and interpreting patterns across the dataset. Verbatim transcripts were produced by a University approved transcription service and anonymised by the lead researcher (GD). Two authors (GD, LB), independently reviewed and analysed the anonymised transcripts generating initial codes using QSR Nvivo 12 software. Themes were developed through an iterative process of comparing codes across focus groups and identifying shared patterns and divergences. The preliminary analysis was presented to the project advisory board to invite further discussion on key findings and theme titles. Feedback from the advisory board was used to challenge assumptions, clarify theme boundaries, and ensure the relevance of interpretations to patient and carer experiences. The coding structure was then further refined and final themes were generated through deliberative discussion in a series of research meetings with three of the authors (BM, GD, LB).

In the spirit of reflexivity, the researchers critically examined how their own backgrounds and positionalities may have influenced their interpretation of the data. GD is a white woman in her early 50's. She is a psychologist and health services Research Fellow who is ambivalent about the benefits and drawbacks of ORA. LB is a white woman in her late 40's with long term medical conditions who believes that patient access to medical records can be useful for patients. BM is a white male academic GP in his early 50s who appreciates both the merits and drawbacks of ORA. CB is an Associate Professor in Health Informatics at Uppsala University Sweden. She is committed to a nuanced understanding of the benefits and risks of ORA and how it can be improved. The remaining authors are professors in Medical Sociology (CS) and Computer Science (GN). They have expertise in engaging underserved patient populations in research (CS) and simplifying medical communication for patient audiences (GN).

3. Results

3.1. Descriptive statistics

Twenty-six participants aged between 17 and 89 years (mean = 45.5; SD = 24.43) took part. There were twelve women and thirteen men, and one identified as non-binary. Eight participants were carers, 5 identified as LGBTQ+ and 53.8% (14/26) had used an online access platform to access their EHR at least once. Further demographic details can be found in Table 1.

3.2. Qualitative themes

'Consultation notes have not been written with patient audiences in mind' was identified as a central statement that encapsulated the majority of participants' discussions about including patients as an additional audience. Each of the three themes reflects participants' attempts to understand the notes, the potential impact on their care experience, and their views on possible solutions to address the identified challenges.

3.2.1. Theme 1: how patients make '(non) sense' of consultation notes

Most participants felt consultation notes predominantly address clinical audiences. However, some recognised that patients may become accustomed to reading and understanding notes as ORA becomes more widespread.

... we may find it difficult and challenging to understand and interpret first of all, but we'll probably get used to the medical speak. (P15:FG3, Female Carer, 66–70 years).

Clinical terminology, acronyms and shorthand were often misunderstood. For example, where a question mark denoted a 'query' (e.g., '? Ca' (query cancer)) several participants thought this was a typographical error. Other sources of confusion included clinical shorthand such as, '2WW' (two-week wait); 'Sx' (symptoms); 'Hx' (history); and more (>) or less than (<) symbols.

With the exception of 'FBC' (full blood count), most participants struggled to comprehend blood test acronyms: for example, 'LFT' being interpreted as 'lateral flow test', rather than 'liver function tests'. Another note included a (fictional) chaperone's initials ('seen with TA': note 1), which some participants assumed referred to a teaching or technical assistant or other clinical acronym. Others observed that abbreviations such as 'appt' (appointment) may not be understood.

Note 3 included a (PHQ-9) score of 19', referring to the Patient Health Questionnaire to screen for depression [34]. Participants struggled to understand the relevance of this.

'The carer in this case will be going "what's 19 mean?", is it good, is it bad [agreement from rest of group] and then they're getting stressed over it' (P11:FG3, Female, 46–50 years)

Participants believed that patients have differing levels of health literacy, and that some may require additional support.

I think the doctor used simple words [note 4], not difficult. But not for all the people. Some people need help with some words. (P17:FG4, Male, 41–45 years)

Participants demonstrated that their capacity to make sense of unfamiliar health information often depended upon other factors such as previous experiences, contextual details, clarity of descriptions, reading proficiency, knowledge of English, and access to support. Participants noted that guessing could have negative consequences.

