South East Clinical Senate

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Patient Access to Healthcare Records

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Foreword

Sharing and accessing patient health data is changing affording the NHS two unique opportunities. Firstly, to fully integrate individual patient care across the many boundaries that hitherto have served as barriers to data sharing within the healthcare system. Secondly, to empower and enable patients to be truly central to their own healthcare management. Patient access to their healthcare records is essential if these are to be realised but there remains inequity of access, poor communication, fragmentation and duplication of effort and resource.

This report is intended to increase awareness and understanding of patient access to healthcare records from a digital perspective, the barriers and facilitators to improved access, what is achievable now and what may be achievable in the future, and critically what patients want from access to their healthcare records.

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1. Background

In England patients have long had the ability to request their own medical record, historically through an onerous and time-consuming paper-based approach made possible by the Access to Health Records Act 1990 [1]. The United Kingdom General Data Protection Regulation (UK GDPR), implemented in the UK through the Data Protection Act 2018, then gave individuals the right of access to their personal data from any health and care organisation that holds records on them. This right is commonly referred to as a ‘subject access request’ but it still remained a laborious process. In 2022, NHS England announced plans to ensure that all adult primary care patients in England would have full online access to new data added to their general practitioner (GP) record. This took note of the principles embodied in the Fuller Stocktake report [2] and was updated with timelines in the ‘Delivery plan for recovering access to primary care in 2023’ [3]. The updated GP contract required new health information to be available to all patients (unless they individually opted out or any exceptions applied) by 31 October 2023. The aim was that all patients aged ≥16 years would be able to read all new information added to their primary care electronic health record via web-based services such as the NHS app [4], including access to test and laboratory results; lists of medications; coded records about problems, diagnoses, and treatments; and the free-text entries written by clinical staff about patients’ consultations.

The NHS Long Term Plan identified mainstreaming of digitally enabled care across the NHS as a key priority with the objective that the “NHS will offer a ‘digital first’ option for most, allowing for longer and richer face-to-face consultations with clinicians where patients want or need it.” [5]. An integral part of this is enabling patient access to their electronic healthcare record (EHR) with a 2-way flow of information and the ability for patients to control certain aspects of their healthcare pathway, for example entering self-recorded blood pressure data or booking an appointment. Core principles for patient access and for the 2-way flow of information include provision of the right information, to the right person, in the right format, through the right channel, at the right time. Healthcare records collect, archive, and manage information concerning a patient's socio-demographic profile, vital signs, allergies, vaccinations, medical history including diagnoses and procedures and medication. Data and records relating to a patient’s healthcare records are generated and stored in hospital systems, primary care, community and social care systems. The administration of EHR data relies on web-based applications or platforms. There are several platforms currently facilitating patient access to healthcare records, but the information should be interoperable to present a ‘single source of truth’ to patients. Poor integration with existing IT systems and EHRs represents a key barrier. The aim is to transform the medical record into a central form of communication among clinicians, patients, and their care partners thus enabling a continuous connection of patients, their health professionals, and other stakeholders (hospitals, primary care practices, ambulance services, diagnostic facilities including radiology and laboratories, pharmacies, care centres) to present and share data pertinent to each individual patient. The main objective of EHR platforms is the secure and transparent exchange of information to ensure complete, efficient, and high-quality treatment.

In England patient access to their healthcare records has been delayed through a variety of potential concerns including:

- Increased primary care workload both through reviewing and explaining viewable medical information in lay terms.
- Reduced primary care efficiency.
- Litigation risks, undermining the patient-doctor relationship.
- Patient harm through anxiety engendered by what they see and possibly misinterpret.
- Risks to patient safety.
- Patients will contest or disagree with what is written about them.
- Health inequities will increase.
- Documentation will be written in a way that reduces its clinical value.

Understanding the implications of patient access to EHRs and their immediate access to test results, exploring ways to improve patient access and portal adoption and use among different sub-populations (i.e. equity of access), and finding ways to leverage portals to improve health and healthcare are therefore key areas for research and proof of added value. A large and growing body of literature has investigated acceptance of EHR from the health professionals' perspective. Less so from the patients' perspective. Whilst acknowledging differences in healthcare systems and cultures, we can nevertheless learn from published evidence from other countries that are further ahead in their patient digital access journeys. These include but are not limited to, the Nordic countries (Norway, Sweden, Finland and Estonia), the Netherlands, and the United States (US).

In Norway the EHR has been fully established for many years, and the patient is both the subject and the owner of the health record. Since 2001, patients have had the legal right to access their health records and digital access since 2013 [6]. In 2022, 3 of 4 health regions offered patients aged ≥16 years and parents of children aged ≤12 years digital access to their hospital's EHR via the National Health Portal Helsenorge.no. Unless healthcare providers deny access all documents available in digital format are accessible by patients as soon as they have been signed off. In Sweden all patients have a single online access point to health care, implemented through the national patient portal 1177.se since 2008. Using government-approved electronic identification (ID) authentication, users can find health care providers, book appointments, and send secure messages [7]. To view their EHR, including the list of prescriptions, test results, and consultation notes from primary and secondary care, patients use the Patient-accessible EHR (PAEHR) service Journalen available on the national patient portal. The Finnish national patient portal My Kanta was first introduced in 2010, and since 2015, the My Kanta patient portal has provided all Finnish citizens who use public health care with access to their health records and medication data (including both primary and secondary care records) together with the functionality of renewing prescriptions [8]. The nationwide health information system in Estonia, which also includes a national patient portal, has been functional since the end of 2008 and all healthcare providers are obliged to share standardised medical documents with the PAEHR [9]. Since 2010, all residents with electronic ID have been able to see their health records, laboratory and examination results, diagnosis, and prescriptions from primary and secondary care. A nationwide appointment booking system was added in 2019. In the Netherlands patients can view their medical records online and may also have data corrected or removed. Patients view their data (blood tests results, medication data, narrative data) from various healthcare providers through a personal health environment, of which there are several. They can also add their own measured data such as weight and blood pressure [10]. In the US, the intent of the 21st Century Cures Act, signed into law in December 2016 was that patients be offered access to all the health information in their electronic medical records including narrative data written by their clinicians. Since April 2021 US medical practices and hospital systems have also been required to provide free and immediate access to laboratory reports, examination notes, biopsy reports, and imaging details directly to patients [11].

This report seeks to describe some of the relevant published evidence to date relating to patient access to EHRs including both patients and healthcare providers perceptions; the current status of patient access in the South East region; what is achievable now and what could be achieved in the future; what patients want; the obstacles, risks and benefits (including digital exclusion); areas for research and recommendations for the future.

2. Evidence

Secure internet-based channels that provide patients with convenient access to personal health records, management of health services, and communication with health professionals are promising tools for promoting patient health outcomes, especially for chronic conditions, through promoting preventive behaviours, for example, taking screening tests, improving patient engagement in health outcomes, and facilitating self-management of chronic conditions. Early observational evidence from the US using data from 3465 pairs (i.e. 6930 patients) of those likely to use patient portals (users) versus those not (non-users) suggested that users were more likely to be younger (63.46 years for users vs 66.08 years for nonusers), white (72.77% [4317/5932] for users vs 52.58% [2139/4068] for non-users), have commercial insurance (60.99% [3618/5932] for users vs 40.12% [1632/4068] for non-users), and have higher annual incomes (US $74,172/year for users vs US $62,940/year for non-users). Even after adjusting for these potential confounders, patient portal use had a positive and clinically meaningful impact on patients' preventive health behaviours but not on chronic health outcomes [12].

Early systematic review summarising evidence chiefly from the US concluded that patient portal interventions were effective in improving some psychological outcomes, medication adherence, and preventive service use. However, there was insufficient evidence to support the use of patient portals to improve clinical outcomes [13]. The authors suggested that understanding the role of patient portals as an effective intervention strategy is an essential step to encourage patients to be actively engaged in their health care.

Another systematic review from the UK assessed the impact of providing patients with access to their general practice EHR and other EHR-linked online services on the provision, quality, and safety of health care. Data from the included studies indicated improved patient satisfaction with online access and services compared with standard provision [14]. There was also improved self-care and better communication and engagement with clinicians. Safety improvements were mainly through identifying medication errors and facilitating more use of preventive services. There were no reports of harm or breaches in privacy. There was an impact on clinician time with a moderate increase in email and variable effects on face-to-face contact but no change in telephone contact. A further study from the UK concluded that digitally enabled healthcare solutions present an approach which can offer numerous potential benefits, including environmental sustainability, economic benefits, and improved patient experience [15].

Much of the published evidence to date derives from those countries where patient access to their EHRs has been established for longest. One systematic review from 2021 suggested that the evidence regarding health outcomes is generally favourable, and that patient portals have the potential to enhance the doctor-patient relationship, improve health status awareness, and increase adherence to therapy. However, it was unclear whether the use of patient portals improves health service utilisation and efficiency [16].

Experience from the Netherlands since July 2020 points to benefits from online patient access to EHRs such as better overview, patient empowerment and improved communication with their general practitioner; but identified needs regarding technological difficulties, data privacy and understanding complex medical language in their record [17,18].

3. Primary care perceptions

In the Netherlands 482 general practices provided responses to a survey which aimed to investigate staff experiences with providing web-based patient access to healthcare records [19]. Experiences were diverse, with 36.9% (178/482) primarily positive, 8.1% (39/482) primarily negative, 42.3% (204/482) neutral, and 12.7% (61/482) could not (yet) indicate how they experienced web-based access. Two-thirds (311/473, 65.8%) of respondents reported an increase in e-consultations and a similar percentage (302/474, 63.7%) indicated an increase in administrative actions associated with web-based access provision. A small proportion of the practices (≤10%) experienced a decrease in patient contacts. Earlier adoption of web-based access was associated with a more positive attitude toward web-based access and early adopters were also more positive about effects related to number of patient contacts and general practice workflow. Overall, the surveyed general practices' experience was either neutral or mostly positive, despite an increased number of patient contacts and administrative burden that were associated with its adoption.

A time series evaluation of a primary care portal in Canada from its implementation in 2010 matched 3696 portal registered patients one to one with non-registered patients [20]. Portal registration was associated with an increase in the number of certain traditional encounters over the period surrounding portal registration. Following the index year there was a significant jump in annual number of visits to physicians in the portal arm (0.42 more visits/year vs control, $P<.001$) but not for visits to nurse practitioners and physician assistants. The annual number of calls to the practice triage nurses also showed a greater increase in the portal arm compared to the control arm after the index year (an additional 0.10 calls, $P=.006$). The average provider time spent on portal-related work was 5.7 minutes per patient per year. Following NHS England's announcement concerning patients' online access to EHRs GPs in England in 2022 were surveyed to explore their experiences and opinions about the impact this might have on patients and GPs' practices. The responses of the 224/400 GPs surveyed who responded were largely negative. Perceptions were that workload would increase, patients may be harmed and there were anticipated legal concerns about possible increased litigation risks and lack of legal guidance concerning how to manage documentation that would be read by patients and potential third parties [21].

A qualitative study in 2023 in 10 general practices in the southwest and northwest of England aimed to identify the unintended consequences of patient online access to healthcare records stating that real world unintended consequences either positive or negative are often speculative with unclear evidence [22]. Despite the limitations of this study, the small sample size of 16 GPs and the demographics of the GPs who were all white and most qualified for over 21 years, aged 55-64 years, it nevertheless reports interesting observations which serve to highlight the complexity of some of the issues. For example, although respondents reported a reduction in workload from printing multiple copies of results there was an increase in workload noted with regards to managing access of records for teenagers and redacting comments in the records the parents did not want the child to see or vice-versa. Safeguarding was also raised with anxieties expressed about adding to the record concerns over domestic violence where a GP may wish to explore this with the patient in the future and/or to alert other professionals.

