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Patient and caregiver perceptions of electronic health records interoperability in the NHS and its impact on care quality: a focus group study

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Abstract

Background The proliferation of electronic health records (EHR) in health systems of many high-income countries has ushered in profound changes to how clinical information is used, stored, and disseminated. For patients, being able to easily access and share their health information electronically through interoperable EHRs can often impact safety and their experience when seeking care across healthcare providers. While extensive research exists examining how EHRs affected workflow and technical challenges such as limited interoperability, much of it was done from the viewpoint of healthcare staff rather than from patients themselves. This leaves a critical knowledge gap in our evidence base to inform better implementation of health information technologies which needs addressing.

Aims and objectives This study aimed to explore how patients with chronic conditions or polypharmacy and their caregivers perceive the current state of EHR interoperability, identify instances where it was associated with negative health outcomes, and elucidate patient-driven recommendations to address concerns raised.

Methods A total of 18 patients and caregivers participated in five online focus groups between May–July 2022. Thematic analysis was performed to generate codes and derive higher-order themes.

Results Participants highlighted that EHR interoperability in the NHS does not meet patient needs and expectations. While patients' understanding of the concept of EHR interoperability was mixed, most were able to describe how the inability to seamlessly share health information within EHR has negatively impacted care. Limited interoperability contributed to inaccurate medical records, perpetuated existing incorrect information, impaired clinical decision-making, and often required patients to resort to using workarounds. Patients also voiced ideas for potential solutions for consideration. These included a move towards a one-centralised system approach, strengthening data security measures to augment other efforts to increase interoperability, prioritising health information technology training for NHS staff, and involving more allied health professionals and patients themselves in the EHR data curation process.

Conclusion Our study contributes to the existing body of literature by providing the perspectives of patients and carers most likely to encounter interoperability challenges and therefore those most ideally positioned to propose

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potential solutions. As highlighted by patients, researchers and policymakers should consider social, educational, and organisational solutions, in addition to technical solutions.

Public interest Summary Lack of interoperability (i.e., the ability to share a patient's health information electronically between healthcare providers) can affect the quality of care received. However, much of the existing research was done from the viewpoint of healthcare staff rather than from patients themselves. This study explored the views of patients regarding what they feel interoperability in the NHS is currently like, how they think it affects their care, and what they think can be done to improve it. Patients reported interoperability to often be poor. It caused inconvenience both to themselves and their healthcare provider, and negatively impacted their experience getting care overall. Patient suggestions for improvement included centralising and reducing the number of existing systems, having more training for healthcare staff, and supporting patients and other healthcare staff in managing their health data.

Keywords Electronic health records, Interoperability, Health information exchange, Patient involvement, Focus groups, Qualitative methods

Background

Since the introduction of Electronic Health Records (EHR), research efforts focussed on exploring the benefits surrounding their implementation and use [1, 2], impact on clinical workflows [3, 4], provider experiences [5, 6], as well as many of the limitations due to the lack of EHR interoperability [7, 8].

In comparison, there is a relative paucity of evidence dedicated to investigating EHR interoperability from the perspective of patients or caregivers, and its impact on the perceived quality of care received. In the context of digital health and health informatics, interoperability can be defined as *"the ability of different information systems, devices and applications (systems) to access, exchange, integrate and cooperatively use data in a coordinated manner, within and across organizational, regional and national boundaries, to provide timely and seamless portability of information and optimize the health of individuals and populations globally"* [9]. However, whether this definition of interoperability and its purported benefits are appreciated in the same light by patients or users of health care, remains to be seen.

A study by Chang et al., highlighted that patients who access care mostly within one health system and had all their medical records in one centralised EHR, tended to have a more positive impression of care coordination. This contrasted with patients who described a sense of *'disconnect'* between their primary care provider and specialists when seeking care across two or more health systems using multiple non-interoperable EHR. The study concluded that patients *'strongly endorsed the need for better communication, interoperable health records, and improved transitions of care between providers and health systems'* [10].

For patients living with chronic conditions or polypharmacy, their often-complex healthcare needs make them especially dependent on health information technologies, such as EHR, that support greater interoperability to

ensure a safe delivery of care [10–12]. As patient-centric care has become increasingly encouraged and patients are better empowered to adopt more assertive roles in their own healthcare decisions, a similar shift regarding the stewardship of healthcare data currently held in EHR can already be seen in some initiatives. For example, organisations such as *Understanding Patient Data* are already working with patient groups across the healthcare landscape to equip patients with the information needed to use their own data effectively [13]. As patients become more empowered to use their data in their care, it is likely that their expectations of EHR will become increasingly voiced. Understanding patient and caregiver perspectives around interoperability, including their perceived risks and potential solutions, will help us anticipate these needs proactively in the design of new EHR systems and the development of healthcare data policies. Evidence gathered will be useful in informing future healthcare technology policies which should better reflect the bespoke needs of patients and caregivers and allow for the better leveraging of digital technologies integrated into the modern healthcare environment.

This study aims to investigate how patients and their caregivers perceive the current status and potential future of EHR interoperability in the English National Health Service (NHS), the country's publicly funded, single-payer healthcare service. Specific study objectives include:

- a) To explore patients' and caregivers' knowledge, understanding, and expectations of concepts such as electronic health records and interoperability.
- b) To explore their perception of the impact of interoperability on patient safety.
- c) To explore potential solutions to address current EHR interoperability challenges.

Methods

Study design

A qualitative methods approach using focus groups was selected for this study given that focus groups inherently amplify insights into particular topics as a result of the organic interactions and group dynamics between the participants themselves [14–16]. Given the lack of extensive prior literature on the topic of EHR interoperability in the NHS from the patients' perspective, focus groups are also well suited to explore participant perceptions and how they arrived at these conclusions [14]. Thematic analysis of the focus group transcripts was performed by two members of the research team (EL, OL).

The Consolidated Criteria for Reporting Qualitative studies (COREQ) guidelines was used to ensure the findings in this report are aligned with best practices for reporting qualitative research [17].

