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A qualitative exploration of patients' experiences, needs and expectations regarding online access to their primary care record

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ABSTRACT

Objectives Primary care records have traditionally served the needs and demands of clinicians rather than those of the patient. In England, general practices must promote and offer registered patients online access to their primary care record, and research has shown benefits to both patients and clinicians of doing so. Despite this, we know little about patients' needs and expectations regarding online access to their record. This study explored what patients and carers want from online access to their electronic primary care health record, their experiences of using it, how they would like to interact with their record and what support they may need.

Design Focus groups and semistructured interviews using purposive sampling to achieve a good sociodemographic spread. Interviews were digitally audiorecorded, transcribed and coded using an established thematic approach.

Setting Focus groups and interviews were conducted in community settings in the UK.

Participants Fifty-four individuals who were either eligible for the National Health Service Health Check, living with more than one long-term condition or caring for someone else.

Results Participants views regarding online access were categorised into four main themes: awareness, capabilities, consequences and inevitability. Participants felt online access should be better promoted, and suggested a number of additional functions, such as better integration with other parts of the healthcare system. It was felt that online access could improve quality of care (eg, through increased transparency) but also have potential negative consequences (eg, by replacing face to face contact). A move towards more online records access was considered inevitable, but participants noted a need for additional support and training in using the online record, especially to ensure that health inequalities are not exacerbated.

Conclusions Discussions with patients and carers about their views of accessing online records have provided useful insights into future directions and potential improvements for this service.

Strengths and limitations of this study

- This is the first UK-based study to explore the experiences, needs, and expectations of patients regarding online access to their primary care record, and to discuss the implications for the development of these services.
- Purposive sampling was employed to ensure a good sociodemographic mix, with individuals from urban and rural areas, and varying degrees of digital and health literacy.
- Patient and public participation in the research ensured it remained patient focused and included views from seldom-heard groups.
- A mixture of focus groups and one to one interviews enabled exploration of shared experiences and understandings while also allowing further probing of minority or controversial opinions and discussion of sensitive issues.
- Potential limitations include the absence of participant validation, and the need for exploration of transferability of findings to different international healthcare settings, which may facilitate the development of a theoretical framework.

INTRODUCTION

The general practitioner (GP) contract in England states all patients should have online access to their full primary care record.[1] While this has not been fully implemented, 24% of patients in England have signed up for online records access (ORA)[2] via the National Health Service (NHS) App or other NHS-approved service.[3] Systematic reviews examining ORA have identified a number of potential benefits and drawbacks.[4–6] Patients can use ORA as an aide-mémoire, to help prepare for their next appointment,[7–9] and report that it saves time by reducing the number of telephone calls and appointments required.[4 7] ORA can increase patients' feelings of autonomy,[10 11] enable them to spot and correct medication errors,[4 6] and positively impacts on clinical measures such as glycated haemoglobin (HbA1c).[6] However, clinicians have expressed concerns that ORA could cause unnecessary anxiety, increase complaints and threaten confidentiality and security.[5] Other concerns relate to: widening health inequalities, risk of coercion and increased clinician workload.[12]

Research has looked at what patients do with ORA and its impact on patient satisfaction and engagement. However, there has been little research examining what patients *want* from ORA. Overlooking patients' needs and expectations may prevent patient ORA from achieving its full potential. Only three qualitative studies have examined what patients want from ORA,[13–15] indicating they want it to: (1) be secure and trustworthy, (2) act as a communication aid, (3) be more interactive, (4) serve an educational function and (5) serve practical functions. These studies identified the importance of ORA aiding communication between patients and healthcare professionals (HCPs), other family members, carers or between HCPs. Patients would like to be able to write into their record,[14 15] and expressed a desire for decision aids,[13] and lifestyle management with signposting to services.[13 14] Sought after educational functions included plain English explanations of medical terms,[14 15] and practical functions including booking appointments,[14] viewing test results[14 15] and accessing information needed to complete benefit applications.[14]

Although these qualitative studies have started to identify what patients want from ORA, only one was primary care based and conducted in the UK, and was carried out over 16 years ago examining a significantly different service than is available today.[15] The authors noted that 'working in partnership with patients to develop systems is essential to their success'.[15] [p38] To achieve this, we need to ascertain what patients would like from ORA rather than simply asking them to evaluate systems that already exist.