Nevertheless, facilitating patients to participate actively in their healthcare is a critical element of patient-centred care. Carefully implemented digital health care services have the potential to improve health care provision and strengthen opportunities for patient self-care, self-management, and shared decision-making. The World Health Organisation identifies five core functions of primary care [23]:

- First contact accessibility creates a strategic entry point for and improves access to health services.
- Continuity promotes the development of long-term personal relationships between a person and a health professional or a team of providers.
- Comprehensiveness ensures that a diverse range of promotive, protective, preventive, curative, rehabilitative, and palliative services are provided.
- Coordination organises services and care across levels of the health system and over time.
- People-centred care ensures that people have the education and support needed to make decisions and participate in their own care.

Cross-sectional survey of United Kingdom (UK) doctors conducted in 2018 using validated psychological instruments indicated that one-third of 1651 responders were burned out and suffering from secondary traumatic stress [24]. Emergency medicine and primary care doctors were most affected, and GPs scored lowest for compassion satisfaction. Since then, there have been additional burdens of increasing patient and management complexity, staffing shortages, crises involving COVID-19, mental health conditions and the growing electronic medical record burden. This cycle of decline in which there are not enough hours in the day for primary care clinicians to do their jobs has promoted interest in the innovative use of artificial intelligence (AI) to reduce clinician burden. Sarkar and Bates suggest 4 specific areas where primary care work could benefit from AI: (1) inbox management, (2) documentation, (3) between-visit panel management, and (4) decision support for diagnosis and treatment [25]. Table 1 summarises the pros and cons of such an approach.

Table 1. Potential for Artificial Intelligence to Reduce Primary Care Workload

Pros	**Cons**
Inbox Management	
Prioritise patient messages; generate draft responses; edit physician messages to optimise communication; reduce administrative burden	Risks dehumanising the clinician-patient relationship, AI may risk sidelining clinicians from important conversations that would benefit from human interaction
Clinician Documentation	
Draft progress notes in real time during visits; draft prior authorisation, disability, and durable medical equipment requests; reduce clinical staff administrative burden	Volume of documentation produced may exacerbate burnout; requires monitoring for safety and usefulness
Between visit management	
Identify patients in need of disease screening/monitoring using unstructured and structured EHR data to determine exclusions; identify patients with incomplete screening/monitoring (e.g. missed appointments), automate communication with patients, and provide scheduling and/or staff notification; generate tailored messages to patients related to the between-visit care needs	Accuracy of AI output dependent on accuracy of training input; AI has the potential to fabricate or confabulate information impacting patient safety
Individualised decision support	
Identify relevant information in structured and unstructured EHR data to prioritise differential diagnoses for new symptoms; recommend medication options for chronic conditions, considering prior medication prescriptions, allergies, adverse effects noted and potential drug interactions in structured and unstructured EHR data	Some suggestions may be wrong and safety and usefulness of AI suggestions requires checking

Nevertheless, there is evidence that the pros of use of AI interventions outweigh the cons. A quality improvement study evaluated the adoption, usability, and utility of AI-generated draft replies to patient messages. The study found improvements in task load and emotional exhaustion scores suggesting that AI generated draft replies have the potential to impact cognitive burden and burnout [26]. There were statistically significant reductions in both 4-item physician task load score derivative (mean [SD], 61.31 [17.23] versus 47.26 [17.11] post; paired difference, -13.87; 95%CI, -17.38 to -9.50; P < .001) and work exhaustion scores (mean [SD], 1.95 [0.79] versus 1.62 [0.68]; paired difference, -0.33; 95%CI, -0.50 to -0.17; P < .001) pre- and post-introduction of the AI intervention.

Patient access has arguably been possible for longest in the Nordic countries and patient users from Norway, Sweden, Finland, Estonia and the Netherlands have indicated more strongly than non-users that online access to medical records would increase their participation in health care, improve the relationship with their general practitioner, and support informed decision-making [18,27].

4. Barriers and facilitators to patient access

A systematic review from 2022 included 36 studies examining the patient's perspective on usage of EHRs, concentrating on their role and the challenges with access to EHRs in 4 stages: awareness, adoption, behaviour and perception, and consequences [28].

- Socio-demographic factors (i.e., age, gender, ethnicity, education level, or income) were strongly associated with the first 3 stages with, for example, higher health consciousness in women than in men and poor competencies in handling EHR systems in older people, or in terms of cultural background such as among Latino people and black people.
- In all 4 stages psychological-cognitive factors were important. Frequent internet usage or online health-related information searching lead to a better handling of an EHR system. Patient empowerment and activation enabled patients to take an active part in the digital treatment process. Patient education and training in access to EHRs facilitated better usage and continued to ensure smooth handling by the patients.
- Health-related factors such as patient-specific systems, guidelines or treatment plans relating to their health status, for example, in case of chronic disability, also positively influenced patient usage.
- Technological and infrastructural attributes were also positive influences; such as good surface design, structured and safe information regarding diagnosis, medication or prescription, or easy and private communication pathways, with specific information regarding the treatment process or direct digital contacts with provider.

- Factors negatively influencing all 4 stages unsurprisingly were the need for assistance during registration and usage, individual and family/peer influenced negative attitudes, and lack of interest in new technologies.

Table 2. Barriers and Facilitators for Patient Access to Healthcare Records

Facilitators	Barriers
Patient empowerment	Digital literacy
Self-management	Internet access
Personalisation	Health literacy
Patient driven approaches	Lack of timely information sharing
Education and training	Ease of information discovery
Healthcare provider encouragement	Privacy and data security
	Language and cultural barriers
	Negative healthcare provider attitude

A more recent qualitative study of the lived experience of using a patient portal in 734 adult patients recruited from a variety of care settings focussed on their perceived benefits and difficulties of using the patient portal, and their trust and concerns about privacy and security [29]. Most of the participants perceived the patient portal functions as beneficial for communicating with health care teams and monitoring health status and care activities. At the same time, about a quarter of them shared difficulties they experienced while using those functions, including not getting timely eMessage responses and difficulty finding information in the portal. Protected log-in processes and trust in healthcare providers were the most mentioned reasons for trusting the privacy and security of the patient portal. The most mentioned reason for concerns about privacy and security was the risk of data breaches such as hacking attacks and identity theft.

Although patient portals empower patients, which can improve health outcomes, increased access to digital information comes with ethical and legal challenges that must also be addressed. Unique considerations exist for 3 patient populations in particular — paediatric, psychiatric and geriatric patients — who are particularly vulnerable. Features of patient portals for these vulnerable groups mandate nuanced considerations for capacity and family dynamics.

5. Older patients and healthcare technology

Ageism in healthcare technology can also be a barrier to its use. The paucity of age-aligned medical access software and products may lead to worsening of digital exclusion and disparities in healthcare. Barriers to use identified by older patients include technical difficulties, privacy concerns and cost of technology. Important desirable features for older patients include the ability to modify text size within the application and an intuitive, simple interface [30]. They often require additional assistance for navigating technical challenges, specifically set-up of accounts, saving and sharing information with caregivers, and sign-in and navigation of portals. Portal application developers and healthcare systems must advance efforts that consider the needs of those who may be older when designing patient portals.

Older patients with chronic conditions are particularly vulnerable to misremembering and mismanaging their care and medication plans. However, one study specifically considering this suggested that these patients and their care partners could receive important benefits from accessing their notes [31]. Healthcare organisations should work to maximise patient's engagement with their health information both through the patient portal and through other methods to ensure that patients and the healthcare systems reap the full benefit of the increased transparency of medical records.

Older respondents with multimorbidity are more likely to share their medical records with other providers. However, respondents who are 75 and older are less likely to share their medical records with another provider. Additionally, respondents who are 65 and older may be less likely to use the EHR for secure direct messaging with their provider [32]. Additional health care strategies and provider communication should be developed to encourage older patients with chronic conditions to leverage the use of patient portals for effective disease management.

Similarly, another study reported that individuals with multimorbidity were more likely to report general use of health information technology (adjusted odds ratio 1.48, 95% confidence intervals 1.01-2.15) and more likely to use health information technology to check test results (adjusted odds ratio 1.85, 95% confidence intervals 1.33-2.58) compared to adults with only one chronic condition. However, there were no significant differences in other forms of health information technology use [33]. The study also observed interactive associations of multimorbidity and age on various components of health information technology use. Compared to younger adults with multimorbidity, older adults (≥ 65 years of age) with multimorbidity were less likely to use almost all aspects of health information technology.

As people grow older, they develop and manage more chronic conditions that often require multiple treatment plans and care from several providers. Use of patient portals can benefit older adults in managing their care, as well as their family caregivers. Although there are some doubts about older adults' ability to use patient portals many older adults worldwide actively use patient portals and value their helpful functions, such as prescription management, laboratory results review, and communication with care teams. When healthcare organisations implement health IT programs to be used by any patient (young, old, computer savvy or computer novice), step-by-step training programs must be developed for older adults and/or technology naive patients. Training sessions could be divided into those for digital naive generations, and those for late adopters of technology. Simple instructional culturally appropriate videos (e.g., animations) would be another way of augmenting training. Unsurprisingly clinician encouragement of patient EHR use is strongly associated with patients accessing EHR. However, research shows that there are also disparities in who receives clinician encouragement related to education, income, sex, and ethnicity [34].

6. Patient portals and adolescents

Research on the use of patient portals by adolescents, young adults and their families is limited. Models of access for adolescents and young adults are shown in Table 3 and the potential benefits and risks in Table 4. Potential benefits of portal use to adolescents include increased engagement in their own health care, direct communication with their health care clinicians, and facilitation of transition of care to new clinicians in adulthood. Clinicians need to educate adolescents on the functions available through the portal, appropriate use and expectations for messaging through the portal, and the pros and cons of viewing EHRs such as test results independently.

Table 3. Models of access for adolescents and young adults (adapted from reference 35)

Patient Age	Patient Access	Parent/Guardian Access
Young Child	None	Full
Adolescent (< 18 yr)*	Full or Limited**	Full or Limited proxy access**
Adult (> 18 yr)	Full	None
Adult (> 18 yr)	Full	Full or Limited proxy access**

*Typically 12-14 years ** Variable access/blocking mutually determined.

Parental proxy access to the adolescent's portal should be carefully and thoughtfully implemented because it poses a potential breach to confidential care via disclosure of sensitive or protected information. Adolescents who choose to deny their parents proxy access to the portal should be supported in that decision. It is important that all clinicians understand portal functionality and have strategies to optimise use within their practice [35].