We were guessing [meaning of blood test acronyms]... if you're meant to read it and be reassured, it had the opposite effect. (P11-FG3, Female, 46–50 years)

Participants employed diverse strategies to understand unfamiliar health information, influenced by their specific needs and the level of support at their disposal.

If I cannot understand English, I can copy and translate [into ChatGPT]. (P17-FG4, Male, 41–45 years)

Although a few indicated that they would ask their GP practice for help with understanding consultation notes, many were hesitant, aware of limited NHS resources or because they anticipated difficulties in getting help.

Otherwise, I have to call the surgery, and I have to ask the receptionist what does that word mean? But ... the lines are very busy and sometimes they don't pick up the phone. (P20:FG4, Female 31–35 years)

I'd feel like I'm taking up time that could be used for people that need to actually go to GP visits. (P01-LGBTQ+ interview, 26–30 years)

Participants commented that they researched information via medical dictionaries or online search, despite concerns that this may exacerbate anxiety. Others considered asking pharmacists, family or friends for help but expressed privacy concerns. Some were happy to trust their GP or were resigned that 'if you have no one else to ask, you just have to let

it go.' (P23:FG4, Female, 66–70 years)

3.2.2. Theme 2: consequences of ORA

3.2.2.1. Benefits for patients and health professionals. Improving the clarity of EHRs could also enhance communication between HCPs and improve continuity of care. Participants suggested that if patients can understand EHR content, this could result in fewer phone calls, less trips to the practice, and thus environmental benefits. They noted this might also release resources for more vulnerable patients. Similarly, they acknowledged advantages of being able to revisit consultation notes, which could support decision-making, adherence to care plans and, 'increase their engagement in the healthcare process' (P02: FG1, Male, 16–20 years).

3.2.2.2. Equality and parity of access. Participants believed patients have a right to see their health information and acknowledged potential for this to enhance communication with HCPs. However, they also recognised disparities in English proficiency or health literacy and acknowledged inequities in access to digital resources.

I'm [81–85], and I think it's difficult sometimes to get able to use this new technology. I've got a smartphone but there are a lot of things I can't do on it because I don't know how. (P12:FG3, Male, 81–85 years)

One participant suggested that while some patients may possess the digital skills to use ORA, they might lack the health literacy to fully understand it. Some participants with English as an additional language spontaneously utilised digital tools such as ChatGPT and Google Translate to aid their understanding of notes during focus groups. They noted however, that many patients may not have these skills. Observations of participants using ChatGPT within focus groups highlighted risks that such tools may deliver misleading information.

3.2.2.3. Impact on patient safety and well-being. Participants recognised that ORA could help improve error detection and mitigate problems associated with missed or delayed postal communications. They appreciated the ability to confirm completion of clinical tasks and valued receiving confirmation of medications or test results, perceiving it as supporting continuity of care.

In contrast, participants also considered that misunderstandings of notes could be detrimental to patient safety and wellbeing.

...having all that ambiguity [researching unfamiliar acronyms online] can just be quite stressful and, you know, I'm quite digitally literate and even then, I find quite difficult. (P09:FG2, Female, 21–25 years)

Participants anticipated that negative reactions to note content may deter patients from accessing care.

...if they didn't listen to me or they, kind of, missed out bits that were really important to me or, kind of, glossed over a lot of what I said... I might, yeah, maybe see a different GP, maybe not go back to a medical practice for a while (P09:FG2, Female, 21–25 years)

Similarly, participants were equivocal about preferred levels of transparency and detail concerning differential diagnoses. They noted that responses to reading 'Ca' within notes 4 and 5 could range from fear to reassurance.