Through our patient and public involvement and engagement (PPIE) work[16] and previous reviews,[4 17 18] we identified three diverse groups likely to have different needs and expectations of ORA: those eligible for the NHS Health Check[19] who value ORA to understand how they might maintain good health[16] and those with multimorbidities and carers, who value it for managing their conditions or the conditions of those they care for.[4] This study, therefore, aims to explore patients' and carers'

- Awareness and experiences of ORA.
- Views and beliefs regarding ORA.
- expressed needs and expectations regarding ORA, including required support.

METHODS

Given the limitations of the existing evidence base in this area, an exploratory qualitative study, informed by grounded theory, was conducted. Data were collected through focus groups and semi-structured interviews in community settings in the UK, followed by an inductive thematic analysis.[20]

Sampling and recruitment

A purposive sampling strategy was employed to achieve maximum variability for factors known to impact ORA, such as age, sex, socioeconomic status and ethnicity.[21] Recruitment methods included using the Greater Manchester Clinical Research Network, approaching community organisations and snowballing. A participant information leaflet described the study in detail and listed the eligibility criteria (see online supplemental appendix 1). Informed written consent was obtained, and focus groups were held until the research team considered that data saturation was approaching as no new themes were being identified,[20] at which point recruitment switched to semistructured interviews to explore issues raised in greater depth. Participants who were interviewed had not previously participated in the focus groups. Recruitment ceased when no further new or discordant themes were identified.

Data collection methods

A total of 11 focus groups and 9 interviews were conducted independently by two of the authors (BM and GD). The topic guide (online supplemental appendix 2) covered five main areas regarding ORA: awareness; experiences; views; needs and expectations; and perceptions of the future. The same topic guide was used for both focus groups and interviews. The focus groups and interviews lasted 30–60 min, were digitally audiorecorded and transcribed by a university approved service.

Patient and public involvement

The topic guide was developed following observations of clinical consultations at a practice where patients have full ORA, a PPIE workshop,[16] and discussions with the Primary Care Research in Manchester Engagement Resource group, two members of which are co-authors of this paper (LB and ML).

Data analysis

Transcripts were anonymised, imported into QSR NVivo V.12,[22] and checked for accuracy. BM and GD independently coded the transcripts, using the thematic analysis approach, which involved six phases; data familiarisation; coding; identification of candidate themes; review and revision of themes; definition and naming of themes; analysis and interpretation of patterns across the data.[20] Although the traditional concept of validity is problematic in qualitative research,[20] discussions among the research team helped identify key issues, verify themes, and ensure consistency of coding. In addition, we sought to enhance dependability of our findings by involving two members of the public (LB and ML) in two half-day workshops during which we refined the themes using Ketso, a toolkit for creative engagement.[23]

RESULTS

Demographics

A total of 27 women and 27 men aged between 21 and 87 years (mean=59.0; SD=15.4) participated from a wide range of socioeconomic backgrounds.[24] We conducted 11 focus groups totalling 45 participants (with 3–6 participants per group), and 9 individual interviews (see table 1).

Themes

Patients' and carers' views of ORA concerned four main themes: (1) awareness, (2) capabilities, (3) consequences and (4) inevitability.