Table 4. Benefits and risk of adolescent and young adult access to EHRs

Benefits

1. **Enhanced communication**
   Enable questions outside of visits, share data, build rapport with clinicians.
   Electronic messages for care delivery and facilitate parent-clinician communication.
   Facilitate transition to adult care.
2. **Engagement**
   Increase patients' engagement in their own health care and potentially reduce requirement for emergency department use in those with multiple complex illnesses.
   Improve adherence to appointments and medication.
   Documentation of family history.
   Correction of incorrect or inaccurate information.
3. **Satisfaction**
   Increased patient satisfaction may improve care and help patients/family/carer understanding and decision making.
   Accessible, accurate, and timely additional medical information is useful for parents of children with chronic health conditions

Risks

1. **Threats to confidentiality**
   Verbal breaches of adolescent confidentiality are common in paediatric hospitals and may increase with increased sharing of EHRs. Issues may include reproductive health care, mental health care, substance abuse treatment and sexually transmitted disease. Adolescent patients may not be aware of their rights and may therefore hesitate to activate the patient portal, or they may risk foregoing necessary care if they have concerns over others' access to their information.
   Inadvertent release of information obtained from a parent to the adolescent.
   Loss of personal connection through electronic healthcare.
   Lack of knowledge for the healthcare provider of who they are receiving communication from i.e. patient or parent/carer.

2. **Inappropriate messaging**
   There must be clearly stated timelines for message response to avoid urgent messages not being received and for patients/parent/carer to understand the provider’s approach to message workflow.
3. **Anxiety**
   Being able to view tests results as soon as available carries benefits and risks, anxieties may be relieved by normal test results but heightened through abnormal results and misinterpretation of results. Ideally truly abnormal results or those subject to misinterpretation require explanation, education and possibly management. This may not be possible electronically without causing great distress.
4. **Healthcare disparities**
   Sociodemographic disparities, language differences, and geographical factors all affect enrolment and activation of patient portals.
   Parents who activate the portal may be more likely to have access to a home computer and be more engaged in their child's healthcare.
   Many families, even after enrolment, may have significant barriers to use such as lack of access to devices or high-speed internet services, which must not be perceived as lack of interest or engagement.

7. Socioeconomic status and inclusion health groups

In the US a trial randomised English-speaking vulnerable patient subgroups such as those with lower socioeconomic status or limited health literacy (LHL) with one or more chronic diseases to receive either an in-person tutorial with a research assistant, or a link to view the tutorial videos on their own. The 2 randomised groups were compared with a third, nonrandomised usual care comparison group [36]. The primary outcome was portal log-in (yes/no) 3 to 6 months post-training, assessed via the electronic health record. Secondary outcomes were self-reported attitudes and skills collected via baseline and follow-up surveys. Although there were significant pre-post improvements in self-rated portal skills ($P = .03$) and eHealth literacy ($P < .01$) those with LHL were less likely to log in post-training ($P < .01$) and neither mode of online training better enabled vulnerable patients to use portals (especially those with LHL).

Experience from the US in reducing disparities in access amongst Hispanics suggest that EHR use was facilitated by having a usual source of care, active e-communication, and having access to Health apps [37]. The authors suggested that interventions focusing on these three factors may potentially reduce racial/ethnic disparities. Another US study examining disparities in patient portal access and the role of providers encouraging patient portal use utilised data from 8028 subjects from a nationally representative survey. The effect of race and ethnicity on the likelihood of being offered, accessing or using a portal, and the reasons for non-use were explored. Black and Hispanic individuals were offered and accessed patient portals at significantly lower rates than White individuals. Those individuals who were offered a portal and encouraged to use it were more likely to access it and Black and Hispanic individuals who were offered and accessed a portal were significantly more likely than Whites to use it to download or transmit information [38]. An earlier study examined the relationship between internet prescription refills and medication adherence among 134 English proficient (EP) and 250 limited English proficient (LEP) patients. LEP patients used the internet refill system significantly less than EP patients. However, although LEP status was negatively associated with adherence, in LEP patients use of the internet refill system was significantly positively associated with adherence [39].

Qualitative study of patients' experience of using web-based patient portals in the UK examined their perceived changes in quality of care and attempted to determine the characteristics of those perceiving the greatest benefit from patient portal use [40]. Of 445 patient respondents who used the Care Information Exchange portal 172 (38.7%) reported that the overall quality of their care was better and only 14 (3.2%) said their care was worse. Those patients self-reporting higher digital health literacy and those belonging to ethnic minority groups were more likely to perceive improvements in care quality. Increased frequency of Care Information Exchange use also predicted perceived better care quality and greater satisfaction with care. The majority of patients felt more in control of their healthcare (61.2%, 273/445) and felt able to play a greater role in decision-making (53.9%, 240/445). Patients reported they could access appointments, diagnoses, and treatment more quickly. The authors suggested that with national policy directed toward addressing health disparities, patient portals could be valuable in improving care quality for ethnic minority groups.

The inclusion health populations share many additional barriers to health care access with respect to geographic location, advanced age, trauma, disabilities, mental health challenges, and homelessness [41]. Barriers to patient access in these populations not only include patient lack of awareness, perceived or actual digital illiteracy, mistrust, lack of user-friendly interfaces, and lack of internet access or technology, but also healthcare professional bias and workload, and misperceptions of usefulness [39, 42]. In considering access for inclusion health populations, Verity & Tzortziou-Brown identified lack of translation availability, digital exclusion, and a complex difficult to navigate healthcare system as key barriers to access [43]. Other themes identified included the importance of trust, face-to-face consultation options for ensuring safety, and the benefits of remote access, particularly in terms of convenience and saving time. Themes on reducing barriers included improving staff capacity and communication, offering tailored options and continuity of care, and simplifying care processes.

Increasing access to EHRs for inclusion health populations could also be facilitated through authorisation of family/carers to share access. Shared access enables information exchange among patients, clinicians, and family/carers. An iterative, patient-centred, co-designed solution involving patients and care partners, clinicians and clinic staff, medical informatics teams, marketing and communications staff, and administrators aimed at increasing use of shared access has been developed for older adult patients [44]. Similar initiatives may also reduce inequities of access in other populations.

8. Access to laboratory and imaging test results

The potential benefits provided by enabling patient access to their laboratory results such as reductions in patient requests burden and improvements in patient satisfaction, disease management, and medical decision making, also come with concerns about causing confusion or anxiety. However, it is possible to clearly convey the meaning of results and any required action by designing systems to present laboratory results adapted to the people who will use them. For example, people with kidney disease in the UK were afforded a two-way communication with their healthcare professionals, viewing their results and letters and being provided with a platform for the recording of patient-entered data such as home blood pressure readings (Renal Patient View) [45]. Such systems are designed to encourage patient participation in the management of their condition, and ultimately to increase patient empowerment and self-management, which are associated with improved clinical outcomes. They should support people in converting the potentially meaningless data of results into meaningful information and actionable knowledge. The authors offered 10 recommendations to help achieve this goal:

1. Whenever possible, provide a clear takeaway message for each result
2. Signal whether differences are meaningful or not
3. When feasible, provide thresholds for concern and action
4. Individualise the frame of reference by allowing custom reference ranges
5. Ensure the system is accessible
6. Provide conversion tools along with results
7. Design in collaboration with users
8. Design for both new and experienced users
9. Make it easy for people use the data as they wish
10. Collaborate with experts from relevant fields.

They suggest that using these 10 methods and strategies renders access to laboratory results into meaningful and actionable communication. In this way, laboratories and medical systems can support patients and families in understanding and using their laboratory results to manage their health.

The disclosure of online test results (i.e., laboratory, radiology and pathology results) on patient portals can vary from immediate disclosure (in real-time) via a delay of up to 28 days to non-disclosure. Dutch experience is that most want their results as soon as possible [46] and use of AI may easily and rapidly achieve several of the recommendations above. For example, in radiology imaging reports have traditionally been written with clinicians as the intended audience in language that is fairly incomprehensible for most patients. Immediate access to readable imaging reports has enormous potential for patient benefit and use of AI is now feasible both for image reporting and presenting image reports in a patient friendly format [47].

Patient and health care provider perspectives on the direct release of laboratory, imaging, and radiology results to patients via web portals was examined in a scoping review of published research from the US, the Netherlands, Canada and Denmark [48]. Particularly important was the timing of the release of test results. In some countries, the policy was for immediate release of most tests directly into patient portals. This clearly presents challenges for providers in that some patients may view the results before the provider has had a chance to review the test results in detail or, alternatively, before other results are available. The key themes that patient and provider perspectives were grouped in from the 27 studies reviewed are listed in Table 5. Of note, relating to arguably the most difficult type of report to understand the vast majority (>88%) of patients felt that releasing radiology reports via the portal was important and they wanted to have their own medical images available to them. Patients reported various degrees of benefits to their health and care, from no change to an increased level of comfort, better understanding of personal health, and enhanced confidence to take action. Access to laboratory and imaging results via a portal was seen as progressive and convenient, reducing wait times for results, leading to improved relationships and communication with healthcare providers, facilitating understanding of health information, and improving engagement in care.

Table 5. Key patient and provider themes relating to immediate release of test results

Patient themes	Provider themes
Emotional response when viewing the results	Providers’ view of benefits of patient access to results via portal
Understanding test results	Effects on healthcare professional workload
Preferences for mode and timing of result release	Concerns about patient anxiety
Information seeking and patients’ actions motivated by viewing results via a portal	Timing of result release into the patient portal
Contemplating change in behaviour and managing own health	The method of result release into the patient portal (manual vs automatic release)
Benefits of accessing test results via a portal	The effects of the hospital health information technology system on patient quality outcomes
Limitations of accessing test results via a portal	
Suggestions for portal improvement	

Only 7 of the 27 studies reviewed included healthcare provider perspectives or analysed the patterns of result release. Among the provider themes changes in the workload and healthcare providers perception of benefits of patient access to results were addressed the most, whereas the mode and timing of result release and concerns about patient anxiety were addressed the least. An important benefit of patient access to their test results is that portals serve as results archives and enable patients to be the information link between different service providers. Patient anxiety was a shared theme across the patient and healthcare provider perspectives. Two main factors contributed to patients’ negative emotions and anxiety: viewing abnormal or incomprehensible test results. Each of these factors was mediated by mode (manual vs auto release) and timing of result release (immediate vs delayed), and whether where required there was timely direct communication between patients and healthcare providers (text, phone call, and visit) either before or shortly after the result was released into the portal. The timing of the result release was important for all.

A qualitative Swedish study sought to provide an in-depth understanding of cancer patients’ attitudes and experiences. Respondents included newly diagnosed patients and those with recurrence and several patients who had advanced cancer and were receiving palliative treatment [49]. In contrast to physician's predictions about anxiety few patients felt worried, confused or offended by reading their notes nor did having access generate increased workload. Patients who were upset by results reported this would be the same if the result were delivered by the physician and receiving them in their own home allowed them the opportunity and time to sufficiently recover and be better prepared for subsequent visits in turn leading to improved communication with their care teams.

For patients, the timing dictated their emotional response and their subsequent actions. Both "too early" and "too late" availability of test results generated anxiety and information seeking actions. Healthcare providers were concerned that patients may view the results before the provider had a chance to review them in detail or, alternatively, before other results were available. To mitigate patient anxiety, aid patients' comprehension of results, and help prevent increases in healthcare provider workload the reviewed studies suggested 3 main strategies. First, healthcare providers requesting the test should educate patients about the purpose and potential findings of the tests at the time of request. Second, to enhance the visual display of test results (one of the patients' suggestions for portal improvement too). The third strategy suggested was to add written interpretations of the test results released into a portal. A point made repeatedly in the published portal literature, echoed by this study, is that patients do not consider portals to replace human interaction, but rather complement it.