[?Ca:note 4] That's quite worrying as a patient, because if the doctor isn't sure that's quite worrying about how they will treat him or her. (P04: FG1, Female, 21–25 years)

From his perspective [note 5], it's quite detailed, it seems to show that, you know, the doctor is taking it seriously, I'd feel, kind of, reassured. (P01:LGBTQ+ interview, 26–30 years)

3.2.2.4. Impact on relationships. Participants acknowledged the

importance of effective communication in fostering trust and observed that EHRs can be used to demonstrate empathy. However, they also made assumptions about a clinician's competency and level of professionalism based on note content and the level of detail included:

[Note 5] looks like something someone would text to someone else... I think it's less professional, so I think you'd be less likely to trust their judgement. (P07:FG2, Male 16–20 years)

Participants also recognised that a lack of detail or different documentation styles could make patients feel embarrassed, angry, intimidated, invalidated or dismissed. For example, one participant considered that noting a patient was transgender within patient-visible consultation notes may be perceived as invalidating, and another perceived that the inclusion of acronyms and unfamiliar medical terms can be intimidating. Likewise, a different participant noted that the inclusion of shorthand such as 'sx' (symptom) made them feel 'angry'. Others considered the inclusion of the term, 'crusty' or 'unusual looking' offensive [note 5].

I'd think, you know, what do you mean, "crusty looking"?... is it because I haven't washed enough, is it because I'm unclean, is that what you're saying? (P09:FG2, Female, 21–25 years)

Nonetheless, participants acknowledged that patients may interpret notes in very different ways and voiced mixed opinions about their content. For instance, there were mixed reactions to the use of the word 'reassured' within note 2.

This "reassured" bit, if I was reading it as a parent who took my child in, I would think that the doctor feels I'm a pain in the bum... "I've reassured her this, I've reassured her that." So, I'd be a bit miffed. (P11:FG3, Female, 46–50 years)

That wouldn't bother me, you see. (P10, FG3, Male 81–85 years)

3.2.2.5. Impact on workload. Participants identified the potential of ORA to impact on HCP workload. They recognised that if patients could understand their records, this could lead to more efficient use of NHS resources. Additionally, participants saw value in being able to share primary care records with other NHS services. Many perceived clinical shorthand as more efficient, and there were frequent concerns about the potential additional burden of adapting notes for patient audiences.

I do think it's the way to go forward from a patient or a carer's point of view. But from a GP's point of view, it must be a nightmare. (P15:FG3, Female, 66–70 years)

Participants also expressed concern that when patients did not understand or felt unhappy about EHR content, this may increase enquiries, complaints and litigation or even prompt more GPs to leave the profession.

3.2.3. Theme 3: 'getting it write': potential adaptations

Participants were asked to share their views and ideas on improving patients' experience of ORA. They identified a need for additional support and suggested a broad range of potential adaptations.

if you're going to do it [ORA] then the people that you're going to let access it need to be able to understand it. (P15:FG3, Female, 66–70 years)

Recommendations included technical support and adaptations beneficial to both patients and HCPs. For instance, participants proposed voice recognition software for dictating notes [35] and predictive text to expand medical shorthand. Other suggestions involved AI 'chat-boxes' for answering questions, a 'hover over' function with links to trusted sources for further information, and the inclusion of pictures.

However, participants expressed concerns about digital poverty, stigmatisation, exclusion, and privacy, particularly for accessing ORA in public spaces. One participant proposed a 'spoiler alert' for sensitive

images to address some of these worries. Participants were mindful that digital solutions could both help and hinder inclusion and underlined the need to provide analogue alternatives. 'Read aloud' or translate functions were also considered helpful.

They can put, symbol of voice, for the people who cannot read. So, they can press this button, and he can explain it in his language. So he can listen and understand what he says. (P16:FG4, Male 41–45 years)

Others considered that a 'glossary' function would be helpful, although carer participants warned that emailing self-help links or signposting glossaries may exacerbate carer burden.