Study population

This study captured the views of adult patients and their non-healthcare trained caregivers (i.e., family members, informal carers) who receive care at NHS facilities that make use of EHR systems. Patients with chronic conditions were chosen as this patient group is expected to experience the greatest reliance on the EHR due to their lengthy medical history, polypharmacy, and often-complex care needs spanning multiple healthcare providers.

The inclusion criteria for participants were as follows:

- Patients aged 18+ who have at least one chronic condition listed in the Charlson Comorbidity Index [18, 19] or non-healthcare trained caregivers who provide care to patients with chronic conditions.
- Patients or non-healthcare trained caregivers whose care frequently requires visits between at two or more healthcare facilities (e.g., GP surgeries and hospitals).
- Able to communicate verbally in English.
- Have internet access and equipment needed to perform video or telephone conferencing.

Sampling and recruitment

Participants were recruited using convenience sampling with the aim of creating four to five focus groups [20–24]. Recruitment was completed in partnership with the *VOICE UK* patient involvement and engagement network in addition to using study advertisements posted on social media platforms (e.g., Twitter, Facebook) [25]. Interested potential participants contacted members of the research team via email and were screened to ensure that they met the study inclusion criteria. Participants did not have any relationship with the researcher

beforehand and received no financial compensation for their participation.

Data collection

A topic guide containing nine open-ended questions exploring the three study aims was used (Appendix 1). The topic guide was developed using evidence from existing available literature on the research topic and input from members of the Research Patients Group (RPG) Patient and Public Involvement and Engagement (PPIE) group. The topic guide was piloted with two PPIE groups and iteratively revised before its use to ensure relevance of its contents. Lay-person appropriate definitions of core concepts such as 'EHR' and 'interoperability' were included as prompts to aid in facilitating the discussion should participants not be familiar with them beforehand. However, these were not used when participants were able to describe in their own words what those concepts meant to them to a reasonable level.

Recruitment took place between May–June 2022. The focus groups were conducted between May–July 2022 and were facilitated in English via online conferencing platforms (e.g., Zoom), with the option for participants to dial in via telephone. The sessions were digitally recorded for transcription verbatim by an independent transcription service. All study material was saved on password-secured servers at Imperial College London, Department of Surgery and Cancer. Only members of the research team and participants were present at the focus groups. Participants did not review the transcripts or the findings. No follow-up focus groups were conducted.

Data analysis

Transcripts were coded and thematically analysed independently by two qualitative researchers with backgrounds in clinical medicine, public health, and patient safety (EL, OL). Regular meetings between members of the research team ensured coding quality and enabled iterative refinement of the codes and subthemes to form higher order themes. Overall, the analysis was both deductive (i.e., partly based on pre-existing knowledge from the literature) and inductive (i.e., additional concepts identified from the data derived from the transcripts) [26].

Results

A total of 18 patients and caregivers participated in our study across five focus groups (minimum two, maximum six participants per group). The focus groups lasted on average 48 min per session.

The three main themes and respective subthemes are mapped in Fig. 1. Please see Table 1 for a breakdown of the participants' basic demographic characteristics.

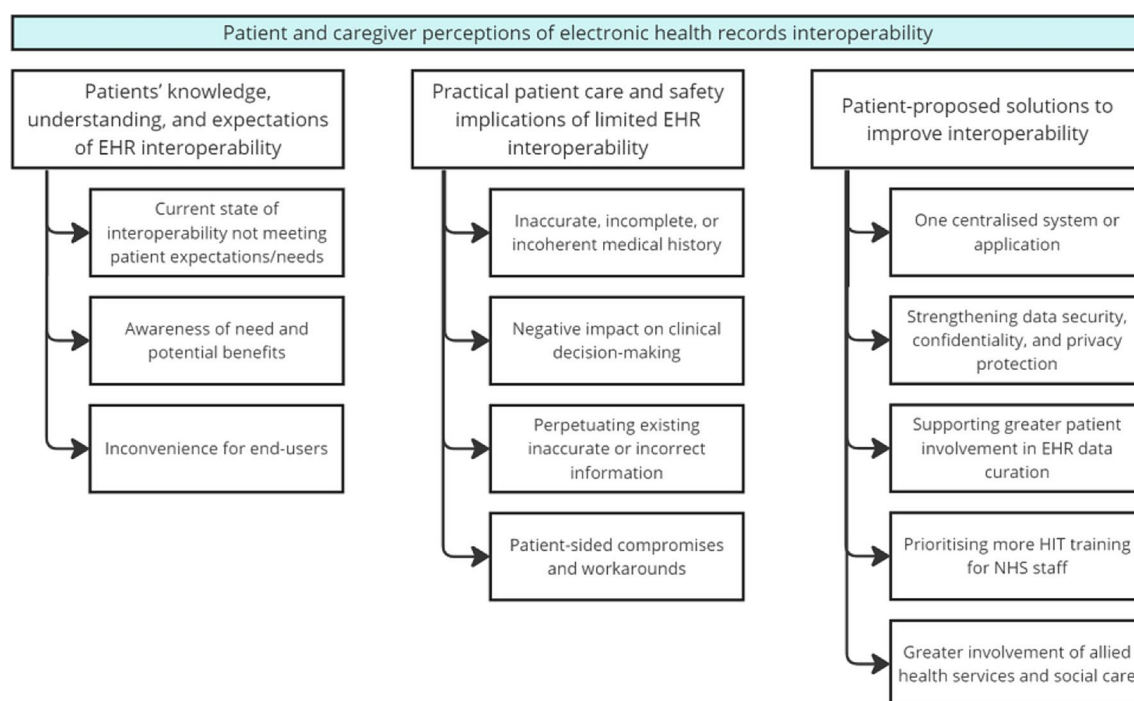


Fig. 1 Mapping of prominent themes identified

Table 1 Basic participant demographic characteristics

	Characteristics	n (%)
Gender	Male	6 (33.3%)
	Female	11 (61.1%)
	Other	0 (0%)
	Missing	1 (5.6%)
Age	18–24 years old	1 (5.6%)
	25–34 years old	0 (0%)
	35–44 years old	2 (11.1%)
	45–54 years old	2 (11.1%)
	55–64 years old	6 (33.3%)
	65 years old and older	6 (33.3%)
	Missing	1 (5.6%)
Ethnic Group	White (English/Welsh/Scottish/Northern Irish/British, Irish, Gypsy or Irish Traveller, Any other White background)	11 (61.1%)
	Mixed/Multiple Ethnic Groups (White and Black Caribbean, White and Black African, White and Asian, Any other Mixed/Multiple ethnic background)	2 (11.1%)
	Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, Any other Asian background)	2 (11.1%)
	Black/African/Caribbean/Black British (African, Caribbean, Any other Black/African/Caribbean background)	1 (5.6%)
	Other Ethnic Group (Arab, Any other ethnic group)	1 (5.6%)
	Missing	1 (5.6%)

Missing details on patient characteristics are due to unreturned demographic questionnaires.

