Article

Not peer-reviewed version

Access to Results: Acceptability of Immediate Access to Hospital Test Results via UK Patient Portal

Astrid Coxon , Ella Malloy , Helena Jopling , Adulis Beyenne , Zarnie Khadjesari *

Posted Date: 1 December 2025

doi: 10.20944/preprints202512.0089.v1

Keywords: electronic health record; patient portal; test results; healthcare; patient experience; health systems

Preprints.org (www.preprints.org) | NOT PEER-REVIEWED | Posted: 1 December 2025 doi:10.20944/preprints202512.0089.v1

Article

Access to Results: Acceptability of Immediate Access to Hospital Test Results via UK Patient Portal

Astrid Coxon [1], Ella Malloy [1], Helena Jopling [2], Adulis Beyenne [3] and Zarnie Khadjesari [1,*]

[1] School of Health Sciences, University of East Anglia, Norwich, Norfolk, UK
[2] West Suffolk NHS Foundation Trust, Bury St Edmunds, UK
[3] York Street Medical Centre, Cambridge, UK
* Correspondence: z.khadjesari@uea.ac.uk

Abstract

Background: Patient portals are online platforms that allow patients to view their medical records and test results. These portals can release patient's medical test results immediately, negating fixed embargo periods before release; however, clinicians are concerned that without clinical guidance, via a face-to-face consultation, patients may misinterpret results, causing unnecessary distress or confusion. **Objective:** To explore patients' views on delayed release of certain medical test results via a hospital patient portal, the acceptability of immediate access to test results, any concerns, and possible barriers or enablers to the roll-out of immediate access. **Methods:** A two-phase mixed method acceptability study, comprising: 1) a cross-sectional survey of portal users' experiences of receiving medical test results and views on potential immediate access via the portal, and 2) semi-structured qualitative interviews exploring patients views on immediate access to test results in more depth. **Results:** 357 portal users completed the survey and 22 took part in interviews. Whilst most survey respondents favoured immediate access, interviews highlighted several potential issues this could cause, including avoidable distress and confusion in understanding results before clinician review. **Conclusions:** Immediate access to test results via the patient portal may only alleviate patient waiting anxiety in some cases. Clear, consistent information regarding procedures and timelines may be more appropriate in supporting patients to engage meaningfully in their healthcare.

Keywords: electronic health record; patient portal; test results; healthcare; patient experience; health systems

Introduction

The National Health Service (NHS) Long Term Plan[1] aims to introduce digital services to enable patients and carers to better manage their health. One such service is the use of patient portals. Patient portals are online platforms which allow patients to more effectively engage with their healthcare and have been found to enhance the delivery of their care[2-4]. These portals provide immediate and remote access to Electronic Health Records, allowing patients to view their medical records and test results, schedule appointments, order repeat prescriptions, and securely message health professionals. Despite being crucial to NHS digital transformation, the adoption and engagement of patient portals in acute NHS Trusts remains slow[3,5].

In a scoping review of the barriers and facilitators to patient portal use and engagement in secondary care, Khadjesari et al[6] found that one key challenge was the timing of releasing test results. Clinicians worry that patients may misinterpret test results when accessed without context or clinician guidance[7–12], potentially causing confusion, unnecessary anxiety, or harmful responses. As such, instant access might require additional support and explanation from healthcare providers[11].

Good Medical Practice guidelines[13], suggest that patients should be aware of what tests are being carried out and why (otherwise informed consent is not obtained). Thus, if healthcare providers follow these guidelines, receiving results as they become available (even before an appointment with

doi:10.20944/preprints202512.0089.v1

a clinician) could alleviate "waiting anxiety" and give patients the chance to discuss their results with family and prepare questions[9,14].

Patients at [anonymised for review] hospital have had access to a patient portal since February 2018 and currently have a three-week wait to receive certain test and scan results. Through informal conversations with patients and staff, views are mixed regarding how and when test results are shared with patients, how patients perceive the patient portal, and whether receiving results via the patient portal is more acceptable or beneficial. Understanding these patient perspectives is essential to informing the best patient-centred result sharing practices. As such, the aim of this two-phase mixed methods acceptability study was to explore the perspectives and preferences of patients at [anonymised for review] regarding the potential roll-out of immediate access to medical test results via the patient portal.

Materials & Methods

Procedure

In Phase 1, a cross-sectional survey was conducted with [anonymised for review] patients registered as users of the patient portal, to assess acceptability of immediate access to test results via the portal. In Phase 2, participants from Phase 1 were recruited to participate in qualitative semi-structured individual interviews to explore their views further, including potential impacts of immediate access to test results, and what support might need to be in place to successfully implement roll-out of immediate access.

Ethical Approval

This study was granted ethical approval by [anonymised for review].

Setting

This study was conducted at [anonymised for review], a 430-bed hospital with associated acute and community services serving a patient population of approximately 280,000 people based in [anonymised for review], UK. [anonymised for review] is part of [anonymised for review] NHS Foundation Trust, one of 17 acute NHS Trusts internationally recognised as providers of exceptional care via digital technology and information[15].

The [anonymised for review] patient portal is a secure web-based portal that patients can log into to access their medical records, view hospital letters and documentation, view and re-arrange upcoming appointments, view and monitor test results, see a record of their procedures and known allergies, and access links to useful healthcare information. The portal is available to all [anonymised for review] hospital patients aged 18 and over and gives them access to information going back to February 2018.

Phase 1: Survey

Survey Development

The survey was adapted from existing validated and reliable questionnaires[7,14,16–18]. Although formal psychometric testing of the adapted survey was not undertaken, its content validity was supported by a review undertaken by an existing patient portal user group and portal steering group; the survey items were reviewed for content relevance, clarity, and comprehensiveness. Based on this feedback some questions were reworded to improve clarity, and the inclusion of additional multiple-choice options that the patient steering group deemed more relevant to the current study.