...stop telling us to go and look things up... I don't want any more jobs put on my shoulders, thank you. (P14:FG3, Female 66–70 years)

Others suggested adapting existing policy and training to enhance practice, raising awareness that patients may not understand medical terminology, allocating more time for clinician documentation, providing separate notes for patients and clinicians, and offering training on writing for patient audiences. Participants emphasised demonstrating sensitivity and respect for patients' feelings, adapting systems to enable the use of preferred pronouns, and raising awareness about language that might be perceived as judgmental or stigmatising.

On my notes, it's listed me as being non-binary as a health condition, which is a bit weird to me... I guess they had no other way, I don't know. (P01-LGBTQ+ interview, 26–30 years)

Participants also offered some recommendations regarding the adaptation of documentation styles, expressing a preference for more detail overall. Other suggestions included writing in 'plain English', inclusion of medical terminology in full, ensuring notes matched what was said in the consultation, offering detailed, clear instructions for managing care, and demonstrating rationale for care plans, testing or follow-up.

4. Discussion and conclusion

4.1. Discussion

Participants in this qualitative study into ORA in England expressed empathy for HCPs and recognised the increasing demands on NHS resources that ORA might present. They acknowledged that the use of clinical terminology and abbreviations might aid efficient communication between clinicians but felt consultation notes currently prioritise clinicians' needs over patients. Participants suggested how ORA could be improved to mitigate unintended consequences on patient safety and well-being, experiences of care, primary care workloads and relationships with staff.

4.1.1. Comparison with prior work

Participants acknowledged benefits consistent with previous international research [1–5]. Those who were carers also identified benefits concerning increased involvement in decision-making and improved continuity of care, echoing previous findings [36,37]. This study supports previous work showing participants recognise the value of medical terminology for clinicians [38], but face challenges understanding it themselves [39–42].

Participants acknowledged difficulties in communicating with their GP surgery or hesitated to burden clinicians with queries. Given these challenges, some participants indicated a preference for using alternative sources to aid understanding of their notes. As Blease [43] surmised, our participants suggested utilising various online resources or seeking guidance from family and friends to clarify note content. Others indicated they would refrain from doing this due to fears about exacerbating anxiety or privacy concerns. Our study adds a novel perspective by revealing that some patients actively resist engaging in such research, relying instead on clinicians for explanations.

Studies show that inappropriate communication can contribute to stigmatisation and reduce quality of care [13,15,16]. This study underlines how increased transparency might affect trust and confidence in clinicians. Our participants formed assumptions about a clinician's professionalism or intent based on subjective interpretations of note content. Detailed notes conveying sensitivity and empathy were seen as fostering trust, while different documentation styles could evoke negative emotions such as embarrassment, anger, or feeling dismissed.

Limited evidence exists regarding the broader impacts of accelerated ORA in England. For instance, while some early adopter sites in England reported no significant increase in workload [44], evidence from a Canadian interrupted time-series analysis suggests that workload may rise as a result of ORA [45]. Simplifying entries could mitigate this risk, as may the potential adoption of generative artificial intelligence to help clinicians write 'patient-friendly' notes. These tools will, however, require ethical, privacy, confidentiality and safety assurances before implementation [43,46].

4.1.2. Strengths and limitations

A strength of this study is its inclusion of participants from diverse underserved groups, with a focus on those particularly vulnerable to digital health disparities [30,31]. While we acknowledge the need for research with other populations that considers patient responses to their own notes, the use of simulated consultation notes within our study offered several advantages. It enabled the creation of diverse scenarios facilitating insights into varied patient experiences. The scenarios included common medical jargon, abbreviations, and complex terminology that patients typically encounter, providing a realistic basis for inviting further discussion. Simulated notes also allowed our participants to discuss sensitive health issues without fear of being judged or revealing personal information. Including carers' perspectives added another layer of depth, highlighting the challenges they may face. Findings highlight the potential for misinterpretation and assumptions about clinicians' intentions or abilities based on record content.