Patients' knowledge, understanding, and expectations of EHR interoperability

Patients demonstrated variable levels of understanding of EHR interoperability. While most were unfamiliar with the term, many participants deduced it pertained to how their clinical data was handled across the NHS. Participants associated the meaning of interoperability with having inadequate levels of access to their own clinical information (i.e., via patient-facing online portals and mobile phone applications), or the lack of a more streamlined appointment scheduling experience.

A minority of patients who stated that they had had previous experience with digital healthcare technologies were better able to describe what EHR interoperability meant for them: the ability to access and share clinical data within connected EHR systems between various healthcare providers involved in their care. This definition was largely similar across this group of participants.

Textbox 1: Patients' knowledge, understanding, and expectations of EHR interoperability

"Just to access, so you can access the record via computer or if it's your own record, an app on your iPhone. Very, very useful, particularly for your own records, ordering medication, whatever it is you want. You don't need to move from the house, you don't even need to speak to anybody, so saves time all around." [R2, Group 3]

Textbox 1: Patients’ knowledge, understanding, and expectations of EHR interoperability

“I had to Google to find out what it meant, so I just found out it means how computers talking together and sharing information. Till now, I didn’t know what it was.”[R3, Group 5]

“I’ve not heard that word in this context before. I’m not, but it sounds like it would be, to me personally, sounds like it would be a good idea. If I go to rheumatology in [HOSPITAL NAME], they have absolutely no clue about my blood test results from my GP. I have to carry things along or forward them because the systems used by are not necessarily the same. So, it would be great if there was a seamless system.”[R2, Group 3]

Current state of interoperability not meeting patient expectations and needs

Participants largely agreed that the current implementation of EHR interoperability across the NHS is not adequately meeting their needs and expectations. Numerous participants detailed instances where their care was negatively affected due to the lack of interoperability (e.g., need for repeat investigations, recounting of medication lists, documentation of incomplete or inaccurate medical histories, and miscommunications between their GP and specialists). These contributed to a frustrating, burdensome, and overall negative experience for patients and their caregivers when accessing both primary and secondary care.

Textbox 2: Current state of interoperability not meeting patient expectations/needs

“And while the GP and hospital speak to each other, the hospitals definitely do not speak to one another. It would save time and clarity and probably costs because sometimes they repeat tests in order to ensure they haven’t missed anything, just because they don’t have it on the system.”[R1, Group 1]

“There are lots of issues and it’s still in its embryonic stage, my worry is that you’ll have acute care, and you have primary care with different systems, and they don’t often integrate or talk with each other. Now put another dimension on that [social care] which, again, is a completely different system.”[R4, Group 2]

“That [repeating medical history] is frustrating and time consuming for both them and me. Because that should all be at their fingertips and it should really be a matter of them seeking clarification, if anything that they’re seeing in the records is not clear.”[R2, Group 1]

Awareness of need and potential benefits

Participants were easily able to recognise the importance and potential benefits to their care of enhanced interoperability. Aside from the apparent, practical benefits such as convenience, interoperability was perceived to enhance patient advocacy and enable greater autonomy in decision-making and care planning. However, participants did indicate that the benefits of interoperability were contingent on the quality of data available in the EHR.

Textbox 3: Awareness of need and potential benefits

“So I think it’s really, really important that our information is shared, but shared correctly. (...) I think it’s hugely important that’s shared, but shared correctly. [...] So obviously, it’s vital that’s shared, but it’s vital it’s correct. That’s not gone along.”[R2, Group 5]

“The accuracy of the records [is important]. It’s okay you reading what the doctor wrote about my consultation last week, hypothetically and theoretically, but if you put down a few, a couple of wrong things, what’s the point of interoperability then? Unless I can actually mention to the doctor that, well the consultants saying the hospital, the doctor got that wrong, then he’s going to get the wrong impression anyway.”[R3, Group 1]

“If the system was totally interoperable, then it could actually offer me choices. ... Have you thought of this? Have you thought of that? Have you considered this? And it would give me choices, which I think is great. As it stands at the moment, it’s, if the GP says something, I do it.”[R3, Group 2]

Inconvenience for end-users

The greatest shortcoming of the current state of interoperability recognised by participants was the inconvenience caused, both to themselves and for healthcare providers. For patients, suboptimal interoperability was perceived to negatively impact continuity of care and pose safety risks as medical records were often incomplete and required rectification. Participants also perceived that inadequate interoperability often translated into suboptimal use of the limited clinical time with healthcare providers due to the amount of time spent reconciling patient information.

Textbox 4: Inconvenience for end-users

“I find it the most inefficient waste of time known to man. I’ve spent the last six, we feel we’ve spent the last six or nine months in our social life has been hospitals and tracking down appointments and tracking down, what did that say, what did this say, what did the other say, cross-referencing between them.”[R1, Group 4]

“Just think of the paperwork you save, time that you save, travel. I’ve got to travel to the nearest hospital 20 odd miles. I could save a fortune in time and my own lifestyle.”[R3, Group 2]

“It’s more an inconvenience or I have to really think ahead, ‘Oh, I’ve had my next battery of blood test, let me quickly forward them before the consultants due to phone me, otherwise I’m wasting her time.”[R2, Group 3]

Practical patient care and safety implications of limited EHR interoperability

Participants showed an extensive awareness of the direct, indirect, and potential impact posed to their immediate care and safety due to the general lack of EHR interoperability in the NHS.