Table 1 Participant demographic characteristics (N=54)

Characteristic	n (%)
Self-identify as carer	19 (35.2)
>1 long-term medical condition	24 (44.4)
Eligible for NHS Health Check	30 (55.6)
Aware of ORA	23 (42.6)
Previously used ORA	10 (18.5)
Frequency of internet usage	
Frequently	41 (75.9)
Occasionally	10 (18.5)
Never	3 (5.6)
Ethnicity	
White	43 (79.6)
Asian	4 (7.4)
Black	7 (13)
Education	
Degree level	12 (22.2)
Further education	7 (13)
School to 16 years of age	25 (46.3)
School to ≤16 years of age	10 (18.5)
Occupation	
Retired	19 (35.2)
Professional	8 (14.8)
Sales/customer service	4 (7.4)
Caring/leisure/other	13 (24.1)
Admin/secretarial	1 (1.9)
Associate/technical	2 (3.7)
Self-employed	3 (5.6)
Not working	4 (7.4)
Index of Multiple Deprivation[24]	
Deciles 1–3 (most deprived)	16 (29.6)
Deciles 4–7	17 (31.5)
Deciles 8–10 (least deprived)	21 (38.9)
Rural–urban classification[30]	
Urban	32 (59.2)
Suburban	9 (16.7)
Rural	13 (24.1)

NHS, National Health Service; ORA, online records access.

Awareness of ORA

Less than half the participants were aware of ORA. Those who were reported it had been promoted by their GP surgery or had heard of it by word of mouth. Some felt they had no reason to use ORA, found it easier to find information by other means, or felt accessing medical records was best left to HCPs. Some expressed annoyance that they had not been informed about ORA, while others stated that learning about the service had not made them any more likely to use it. Participants felt ORA was poorly advertised, and suggested promoting it via media advertisements, posters in surgeries and during GP consultations.

Capabilities of ORAs

Access to information

Participants reported ORA enabled them to view: test results, medication lists, allergies, immunisations, appointment details, problem lists, secondary care letters and consultation notes, but expressed dissatisfaction with the content, detail and presentation of the information. Suggested improvements included: direct links to sources of support, more information about the HCPs providing care, better integration with other services, full retrospective access, easier and more consistent access to information, use of plain English and links to trusted sources of information. Several wished to access all their health and care records via one fully integrated system.

Enabling active involvement

Participants who had used ORA noted that it enabled them to be more actively involved in their own health and care, and those who had not felt it could, by facilitating: self-monitoring, self-education (eg, looking up meanings of terms seen in record), self-reassurance, appointment preparation, use of the record as an aide-mémoire or motivational tool, paperwork completion, communication with HCPs when away from home and addressing dissatisfaction with care. Examples of using ORA to self-motivate and self-monitor included tracking blood glucose, weight loss or cholesterol.

> ‘when people have got something like that, to lose weight and to watch their cholesterol, I think by having something online, it’s something for them to go to and check, I don’t know, daily, weekly, monthly, whatever they want to do, it just gives them a bit more motivation.’ (Interview; P45)

Interactive capabilities

Participants reported finding interactive capabilities of ORA systems useful, especially appointment booking, and ordering prescriptions, but found difficulties with basic interactive functions (eg, login, printing, searching, downloading information). Some valued being able to book appointments online as an alternative to having to explain reasons for appointment requests to receptionists.

> ‘I rang the surgery, they said, no, there’s nothing for two weeks, or whatever. My sister, who’s on it, said, use your patient access, because I’d forgotten. I went on and I was able to book an appointment for the next day’. (Focus Group (FG); P32)

Participants reported that ORA could make their role as a carer easier by acting as an aide memoire, giving them more control over medications, reminding parents when their child’s immunisations were due, or helping complete benefit applications.

> 'I help her to fill in her PIP forms and things like that, and it was an absolute nightmare back and forward, back and forward to the GP … if I could have accessed that on her behalf, it would have been a million times easier' (FG; P52)

Suggested improvements to interactive capabilities included more advanced login methods, a triage feature for online appointment booking, medication reminders and pharmacy stock checks.

> 'I'd much prefer that it loaded up on the app that I need whatever antibiotic as soon as I leave the GP, tap it, it says it's in stock at your specific pharmacy. Amazon have, like, 'there's 15 of these in stock' (Interview; P45)

Consequences of online access to records

Patient safety

Participants noted that ORA could improve safety by reducing the likelihood that test results would go unnoticed, or enabling them to spot errors in their record.