Sampling Procedure

From October-December 2024, adult patients (aged 18 and above) registered as users of the [anonymised for review] patient portal were invited to participate in an anonymous online survey via Microsoft Forms. Participants were recruited via a banner on the [anonymised for review] website or via an email (sent by the [anonymised for review] communications team) to portal users about changes to the portal interface and on the website landing page for portal log-in and registration.

Given that this study was descriptive and did not test hypotheses, a formal power analysis was not deemed appropriate. Instead, sample size adequacy was determined by a precision-based approach, of which the aim is to assess how well sample estimates reflect the true values in the population[20]. The precision-based approach determines the number of participants needed to achieve a desired level of precision (i.e., acceptable confidence interval (CI) widths or margin of error). Given the approximate population size of 20,000 registered users, the sample size of 357 respondents provides a maximum 95% CI margin of error of ±5.1%, which is generally considered acceptable for descriptive survey research[20].

Survey Procedure

A participant information sheet and digital consent form were incorporated into the online survey (see Appendix A). As well as demographic information (age, gender, existing long-term conditions, highest level of education, ethnicity), participants answered questions about their experiences of receiving medical test results, and their opinions on how and when such information is provided to them. The survey was available for four weeks. At the end of the survey, participants were offered the opportunity to enter a prize draw to win one of three £50 shopping vouchers. Participants could also choose to register their interest in participating in the next phase of the research (qualitative interviews).

Data Analysis

We used descriptive statistics to present the findings of the survey. Question-level data is reported as count and percentage of respondents for each question. Free-text answers to open questions were used to inform the design of the topic guide in Phase 2 interviews.

Phase 2: Interviews

Interview Development

An interview topic guide (see Appendix B) was designed based on findings from Phase 1 of the study, published academic literature and NHS reports, and in consultation with members of an existing [anonymised for review] patient portal user group and our study team.

Sampling Procedure

Respondents to the Phase 1 survey who registered their interest in participating in Phase 2 interviews were contacted by the lead researcher (AC) with further information about the interview process. Individuals who agreed to take part were asked to complete a digital consent form and provide demographic information (age, gender, ethnicity, and long-term conditions). Consent forms were digitally countersigned by the lead researcher (with a copy provided to participants).

Interview Procedure

Interviews were arranged according to participants’ availability and preference (i.e., in-person at [anonymised for review], or remotely via Microsoft Teams). Participants were asked questions about their experiences of receiving medical test results and using the [anonymised for review] patient portal. They were also asked to provide their perspectives on immediate access to medical test results, including the pros and cons of this, what support or resources should be put in place

Preprints.org (www.preprints.org) | NOT PEER-REVIEWED | Posted: 1 December 2025 doi:10.20944/preprints202512.0089.v1

alongside a potential roll-out of immediate access, and any other issues or concerns regarding patient access to medical test results via the portal. Whilst the topic guide provided a loose structure, the interviews were semi-structured, allowing participants to freely discuss and explore topics related to the patient portal and accessing medical information.

In-person interviews were recorded using a handheld audio-recording device; remote-interviews were recorded directly within Teams. Interviews were transcribed using automated transcription (Microsoft Word and Microsoft Teams) and checked for accuracy by the lead researcher (AC). All participants were emailed with a £20 digital shopping voucher, and participants attending in-person interviews were reimbursed travel and parking expenses.

Data Analysis

The dataset was analysed thematically[19,21], using an exploratory inductive approach. The interview transcripts were coded by one researcher (XX) and reviewed in discussion with the research team (XX, XX) to develop an initial set of themes. These themes were synthesised with findings from Phase 1 to construct an overall narrative about patient experiences and views on the acceptability of immediate access to test results via the patient portal.

Results

Phase 1

Participant Information

Of the approximately 20,000 registered patient portal users emailed, 357 (1.79%) completed the survey. Of these, 132 (36.97%) identified as male, 224 (62.75%) as female, and one (0.28%) as other/unknown. Most participants were white English, Welsh, Scottish, Northern Irish, or British (n = 320; 89.64%). More than half (66.95%) were aged 55 or over (n = 239). A detailed breakdown of participant characteristics is given in Table 1. While the sample may not fully represent all patient portal users, particularly those who are less digitally engaged or from demographic groups underrepresented in research, the sample broadly reflects the demographic profile of active portal users within the organisation, thus supporting the contextual relevance of the findings. However, it should be noted that generalisability of the findings to vastly different demographic settings should be interpreted cautiously.

Table 1. Phase 1 participant characteristics.

	n	%
Participant characteristics	357	100
Gender		
Male	132	36.97
Female	224	62.75
Other/unknown	1	0.28
Age		
18-24	4	1.12
25-34	32	8.96
35-44	44	12.32
45-54	38	10.64
55-64	76	21.29
65-74	97	27.17
75-84	58	16.25

	n	%
85+	8	2.24
Ethnicity		
White English/Welsh/Scottish/ Northern Irish/British	320	89.64
Other	31	8.68
Prefer not to say	6	1.68
Highest grade/level of education		
Secondary education or below	100	28.01
A-levels, BTEC or equivalent	69	19.33
Undergraduate degree or equivalent	126	35.29
Postgraduate qualification	52	14.57
Doctoral degree	7	1.96
Other	3	0.84
Long-term conditions [a]		
High blood pressure	121	33.89
High cholesterol	83	23.25
Heart disease	33	9.24
Chronic kidney disease	29	8.12
Stroke disease	13	3.64
COPD or asthma	53	14.85
Diabetes	42	11.76
Dementia	1	0.28
Cancer	82	22.97
Arthritis	86	24.09
Schizophrenia, bipolar, and/or psychosis	4	1.12
Depression and/or anxiety	53	14.85
Other	103	28.85
None of these	53	14.85
Self-reported health rating		
Poor	56	15.69
Fair	118	33.05
Good	113	31.65
Very good	56	15.69
Excellent	14	3.92

[a] 200 (56.02%) participants reported having two or more long-term conditions.