Inaccurate, incomplete, or incoherent medical history

Almost all participants described instances where they identified inaccurate or incomplete clinical information in their EHR during their clinical encounters, resulting in repeat history taking or testing. Patients recounted they often had to serve as the final authority on the accuracy of information found in their EHR and perceived that providers used their knowledge as a ‘double check’ for

the information in the EHR (e.g., medical history, ongoing medications, or detailed reasons behind why a particular clinical decision was made). Participants reported that this redundant disclosure of their information was a source of annoyance and frustration. Others expressed some level of discomfort being the final backstop regarding the veracity of their EHR contents as they did not possess the underlying medical knowledge, did not know what information was important to healthcare providers, or could not recall all the details required.

Similarly, further risks to care were posed when inaccurate information ‘followed’ the patient through their care. Participants often reported the perpetuation of incorrect clinical information over time. Some errors, such as misdiagnoses of mental health conditions, were highlighted to be especially stigmatising when repeated across different healthcare providers or settings. For example, one participant recounted a hospital encounter where a family member was misdiagnosed as suffering from dementia upon admission. In subsequent admissions, various clinical symptoms were wrongfully attributed to being related to dementia rather than being investigated for alternative contributing aetiology. Patients wishing to correct these errors were often hampered by lengthy delays caused by various bureaucratic barriers and limited provider time to make the necessary corrections.

Textbox 5: Inaccurate, incomplete, incoherent medical history

"My NHS, electronic health record from the GP, got hundreds of pages literally, because it was obviously since I was more or less born, I suppose (...). It was quite interesting because some of it was a work of fiction, some of the things on there were not me, belonging to me."[R1, Group 4]

"How much of what's recorded about us is correct and we're aware of that, do you see what I mean? Because quite often, it's up to the healthcare professionals opinion, or how much they know about you as to what they record. So I'm in a situation at the moment where I'm potentially trying to amend one of the diagnoses on my mental health file, because I'm arguing that it's actually a neurodivergent diagnosis... For me, it's about what's on those records, and some of the stigma that can come with, you know, what is recorded."[R5, Group 2]

"When she was in the hospital and I was not there, one of the nurses wrote down in the records that she has got dementia. Now my mother had all the faculties, she knew what she was, she could speak English to communicate and everything else, but the nurse slowed down by misdiagnosing delirium as dementia. And that has stayed and I have raised that issue again and again, with the Health Trust, I have raised complaints, I've tried to get that removed, but it stay on the record. [...] Now, every time my mother goes into A&E, the first thing any A&E doctor sees, is she suffers from dementia, and I have to fight against them and say, what are you guys talking about?"[R1, Group 2]

"Because my GP surgery could not provide any correction to all kinds of errors, I had no choice but deregister from the GP surgery, register with a new one."[R2, Group 2]

Negative impact on clinical decision-making
Limited EHR interoperability was perceived by participants to negatively impact clinical decision-making

by healthcare providers. This was primarily due to the often inaccessible, incomplete, or inaccurate information contained within EHR on which providers had to base their decisions. No participants recounted exact instances where they experienced direct harm as a result. However, a small minority of participants were able to point to medical harm resulting from inadequate clinical information sharing reported in the recent media, and highlighted that poor interoperability at least partly contributed to those harm events.

Textbox 6: Negative impact on clinical decision-making

"I mean, in my own experience, it has caused errors in the capacity of decision-making. Where like I've consulted my GP for certain things because they hadn't a full up-to-date picture of my needs and circumstances (...) So I do think there not being the opportunity to share information does increase the likelihood of poor decision making and errors by healthcare professionals."[R1, Group 3]

"We do get that at the surgery because we can't read the hospital record. A patient will come in and say, "Oh I need such and such medication immediately," and of course, there's nothing on the record to indicate this because we can't see the clinical letter. It's then a case of drop everything, contact the hospital, hope somebody picks the phone up, or do it electronically, email, whatever, to get a clinical letter so that the GP can then prescribe the medication or whatever the issue is that they need to have done. So there can be problems there, or if the patient didn't quite understand what it was that the hospital wanted the GP to do as the next step, and the GP can't see that clinical letter. Where do they go from there in terms of helping the patient?"[R2, Group 3]

Patient-sided compromises to facilitate information sharing
Given the current lack of interoperability, participants reported that they frequently had to be the primary means of facilitating information sharing between various healthcare providers involved in their care. Inaccessible documents (e.g., discharge summaries) on the EHR meant that patients frequently stepped into the role of the ‘go between’ in order to convey their care plan to their GPs as directed by hospital-based healthcare providers post discharge. In other instances, this also prompted patients to be more reliant upon physical documents (e.g., GP letters, medication lists, vaccination records) as their preferred and trusted means of conveying information.

Textbox 8: Patient-sided compromises and workarounds

"It's lacking in productivity; it's lacking in efficiency. It means it's resource intensive, not just for us, but for obviously the other sides of things. And it relies upon me to keep it all together. Now, how long can I do that, me? I mean, sort of lose the plot at some point. That's dangerous, that could be dangerous."[R1, Group 4]

"I come across a couple of other people who I've sort of said, and some of them don't use the electronic systems, they prefer just the paper trail."[R1, Group 4]

Textbox 8: Patient-sided compromises and workarounds

"But there certainly could have been implications because the systems are not talking to each other and people don't have time to look at everything. Whereas if I had been more aware at that point and I wasn't, I would've been looking at the systems trying to find out, "Okay, what did that x-ray say? What was that?"[R1, Group 4]

Potential solutions to the EHR interoperability issue proposed from patients' perspectives
One centralised system or application

Participants reported poor experiences trying to manage the current collection of mobile apps and online portals. Often, information in one application would conflict with that found in another and patients reported not having a way to correct it. There was near unanimous recommendation from participants for future EHR improvement efforts to be spent on having one, harmonised, interoperable approach to EHR systems in use across the NHS where their clinical data can be easily accessed, updated, and shared. However, many expressed doubts about if, how, and when this could be accomplished. Participants were aware of previous failed attempts at developing a centralised system (i.e., NPfIT), but were unable to point to specific learning points which can improve a renewed attempt at a similar endeavour.