Limitations include the relatively small sample, limiting the extent to which the findings can be generalised to broader patient populations. The simulated notes may not fully reflect the nuanced experience of attending a live consultation, and were authored by a single GP and thus may not reflect the differences in style and tone amongst clinicians. Despite these limitations, the study enhances understandings of the wider challenges that underserved patients and carers may face in interpreting online consultation notes. Future work could utilise anonymised notes from genuine consultations to capture variability between different clinicians.

5. Conclusion

HCPs need support to manage the challenges of writing consultation notes for patient readers, while continuing to maintain effective clinical care. The need to support patient understanding of consultation notes to maximise patient benefit and prevent exclusion was also identified.

Practice Implications

This study emphasises the need to accommodate diverse patient requirements to ensure that consultation notes are accessible and meaningful to a broader patient audience. Documentation standards may need to be adapted to incorporate the needs of a relatively new patient and carer audience. For example, the use of plain language, avoidance of jargon, and sensitivity in phrasing could be considered in future guidance on EHR communication. This has potential workload implications, and adapting documentation style may meet some resistance from HCPs. Participants made several suggestions about how ORA may be improved. Potential adaptations included technology-led solutions to support patient understanding as well as suggestions for adapting clinical documentation practice. Future work could explore how to support

clinicians in meeting patients and carers' needs when documenting consultations. Additionally, this study highlights opportunities for further research on leveraging technology to aid patient understanding and adapt clinical documentation practices. Future studies, for example, could examine utilising generative artificial intelligence to help clinicians write notes that cater to a patient audience whilst maintaining their clinical integrity [46,47], or investigate how 'hover-over' definitions or separate 'patient-friendly' versions of clinical entries could be incorporated into the EHR.

CCRediT authorship contribution statement

Gail Davidge: Writing – original draft, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Caroline Sanders:** Writing – review & editing, Supervision, Methodology, Funding acquisition. **Goran Nenadic:** Writing – review & editing. **Lindsey Brown:** Writing – review & editing, Validation, Resources, Methodology, Investigation, Funding acquisition, Formal analysis. **Charlotte Blease:** Writing – review & editing, Supervision, Funding acquisition. **Brian McMillan:** Writing – review & editing, Validation, Supervision, Methodology, Funding acquisition, Formal analysis.

Funding

This work was supported by a grant from the National Institute for Health and Care Research School for Primary Care Research (NIHR SPCR-2021–2026:608) awarded to Dr Gail Davidge and an NIHR Advanced Fellowship awarded to Dr Brian McMillan (NIHR300887). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We are extremely grateful to all those who participated in the study and to the gatekeepers of the organisations that helped us with recruiting our participants. We would also like to thank the Primary Care Research in Manchester Engagement Resource (PRIMER) at the University of Manchester and members of the Getting it Write Advisory Group for their valuable input and support with the pilot of fictional patient vignettes and subsequent study design and development of participant materials. We are deeply grateful for the invaluable contributions of our PPI Lead, Lindsey Brown. Lindsey played a pivotal role in the research process, working closely with the research lead to co-design research materials and co-facilitate four focus groups. In addition, Lindsey made an excellent contribution to the thematic analysis and supported the research team with disseminating the study findings to public and academic audiences at a research conference and as a co-author of this paper.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2025.109192](https://doi.org/10.1016/j.pec.2025.109192).