A further single study sought to survey patients' perspectives concerning immediate access to test results through an online patient portal in 4 US academic medical institutions [50]. Respondents numbered 8139 but represented only 18.8% of those surveyed and of these 94.5% spoke English as their first language. Median age was 64 years (IQR, 50-72). Most respondents (95.7%), including 2337 of 2453 individuals (95.3%) who received nonnormal results, preferred to receive test results immediately through the portal. Few respondents (7.5%) reported that reviewing results prior to contact from a healthcare provider increased worry, though increased worry was more common among respondents who received abnormal results (16.5%) than those whose results were normal (5.0%). There was an association between worry and abnormal results which was mitigated by pre-counselling. The authors concluded that respondents preferred to receive test results immediately via the patient portal despite viewing results prior to discussion with healthcare providers and this preference persisted among patients with abnormal results.

More recent examination of implementation of immediate test result release to a patient portal in a single centre found increased and faster viewing of test results across all patient care areas but most notably in the outpatient setting [51]. The authors observed that a shift to immediate release of diagnostic test results may unintentionally increase provider workload responding to patient test result queries, making it challenging for providers to communicate bad news and that adding time for pre-emptive counselling may be difficult. Despite this there was no serious patient self-harm from immediate release to the patient portal. The same disparities in patient portal utilisation reported in previous studies were found (less utilisation in patients with lower income, lower education, non-White race, preferred language other than English, public or no health insurance, male sex and older age).

9. What do patients want?

Many of the studies referenced above that sought the views and perceptions of patients concerning access to EHRs and use of patient portals also detailed recommendations from patients. As a part of a larger systematic review, Reynolds et al examined the patient portal literature and identified 42 studies that reported patient's or their caregiver's suggestions to improve patient portals. The results suggested that patients and caregivers want patient portals to (i) support human connection (e.g., virtual patient-provider interactions), (ii) give patients more control (e.g., over their medical record) and be designed for the variation in patient and caregiver experiences, and (iii) be innovative (e.g., provide contextualised medical advice) [52].

It is important to consider patients as a heterogenous group who have different needs and wants [49]. The level of access individuals want will differ and consideration of these differences is important in the ongoing development of access to EHRs. Also critical is to go further than asking patients to evaluate what already exists and ascertain what it is patients want. In the event that patient needs and expectations be overlooked the full potential of access to EHRs may not be achieved [53].

Table 6 summarises the functionality that patients would want to have made available to them through patient portals. We also sought the views of a number patient and public partners (Appendix A).

Table 6. What functionality do patients want?	
Function	**Use**
Appointment scheduling	Schedule and change routine appointments Securely schedule appointments for confidential care (eg. STD clinics, substance abuse treatment centres)
Telehealth	Access telehealth appointments (routine or confidential) Access health care when transportation is unavailable
View Care Team	Keep track of all care team members and clinicians Facilitate transition of health care to new clinicians
Secure Messaging	Send and receive secure messages Communication with provider(s), messaging, video conferencing Notifications to provider specifically medication and adherence-related Ask questions about care plan Enquire about options for confidential care services Reminders (e.g., upcoming appointment, prescriptions, preventive care) Notifications about new content such as test results Decision making (e.g., advance care planning)
Photos and Videos	Send photos or videos to clinicians Enhance telehealth visits by providing quality clinical images
Medical Record	View historical information (personal and family medical history, immunisation records, allergies) View current medical information (medications, test results, clinical notes, upcoming appointments) Automatic upload of home readings from different types of devices, eg BP, O2 sats, glucose View patient education materials relating to diagnoses, medications and test results Complete screening tools and other data collection forms online prior to visit Complete screening assessments that communicate with larger EHR

Medicines Management	Ask questions about medications Request repeat prescriptions
Immunisations	Review immunisation records Print out immunisation records for travel, work, school
Letters and information	Updates from clinic visits and hospital admission Explanation of test requests, test results and actions required Explanation of medication changes and any expected side effects or potential interactions View clinic letters and discharge summaries View medical reports (eg for insurance, sickness absence) More personal health and healthcare information (condition-specific and contextualised)
Sharing of Records	Share view of patient portal with family members Provide access to “outside” healthcare clinicians Manage proxy access
Resource Links and education	Access reputable medical information, recommended by the healthcare organisations Access education, training, or support materials for patient portals
Usability	More user-friendly format, easier to use and navigate Better display of information, especially test results Range of platform options (smart phone, tablet, laptop etc) Rapid but secure log-in Improved accessibility (e.g., visual impairment) Reduced constraints (e.g., days/times blocked from online appointment scheduling) Notifications before automatic actions (e.g., before a session times-out)
Account Settings	Update photo, address, telephone numbers, email Select communication preferences (eg, email, text, phone)

To elicit real time information and opinions from service users with regards to digital and online healthcare access in the South East region, and improve our understanding of what functionality patients want, the clinical senate management team conducted a patient and public survey and focus groups. The survey was accessed via Microsoft Forms and sent to the groups listed in appendix A. The survey received 50 responses, 62% of respondents were female. The highest number of respondents (19, 38%) were in the age band 15-24 years, thought to be reflective of the focus groups in this age band. Seventeen respondents (34%) were in the age band 65-84 years. Respondents identified predominately as white (36 respondents, 72%), 9 (18%) respondents identified as Asian, Asian British or Asian Welsh, 1 (2%) as Black, Black British, Black Welsh, 1 (2%) as mixed or multiple and 2 (4%) as other.

The survey was designed to understand the current digital literacy of respondents and what they would like to have access to in terms of their healthcare. There were free text options asking for general comments and if there was anything else the respondent wished to have access to that was not already listed in the survey. The survey was piloted with the Clinical Senate patient and public partners and small changes were made as a result to the information provided at the beginning of the survey and wording of some of the questions prior to it going live. See appendix B for survey questions.

Forty-six percent of respondents could do one or more fundamental internet tasks, these included switching the device on and logging in, using controls such as the mouse, browsing the internet and changing their log-in when prompted. 76% of respondents could do all the tasks listed and none of the respondents reported being unable to do any of the tasks. Over 50% of respondents wished to have access to all suggested facilities. These included booking and changing routine appointments, access to consultations with healthcare providers in-person and online, via telephone or video, sending and receiving secure messages, communicating with their healthcare provider receiving updates and reminders, sending photos, asking questions about medicines management and receiving explanations of test requests, results and actions required.

In terms of what respondents wished to be able to do; being able to book and change routine appointments (48 respondents, 96%), being able to provide information about their healthcare to new clinicians who became involved in their care (41, 82%), sending and receiving secure messages (47 respondents, 94%), asking questions or requesting changes to their care (44 respondents, 88%), seeing historical information (46 respondents, 92%), reviewing immunisation records (48 respondents, 96%) and receiving explanations of test requests, results, and actions required (48 respondents, 96%) scored the highest number of positive responses.

The ability to share records with others elicited the lowest positive response, with 24 (48%) wishing to be able to share their records with family members and 33 (66%)

with healthcare providers for other organisations. Thirty (60%) respondents would want to give proxy access, with 23 (46%) wanting to give parental access.

Almost all, 42 respondents (84%) wanted the availability of consultations with healthcare providers in-person or online via telephone or video.

Responses to the free text question, ‘Is there anything else you would like to have not previously listed?’, related to access and communication, such as, a single portal, having a fast login, access to aspects of the service available when the surgery closes, to be able to see treatment from paramedics, information on expected referral times and easy to access online forms when requesting help.

When asked if respondents had any other comments positivity was expressed about the current NHS App and that digital access may lessen inequalities for example with neurodivergent groups. There was also some anxiety about certain online services such as receiving genetic test results in this way, the danger of self-diagnosis, or the operability of the online service. One respondent stated; ‘*Better to have limited facilities which work rather than Grand Designs with errors*’. Other comments reflected the need for control and empowerment such as;

‘Make sure we have somewhere to go to get up to date information about what is available and how to find it.’

and

‘*Want all access and be able to make decisions myself about what I see and what questions would be helpful to be answered’*

For a full breakdown of survey responses see appendix C.

Our survey results mirror many of the issues and challenges identified in the literature such as the safety and reliability of online patient portals and the wish for increased control over what patients can access and when. We acknowledge the limitation of the sample size and the method of accessing it. The online only access introduced bias towards respondents with some digital literacy and interest in online services which may not be reflective of the wider population. Nevertheless, there was clearly appetite for more online patient record access, and access to treatment and information options.

We mitigated some of the difficulties for respondents in terms of online survey access and digital literacy through focus groups with a number of communities in the South East Region. The aim was to explore their views, desires and any perceived barriers to having meaningful and effective access to their healthcare records. These focus groups enabled us to gain greater insight into what some communities within the South East Region feel is necessary to maximise the use and benefits of online services. The groups allowed us to build on emerging themes from the literature review and survey responses and develop ideas further, for example with regards to privacy and safety.

We conducted focus groups with university attendees (4 participants), sixth formers (16-18years, 17 participants) and the gypsy-traveller community (5 participants). Although a further focus group with older adults with mental health problems was planned we were unable to recruit participants. Information gained from the focus groups was extremely valuable and we are grateful to the participants for their time and willingness to engage openly with us.

The focus group responses were categorised into themes. There was some commonality across the groups for example in terms of the safety, accessibility and communication of online healthcare services. Concerns were raised over the ownership of the data stored, a lack of trust over the safety and confidentiality of stored data. Both the university group and the gipsy-traveller group raised concerns regarding accessibility when living in different places. For example university students struggled to access information from their *‘home GP*’ when seeing their *‘university GP’*. The traveller community preferred in-person appointments but found the timing and waits to be seen problematic which was compounded if unable to understand the results/letters they had received.

General literacy, reading and writing, health literacy and consequently digital literacy was a significant problem for the traveller community. The low levels of literacy impacted their ability to understand the data even if digital access was not the issue. They were not consistently able to understand messages if they came through an app or via text or email. They reported this made them *‘feel stupid’* and even if they had a device that could read the message/email aloud, there was reluctance to do this due to privacy concerns. They had a lack of confidence generally with regards to the technology although they did find text appointment reminders helpful.

Communication frustrations were raised multiple times by all groups, be that lack of information, lack of control over what is received and/or lack of understanding. Comments regarding communication issues highlight the importance of continuity and personalised care. For example, the annoyance at having to constantly repeat information to different healthcare professionals and a wish to see the same healthcare professional to avoid the need to explain treatment history.

As perhaps could be expected the sixth formers had a high degree of confidence with technology, suggesting the use of AI chat boxes for asking health related questions. Nevertheless, digital access for this group requires consideration as only 20% of the group were aware of the NHS App with only one member accessing information via the App, which was a COVID pass required for travel, possibly highlighting the perceived relevance of information on the App for this age group. A further issue for some members of this group was having sufficient memory on their mobile phones to download the NHS App with gaming apps taking priority.

The safety of stored data to a greater or lesser degree was an issue for all participants and was associated with anxieties over privacy. The ownership of data and who has access to stored personal data were raised. Concerns over the degree of parental access was expressed with the solution *of 'parental controls, but for parents'* suggested, meaning the teenage patient should be able to set the controls regarding what healthcare information their parent could access.

Privacy was a particular worry for the traveller community. The focus group was female only as *'travelling women don't share [health matters] with their men folk'*. They would be embarrassed to discuss their health with their children and would not want to worry them. Most would also prefer to see a female healthcare professional and be unlikely to fully disclose the problem if they saw a male or may not attend if knew the healthcare professional to be male.