Textbox 9: One centralised system or application

"But just one for everybody. So not just for me, but for the doctors, the GP, and for the consultants in the hospitals or clinics, or whatever it is. One system. I don't understand why there isn't one."[R1, Group 4]

"I would've said that I think it all collective belongs to the NHS who then distribute the information however they need. [...] Yeah, exactly. The central database would be for the NHS, and then if you have certain sort of conditions or specialized departments, they can use that centralized database to get that information."[R2, Group 5]

"Because since I can, with my hospital, I can have the truth, single truth about me, my real diagnosis and problems, etc. That's something I can use with emergency responders and other people."[R2, Group 2]

Strengthening data security, confidentiality, and privacy protection

Participants were weary of the elevated risks of data breaches associated with increased EHR interoperability, particularly surrounding how sensitive clinical information (e.g., diagnoses regarding mental health, sexually transmitted diseases) may be mishandled with highly stigmatising ramifications. Most were clear that the greater dissemination of clinical data must not be commercialised or used to identify financial or political information. Participants emphasized the need for strengthened data protection measures in parallel with interoperability improvement efforts.

Textbox 10: Strengthening data security, confidentiality, and privacy protection

"I think just being mindful of the fact that the same data protection rules apply to electronic records as they did physical records is important to know. Just because they're electronically it doesn't mean that they should be taken for granted. They still have to be treated with the same level of care."[R1, Group 3]

"Because there are some different groups involved in the NHS, some private sector companies and obviously some public sector, and don't want our information going out or getting sold, or just you need to ensure that our information gets through to our people, but in a professional way, and in a way that's just not... That can get be handed to the wrong people."[R2, Group 5]

"I think it's very, very important for patients to believe and feel that their records are secure. I mean that's totally... I would think perhaps all patients want that."[R2, Group 3]

Supporting greater patient involvement in EHR data curation

Greater support for patient involvement in their own EHR data to improve its overall accuracy, completeness, and quality was expressed by almost all study participants. Patients noted that interoperability between EHR was only valuable so long as data within it was accurate. At present, their health information within EHR is often inconsistent and incomplete, thus limiting the overall user experience for patients even when interoperable systems were made available. By contributing to the curation of own health data, patients thought that they can indirectly help efforts to hasten interoperability by contributing to the quality of the data in the records. Patients believed they are well-suited to play a constructive role in achieving that aim, especially when clinicians simply do not have the resources or time to do so.

However, views varied greatly surrounding the extent to which patients should be able to directly intervene in their own clinical data found in EHR. Most participants reported that while they would appreciate having greater access, the final authority on the information documented should remain with healthcare providers, ideally their GPs. Some participants acknowledged that asking their GPs to do so is unlikely to be feasible given their workloads and proposed a more centralised NHS entity dedicated to managing EHR data on behalf of both providers and patients. Patients believed their own contribution should come in the form of a partnership by flagging errors themselves so that they are quickly addressed while leaving more technical, clinical information curation with healthcare providers.

Divergent views included participants who believed patients would not care to be involved so long as the information was well-maintained. A small minority expressed concerns that patient involvement may be detrimental in cases when over-enthusiastic patients scrutinising their own records may generate increased

workloads for healthcare staff needing to address every concern raised.

Textbox 11: Supporting greater patient involvement in EHR data curation

"I think patients should be users. That means they can access all their records, but they can't change them. I think changing a record is down to the doctor, with the cooperation of the patient and agreement of the patient."[R3, Group 1]

"I think the healthcare professional should have ownership of it, but the patient has the right to amend, and make changes to the information stored on it at any time."[R1, Group 3]

"I would agree in the sense that if you have too many hands involved, there could be too many people with editing access and that's never a good thing. The doctors should normally have the best perspective on the health side of things."[R1, Group 1]

"Well, I would obviously like to say I have ownership of it, but I'm not sure if that's really a good idea. Well, I should, but I should have joined ownership. But it has to be, I mean I couldn't administrate it. I mean, I wouldn't necessarily have the technical power to do that. It would have to come from, I don't think, I mean, consultants obviously can't do this, and they're not doing it, they're just going through a system that's been set up by somebody. GPs aren't doing it, they're just going through. So there should be an authority, NHS authority that, I don't know."[R1, Group 4]

Prioritising more HIT training for NHS staff

Greater investment in HIT training for NHS staff, both frontline healthcare workers as well as administrators involved in the maintenance and procurement of EHR systems, was a point for improvement identified by patients. More standardised training and familiarisation with the various EHR platforms available, their functions, and how to perform common procedures (e.g., inputting GP letters, filing a scan/lab result), was perceived to facilitate advancement of user-level interoperability. Participants believed that training for administrators would also be beneficial to ensure that EHR systems procured are aligned with the needs of healthcare providers.

Textbox 12: Prioritising more HIT training for NHS staff

"One of the problems we have, we had actually was consultants things used to, if they wanted to give a patient an x-ray, you have to have it clear, or a scan, or something like that. They used to fill in a card and then it would then go to an admin person like me and it would be logged. But they had this idea of consultants ordered their own tests, they did it all online and there was codes. And it became, I mean, consultants are pretty wonderful at what they do, but I'm not necessarily IT specialists...They didn't really know how to work systems. They only got a basic training."[R1, Group 5]

"Years ago, each section and each manager favoured a particular operating system that his friend had told him was fine. His friend who told him it's fine, in those days, people had very, very little experience of computers... And so that tried to transition from paper to electronics, was a minefield of personalities and people tried to cover up their ignorance of the system, and relying on specialists and consultants to show them the way. I think that this is still a problem with the National Health."[R4, Group 1]

Greater involvement of allied health services and social care

Participants reported that greater involvement of allied health professionals would not only help with the comprehensiveness of the stored data but may also serve as a backstop to doctors in spotting errors, particularly of non-medical issues such as social care needs. As many patients are attended to by a range of healthcare staff, participants expressed the desire that future improvements to EHR and interoperability should work towards a more holistic medical record that is better representative of their overall health and well-being.