Survey Findings

Of the 357 participants, 84.97% (n = 303) reported checking the patient portal when waiting for medical test results (see Table 1 in Appendix C for full findings); 91.04% (n = 325) stated they would prefer to continue receiving their test results via the patient portal, rather than by other means such as post or telephone. Most of the respondents (94.12%; n = 336) stated that they would want to access their test results via the patient portal before they were contacted by a clinician; more than half of the participants stated that they would be less worried (37.82%; n = 135) or much less worried (31.65%; n = 113) about their health if they were able to do this.

Most of the participants (95.52%; n = 341) stated that, in future, they would like to be notified that they have a new test result via the patient portal, even if this meant they may see the result before nurse or doctor contact. When questioned about viewing test results via the patient portal, 208 (58.26%) participants stated this was “not confusing at all” and 96 (26.89%) stated “not very confusing”. However, in a follow-up question, “what was confusing about viewing your medical test results on the patient portal?”, 109 (30.53%) participants responded, “I did not know how to interpret the results”. Just over a quarter of participants (27.45%; n = 98) stated they did not seek additional information about the results/tests. The most common source of additional information was an internet search (52.94%; n = 189).

In the free-text responses, participants raised issues related to how the patient portal functions. Several participants requested that everything be incorporated into a single system within the NHS App. Many participants stated that they would like some sort of notification when a new test result is available, either via a text message, email, or phone alert, rather than having to regularly log into the portal to manually check whether results had been uploaded. A few participants described issues in accessing the portal but were unsure of where to get assistance with this. One participant stated they did not recall ever being instructed in how to use the portal, highlighting a potential need for clearer user support and guidance.

Some participants also used free-text responses to highlight issues with projected timelines, with some reporting having to wait much longer than the estimated three weeks to receive a test result, creating concern that information had not been processed, had been missed, or “lost in the system”. A few participants highlighted that some of their test results have never become available on the portal.

Many participants also shared positive experiences of using the patient portal to access their test results, explaining that it made information easy to access and clear to understand, easy to see trends in their historic results, and gave them a sense of ownership of their healthcare journey.

Phase 2

Participant Information

Interviews were conducted with 22 participants (from 177 survey respondents who initially registered interest in taking part in Phase 2; 12.43%). Of these, 10 were male and 12 female; 18 were white English/Welsh/Scottish/British, one was white & Asian, and three did not provide their ethnicity. Six participants did not report having any long-term conditions, four had one long-term condition, and the remaining 12 had multiple conditions. Full participant characteristics are shown in Table 3.

Table 3. Phase 2 participant characteristics.

Gender	
Male	10
Female	12
Ethnicity	
White English/Welsh/Scottish/Northern Irish/British	18
White & Asian	1
Not provided	3
Age	
25-34	1
55-64	6
65-74	8
75-84	4

doi:10.20944/preprints202512.0089.v1

Not provided	3
Long-term conditions [a]	
Arthritis	5
Cancer	8
Chronic kidney disease	3
COPD/asthma	2
Depression/anxiety	2
Diabetes	1
Heart disease	2
High blood pressure	7
High cholesterol	7
None reported	6

[a] Participants could select as many options as applied; 4 participants reported having one long-term condition,12 reported having more than one.

Interview Findings

Five interviews were conducted in-person at [anonymised for review] hospital, and 17 remotely via Microsoft Teams. Interviews ranged from 17-68 minutes in length (average duration 37 minutes 56 seconds). Following thematic analysis of the whole dataset, three main themes were developed: 1) “waiting anxiety”, 2) “taking ownership of my healthcare” and 3) “how test results could and should be shared”.

Theme 1: Waiting Anxiety

At the start of each interview, the interviewer briefly explained the current three-week holding period on release of certain test results, and participants were then asked to share experiences of receiving medical test results. All of the participants mentioned anxiety caused by the wait between having a medical test and receiving the results:

> *“…you get yourself so anxious about it, and how long would you have to wait for those results.” P006*

Some participants highlighted a lack of clarity and consistency concerning timescales; they were not always sure when to expect to receive their test results, which contributed to a sense of waiting anxiety. One participant explained that, in the intervening time, patients may not only be anxious waiting, but may compound their anxiety by Googling their test, exploring potential outcomes and implications:

> *“…then I do wonder, what rabbit holes people go down when they’re wondering and waiting.” P056*

Some of the participants stated that, had they had access to their results sooner, before their consultation with a healthcare professional, they would have felt better informed and prepared for their consultation, and better able to ask appropriate questions:

> *“…by having that information ahead of time, I could have actually asked more questions, well, been prepared, I think, that things weren’t as good as I thought…” P045*

A few participants highlighted that an additional factor in their waiting anxiety was a concern that they might have been “lost in the system”; one participant stated that the portal was a useful means to reassure themselves that things were still in hand and results still being processed:

> *“For me, the portal is my way of finding out what’s going on and the fact that I’ve not been lost in everything.” P050*

Theme 2: Taking Ownership of My Healthcare

Several participants (including some from Phase 1 of the study) framed immediate access to test results as a matter of principle – they stated that as these results were their data, they had a right to access them as soon as they were available:

> *"I prefer to have that information as soon as it's available. It's my information. I don't see why anyone should hold it back from me." P134*

However, some participants highlighted that access to test results too early, such as before they had been seen and interpreted by a clinician, or before multiple tests could be taken into consideration to provide a complete picture of a patient's health, could cause confusion and unnecessary distress:

> *"My experience when I was diagnosed with cancer was that it was a process of eliminating alternatives. So it wasn't that people were concealing stuff from me - a number of pieces of data were coalescing and any premature release could have been partial, misleading, and though well-intentioned, unhelpful. Quite apart from the fact that it might have been emotionally distressing, it just might have sent me off down the wrong lane." P105*