Participant responses from the focus groups provided a richness that was not possible to achieve via a survey. Themes identified reflected those in the survey and the literature, for example the safety and accessibility of online healthcare information. However, what was strongly communicated via the focus groups responses was the need for patient choice and continuity of care. This is an area where the opportunity for co-designing services with patients should be realised and would consequently contribute to an increase in successful adoption and outcomes.

We would also recommend adopting proportionate universalism for inclusion health groups. The focus groups highlighted some concerns specific to the travelling community and while acknowledging this was a small sample of one inclusion health group, work with other groups, such as the homeless commend and demonstrate the success of this approach [54].

The themes and full responses of focus group participants can be found in appendix D.

10. What can be achievable now?

Access to the internet

There were 66.33 million internet users in the United Kingdom in January 2024, an internet penetration rate of 97.8 percent of the total population [55]. At the same time there were 88.86 million cellular mobile connections active in the United Kingdom, equivalent to 131.0 percent of the population. Median mobile internet connection speed via cellular networks was 48.43 Mbps and Median fixed internet connection speed 92.10 Mbps. That suggests that those able to connect to the internet are more than likely able to access patient portals provided they are sufficiently digitally literate. For perspective, the data also means that 1.52 million people in the UK did not use the internet at the start of 2024, suggesting that 2.2 percent of the population remained offline at the beginning of the year.

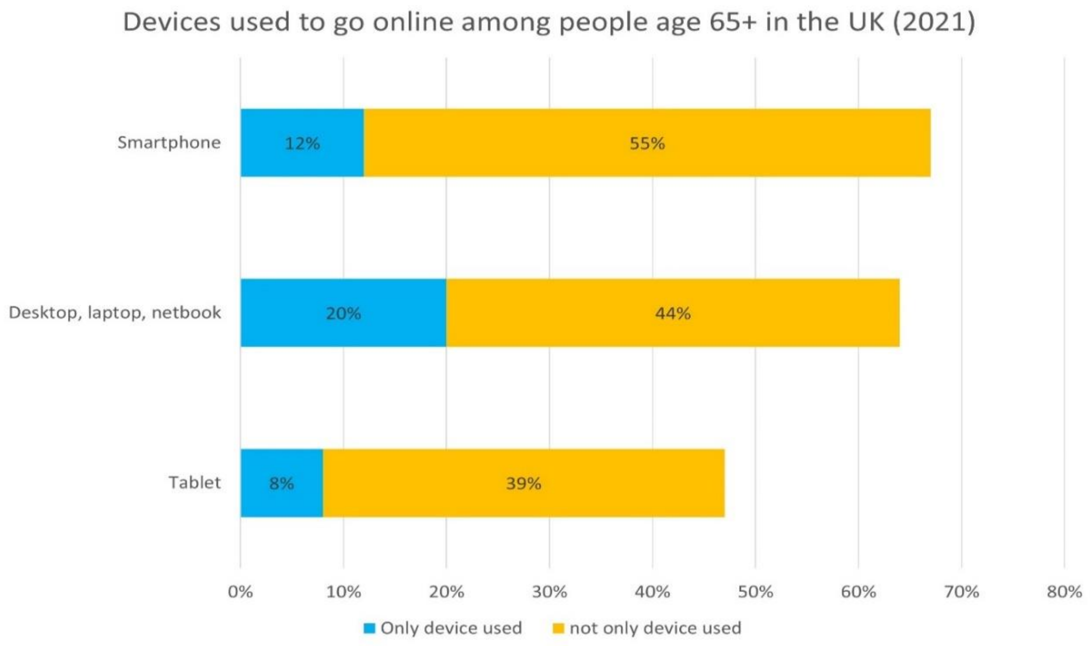
Survey of internet users aged 16-64 indicated that researching health issues and healthcare products was a primary reason for using the internet in 36.9% [55]. Over half of the UK population (36.29 million, 53.5%) were using digital health treatment and care at the start of 2024, an increase of 12.6% over the previous year. However, only 1.93 million people were using online doctor consultation services at the start of 2024, albeit this was an increase of 5.5% over the previous year [55].

Data concerning age and internet use indicated that in 2022 around 2 million (34%) people aged 75 and over and around 0.7 million (10%) people aged 65 to 74 do not use the internet [56]. Not everyone who gets online, stays online. As of 2022, almost 500,000 people aged 65 over had used the internet in the past, but not recently. During 2020-21 in the UK 85% of recent internet users aged 75 and over and 94% aged 65 to 74 browsed the internet at least once a month. Although the majority of older people use a mobile phone 13% aged 65 and over did not. Of the 87% who did use a mobile phone roughly two thirds used a smartphone, data reflected in the device used to connect that those who do use the internet employ (Figure 1).

The groups more likely to face digital exclusion are those aged 75 and over, those with low income and unemployed, the socially excluded (homeless, asylum seekers, contact with justice system), disabled and people with life impacting conditions, those with poor broadband and mobile coverage, and those with low English language proficiency.

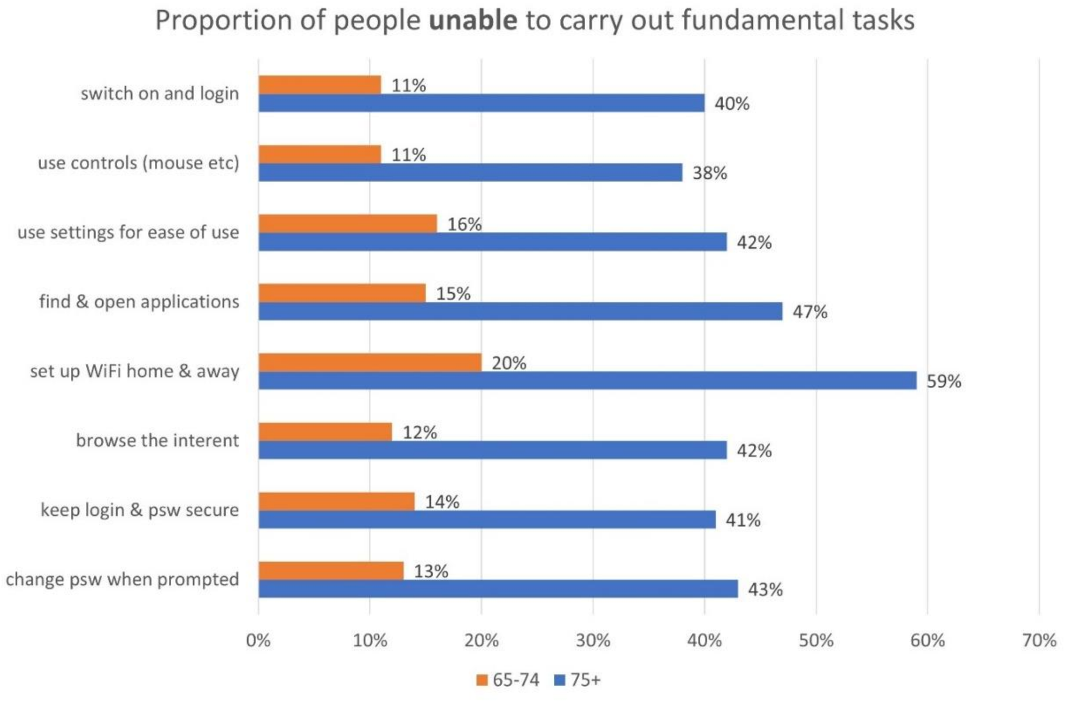
Many people who are able to connect to and use the internet have limited digital skills. Around 69% of people aged 75 and over and 30% of people aged 65 to 74 are not able to complete eight of the most fundamental tasks required to use the internet safely and successfully (Figure 2).

Figure 1. Device used to connect to the internet by age



Source: Reference 56

Figure 2. Proportion of people unable to complete 8 fundamental internet access tasks by age



Source: Reference 56

NHS App

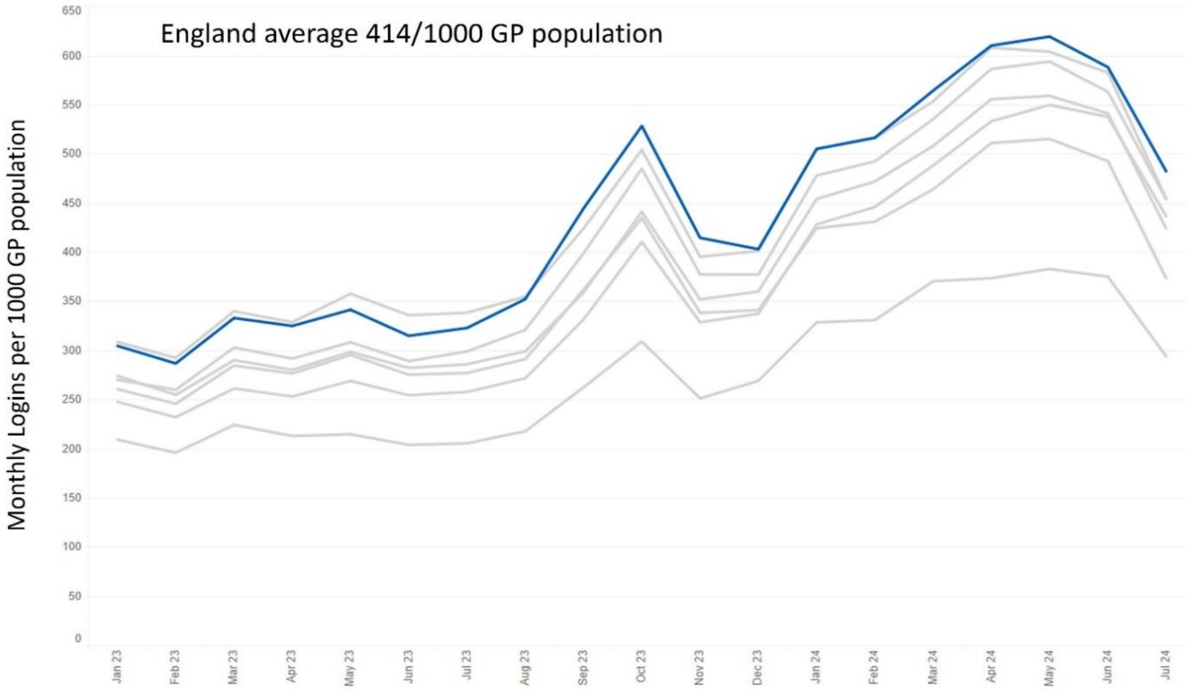
NHS England encourage patients and their healthcare providers to enable and allow patients to play an active role in shared decision-making and care. This shift is supported by access to EHRs via patient portals supported by the NHS App. NHS App usage increased during the Covid-19 pandemic and lockdown, but its use was not universal. Between January 2019 and May 2021 analyses by sociodemographic data found 25% lower registrations in the most deprived practices ($P<0.001$), and 44% more registrations in the largest sized practices ($P<0.001$). Registration rates were 36% higher in practices with the highest proportion of registered White patients ($P<0.001$), 23% higher in practices with the largest proportion of 15-34-year-olds ($P<0.001$) and 2% lower in practices with highest proportion of people with long-term care needs ($P<0.001$) [57].

Through patient portals there is secure and convenient access to a patient’s healthcare information, which can facilitate active engagement in their care. Patient portals already can provide access to diagnosis, laboratory and diagnostic imaging results, medication lists, booking and viewing appointment times, sending and receiving secure messages with their health care team, requesting prescription refills and conducting video visits, among other functionalities. Functionalities now available through the NHS App are viewing prescriptions and requesting repeat prescriptions, secure messaging, viewing patient GP health records, viewing hospital referrals, appointments and letters and viewing waiting times for hospital treatment.