Textbox 13: Greater involvement of allied health services and social care

"I think electronic health records is everything that's recorded by clinicians, but it shouldn't be just clinicians. I think it's really, it should be everything that's recorded by health and social care providers."[R1, Group 2]

"There are lots of issues and it's still in its embryonic stage, my worry is that you'll have acute care, and you have primary care with different systems and they don't often integrate or talk with each other. Now put another dimension on that [social care] which, again, is a completely different system."[R4, Group 2]

Discussion

Summary of main findings

Interoperability was largely an unfamiliar concept to patients and caregivers. Once a brief definition was provided however, most participants recognised its necessity and potential benefits. Participants were able to highlight how the lack of EHR interoperability negatively impacted their care, predominantly as a source of notable inconvenience for themselves and their healthcare providers.

Limited interoperability has reportedly contributed to inaccurate, incomplete, or incoherent medical histories within EHR which were often difficult to amend, thereby leading to the unencumbered perpetuation of errors. Patients recounted that this has negatively impacted clinical decision-making. Consequences ranged from repeat history taking or investigations, to more serious ones such as misdiagnoses of potentially stigmatising conditions. Patients regularly had to serve as the main means to ensure information was shared appropriately. This often included carrying paper-based documentation when travelling between providers, verbally conveying care plans, and acting as the final backstop for providers to verify clinical information found within EHR.

Participants proposed several solutions or factors which should be considered in any future attempts to address poor EHR interoperability. Most participants conveyed a desire for 'one centralised system'. As improving interoperability will result in greater amounts of clinical information being shared, participants stressed the importance of a corresponding increase in data and privacy protection measures. There was an overarching

sentiment that efforts to improve provider-to-provider information sharing should also include parallel efforts to improve information sharing with patients. Patient participants perceived that increased interoperability with their involvement would attenuate the current risks of information sharing, namely sharing of inaccurate information between different providers. More robust training for NHS staff to foster better HIT competency and greater involvement of allied health services and social care in the upkeep of EHR content were areas in which participants believe further efforts should be made to improve overall EHR interoperability.

Strengths and limitations

This study contributes to the growing body of evidence investigating how patient perspectives can be used to inform future directions for key healthcare challenges. The topic guide was informed by existing literature and was piloted with two patient research groups before use. The focus groups were conducted online, which allowed patients and caregivers from across the UK to participate and thus broadened the range of perspectives included.

However, our findings must also be taken in the context of certain limitations. Firstly, the definition of ‘interoperability’ used in the discussions varied given that they were often derived from patients themselves and the term itself carries different meanings when used in common parlance. Thus, this may limit the usefulness of the study findings in a health informatics context. Secondly, the relatively small number of participants, mostly of elderly age, limits the range of views and perspectives discussed in our focus groups. There is also some level of self-selection bias as participants are likely to be patients who feel more strongly about their views or are more able or inclined to participate.

The inclusion of only adult patients with chronic conditions also neglects exploration of the views of other patient groups, such as parents and children. The inclusion of only patients who were able to participate using video conferencing introduced selection bias for those who are more digitally literate, and likely from socioeconomic backgrounds who could afford the technology necessary. Lastly, the restriction of participants to only those able to converse in English likely contributed to excluding those less proficient, or unable to speak the language.

Comparison with prior work

Few studies have investigated specifically EHR interoperability and its practical implications on patient care from their perspective [27].

Kelly et al., summarised how current EHR interoperability levels contributed to suboptimal care for dialysis patients in the US [28]. Specifically, patient perceptions

of HIE were found to be dependent on the perceived risks and benefits to their care resulting from increased clinical data sharing, which were based on bespoke lived experiences. For example, patients from ethnic minority backgrounds were found to have greater concerns regarding the sharing of their clinical information through HIEs. The authors also pointed to potential solutions to the patients identified to mitigate these concerns, many of which align with those reported in our own study including greater patient engagement and increasing opportunities for patient feedback longitudinally [28].

In 2016, Legler et al., conducted a survey study which explored patient satisfaction levels and their perception of their healthcare provider’s knowledge of their medical history after the introduction of a centralised portal [27]. While the portal did not allow for the manipulation or transfer of patient health data stored across the US VA, Department of Defense, and community providers, the authors nonetheless found that merely using it to view its contents resulted in patients being 14% more likely to report higher levels of satisfaction with their healthcare providers as they appeared more knowledgeable about their medical history [27]. This was especially noticeable for patients with long-standing relationships with their healthcare providers [27]. However, the authors also noted that providers were more likely to use the portal with newer patients and thus be the ones more likely to reap the greatest clinical benefits compared to patients with existing relationships [27].

A recent publication by Hussein et al., investigated patient-generated health data (PGHD) interoperability from three distinct perspectives (technological, clinical, and users) concerning the proposed DH-Convenor platform, an initiative to support the collection, organisation, and interoperability of PGHD in the Austrian national health system [29]. Many of the overarching opportunities and barriers identified mirror the views expressed by our study participants. For example, the authors found that patients were largely accepting of the clinical necessity for PGHD interoperability and its purported benefits. However, participants clearly opposed the sharing of socioeconomic data and any attempts to use patient data for commercial or political purposes [29].

A qualitative study by Sanyer et al., examined patient perspectives on clinical information sharing via EHR in team-based care [30]. Though authors noted that patients recognised the value of centralising their clinical information, concerns were raised towards documentation inaccuracies and the associated difficulties in resolving them [30]. Patients acknowledged that the ability to share health information amongst members of their care team was important, but also voiced apprehensions regarding data security, who should have access to their information, and the scope of information shared [30]. This was

especially poignant for sensitive clinical information such as mental health diagnoses. Aside from the sharing of 'basic' information (e.g., name, date of birth) with all members of the care team, patients were only willing to share more sensitive or personal information found in their EHR with their immediate healthcare provider or someone the patient already had a well-established relationship with (i.e., GP) [30].