Other participants pushed back at what they saw as paternalistic withholding of information, stating that they were responsible adults, and had a right to make informed decisions and manage their own responses to this information:

> *"I might misinterpret something, there is a slight risk that I acknowledge in being given information that is not in a field that I am competent to judge, or that I am well informed about. I acknowledge that risk, but I think it's up to me whether I take that risk." P143*

Related to this, several participants acknowledged the changing landscape of the NHS, and how they felt encouraged to take a more active role in their healthcare journey. Some spoke about how using the patient portal enabled this. Most participants had experienced previous significant health events or had long-term conditions (see Table 3), meaning they felt more confident in their ability to interpret the "raw data" or medical test results; some participants had friends or family in the healthcare sector, and one participant explicitly mentioned being a retired nurse:

> *"For me, having that little bit of, well, 43 years' worth of medical knowledge, it really helped me process what was likely to happen." P050*

However, others highlighted that having access to more information did not necessarily equate to feeling more informed:

> *"…when the results come in, I'm never always sure what they mean, and I'm somebody who likes to know. I like to know things. I'm not somebody who just thinks, 'Oh well, that says normal'. But what? What is normal? I don't understand." P078*

In such instances, waiting anxiety could be compounded, as patients may feel a more urgent need to discuss the results with a clinician; Immediate access to test results does not guarantee immediate access to a healthcare professional. Rather than reassuring patients, this may cause an increase in number of phone calls to the hospital, adding to healthcare professionals' workload:

> *"I can see the downside to it being you might see something in the results you weren't expecting and think 'I want to talk to somebody now." P095*

Theme 3: How Test Results Could and Should be Shared.

When discussing how they felt medical test results should be shared with patients going forwards, some participants felt normal results (i.e., "in the clear" results) should be shared as soon as possible, to alleviate anxiety:

> *"…if things are good, then why not put it all on your app?" P065*

Contrasting with the potential increase in phone calls mentioned above, one participant explained the potential easing of burden on hospital staff this might have:

> *"If you put more people's mind at rest, it cuts down the anxious phone calls." P056*

However, participants acknowledged that this carries the risk that those patients left waiting for test results will assume that their results are non-normal, replacing one anxiety with another.

Regardless, some participants voiced a personal preference to have access to their results as soon as possible but acknowledged that this wouldn't be right for everyone.

Some participants suggested a potential solution to this would be a robust opt-in system where, at the time a test is first arranged, a clinician clearly explains the option and consequences of immediate access (i.e., that patients will be able to view a result, but this may be before a clinician has reviewed and interpreted the raw results). However, the format of this opting in procedure would have to be carefully considered; one participant explained that waiting three weeks to view their results before discussing these with a clinician might be frustrating for them, but for someone else, seeing their results immediately and then having to wait three weeks to discuss them with a clinician may cause a lot of distress:

"I would like to have it, and I think I should have it, but I think it would be selfish of me to push that point of view too much. […] that's my three weeks frustration against somebody's three weeks of total angst." P071

Most of the participants agreed that clarity and consistency of communication was paramount; some aspects of waiting anxiety described by participants were due to uncertainty regarding when and how information would be shared with them, why there were fixed holding periods for certain test results, and what more complex diagnostic processes might actually involve. Participants suggested that clearer communication (both directly from hospital staff, and the patient portal) could help alleviate patient worry:

"They need to be told at the time of the test what happens next. Something like 'a doctor will be in touch with you within X number of weeks' and that message needs to be available on their portal as well so they can access it there as well to remind themselves." P111

And help to manage patient expectations:

"If they're told that this particular test requires a number of different things, you're going to manage the expectation of the patient and you'll then hopefully get a happier patient who will know about the wait." P126

Finally, participants highlighted the importance of signposting to appropriate further reading. This could easily be linked directly within the portal when tests are ordered or results are shared, to help patients find further information from appropriate sources:

"If there were trusted sources linked to it, I think that would make it easier for them to find the correct information at least." P069

Discussion

This two-phase mixed methods acceptability study aimed to explore the perspectives and preferences of patients at [anonymised for review] regarding the potential roll-out of immediate access to medical test results via the patient portal.

Our findings from the Phase 1 survey suggested that patient portal users want immediate access to all medical test results, regardless of whether they are contextualised, explained, or have been seen or reviewed by a clinician. However, nearly a third of survey respondents stated that they sometimes found reviewing their medical test results on the patient portal confusing as they are difficult to interpret. Our phase 2 interviews found views on immediate access varied by existing medical knowledge, social support, and previous significant health events. Whilst earlier access to test results was found to potentially alleviate the uncertainty of "waiting anxiety", "non-normal" results could cause further distress, particularly if patients do not have the pre-existing medical knowledge needed to interpret the raw data[21].

In Phase 2 theme 1, all participants highlighted the anxiety caused by waiting for medical test results to be released. This often caused excessive worrying, information-seeking, repeated checking of the online portal, and increased calls to healthcare professionals. However, their views on how this could and should be addressed was more nuanced than blanket requests for immediate access. Whilst some participants framed immediate access to their data as a matter of principle, others recognised the unintended distress this might cause. In the US, where the 21st Century Cures Act Final Rule has mandated the immediate electronic sharing of test results with patients, a small number of recent studies have explored the impact of immediate release on patient populations, highlighting the increased worry that this creates, particularly when results are abnormal[14,23,24].

Theme 2 highlighted that patients are increasingly encouraged to take ownership of their own healthcare journey, and the participants discussed the benefits of portal access of a way of doing this. Some participants stated they wanted to be able to access their test results sooner (i.e., prior to a face-to-face consultation with a clinician) to give them time to process difficult news and prepare better for clinician consultations. This aligns with previous findings on patient preferences and usage of patient portals in the US and the Netherlands[25–27]; however, sharing results without interpretation or context may increase patient anxiety (see previous findings from US[28] and UK-based research[29] on patient preferences) and lead to increased worried calls to clinicians for clarification and reassurance[7]. This aligns with previously identified clinician concerns from US-based research[8,11,12]. If test results are to be released sooner to patients, some interpretation or explanation is needed to make these comprehensible to patients without pre-existing medical knowledge[22,26].