References

- [1] Neves AL, Freise L, Laranjo L, Carter AW, Darzi A, Mayer E. Impact of providing patients access to electronic health records on quality and safety of care: a systematic review and meta-analysis. *BMJ Qual Saf* 2020 Dec;29:1019–32. <https://doi.org/10.1136/bmjqs-2019-010581>.
- [2] Tapuria A, Porat T, Kalra D, Dsouza G, Xiaohui S, Curcin V. Impact of patient access to their electronic health record: systematic review. *Inf Health Soc Care* 2021 Jun;46(2):192–204. <https://doi.org/10.1080/17538157.2021.1879810>.
- [3] Ammenwerth E, Neyer S, Hörbst A, Mueller G, Siebert U, Schnell-Inderst P. Adult patient access to electronic health records. *Cochrane Database Syst Rev* 2021 Feb 26;2:CD012707. <https://doi.org/10.1002/14651858.CD012707.pub2>.
- [4] Walker J, Leveille S, Bell S, et al. Opennotes after 7 years: patient experiences with ongoing access to their clinicians' outpatient visit notes. *J Med Internet Res* 2019 May 6;21:e13876. <https://doi.org/10.2196/13876>.
- [5] Benjamins J, Haveman-Nies A, Gunnink M, Goudkuijl A, Vet E de. How the use of a patient-accessible health record contributes to patient-centered care: scoping review. *J Med Internet Res* 2021 Jan 11;23:e17655. <https://doi.org/10.2196/17655>.
- [6] Department of Health & Social Care. G7 patient access to health records: final report. [Cited 23 Jun 2024]. Available from: (<https://www.gov.uk/government/publications/g7-health-track-digital-health-final-reports/g7-patient-access-to-health-records-final-report>).
- [7] N.H.S. England. Changes to the GP Contract in 2023/24. [Cited 19 March 2024]. Available from: (<https://www.england.nhs.uk/long-read/changes-to-the-gp-contract-in-2023-24/>).
- [8] N.H.S. England. Delivery plan for recovering access to primary care: update and actions for 2024/25. [Cited 17 April 2024]. Available from: (<https://www.england.nhs.uk/long-read/delivery-plan-for-recovering-access-to-primary-care-update-and-actions-for-2024-25/>).
- [9] N.H.S. England. N.H.S. App reaches record users on fifth anniversary. [Cited 20 Mar 2024]. Available from: (<https://www.england.nhs.uk/2023/12/nhs-app-reaches-record-users-on-fifth-anniversary/>).
- [10] Blease C, Salmi L, Rexhepi H, Haggglund M, DesRoches CM. Patients, clinicians and open notes: information blocking as a case of epistemic injustice. *J Med Ethics* 2021 May 14;48:785–93. <https://doi.org/10.1136/medethics-2021-107275>.
- [11] Verity A, Brown VT. Inclusion health patient perspectives on remote access to general practice: a qualitative study. *BJGP Open* 2023 Jun 1;7:BJGPO.2023.0023. <https://doi.org/10.3399/BJGPO.2023.0023>.
- [12] Porter AS, O'Callaghan J, Englund KA, Lorenz RR, Kodish E. Problems with the problem list: challenges of transparency in an era of patient curation. *J Am Med Assoc* 2020 Jun 1;327:981–4. <https://doi.org/10.1093/jama/ocaa040>.