> 'I had to correct, both on the dates and on the data… because if, for example, I get taken to hospital and the hospital can access this and they're going to make decisions based on the evidence that they see in front of them … that might affect my life' (FG; P19)

Others noted however that ORA could negatively impact patient safety by encouraging unreliable self-diagnosis, self-medication or discouraging HCPs from documenting concerns regarding issues such as mental health or abuse, for fear of upsetting patients.

Communication between HCPs

Concerns such as those raised above could impact negatively on communication between HCPs, and there was some discussion about how this could be addressed.

> 'you wouldn't want to be doubling any doctor's workload in terms of writing an account that's for the patient and writing an account that's for another professional to read, but I'm not sure that one could always serve both' (FG; P22)

It was however felt that ORA could aid communication between HCPs indirectly by giving patients the ability to show HCPs not usually involved in their care their medical notes while away from home. Participants suggested communication between HCPs could be improved further by greater integration of primary, secondary and community healthcare records.

The HCP–patient relationship

Participants felt ORA could foster a culture of openness, improve communication and increase accountability.

> 'your MP [Member of Parliament], or whatever, they're all accountable, we can look up what they're saying and all that, why not my GP? (FG; P30)

Participants also noted that having access to hospital letters could improve communication by empowering them to question conflicting advice. Greater transparency from ORA could also raise standards of care by enabling holding HCPs to account.

> 'it would improve standards that way because doctors would know what they write is there for everyone to see' (Interview; P36)

Some worried that ORA could replace face to face contact with HCPs or increase social isolation.

> 'don't do it by computer, just go down yourself and order it and make a day out of it. Take your friend, go to the bar, have a snack or a cup of coffee … it keeps you out of the house' (FG; P15)

Test results

A common concern was that test results which may previously have been cautiously explained during consultations could be viewed by patients before there was a chance to discuss them.

> 'if you get a really bad test result sometimes the doctor can kind of reassure you about ways that they can help you, but if you just find out about it you might just completely worry about it' (Interview; P53)

Proposed solutions included entries about results being written in plain English or for patients to have 'write' access to their notes to instigate dialogue, with some participants suggesting enabling patients to share information from wearables or the 'internet of things'. Solutions proposed to address the issue of test results causing anxiety included systems ensuring patients could not see results until they had first been viewed by a clinician, although some were conflicted.

> 'I'd want to see them straight away … I don't necessarily think that would be a beneficial thing to do though, I think obviously once the doctor's interpreted it, they can sort of let you know what you need to know in a way that you need to know it. I mean, I get anxious around health things anyway' (FG; P50)

One participant proposed a built-in feature to enable identification of individuals for whom ORA may be causing anxiety.

> 'Because that would be a failsafe thing if you had someone who was constantly and obviously very anxiously accessing their records, that should flag up that that person needs to have a conversation' (FG; P23)

Health inequalities

Participants noted how ORA could lessen health inequalities. For example, one wheelchair user noted that online access could improve their access to healthcare, others living in rural areas noted similar benefits.

> ‘there’s no point driving ten miles, to ask one question, when you could do it online in two minutes’. (Interview; P45)

There were significant concerns, however, that ORA could exacerbate health inequalities. Digital literacy was a particular concern, especially as surgery staff were not always able to help. In addition, those who are reliant on using computers and free WiFi in public spaces may be disadvantaged in terms of privacy. Concerns were also voiced regarding general literacy, not speaking English as a first language, and identification required to register.

Participants suggested addressing inequalities in digital literacy by providing training, either at GP surgeries or community locations, as well as access to resources.

> ‘…have a list of places that people can go for help… or even have an open day or an hour, just for people to take that information when they register, and then maybe someone there to show them how to use it’. (FG; P32)

Literacy and language issues could be partially mitigated by incorporating a ‘medical dictionary’ and translate function, or providing training for GPs on writing consultation notes. Participants also suggested that problems related to registration could be addressed by simplifying the paperwork and extending the types of identification accepted.

Confidentiality and security

While many participants felt that the security of ORA was adequate, others expressed serious concerns. Those with the strongest objections to ORA tended to be older, have less confidence in using the internet, and felt older people might be more likely to be targeted by fraudsters. Concerns were also raised about unwanted access due to the coercion of an abusive partner or employer.