In theme 3, participants shared their perspectives on how hospitals could and should share medical test results with patients via the patient portal. Personal preferences varied, with some participants (particularly those with existing medical knowledge, or previous experiences of significant health events) preferring immediate access to all test results, and others stating that more serious medical tests need to be discussed in-person with clinician support.

Recommendations for Practice

In-line with research conducted in the US and Europe[14,26], our findings suggest that patients could best be supported through improved clarity and communication regarding the healthcare pathway and diagnostic processes. This can include providing clear timescales, why a test has been ordered, how and when results will be shared (and why there might be a delay in releasing certain test results), possible outcomes, and signposting to further information from trusted sources[28,30]. This aligns with recently published NHS England guidelines[31], which emphasise the importance of clear communication with patients regarding testing procedures and projected timescales to enable meaningful patient involvement in their healthcare.

Strengths and Limitations

To our knowledge, this is the first UK-based study of patients’ views regarding the timing of medical test result release via an online patient portal. The findings from this study contribute to a growing body of research highlighting the need for careful consideration of patient needs and preferences when sharing the results of medical tests via online patient portals.

Nevertheless, this project had some limitations. Firstly, this study was conducted with patients from one hospital in the [anonymised for review] of England, which may limit the generalisability of findings. However, the conclusions reached do corroborate existing published research on the topic of patient immediate access to medical test results via their electronic health record.

Some sub-groups of the [anonymised for review] patient population may have been underrepresented in this research; participants in both phases of the study were mostly white British or Irish, and most participants were aged 55 and above (only one participant in phase 2 was under 55). Findings should thus be interpreted with caution due to potential limitations in external validity. The sample may not be fully representative of all patient portal users however, the demographic profile of the sample was consistent with the demographic makeup of the [anonymised for review] hospital that was the interest of this study. Nevertheless, future research could consider how to better engage participants from potentially underrepresented groups to ensure that their views are included in practice guidelines.

For Phase 1 of the study, 20,000 registered portal users were emailed an invitation to participate. However, not all of these are active portal users; if they had a one-off admission or pregnancy at [anonymised for review] but are not a “regular customer”, they may have been enrolled on the portal for that episode of care but may not have needed or been motivated to use the portal thereafter. As such, the response rate to the survey (1.79%) may be conservatively low with regards to active portal users.

With regards to the Phase 2 interviews, opportunities for in-person interviews were limited due to room availability at [anonymised for review]. This meant that most interviews were conducted remotely via Microsoft Teams, which was not the first choice for some participants, and may have discouraged some patients from taking part. However, as participation required that patients were active patient portal users, most had the technological competence needed to participate remotely. In future, researchers could consider offering alternative modes of interviewing, such as via telephone.

Finally, this study was conducted during and shortly after [anonymised for review] switched to a new patient portal. This impacted patient and public involvement in the design (as the portal user group had been temporarily disbanded during the switch over) but also had implications for when and how the study was advertised. In a small number of cases, study participants used the research process to raise issues with the functionality of the new portal platform. Although participant engagement in both phases of the study was in-line with expectations, future studies should take into account any planned changes or maintenance to the patient portal, so as to minimise potential impact on participant engagement.

Conclusion

In conclusion, immediate access to medical test results via the [anonymised for review] patient portal may only alleviate patient waiting anxiety in some cases, whilst potentially causing preventable distress and confusion in others. Immediate access prior to clinician review may only be useful to patients with sufficient pre-existing medical knowledge, or those who have had similar previous significant health events. In line with NHS England guidance[31], the findings from this study suggest that a more appropriate approach would be to provide clear and consistent information to patients throughout the process of every medical test, to enable them to be meaningfully involved in their own healthcare journey.

Ethical approval: This study was granted ethical approval by the NHS Research Ethics Committee in September 2024.

Informed consent: Informed written consent was obtained prior to the commencement of the study.

Data availability statement: The Phase 1 questionnaire dataset and a thematic map from Phase 2 interviews are available from the corresponding author on request.

Acknowledgments: We would like to thank the interviewees for their time and valuable contribution to this research. The research was funded by UEA Health and Social Care Partners (UEAHSCP). ZK holds a Cancer Research UK fellowship.

Competing interests: There are no relevant financial or non-financial competing interests to report.

Appendix A: Access to Results Study Phase 1 Questionnaire

1. Have you viewed results from a medical test on the patient portal at [anonymised for review] Hospital in the past month?
    a. Yes
    b. No
2. Which of the following best describes what you usually do when waiting for test results?
    a. I wait for my doctor's surgery to call me with the results
    b. I check for the results on the patient portal
    c. Other (please specify)

When you answer the following questions, please think about the most recent test result you received from [anonymised for review] Hospital. If you had results from several tests on the same day, please think about the one that was most concerning to you.

3. Did the nurse or doctor explain why the test was being done before it was done?
    a. Yes
    b. No
4. What type of test did you receive? If you received several tests, please think of the one that was most concerning for you.
    a. Blood test
    b. Imaging test like an x-ray, CAT scan, MRI, or ultrasound
    c. Biopsy
    d. Genetic test
    e. COVID-19 test
    f. Other (please specify)
    g. I don't know
5. Why did your doctor or nurse order this test?
    a. To look into new symptoms or new health problems you were having
    b. To follow a health condition you know that you have
    c. For regular screening (for example, checking your cholesterol)
    d. Other (please specify)
6. What was the result?
    a. Normal
    b. Not normal
    c. Other (please specify)
    d. I don't know
7. If you had the option to, would you want to see this test result on the patient portal before you were contacted by a nurse or doctor about it?
    a. Yes
    b. No
    c. I don't know
8. Do you think if you had the option to see the results of your medical test before you could discuss it with a doctor or nurse it would have made you more or less worried about your health?
    a. Much less worried
    b. Less worried
    c. No change
    d. More worried
    e. Much more worried
    f. I was never worried