- [13] Alpert AB, Mehringer JE, Orta SJ, et al. Experiences of transgender people reviewing their electronic health records, a qualitative study. *J Gen Intern Med* 2023 Mar 1;38:970–7. <https://doi.org/10.1007/s11606-022-07671-6>.
- [14] Fernandez L, Fossa A, Dong Z, et al. Words matter: what do patients find judgmental or offensive in outpatient notes? *J Gen Intern Med* 2021 Sep;36:2571–8. <https://doi.org/10.1007/s11606-020-06432-7>.
- [15] Goddu P, O'Conor KJ, Lanzkron S, et al. Do words matter? stigmatizing language and the transmission of bias in the medical record. *J Gen Intern Med* 2018 May;33:685–91. <https://doi.org/10.1007/s11606-017-4289-2>.
- [16] Park J, Saha S, Chee B, Taylor J, Beach MC. Physician use of stigmatizing language in patient medical records. *JAMA Netw Open* 2021 Jul 14;4:e2117052. <https://doi.org/10.1001/jamanetworkopen.2021.17052>.
- [17] Blease C. Sharing online clinical notes with patients: implications for nocebo effects and health equity. *J Med Ethics* 2023 Jan;49(1):14. <https://doi.org/10.1136/jme-2022-108413>.
- [18] Belyeu BM, Klein JW, Reisch LM, et al. Patients' perceptions of their doctors' notes and after-visit summaries: A mixed methods study of patients at safety-net clinics. *Health Expect* 2018 Apr;21:485–93. <https://doi.org/10.1111/hex.12641>.
- [19] Hannan A, Webber F. Towards a partnership of trust. *Stud Health Technol Inf* 2007;127:108–16.
- [20] Birkhäuser J, Gaab J, Kossowsky J, Hasler S, Kruppenacher P, Werner C, Gerger H. In: Nater UM, editor. Trust in the health care professional and health outcome: A meta-analysis, 12. *PLOS ONE*; 2017 Feb 7, e0170988. <https://doi.org/10.1371/journal.pone.0170988>.
- [21] Leveille SG, Fitzgerald P, Harcourt K, et al. Patients evaluate visit notes written by their clinicians: a mixed methods investigation. *J Gen Intern Med* 2020 Dec;35:3510–6. <https://doi.org/10.1007/s11606-020-06014-7>.
- [22] Davidge G, Brown L, Lyons M, et al. Primary care staff's views and experience of patients' online access to their electronic health record: a qualitative exploration. *Br J Gen Pr* 2023 Jun;73:e418–26. <https://doi.org/10.3399/BJGP.2022.0436>.
- [23] Turner A, Morris R, McDonagh L, et al. Unintended consequences of patient online access to health records: a qualitative study in UK primary care. e67-74 *Br J Gen Pr* 2023;2023(73). <https://doi.org/10.3399/BJGP.2021.0720>.
- [24] Blease C, Torous J, Haggglund M. Does patient access to clinical notes change documentation? *Front Public Health* 2020 Nov 27;8:577896. <https://doi.org/10.3389/fpubh.2020.577896>.
- [25] Keselman A, Slaughter L, Arnott-Smith C, et al. Towards consumer-friendly phrs: patients' experience with reviewing their health records. *AMIA Annu Symp Proc* 2007;2007:399–403.
- [26] Vanka A, Johnston KT, Delbanco T, DesRoches CM, Garcia A, Salmi L, Blease C. Guidelines for patient-centered documentation in the era of open notes: qualitative study. *JMIR. Med Educ* 2025 Jan 20;11(1):e59301.