NHS App registrations have increased from 21.57 million in December 2021 to 32.64 million at the end of July 2024. Although the target was to have 75% of people registered by 2024 currently 60% of GP patients age 13+ are registered for the NHS App. The number of logins in July 2024 was 26,242,481 which although much less than a peak during Covid of 60,463,210 in December 2021 still represents a monthly average of 41.4% of the GP registered population.

In the South East 61% of GP patients age 13+ are registered. In England in July 2024 monthly logins averaged 414 per 1000 GP population and the highest was 479 in the South East region (Figure 3). Within the South East the range was from 377 to 569 per 1000 GP population.

Figure 3. Monthly NHS App Logins in England by Region (South East in blue)



Source: NHS App Reporting Dashboard

Looking ahead the plan is to build functionality into the NHS App to support wellness and promote health by incorporating screening and other vaccination programmes in addition to Covid 19. The South East has made good progress and the work to integrate acute trust patient portals into the NHS App has seen 17 of the 18 integrated by March 2024 ensuring a regional coverage of significantly higher than the national average.

Integrating a patient’s own data from across the healthcare system into their own personal health record is a goal shared by all and there are solutions available that purport to do this. One of the most available providers of access to healthcare data to create a personal health record supported by the NHS app is Patients Know Best (PKB) [58]. PKB already supports 19 ICSs in collating and linking GP and hospital records into a personal health record for about 18 million patients to date. PKB is funded by NHS organisations such as hospitals, health boards and local practices and is therefore for patients is free at the point of care.

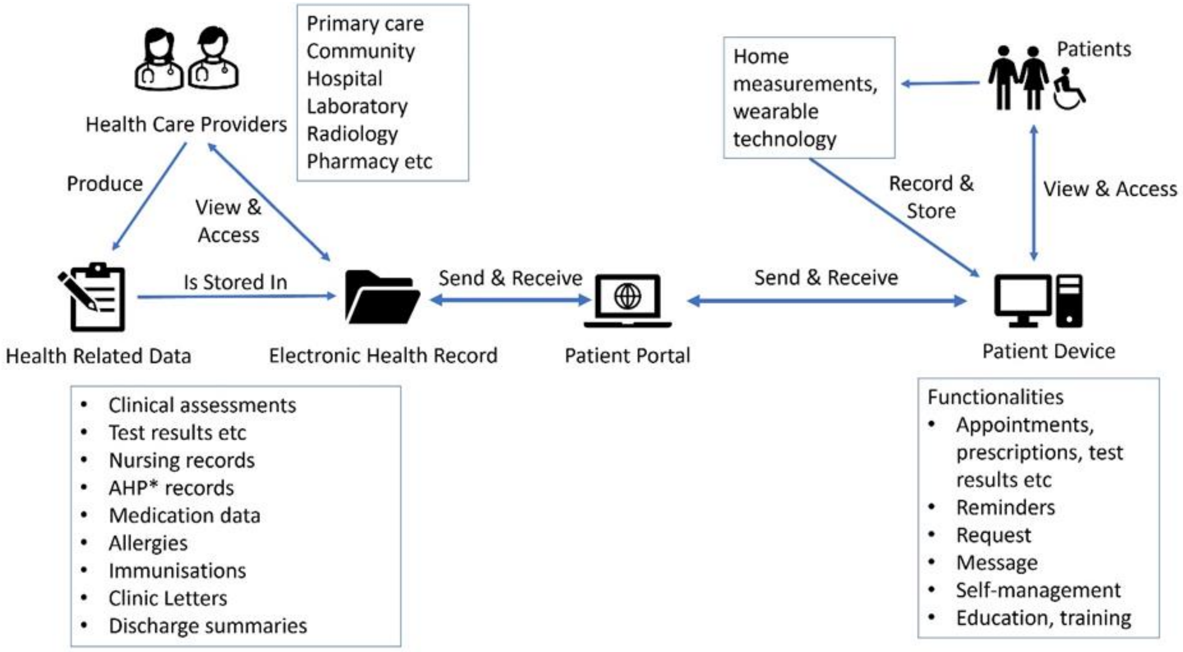
There is still work to do, not just to address the digitally excluded but also those with low health literacy. It is estimated that 7.1 million adults in the UK read at or below the level of an average 9-year-old, with more than 4 in 10 adults struggling to understand health content written for the public [59]. Low health literacy is linked to poor health outcomes and groups particularly at risk include people with language barriers, people with learning disabilities and people living with dementia. The NHS also needs to recognise the financial cost for many of digital access.

11. What could be achieved in the future?

Currently although the campaign to achieve 75% of the population registered to use the NHS App is making good progress the functionality for those already registered is well below what can potentially be achieved with existing technology and systems.

Figure 4 is just one illustration of how patients could be linked to their healthcare providers in the future with 2-way information flows between patients/families/carers and healthcare providers.

Figure 4. Patient access to healthcare records and linking patients to providers



*AHP, allied health professionals

That 2-way transfer of information includes patient appointment booking and rescheduling, provision of patient generated data either from their own measurements or from wearable devices, patient information, education and training, and much more sophisticated messaging which already exists but is not readily available. Links to patient friendly information and translation into different languages with appropriate cultural delivery should also be achievable.

We should adopt the benefits of patient access to healthcare records; patient portals have demonstrated benefit by enabling the discovery of medical errors, improving adherence to medications, and providing improved patient-provider communication

[60]. Data from the US Health Information National Trends Survey suggested that patients are more likely to interact with their records and their providers when accessing their electronic medical records using a mobile health app [61]. The impacts of mobile health app usage fade with age for tasks consisting of viewing, downloading, and transmitting medical results to a third party, but not for those involving patient-provider interaction or patient-personal health information interaction. Breast cancer literature indicates that electronic messaging with providers was associated with clinical benefits for breast cancer patients and improved screening behaviours [62]. In Dermatology digital media are widely accepted by both patients and dermatologists and can positively influence both the dermatological patient journey and patient-physician relationship [63].

We should also learn from where initiatives have sounded a note of caution. A systematic review of use of digital health interventions in promoting physical activity identified 130 randomised controlled trials [64]. Compared with usual care or minimal intervention, digital health interventions increased objectively measured physical activity and physical function, the secondary outcomes also favoured the digital health interventions for subjectively measured physical activity and physical function, depression, anxiety, and health-related quality of life at the end of the intervention but only subjectively measured physical activity at follow-up. The risk of nonserious adverse events, but not serious adverse events, was higher in the digital health interventions at the end of the intervention, but no difference was seen at follow-up. The authors concluded that digital health interventions improved physical activity and physical function across various chronic conditions. Effects on depression, anxiety, and health-related quality of life were only observed at the end of the intervention. However, the risk of nonserious adverse events was present during the intervention, which needs to be understood.

12. Artificial Intelligence

Artificial intelligence (AI) has rapidly established progress in tasks such as diagnostics, data analysis, and precision medicine. We have alluded to the role of AI in potentially reducing primary care workload (Table 1) and the development of language models unlock a number of possibilities for effective patient communication. The aim of patient access to healthcare records is to ensure patients fully understand health information, better navigate the health care system, engage in the health care process and manage their own health. The overall goal being to improve outcomes and quality of care. Patient-orientated communication is central to achieving this [65] and the recent availability of what are termed large language models (LLMs) are potential tools to achieve this. LLMs are machine learning models that can comprehend and generate human language text and are called large because they’re trained on vast amounts of data. The continued growth of AI has spurred interest and debate concerning their broader use in patient care.

LLMs like ChatGPT, Med-PaLM and OpenMedLM [66-68], generate responses in a conversational manner to written statements entered by users in a chat window. This is achieved without the need for coding, as the models utilise their training and data to generate contextually relevant responses, offering the possibility to offer safe and helpful answers to questions posed by patients. They can also be used to transform medical letters, investigation reports and discharge summaries into a patient-friendly format [69].

There are caveats, particularly patient safety concerns from inaccurate outputs generated by AI termed hallucinations [70]. These are not unsurmountable and the system itself can be used to catch its own mistakes and if used carefully and with caution, these evolving tools have the potential to help healthcare providers deliver quality care. A further caveat is the ability of AI to duplicate the human aspects of care, including empathy and compassion which, together with critical thinking and complex decision-making, are essential for holistic patient care. Nevertheless, AI can empower the practice of medicine, potentially address physician burnout by automating repetitive and monotonous administrative tasks and may have a role in improving access to care and addressing clinician workforce shortages.

13. Conclusions and recommendations

From the health care system perspective, an increased usage of EHR systems by patients able to access and use patient portals could redirect non-digital healthcare resource to those patients not able to access and use patient portals. Increased EHR usage can improve the usefulness of information exchange on EHR platforms and justify delivery of patient portals. Being creative in developing innovative and useful features of these systems, in particular 2-way flows of information and data, is imperative. An in-depth knowledge and understanding of the levers for increasing patient access to healthcare records is required to develop mediated health communication targeted at raising the awareness of access to EHR and bringing patients further along the entire usage process. Recent trends toward understanding the implications of immediate access to most test results gained from other countries experiences, exploring ways to close gaps in portal adoption and use among different sub-populations, and finding ways to leverage portals to improve health and health care are the next steps and are key areas that require more research. Clearly implementation of patient access to EHRs has the potential to widen health disparities and policy needs to mitigate this through changes to help those with lower socioeconomic status gain access.

Healthcare professionals can help engage patients in their care and promote patient autonomy and informed decision-making through better understanding of what functionality patients require via patient portals and through guidance on how to access and use portals. Healthcare professionals also need supporting through ensuring that they have the time to teach patients and to adapt their record keeping to transparent and immediate access. Clearly encouraging patient portal use has the additional benefits of enabling all stakeholders to share information and prevent duplication of effort.

To mitigate issues of patient anxiety arising from accessing uninterpreted test results in real time patients need to be aware of the purpose of the tests, the timing of result release, likely findings, and next steps in the event of abnormal results. Timely and adequate communication between healthcare professionals and patients is the key to the successful implementation of a direct result release via portals. It is therefore important to consider the embargo period in relation to the patient population, physician specialty, and type of results being released. The very real issues of healthcare providers key concerns need to be addressed and mitigated, in particular extra work, reduced efficiency, increased burnout and legal concerns. Healthcare providers are also concerned about increased patient anxiety and possible safeguarding risks.

The NHS must continue to invest in the infrastructure necessary to deliver virtual services, including offering flexible, multimodal options that can meet the preferences and needs of diverse patient populations.

All of us need to support patients better, especially through transitions in access to EHR and engagement in their health care and we must understand and address clinician concerns and resistance to changing note documentation practices to communicate better with patients.

Healthcare leaders and researchers should develop, evaluate, and disseminate the results of innovative portal efforts to equitably engage patients and healthcare professionals. They should also engage diverse patients in the design and testing of portals and features.

Providers of EHR systems and patient portals should make it easier to create a proxy account and offer patients more control over what formal proxies can access.

Limited health and digital literacy are common and impact on confidence and satisfaction with telemedicine therefore clinical services need to take account of people unable to access services digitally. Engaging with service users to co-design services will assist to mitigate adoption and uptake risks.