Preprints.org (www.preprints.org) | NOT PEER-REVIEWED | Posted: 1 December 2025 doi:10.20944/preprints202512.0089.v1

9. What would have been different (good or bad) if you had the opportunity to see your medical test results before you could discuss them with a doctor or nurse?
10. Where did you go for more information about the results of your medical test?
    a. A family member or relative
    b. A friend
    c. Another healthcare provider like a doctor or nurse
    d. Someone you work with
    e. Social media, e.g. Facebook, Twitter or Instagram
    f. An internet search (please specify)
    g. Other (please specify)
    h. I did not seek additional information
11. How confusing was viewing your test result on the patient portal?
    a. Very confusing
    b. Somewhat confusing
    c. Not very confusing
    d. Not confusing at all
    e. Not sure
12. What was confusing about viewing your medical test results on the patient portal? Select all that apply
    a. The test result was difficult to find
    b. I did not know how to interpret the test results
    c. I had never used patient portal before
    d. The result was for a test that I did not know I had
    e. Nothing was confusing
    f. Other (please specify)
13. How did the doctor or nurse contact you about your results? Select all that apply
    a. Sent a message through the patient portal
    b. Spoke with me over the phone
    c. Left a voice message on the phone
    d. At an in-person or telemedicine visit
    e. Sent a letter through the post
    f. Other (please specify)
    g. I was never contacted by a doctor or nurse
14. In the future, how would you like to receive new test results? Select all that apply
    a. Letter in the post
    b. Phone call from a healthcare professional
    c. Text message from [anonymised for review] Hospital
    d. View it on the patient portal
    e. Other (please specify)
    f. Don’t know/not sure

15. In the future, would you like to be notified that you have a new test result on the patient portal even if it means that you may see a result before your doctor or nurse is able to contact you about it?
    a. Yes
    b. No
    c. Other (please specify)
16. Is there anything else you'd like to share regarding your experience with checking test results through the patient portal?

Demographic Questions

1. In general, how would you rate your health?
    a. Excellent
    b. Very good
    c. Good
    d. Fair
    e. Poor
2. Long-term conditions. Have you been diagnosed with any of the following? Select all that apply
    a. High blood pressure
    b. High cholesterol
    c. Heart disease
    d. Chronic kidney disease
    e. Stroke disease
    f. COPD or asthma
    g. Diabetes
    h. Dementia
    i. Cancer
    j. Arthritis
    k. Schizophrenia, bipolar, and/or psychosis
    l. Depression and/or anxiety
    m. Other (please specify)
    n. None of these
3. What is your gender?
    a. Male
    b. Female
    c. Trans man
    d. Trans woman
    e. Non-binary
    f. Any other gender identity
    g. Prefer not to say
4. What is your age?

    a. 18-24
    b. 25-34
    c. 35-44
    d. 45-54
    e. 55-64
    f. 65-74
    g. 75-84
    h. 85+

5. What is your ethnicity?
    a. Asian, Asian British, or Asian Welsh
        i. Bangladeshi
        ii. Indian
        iii. Pakistani
        iv. Other Asian
    b. Black, Black British, Black Welsh, Caribbean or African
        i. African
        ii. Caribbean
        iii. Other Black
    c. Mixed or Multiple ethnic groups
        i. White and Asian
        ii. White and Black African
        iii. White and Black Caribbean
        iv. Other Mixed or Multiple ethnic groups
    d. White
        i. English, Welsh, Scottish, Northern Irish or British
        ii. Irish
        iii. Gypsy or Irish Traveller
        iv. Roma
        v. Other White
    e. Other ethnic group
        i. Arab
        ii. Any other ethnic group
6. What is the highest grade or level of education that you have completed?
    a. Secondary education (e.g., GCSEs, O-levels or equivalent) or below
    b. A-levels, BTECs or equivalent
    c. Higher education, e.g. undergraduate degree, diploma or equivalent
    d. Postgraduate qualification, e.g. Masters degree or equivalent
    e. Doctoral degree, e.g. PhD or equivalent
    f. Other (please specify)
7. What is your postcode?
8. How long have you been using the patient portal?

9. On average, how frequently do you use the patient portal?
    a. Daily
    b. A few times a week
    c. Once a week
    d. 2-3 times a month
    e. Once a month
    f. Once every few months
    g. A few times a year
    h. Once a year
    i. Less than once a year

Appendix B: Access to Results Study Phase 2 Topic Guide

Introduction

- Introduce self and explain the purpose of the interview.
- Explain the interview process and obtain informed consent.

Current Experiences with Hospital Patient Portal

- How do you currently access your medical test results?
- How do you use the patient portal?
- What are the pros and cons of using the patient portal?

Acceptability of Immediate Access to Test Results

Explain proposed immediate access to all test results, including caveat that this might mean seeing results before clinician has/may be waiting period before being able to discuss with clinician

- How do you feel about having immediate access to your medical test results via the hospital patient portal?
- In what ways might immediate access be helpful or beneficial to you?
- What concerns, if any, do you have about having immediate access to your test results?

Potential Support Measures

- What information or resources do you think should be available alongside the test results to help you understand them?
- How might the hospital provide support for any distress caused by accessing test results before discussing them with a clinician?
- What other measures should be in place to ensure a smooth rollout of immediate access to test results via the patient portal?

Closing

- Ask if there’s anything else the participant would like to share or discuss.
- Thank the participant for their time and provide information on the next steps in the research process.