Implications for policy, practice, and further research

The past two decades of EHR use have demonstrated the importance of greater data sharing and the necessity of interoperability in the HIT infrastructure of modern healthcare systems. As demonstrated in our study, the need for a more coordinated, interoperable EHR system is evident. Despite the priority often being placed on tailoring such systems to the requirements of healthcare providers, our recent experiences, especially throughout the pandemic, have made apparent the urgency with which future EHR systems and the policies surrounding their use, must better accommodate the needs and expectations of patients. Tackling the lack of interoperability will necessitate fundamental changes ranging from the types of data that are stored and how it is shared, to addressing more systemic questions such as aligning information governance with evolving patient preferences. A renewed attempt at realising some form of a centralised EHR system should be revisited, especially given that the recognition of its need is apparent even amongst patients.

As shown in our findings, the idea of increased EHR interoperability is synonymous with greater access to patient data for more stakeholders, including for patients themselves. This raises a question as to the degree to which patients should be involved in the curation of their own health data, if at all, to address inaccuracies contained within EHRs. Options range from GPs remaining primarily responsible for data entry and curation, to a shift to patient-proposed changes which require approval by a healthcare provider. However, there remains considerable uncertainty surrounding these potential solutions given that they may inadvertently worsen workloads for healthcare providers whilst not meaningfully improving EHR data quality. The need for GPs to review the proposed changes will likely interrupt well-established clinical workflows and introduce clutter to existing EHR data. As demonstrated in our study, there is no consensus surrounding this, though the need to find a balance so as to realise the benefits of having the data within EHRs be more interoperable, is well recognised by patients and caregivers.

HIT policies and procurement contracts must encourage vendors to incorporate patient involvement aspects into their design of future EHR systems from the outset and ensure that as information sharing is enhanced for

providers, it is also made more robust for patients. As illustrated by our participants and supported by findings from other similar studies, the greater sharing of clinical information possible through better interoperability is contingent upon efforts to strengthen data security and privacy protections [29–31].

Future research should seek to quantify any improvements through the implementation of new EHR interoperability interventions. Outcome measures of interest may include the accuracy of stored clinical information, patient safety incidents, user satisfaction, or time spent reconciling patient information. These efforts would help demonstrate the value of expanding EHR interoperability and serve to corroborate the findings found in patient-centric qualitative studies such as our own. Likewise, additional qualitative studies focussing on underrepresented ethnic minority groups, non-English speaking communities, and different target patient demographics (e.g., paediatrics), would also be useful in ensuring future efforts at improving EHR interoperability are inclusive of their needs.

Conclusion

Our study has demonstrated that patients and caregivers are keenly aware of how the current state of NHS EHR interoperability affects the safe and efficient delivery of their care. Their perspectives offer policymakers and health information technologists valuable insight into the impact current levels of EHR interoperability have on clinical care for patients with complex conditions and illustrates patient-derived solutions for enhanced interoperability.

In its current form, EHR interoperability remains lacklustre in fulfilling the needs and expectations of patients, often causing inconvenience for users, contributing to inaccurate or incomplete medical histories, impairing clinical decision-making for healthcare providers, and requiring clumsy workarounds from patients themselves to mitigate its deficiencies. Only by comprehensively addressing these issues raised by patients would health systems be able to realise the purported benefits of EHR with greater interoperability.

Abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research.
EHR	Electronic health records.
GP	General practitioners.
HIE	Health information exchange.
HIT	Health information technologies.
JLV	Joint Legacy Viewer.
NHS	National Health Service.
PGHD	Patient-generated health data.
PHR	Personal health records.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12911-024-02789-5>.

Supplementary Material 1

Supplementary Material 2

Author contributions

EL and ALN conceived of and designed the study. EL and OL conducted the focus groups. EL and OL analysed and interpreted the resultant transcripts. EL drafted the initial manuscript. EL, OL, and ALN contributed to writing the manuscript. EL, ALN, OL, JC, HA, and AD were all contributors to editing the manuscript. All authors have read and approved the contents of the final manuscript.

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Data availability

Data is available upon reasonable request to the corresponding author.

Declarations

Ethical approval and consent to participate

Overall ethical approval for this study was granted by the Imperial College Research Ethics Committee (ICREC) (Reference No. 22IC7425). This is a dedicated ethics oversight body at Imperial College London for all health-related research involving human participants. All participants provided written informed consent prior to participating in the study and consented to their focus group sessions being recorded.

Consent for publication

All participants provided written informed consent for anonymised quotes from their focus groups to be used in the publication of this study.

Competing interests

HA is the chief scientific officer of Pre-emptive Health and Medicine at Flagship Pioneering. AD is the executive chair of Pre-emptive Health and Medicine at Flagship Pioneering. All other authors do not have any competing interests.