Areas for future research

Patient access to healthcare records lends itself to research – research to understand what works and adds value to patient access to healthcare records and what does not. High-quality studies are needed to fully understand, improve, and evaluate their impact. Finally, the 2-way flow of information made possible by patient access to healthcare records and their healthcare providers also lends itself to identification and recruitment of patients into future research studies. Suggested areas are:

- Data on how provider attitudes and practices change when supporting patients viewing test results via a portal.
- How to better support patients as they view their EHR, especially test results, outside of interactions with health care professionals (e.g., understanding the potential role of artificial intelligence tools such as chatbots).
- Direct consequences of immediate access to EHR, and especially test results, for patients across health care contexts (e.g., safety net).
- How newer mechanisms for viewing and leveraging a patient's clinical data will affect patient portal engagement.
- How to integrate AI whilst ensuring its accuracy, safety, and effectiveness.
- How to address persistent disparities in the uptake, use, and effectiveness of portals.
- How proxy accounts could be improved to better support caregiver needs and how to increase proxy account creation.
- How to build on the progress in portal engagement made during COVID-19 for sustainability outside of the public health crisis.
- In addition to quantitative methods employ qualitative research methods, these can help us better understand opinions and experiences which are critical when aiming to provide person centred care.
- How to best support inclusion health groups.

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Appendix B – Patient Access to Healthcare Records Sample Survey

Thank you for agreeing to take part in this piece of work. The below provides some more information which we hope you will find helpful. Should you require anything further please do not hesitate to ask.

The South East Clinical Senate is currently undertaking a project looking at patient access to healthcare records reviewing the current evidence and the status of the patient access across the southeast. At present patients may have several different electronic healthcare records for example, their primary care (GP) record, hospital records (both local hospitals and referral hospitals), community records and sometimes mental health records too. Although there is communication between healthcare providers these separate records are not currently joined together, but potentially may all be accessed by patients using the NHS app. We are asking the following questions.

What is achievable now and what could be achievable in the future?
What are the obstacles, risks and benefits?
How do we ensure we meet the needs of inclusion health groups?
and, critically
What do patients and the wider public want?

In the 'How do we ensure we meet the needs of inclusion health groups?' and 'What do patients want?' sections of the report we wish to represent patient views across the southeast and are asking patients and the wider public to complete a survey and/or take part in a focus group.

The survey has 20 short question and will take approximately 10 minutes to complete. Your answers will be collated and combined with other people's answers to enable us to give the consensus view of different groups across the southeast.

1. Choose one option that best describes you.	**Please tick**
Female	
Male	
Prefer to self-describe - please write here	
Prefer not to say	
2. Please indicate your age band below	**Please tick**
15-24years	
25-34 years	

35-44 years	
45-54 years	
55-64 years	
65-84 years	
Up to 85 years and over	
3. Choose one option that best describes your ethnic group or background	**Please tick**
Asian, Asian British, Asian Welsh	
Black, Black British, Black Welsh, Caribbean or African	
Mixed or Multiple	
White	
Other ethnic group	
4. Thinking about fundamental internet access tasks. Place a tick in the box for each of the following tasks you are able to do.	**Please tick**
Switch on and login	
Use controls (mouse etc)	
Change settings for ease of use	
Set up WiFi both at home and away	
Browse the internet	
Keep your login and password secure	
Change your password when prompted	

Thinking now about what you would like to have access to. What would you like to be able to do and read online in terms of your healthcare? Please answer the questions below.

Do you want to have the following available to you via online access? (tick all that apply).		**Please tick**
Facility	**Description**	
5. Appointment scheduling (This concerns specific transactions in date and time. Booking, changing, updating appointments whether at GP surgery or hospital)	Book and change routine appointments.	
	Securely book appointments for confidential care (For example, sexually transmitted disease (STD) clinics, contraception, substance use treatment centres).	
6. Consultations	Distinct from appointments above. Specifically in-person or online via telephone or video with a healthcare professional.	
7. Telehealth	Access appointments (routine or confidential) by telephone or video call.	
	Access appointments via telephone or video call when you do not have transport available.	

8. View Care Team (you may have more than one, for example your GP and practice or specialist nurse, your hospital doctor etc)	Keep track of all your care team members and clinicians.	
	Be able to provide information about your healthcare to new clinicians who become involved in your care.	
9. Secure Messaging	Send and receive secure messages.	
	Communication with healthcare provider (for example, doctors and nurse both in the hospital and community) using text messaging.	
	Ask questions and/or request change to your care.	
	Enquire about options for confidential care services.	
	Get reminders (e.g., upcoming appointment, prescriptions, preventive care).	
	Get notifications about new content such as when your test results are available.	
	To make decisions with your healthcare professional (nurse, doctor, physio) in advance of your appointment. Such as, not to have any treatment in certain situations.	
10. Photos and Videos	Send photos or videos to healthcare professionals, for example, to doctors, nurse, physios to improve your telehealth appointments by providing photographs of your condition.	
11. Medical Record	See historical information (personal and family medical history, immunisation records, allergies) Complete screening assessments that communicate with your healthcare records without needing to be manually transcribed.	
	See current medical information (medications, test results, clinical notes, upcoming appointments).	
	To be able to have home readings for example of blood pressure, oxygen saturation or blood sugar automatically uploaded from different types of devices or to send manually.	
	See patient education materials relating to diagnoses, medications and test results.	
	Complete screening tools and other data collection forms online prior to visit.	
	Complete screening assessments that communicate with larger Electronic Healthcare Record (EHR) systems.	
12. Medicines Management	Ask questions about medications, for example dosing, side effects, drug interactions.	
	Request repeat prescriptions.	
13. Immunisations	Review immunisation records.	
	Print out immunisation records for travel, work, school.	

14. Letters and information	Updates from clinic visits and hospital admission.	
	Explanation of test requests, test results and actions required.	
	Explanation of medication changes and any expected side effects or potential interactions.	
	See clinic letters and discharge summaries.	
	See medical reports (for example, for insurance, sickness absence).	
	Signposted to links to accredited information sites that the healthcare provider recommends.	
15. Sharing of Records	Share information on your patient portal with family members.	
	Give access to healthcare professionals from other organisations.	
	Manage proxy access (give access for someone to act on your behalf).	
	Be able to give parental access (children aged 16-18 years).	
16. Resource Links and education	Access medical and wellbeing information, recommended by the healthcare organisations.	
	Access education, training, or support materials for patient portals (how to get the most out of your online access).	
17. Usability	More user-friendly format, easier to use and navigate.	
	Better display of information, especially test results.	
	Range of platform options (smart phone, tablet, laptop etc).	
	Rapid but secure log-in.	
	Improved accessibility (e.g., visual impairment).	
	Reduced constraints (e.g., days/times blocked from online appointment scheduling).	
	Notifications before automatic actions (e.g., before a session times-out).	
18 Account Settings	Update photo, address, telephone numbers, email.	
	Select communication preferences (eg, email, text, phone).	

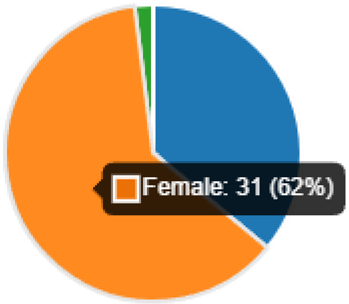
19. Is there anything else you would like to have that is not listed above?

20. Do you have any other comments?

Appendix C - Survey Results

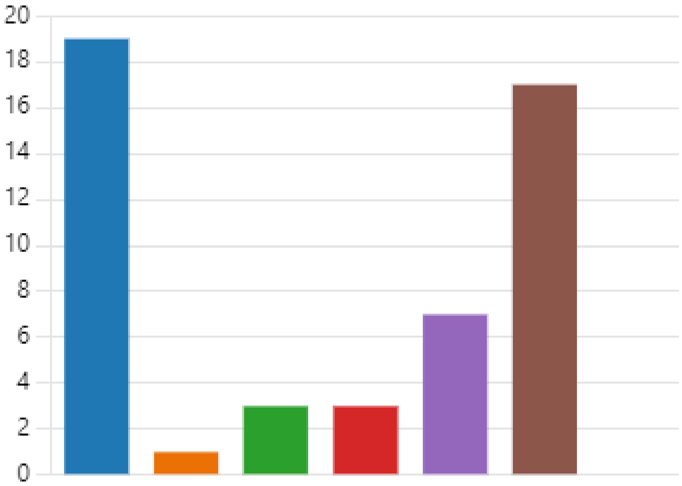
1. Choose one option that best describes you

🟦	Male	18
🟧	Female	31
🟩	Prefer not to say	1
🟥	Other	0



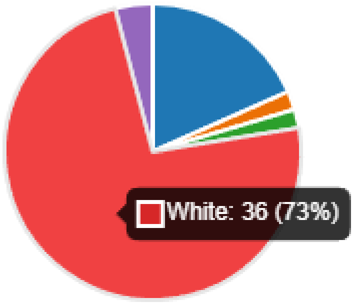
2. Please indicate your age band

🟦	15-24 years	19
🟧	25-34 years	1
🟩	35-44 years	3
🟥	45-54 years	3
🟪	55-64 years	7
🟫	65-84 years	17
■	85 years and older	0



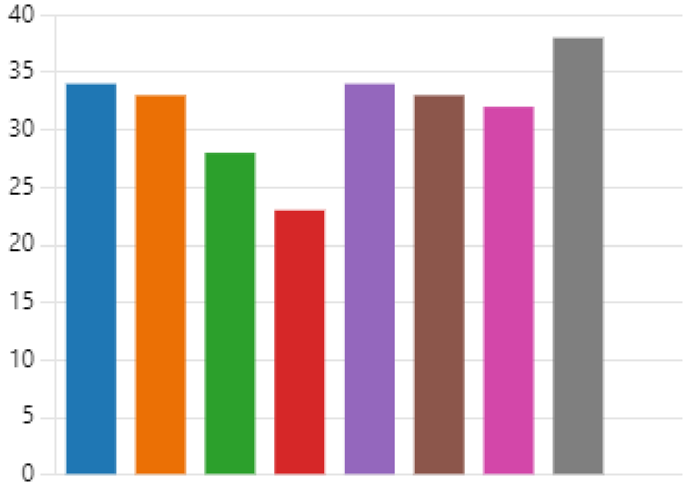
3. Choose one option that best describes your ethnic group or background

🟦	Asian, Asian British, Asian Welsh	9
🟧	Black, Black British, Black Welsh, African, Caribbean	1
🟩	Mixed or multiple	1
🟥	White	36
🟪	Other	2



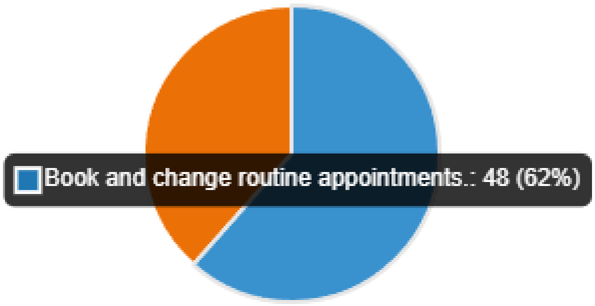
4. Thinking about fundamental internet access tasks. Select each of the following options you are able to do.