- [27] Blease C, Torous J, Dong Z, et al. Patient online record access in english primary care: qualitative survey study of general practitioners' views. *J Med Internet Res* 2023 Feb 22;25:e43496. <https://doi.org/10.2196/43496>.
- [28] Blease C, Cohen IG, Hoffman S. Sharing clinical notes: potential medical-legal benefits and risks. *JAMA* 2022 Feb 22;327:717–8. <https://doi.org/10.1001/jama.2021.23179>.
- [29] McMillan B, Davidge G, Nadeem F, Dowding D, Wilson K, Davies A. Navigating the electronic health record in university education: helping health care professionals of the future prepare for 21st century practice. *BMJ Health Care Inf* 2023 Mar 13;30:e100722. <https://doi.org/10.1136/bmjhci-2022-100722>.
- [30] Blease C, Fernandez L, Bell SK, Delbanco T, DesRoches C. Empowering patients and reducing inequities: is there potential in sharing clinical notes? *BMJ Qual Saf* BMJ Publ Group Ltd 2020 Oct 1;29:1–2. <https://doi.org/10.1136/bmjqs-2019-010490>.
- [31] NIHR. Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project. [Cited 4 April 2024]. Available from: (<https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435>).
- [32] Braun V, Clarke V. *Successful qualitative research: A practical guide for beginners*. London: Sage; 2013.
- [33] Tremblay D, Turcotte A, Touati N, et al. Development and use of research vignettes to collect qualitative data from healthcare professionals: a scoping review. *BMJ Open* 2022 Jan;12:e057095. <https://doi.org/10.1136/bmjopen-2021-057095>.
- [34] Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med* 2001 Sep;16:606–13. <https://doi.org/10.1046/j.1525-1497.2001.016009606.x>.
- [35] Heidi. The AI Medical Scribe for all clinicians. [Cited 17 April 2024]. Available from: (<https://www.heidihealth.com>).
- [36] Gerard M, Fossa A, Folcarelli PH, Walker J, Bell SK. What patients value about reading visit notes: a qualitative inquiry of patient experiences with their health information. *J Med Internet Res* 2017 Jul 14;19:e237. <https://doi.org/10.2196/jmir.7212>.
- [37] Wolff JL, Darer JD, Berger A, et al. Inviting patients and care partners to read doctors' notes: OpenNotes and shared access to electronic medical records. 24: e166–72 *J Am Med Inf Assoc* 2017 Apr 1. <https://doi.org/10.1093/jamia/ocw108>.
- [38] McMillan B, Eastham R, Brown B, Fitton R, Dickinson D. Primary care patient records in the United Kingdom: past, present, and future research priorities. *J Med Internet Res* 2018 Dec 19;20:e11293. <https://doi.org/10.2196/11293>.
- [39] Rau NM, Basir MA, Flynn KE. Parental understanding of crucial medical jargon used in prenatal prematurity counseling. *BMC Med Inf Decis Mak* 2020 Jul 22;20:169. <https://doi.org/10.1186/s12911-020-01188-w>.
- [40] Chapman K, Abraham C, Jenkins V, Fallowfield L. Lay understanding of terms used in cancer consultations. *Psychooncology* 2003 Sep;12:557–66. <https://doi.org/10.1002/pon.673>.
- [41] Castro CM, Wilson C, Wang F, Schillinger D. Babel babble: physicians' use of unclarified medical jargon with patients. *Am J Health Behav* 2007;31:S85–95. <https://doi.org/10.5555/ajhb.2007.31.suppl.s85>.
- [42] O'Connell RL, Hartridge-Lambert SK, Din N, John ERS, Hitchins C, Johnson T. Patients' understanding of medical terminology used in the breast clinic. *Breast* 2013 Oct 1;22:836–8. <https://doi.org/10.1016/j.breast.2013.02.019>.
- [43] Blease C. Open AI meets open notes: surveillance capitalism, patient privacy and online record access. *J Med Ethics* 2024 Feb;50:84–9. <https://doi.org/10.1136/jme-2023-109574>.
- [44] N.H.S. England Digital. Resources for local commissioners. [cited 15 April 2024]. Available from: (<https://digital.nhs.uk/services/nhs-app/nhs-app-guidance-for-gp-practices/guidance-on-nhs-app-features/online-access-to-gp-health-records/resources-for-local-commissioners>).
- [45] Ferguson K, Fraser M, Tuna M, Bruntz C, Dahrouge S. The impact of an electronic portal on patient encounters in primary care: interrupted time-series analysis. *JMIR Med Inf* 2023 Feb 6;11:e43567. <https://doi.org/10.2196/43567>.
- [46] Blease C, Torous J, McMillan B, Hägglund M, Mandl KD. Generative language models and open notes: exploring the promise and limitations. *JMIR Med Educ* 2024 Jan 4;10:e51183. <https://doi.org/10.2196/51183>.
- [47] Kharko A, McMillan B, Hagström J, Muli I, Davidge G, Hägglund M, Blease C. Generative artificial intelligence writing open notes: a mixed methods assessment of the functionality of GPT 3.5 and GPT 4.0. *Digit Health* 2024 Oct;10:20552076241291384.

Glossary

- EHR*: Electronic Health Record
FG: Focus Group
GDPR: General Data Protection Regulation
GP: General Practitioner
HCPs: Health care Professionals
NHS: National Health Service
ORA: Online records access
PPi: Patient and Public Involvement
PRIMER: Primary Care Research in Manchester Engagement Resource