> ‘if someone phones in sick for work and their employer for whatever reason challenges them … Is the employer going to then, sort of, force this person to basically hand over their phone and [say] ‘I’ll just have a look, make sure you’ve been to the doctor’?…’ (FG; P51)

A number of participants also highlighted anxieties about data sharing with private companies, or that security can be affected by simple user oversights, such as not password protecting a mobile phone. Most participants indicated that measures such as two-factor authentication or biometric access would make them feel more confident. Others stated that they would like control over who can access which parts of their record. This included proxy access (permitted access by a relative or carer) and the ability to revoke such access easily in the future.

> ‘would I want my immediate family reading what I've said? … I think it might have to be potentially an option within the system to say that that individual can have access to certain aspects of my records but not the entire thing’ (Interview; P37)

Impact on resource allocation

Participants generally felt ORA could reduce the need to travel to appointments or spend time in long telephone queues.

> ‘I was on the phone for ages, I couldn't get through…I needed my blood results because I was going to an appointment, so I ended up jumping in the car, driving down and saying, can you please…and they printed it out and gave it to me. So yeah, I could have just literally tabbed on and printed it out myself’ (Interview; P37)
>
> ‘There might be issues where it’s a simple question to a GP that could just be a text and a text back, job done, rather than setting up a whole appointment’ (Interview; P44)

There were mixed views regarding the impact of ORA on primary care staff resource allocation. Participants suggested it could reduce demand for GP appointments and reduce practice workload. It was also felt ORA might prompt preventative action from patients which could further reduce pressures on primary care. Despite these positives, there were concerns that ORA could increase HCP workload in a variety of ways such as prompting patients to call practices to discuss test results they had seen but not understood, or GPs needing to spend more time documenting consultations.

Inevitability of shift towards online services

While there was some resistance to the move towards online services, especially among some of the older participants and those from ethnic minority groups, there was an acknowledgement that much personal data is already held online.

> ‘Our records are online anyway, aren’t they, really? Everything’s online already …so it’s just really us being able to get access to it really’ (FG; P40)

Participants compared ORA with previous transformational societal changes, such as: the postal system, aviation and online banking.

> ‘Yeah, I do online banking. You’re not forced to do it these days, but that seems to be the way that everything’s going, so you’ve kind of got to roll with it’ (Interview; P45)

Several participants noted generational differences in terms of acceptance of ORA, and one discussion focused on how those who resist services such as ORA tend to be older, and are gradually being replaced by more technologically savvy generations.

> ‘It will become much more universal that everybody knows that you have to access the internet in order to

live a normal life, and the older people who still won't look at it won't be here forever, probably.' (FG; P9)

DISCUSSION

Participants saw both benefits and drawbacks to ORA, but a move towards more online health services was considered inevitable. The results of this study highlight a range of ways in which ORA can be promoted to those who lack awareness of, or motivation to use, this service. It has shown how systems could be improved to better meet the needs and preferences of patients, address their concerns about privacy and security, increase patient involvement in care, strengthen relationships between patients and care providers, and reduce risks to patient safety. Additionally, while ORA has the potential to exacerbate health inequalities, it may also decrease them, especially where training or facilities are made available, and consultation summaries and interpretations of test results are written in plain English.

Comparison with existing literature

Our findings resonate with previous qualitative work in this area.[9 10 13–15] Concerns regarding security and trustworthiness, and ORA acting as a communication aid were discussed in our consequences theme. ORA providing greater interactivity, and serving educational and practical functions were topics discussed in our capabilities theme. In line with previous studies,[9 10 14 15] instant access to test results was listed as both a benefit (eg, in terms of convenience) and a drawback (eg, the potential to cause unnecessary anxiety), prompting suggestions for improvement such as plain English definitions or prescreening of results by clinicians. Our study has updated this knowledge and cast further light on what patients want from ORA in primary care. Unlike previous work in this area, which was concerned with evaluating pre-existing[10 13 15] or tertiary care systems for specific conditions,[14] our study examined people's views regarding ORA in primary care, and what features and functions patients would like to see in such systems in the future. This work compliments a recent systematic review in this area demonstrating the clinical benefit of online access[6] by providing in-depth insights into how we might further increase patient engagement.