Appendix C: Table 2. Receiving Test Results and Patient Portal Preferences.

	n	%	95% CI
Which of the following best describes what you usually do when waiting for test results?			
I check for the results on the patient portal	303	84.87	81.2–88.6
I wait for my doctor's surgery to call me with the results	26	7.28	4.6–10.0
Other	28	7.84	5.1–10.6
Have you viewed results from a medical test on the patient portal at [anonymised for review] Hospital in the past month?			
Yes	237	66.39	61.5–71.3
No	120	33.61	28.7–38.5
What type of test did you receive? If you received several tests, please think of the one that was most concerning for you.			
Blood test	209	58.54	53.4–63.7
Imaging (e.g., x-ray, CAT, MRI, ultrasound)	104	29.13	24.4–33.8
Biopsy	21	5.88	3.4–8.3
Genetic test	1	0.28	-0.3–0.8
COVID-19 test	2	0.56	-0.2–1.3
Other	19	5.32	3.0–7.7
I don't know	1	0.28	-0.3–0.8
Did the nurse or doctor explain why the test was being done before it was done?			
Yes	324	90.76	87.8–93.8
No	33	9.24	6.2–12.2
Why did your doctor or nurse order this test?			
To look into new symptoms or new health problems you were having	123	34.45	29.5–39.4
To follow a health condition you know you have	171	47.90	42.7–53.1
For regular screen (for example, checking your cholesterol)	43	12.04	8.7–15.4
Other	20	5.60	3.2–8.0
What was the result?			
Normal	167	46.78	41.6–52.0
Not normal	126	35.29	30.3–40.3
Other	33	9.24	6.2–12.2
I don't know	31	8.68	5.8–11.6
If you had the option to, would you want to see this test result on the patient portal before you were contacted by a nurse or doctor about it?			
Yes	336	94.12	91.7–96.6
No	11	3.08	1.3–4.9
I don't know	10	2.80	1.1–4.5
Do you think if you had the option to see the results of your medical test before you could discuss it with a doctor or nurse, this would have made you more or less worried about your health?			
Much less worried	113	31.65	26.8–36.5
Less worried	135	37.82	32.8–42.8

	n	%	95% CI
No change	96	26.89	22.3–31.5
More worried	12	3.36	1.5–5.2
Much more worried	1	0.28	-0.3–0.8
Where did you go for more information about the results of your medical tests? Select all that apply			
A family member or relative	45	12.61	9.2–16.0
A friend	14	3.92	1.9–5.9
Another healthcare provider, like a doctor or nurse	98	27.45	22.8–32.1
Someone you work with	10	2.80	1.1–4.5
Social media, e.g. Facebook, Twitter or Instagram	7	1.96	0.5–3.4
An internet search	189	52.94	47.8–58.1
Other	19	5.32	3.0–7.7
I did not seek additional information	98	27.45	22.8–32.1
How confusing was viewing your test result on the patient portal?			
Very confusing	5	1.40	0.2–2.6
Somewhat confusing	33	9.24	6.2–12.2
Not very confusing	96	26.89	22.3–31.5
Not confusing at all	208	58.26	53.1–63.4
Not sure	15	4.20	2.1–6.3
What was confusing about viewing your medical test results on the patient portal? Select all that apply			
The test result was difficult to find	28	7.84	5.1–10.6
I did not know how to interpret the test results	109	30.53	25.8–35.3
I had not used the patient portal before	18	5.04	2.8–7.3
The result was for a test that I did not know I had	14	3.92	1.9–5.9
Other [a]	199	55.74	50.6–60.9
How did the doctor or nurse contact you about your results? Select all that apply			
Sent a message through the patient portal	27	7.56	4.8–10.3
Spoke with me over the phone	98	27.45	22.8–32.1
Left a voice message on the phone	9	2.52	0.9–4.1
At an in-person or telemedicine visit	51	14.29	10.7–17.9
Sent a letter through the post	73	20.45	16.3–24.6
Other	45	12.61	9.2–16.0
I was never contacted by a doctor or nurse	111	31.09	26.3–35.9
In the future, how would you like to receive new test results? Select all that apply			
Letter in the post	64	17.93	13.9–21.9
Phone call from a healthcare professional	113	31.65	26.8–36.5
View it on the patient portal	325	91.04	88.1–94.0
Text message from [anonymised for review] hospital	115	32.21	27.4–37.1
Other	26	7.28	4.6–10.0
Don’t know/not sure	2	0.56	-0.2–1.3

	n	%	95% CI
In the future, would you like to be notified that you have a new test result on the patient portal even if it means that you may see a result before your doctor or nurse is able to contact you about it?			
Yes	341	95.52	93.4–97.7
No	8	2.24	0.7–3.8
Other	8	2.24	0.7–3.8

[a] Most responses stated "nothing was confusing" or similar in the "Other" free-text box for this question.

With 357 respondents from approximately 20,000 registered users, the maximum 95% margin of error for estimated percentages was ±5.1 percentage points. Confidence intervals for individual items were narrower than this indicating that the results provide a reliable description of respondents' views.