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References

1. Tamblin R, Abrahamowicz M, Buckeridge DL, Bustillo M, Forster AJ, Girard N et al. Effect of an Electronic Medication Reconciliation Intervention on Adverse Drug Events A Cluster Randomized Trial + Supplemental content and Audio. *JAMA Netw Open* [Internet]. 2019;2(9):1910756. <https://jamanetwork.com/>
2. Xiao AQ, Acosta FX. Implementation and Impact of Psychiatric Electronic Medical Records in a Public Medical Center. *Perspect Heal Inf Manag*. 2016;13(Fall).
3. Ramaiah M, Subrahmanian E, Sriram RD, Lide BB. Workflow and electronic health records in small medical practices. *Perspect Health Inf Manag*. 2012;9.
4. Koldby S, Schou Jensen I. Clinical simulation and workflow by use of two clinical information systems, the electronic health record and digital dictation. *Stud Health Technol Inf*. 2013;192(1–2):402–6.
5. Abramson EL, Patel V, Malhotra S, Pfoh ER, Nena Osorio S, Cheriff A et al. Physician experiences transitioning between an older versus newer electronic health record for electronic prescribing. *Int J Med Inform* [Internet]. 2012;81(8):539–48. <https://doi.org/10.1016/j.ijmedinf.2012.02.010>
6. Raglan GB, Margolis B, Paulus RA, Schulkin J. Electronic health record adoption among obstetrician/gynecologists in the United States: physician practices and satisfaction. *J Healthc Qual*. 2017;39(3):144–52.
7. Clarke JM, Warren LR, Arora S, Barahona M, Darzi AW. Guiding interoperable electronic health records through patient-sharing networks. *npj Digit Med* [Internet]. 2018;1(1):1–6. <https://doi.org/10.1038/s41746-018-0072-y>
8. Warren LR, Clarke JM, Arora S, Darzi AW. Improving data sharing between acute hospitals in England: an overview of health record system distribution and retrospective observational analysis of inter-hospital transitions of care. *BMJ Open* [Internet]. 2019;9(12):e031637. <http://bmjopen.bmj.com/lookup/doi/https://doi.org/10.1136/bmjopen-2019-031637>
9. HIMSS. Interoperability in Healthcare | HIMSS [Internet]. 2022 [cited 2022 Feb 4]. <https://www.himss.org/resources/interoperability-healthcare>
10. Chang L, Wanner KJ, Kovalsky D, Smith KL, Rhodes KV. It's Really Overwhelming: Patient perspectives on care coordination. *J Am Board Fam Med* [Internet]. 2018 Sep 1 [cited 2023 Jun 20];31(5):682–90. <https://www.jabfm.org/content/31/5/682>
11. Arora P, Kausz AT, Obrador GT, Ruthazer R, Khan S, Jenuleson CS, et al. Hospital utilization among chronic dialysis patients. *J Am Soc Nephrol*. 2000;11(4):740–6.
12. Gorodetskaya I, Zenios S, McCulloch CE, Bostrom A, Hsu CY, Bindman AB, et al. Health-related quality of life and estimates of utility in chronic kidney disease. *Kidney Int*. 2005;68(6):2801–8.
13. Understanding Patient Data [Internet]. 2018 [cited 2023 Oct 20]. <https://understandingpatientdata.org.uk/>
14. Bowling A. Research methods in Health. Mc Graw Hill. 2014. 512 p.
15. Morgan D. Focus Groups as Qualitative Research. Focus Groups as Qualitative Research. SAGE Publications, Inc.; 2012.
16. Wilkinson S. Focus group methodology: a review. *Int J Soc Res Methodol* [Internet]. 1998 Jan 10 [cited 2023 Jun 17];1(3):181–203. <http://www.tandfonline.com/doi/abs/https://doi.org/10.1080/13645579.1998.10846874>
17. Booth A, Hannes K, Harden A, Noyes J, Harris J, Tong A. COREQ (Consolidated Criteria for Reporting Qualitative Studies). Guidel Report Heal Res A User's Man [Internet]. 2014 Aug 22 [cited 2021 Jul 13];214–26. <https://onlineibrary.wiley.com/doi/full/https://doi.org/10.1002/9781118715598.ch21>
18. Charlson. Comorbidity Index (CCI) - MDCalc [Internet]. [cited 2021 Dec 17]. <https://www.mdcalc.com/charlson-comorbidity-index-cci>
19. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* [Internet]. 1987 [cited 2023 Jun 22];40(5):373–83. <https://pubmed.ncbi.nlm.nih.gov/3558716/>
20. Carlsen B, Glenton C. What about N? A methodological study of sample-size reporting in focus group studies. *BMC Med Res Methodol* [Internet]. 2011;11(26):26. <http://www.ncbi.nlm.nih.gov/pubmed/21396104>
21. Hennink MM, Kaiser BN, Weber MB. Sizes in Focus Group Research. What Influences Saturation? Estimating Sample. *Qual Health Res* [Internet]. 2019 Jan 10 [cited 2023 Jun 17];29(10):1483–96. <https://journals.sagepub.com/doi/abs/10.1177/1049732318821692?journalCode=qhrr>
22. Guest G, Namey E, McKenna K. How Many Focus Groups Are Enough? Building an Evidence Base for Nonprobability Sample Sizes. Field methods [Internet]. 2017 Feb 24 [cited 2023 Jun 17];29(1):3–22. <https://journals.sagepub.com/doi/abs/10.1177/1525822X16639015?journalCode=fmxd>
23. McQuarrie EF, Krueger RA. Focus Groups: A Practical Guide for Applied Research. *J Mark Res* [Internet]. 1989 [cited 2023 Jun 17];26(3):371. Available from: https://books.google.co.uk/books?hl=en&lr=&id=8wASBAAQBAJ&oi=fnd&pg=PP1&ots=XfiMBvcHrV&sig=COJHfW93bTT9vMN7ybvXTVzQ7uw&redir_esc=y#v=onepage&q&f=false
24. Tang KC, Davis A. Critical qqs in the determination of focus group size. *Fam Pract* [Internet]. 1995 [cited 2023 Jun 18];12(4):474–5. <https://academic.oup.com/fampra/article/12/4/474/741127>

25. VOICE. VOICE About Us. [cited 2023 Oct 17];1–3. <https://voice-global.org/for-collaborators>
26. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
27. Legler A, Price M, Parikh M, Nebeker JR, Ward MC, Wedemeyer L, et al. Effect on VA Patient satisfaction of Provider's Use of an Integrated Viewer of Multiple Electronic Health Records. *J Gen Intern Med*. 2019;34(1):132–6.
28. Kelly YP, Kuperman GJ, Steele DJR, Mendu ML. Interoperability, Patient Electronic Health Record Accessibility. Opportunities to improve Care Delivery for Dialysis patients. *American Journal of Kidney Diseases*. Volume 76. W.B. Saunders; 2020. pp. 427–30.
29. Hussein R, Crutzen R, Gutenberg J, Kulnik ST, Sareban M, Niebauer J. Patient-generated health data (PGHD) interoperability: An integrative perspective. *Public Heal Informatics Proc MIE*. 2021. 2021;228–32.
30. Sanyer O, Butler JM, Fortenberry K, Webb-Allen T, Ose D. Information sharing via electronic health records in team-based care: the patient perspective. *Fam Pract [Internet]*. 2021 Jul 28 [cited 2023 Apr 16];38(4):468–72. <https://academic.oup.com/fampra/article/38/4/468/6158090>
31. Vermeir P, Degroote S, Vandijck D, Van Tiggelen H, Peleman R, Verhaeghe R et al. The patient perspective on the effects of medical record accessibility: a systematic review. *Acta Clin Belgica Int J Clin Lab Med [Internet]*. 2017;72(3):186–94. <https://doi.org/10.1080/17843286.2016.1275375>

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