This study contains a number of novel findings regarding the needs and expectations of patients and carers with respect to ORA. Many people are still unaware this service exists[25] and it needs to be better promoted if the UK government's vision is to be realised. It has also revealed an understandable desire for greater consistency across time and between users in terms of what people can actually see with ORA. Interesting suggestions regarding the capabilities of ORA systems include incorporating the ability for patients to check if their pharmacy is out of stock of their medication; this issue has become particularly troublesome for primary care patients in recent years.[26] Our findings regarding patients' wishes to integrate online records systems with wearable devices are also novel, as are suggestions to provide a greater degree of control over who can access one's record and the ability to set varying levels of access to different third parties. Such features are commonplace on social media platforms such as Facebook. The suggestion of allowing patients to request different modes of appointment (ie, telephone, video, face to face) is especially interesting given recent changes to the way GPs are working in light of the coronavirus pandemic.

Strengths and limitations

The strengths of this study include the diversity of the sample in terms of age, socioeconomic status and ethnicity, and the inclusion of participants from seldom heard communities. Such individuals are more likely to be affected by issues such as health inequalities and the 'digital divide'.[27]

Limitations to this study include the fact that we did not validate our findings with study participants and the researchers' backgrounds may have influenced the dynamic of the interviews and subsequent findings. Despite this, consideration of reflexivity, and discussions with the rest of the research team, including two members of the public, helped to avoid an overly narrow interpretation of the findings. Also, the study examined the views of participants regarding ORA, rather than making observations of their actual behaviour. We took the commonly adopted critical realist perspective, which holds that some degree of truth can be ascertained through the examination of qualitative data, while acknowledging that this is nuanced by human interpretation.[20] Lastly, this exploratory study has not delivered a theoretical framework, but was designed to identify patients' experiences, needs and expectations regarding online access to their primary care record in the UK. Future qualitative work could explore the transferability of our findings to other healthcare systems and settings, and planned feasibility work will cast more light on the impact of incorporating participants' suggested improvements into ORA systems. Future quantitative research studies could also further explore differences in views and behaviour with respect to ORA between different sociodemographic groups.

Implications for policy, practice and research

If we are to fulfil the UK Government's expectations that all patients should have online access to their full primary care record,[28] we will need to ensure that online access is better promoted. As more patients start using ORA, we will also need to provide better support for patients and carers to get the most out of this service as well as additional training for practice staff.

Although patients have had the statutory right to access to their medical records since 1991,[29] HCPs now need to be even more mindful of the fact that their entries may be viewed by patients. GPs and other HCPs will need to adapt the way they write in the record so that it can be easily understood by patients, as not doing so may result in an increased workload due to more patient enquires. HCPs will also need to ensure that systems are in place to communicate concerns regarding sensitive issues such as safeguarding or domestic abuse to other HCPs without compromising the HCP-patient relationship or putting patients at risk.

If we are to meet patient expectations regarding ORA, we need to go beyond simply enabling patients to view information. We should aim to collaborate with patients, carers, clinicians, the IT industry, behaviour change experts, policy-makers and the NHS to shape the online record into an interactive tool than can motivate, educate and provide the opportunity for patients to become more engaged in their own healthcare. This will provide a new set of challenges, such as developing accreditation to ensure that the data provided by wearables is accurate and reliable. We also need to be mindful that the shift towards more provision of services via online systems does not exacerbate health inequalities.

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Contributors BM conceived the original idea for the study. BM, LB, ML, HA, RG, FM, RLM and CS developed the study design, obtained funding and refined the study protocol. BM and GD undertook data collection. BM and GD undertook analysis and interpretation with contributions from all coauthors. All coauthors prepared the manuscript. All authors read and approved the final manuscript.

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