References

1. NHS Long Term Plan. NHS Long Term Plan. January 2019. Accessed May 22, 2024. https://www.longtermplan.nhs.uk/
2. Alturkistani A, Beaney T, Greenfield G, Costelloe CE. Patient portal registration and healthcare utilisation in general practices in England: a longitudinal cohort study. BJGP Open. 2023:BJGPO.2023.0106. doi:10.3399/BJGPO.2023.0106
3. KC S, Tewolde S, Laverty AA, et al. Uptake and adoption of the NHS App in England: an observational study. Br J Gen Pract. 2023;73(737):e932-e940. doi:10.3399/BJGP.2022.0150
4. NHS Digital. Personal Health Records adoption toolkit. NHS England Digital. 2022. Accessed May 20, 2024. https://digital.nhs.uk/services/personal-health-records-adoption-service/personal-health-records-adoption-toolkit
5. KC S, Papoutsi C, Reidy C, et al. Differences in Use of a Patient Portal Across Sociodemographic Groups: Observational Study of the NHS App in England. J Med Internet Res. 2024;26(1):e56320. doi:10.2196/56320
6. Khadjesari Z, Houghton J, Brown TJ, Jopling H, Stevenson F, Lynch J. Contextual Factors That Impact the Implementation of Patient Portals With a Focus on Older People in Acute Care Hospitals: Scoping Review. JMIR Aging. 2023;6:e31812. doi:10.2196/31812
7. Bruno B, Steele S, Carbone J, Schneider K, Posk L, Rose SL. Informed or anxious: patient preferences for release of test results of increasing sensitivity on electronic patient portals. Health Technol. 2022;12(1):59-67. doi:10.1007/s12553-021-00628-5
8. Callen J, Giardina TD, Singh H, et al. Emergency Physicians' Views of Direct Notification of Laboratory and Radiology Results to Patients Using the Internet: A Multisite Survey. J Med Internet Res. 2015;17(3):e60. doi:10.2196/jmir.3721
9. Giardina TD, Singh H. Should Patients Get Direct Access to Their Laboratory Test Results?: An Answer With Many Questions. *JAMA*. 2011;306(22). doi:10.1001/jama.2011.1797
10. Krasowski MD, Grieme CV, Cassady B, et al. Variation in Results Release and Patient Portal Access to Diagnostic Test Results at an Academic Medical Center. J Pathol Inform. 2017;8(1):45. doi:10.4103/jpi.jpi_53_17
11. Giardina TD, Callen J, Georgiou A, et al. Releasing test results directly to patients: A multisite survey of physician perspectives. Patient Educ Couns. 2015;98(6):788-796. doi:10.1016/j.pec.2015.02.011
12. Leonard LD, Himelhoch B, Huynh V, et al. Patient and clinician perceptions of the immediate release of electronic health information. Am J Surg. 2022;224(1):27-34. doi:10.1016/j.amjsurg.2021.12.002
13. General Medical Council. Good medical practice. Published online 2023. https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/good-medical-practice

14. Steitz BD, Turer RW, Lin CT, et al. Perspectives of Patients About Immediate Access to Test Results Through an Online Patient Portal. JAMA Netw Open. 2023;6(3):e233572. doi:10.1001/jamanetworkopen.2023.3572
15. NHS England. Global Digital Exemplars. 2020. Accessed June 11, 2024. https://www.england.nhs.uk/digitaltechnology/connecteddigitalsystems/exemplars/
16. Turer RW, DesRoches CM, Salmi L, Helmer T, Rosenbloom ST. Patient Perceptions of Receiving COVID-19 Test Results via an Online Patient Portal: An Open Results Survey. Appl Clin Inform. 2021;12(04):954-959. doi:10.1055/s-0041-1736221
17. 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;21(5):e13876. doi:10.2196/13876
18. Wright JA, Leveille SG, Chimowitz H, et al. Validation of a brief scale to assess ambulatory patients' perceptions of reading visit notes: a scale development study. BMJ Open. 2020;10(10):e034517. doi:10.1136/bmjopen-2019-034517
19. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
20. 20. Lohr, S. L. (2019). *Sampling: Design and Analysis* (2nd ed.). Chapman & Hall/CRC
21. Braun V, Clarke V. What can “thematic analysis” offer health and wellbeing researchers? Int J Qual Stud Health Well-Being. 2014;9(1):26152. doi:10.3402/qhw.v9.26152
22. Lustria MLA, Aliche O, Killian MO, He Z. Enhancing patient engagement and understanding: is providing direct access to laboratory results through patient portals adequate? JAMIA Open. 2025;8(2):ooaf009. doi:10.1093/jamiaopen/ooaf009
23. Wiederhold BK. Why We Need to Consider Patient-Centered Care in Online Records. Cyberpsychology Behav Soc Netw. 2024;27(6):359-360. doi:10.1089/cyber.2023.29306.editorial
24. Steitz BD, Turer RW, Salmi L, et al. Repeated Access to Patient Portal While Awaiting Test Results and Patient-Initiated Messaging. JAMA Netw Open. 2025;8(4):e254019. doi:10.1001/jamanetworkopen.2025.4019
25. Pinotti CS, Pooni R, Gaizo VD, et al. Patient and Family Perceptions of Real-Time Access to Electronic Health Information: A Social Media Survey. Appl Clin Inform. 2025;16:327-336. doi:10.1055/a-2487-7414
26. Hulter P, Weggelaar-Jansen AMJWM, Ahaus K, Pluut B. Patient discourses on real-time access to test results via hospital portals: a discourse analysis of semistructured interviews with Dutch patients. Published online November 1, 2024. doi:10.1136/bmjopen-2024-088201
27. Hulter P, Langendoen W, Pluut B, et al. Patients' choices regarding online access to laboratory, radiology and pathology test results on a hospital patient portal. Rubinelli S, ed. PLOS ONE. 2023;18(2):e0280768. doi:10.1371/journal.pone.0280768
28. Giardina TD, Baldwin J, Nystrom DT, Sittig DF, Singh H. Patient perceptions of receiving test results via online portals: a mixed-methods study. J Am Med Inform Assoc. 2018;25(4):440-446. doi:10.1093/jamia/ocx140
29. Turner A, Morris R, McDonagh L, et al. Unintended consequences of patient online access to health records: a qualitative study in UK primary care. Br J Gen Pract. 2023;73(726):e67-e74. doi:10.3399/BJGP.2021.0720
30. Van Kuppenveld SI, Van Os-Medendorp H, Tiemessen NA, Van Delden JJ. Real-Time Access to Electronic Health Record via a Patient Portal: Is it Harmful? A Retrospective Observational Study. J Med Internet Res. 2020;22(2):e13622. doi:10.2196/13622
31. NHS England. Clinical guidance for automation of results release in patient engagement portals. Published online July 24, 2024. Accessed April 14, 2025. https://www.england.nhs.uk/long-read/clinical-guidance-for-automation-of-results-release-in-patient-engagement-portals/