🟦	Switch on and log in	34
🟧	Use controls (mouse etc.)	33
🟩	Change settings for ease of use	28
🟥	Set up Wi-Fi both at home and away	23
🟪	Browse the internet	34
🟫	Keep your log-in and password secure	33
■	Change your log-in when prompted	32
■	All of the above	38
🟨	None of the above	0



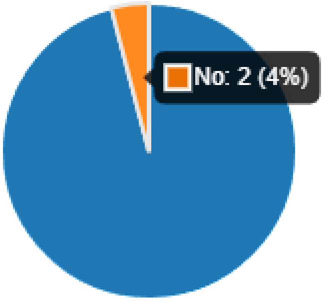
5. Appointment scheduling. (This concerns specific transactions in date and time. Booking, changing, updating appointments whether at GP surgery or hospital)

🟦	Book and change routine appointments.	48
🟧	Securely book appointments for confidential care (For example sexually transmitted disease (STD) clinics, contraception, substance use treatment centres).	30



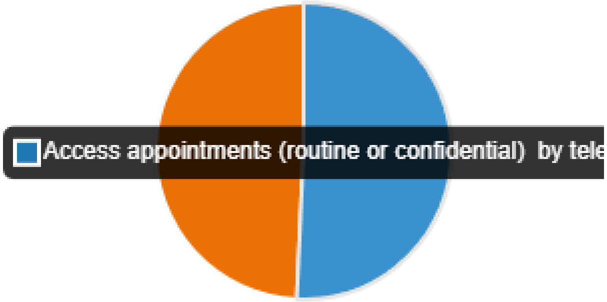
6. Consultations. Distinct from appointments above. Specifically in-person or online via telephone or video with a healthcare professional

🟦	Yes	47
🟧	No	2



7. Telehealth

🟦	Access appointments (routine or confidential) by telephone or video call.	35
🟧	Access appointments by telephone or video call when you do not have transport available.	34

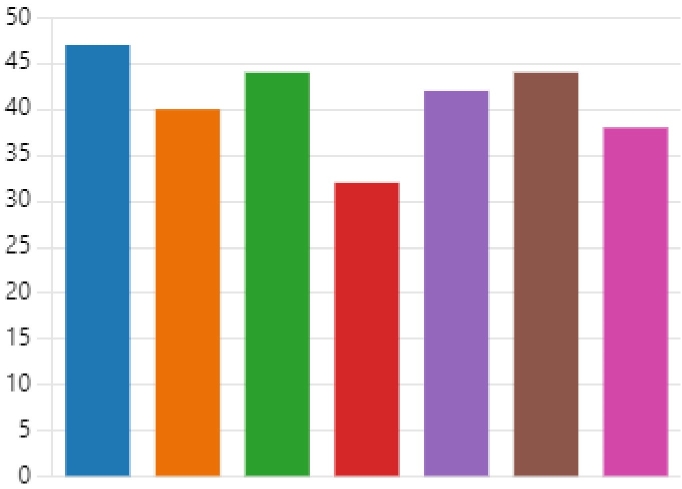


8. View care team (you may have more than one, for example GP and practice or specialist nurse, your hospital doctor etc.)

🟦	Keep track of all of your care team members and clinicians.	43
🟧	Be able to provide information about your healthcare to new clinicians who become involved in your care.	41

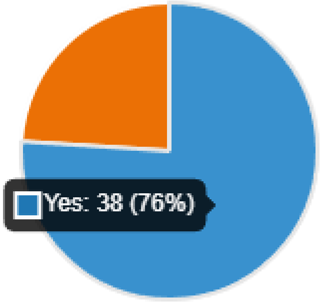
9. Secure messaging

🟦	Send and receive secure messages.	47
🟧	Communication with healthcare provider (for example, doctors and nurse both in hospital and community) using text messaging.	40
🟩	Ask questions and/or request change to your care.	44
🟥	Enquire about options for confidential care services.	32
🟪	Get reminders (e.g. upcoming appointments, prescriptions, preventative care).	42
🟫	Get notifications about new content such as when your test results are available.	44
■	To make decisions with your healthcare professional (nurse, doctor, physio) in advance of your appointment. Such as, not to have any treatment in certain situations.	38



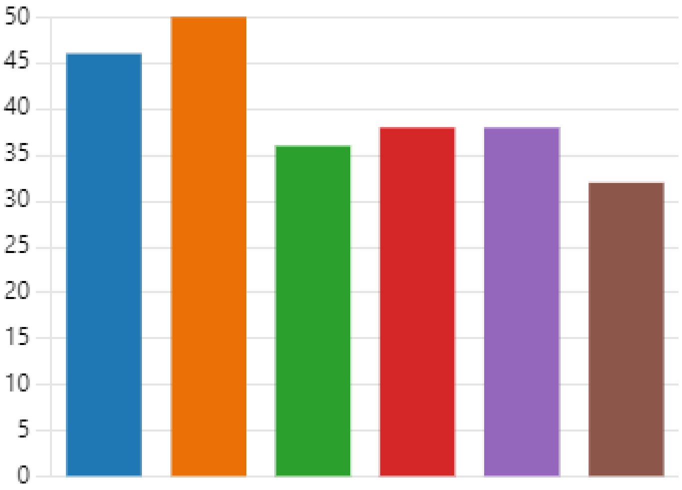
10. Photos and videos. Send photo or videos to healthcare professionals, for example to doctors, nurse, physios to improve your telehealth appointments by providing photographs of your condition

🟦	Yes	38
🟧	No	12



11. Medical record

🟦	See historical information (personal and family medical history, immunisation records, allergies), Complete screening assessments that communicate with your healthcare records without needing to be manually transcribed.	46
🟧	See current medical information (medications, test results, clinical notes, upcoming appointments).	50
🟩	To be able to have home readings for example of blood pressure, oxygen saturation or blood sugar automatically be uploaded from different types of devices or to send manually.	36
🟥	See patient education materials relating to diagnosis, medications and test results.	38
🟪	Complete screening tools and other data collection forms online prior to visit.	38
🟫	Complete screening assessments that communicate with larger Electronic Healthcare Record systems.	32

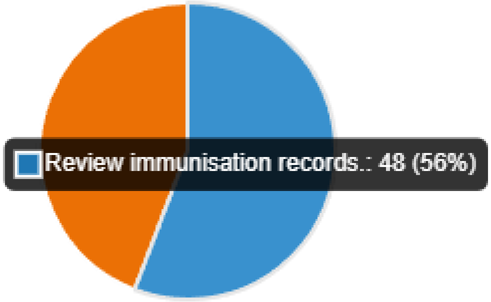


12. Medicines management

🟦	Ask questions about medications, for example dosing, side effects, drug interactions.	44
🟧	Request repeat prescriptions.	44

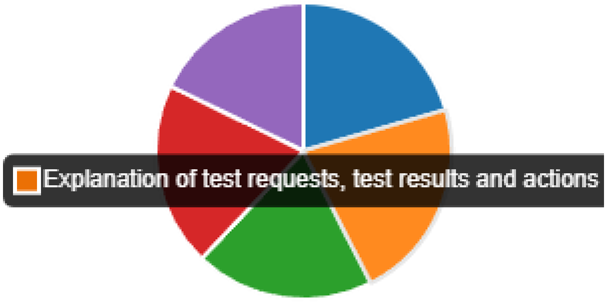
13. Immunisations

🟦	Review immunisation records.	48
🟧	Print out immunisation records for travel, work school.	38



14. Letters and information

🟦	Updates from clinic visits and hospital admission.	45
🟧	Explanation of test requests, test results and actions required.	48
🟩	Explanation of medication changes and any expected side effects or potential interactions.	43
🟥	See clinic letters and discharge summaries.	44
🟪	See medical reports (for example for insurance, sickness absence).	39



15. Sharing of records

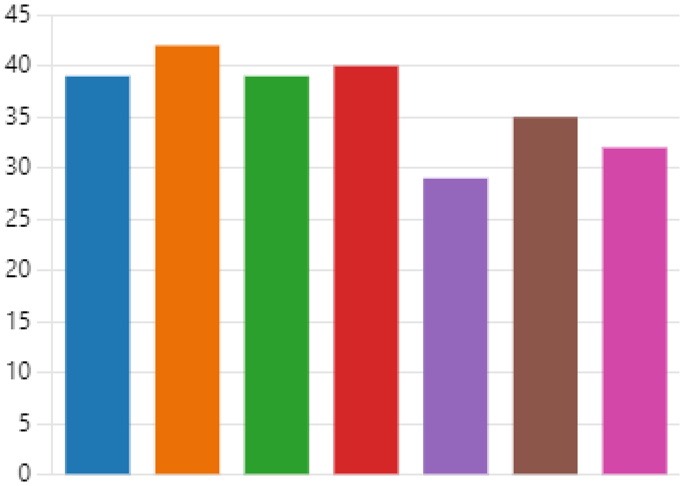
🟦	Share information on your patient portal with family members.	24
🟧	Give access to healthcare professionals from other organisations.	33
🟩	Manage proxy access (give access for someone to manage on your behalf).	30
🟥	Be able to give parental access (children aged 16-18).	23

16. Resource Links and education

🟦	Access medical and wellbeing information, recommended by healthcare organisations.	42
🟧	Access education, training or support materials for patient portals (how to get the most out of your online access).	33

17. Usability

🟦	More user-friendly format, easier to use and navigate.	39
🟧	Better display of information, especially test results.	42
🟩	Range of platform options (smart phone, tablet, laptop etc.).	39
🟥	Rapid but secure log-in.	40
🟪	Improved accessibility (e.g. visual impairment).	29
🟫	Reduced constraints (e.g. days/times blocked from online appointment scheduling).	35
■	Notifications before automatic actions (e.g. before a session times out).	32



18. Account settings

🟦	Update photo, address, telephone numbers, email.	43
🟧	Select communication preferences (e.g. email, text. phone).	47

19. Is there anything else you would like to have that is not listed above?

- A fast login service that doesn't have aspects of request that close when the surgery closes, thank you
- Read reports of previous scans (once already discussed with a professional)
- Access to discharge records
- Contact with a human Health Professional preferred to a electronic gizmo
- To be able to see results from treatment by paramedics and also from being taken to A & E.
- To have a simple guide to where all these information places are
- Choice of a degree of medical description e.g basic language, scientifically comprehensive or full and advanced medical detail
- Information on the process following a treatment request/GP referral. How long are the waiting times between each step e.g. GP appointment, consultant review, treatment? What are those steps - what is the organisational structure (GP, consultant, specialists)?
- It would be useful to be able to book a blood test or other tests easily online without the need to schedule an appointment before being able to do the blood test.
- One entry portal
- The forms to book appointments for GP should be easy enough and not request information such as what do you want from the doctor. Someone more health literate will request more than maybe a person that does not and might therefore get a different level of care as a result of how they complete the form.

20. Do you have any other comments?

- The NHS App I already have is good
- This sort of access would help to lessen the health inequalities faced by neurodivergent people as often telephone calls are difficult for them to cope with meaning they are unable to seek help when needed.
- Clear understanding of test results and impact on your current health
- Having everything in one place and to be able to communicate in real time with healthcare professionals would be a good step forward
- Better to have limited facilities which work rather than Grand Designs with errors.
- Make sure we have somewhere to go to get up to date information about what is available and how to find it.
- The system where patients can access all of these, especially health records, should be centralised across whole nation not just regional. This will aid when people relocate, help students at university etc. And make

sure information from all referral services are on this site, as much information as possible. I think centralisation and alignment is important.

- Want all access and be able to make decisions myself about what I see and what questions would be helpful to be answered
- I wouldn’t want to see genetic testing results, unless I specifically requested.
- Really want to have health records shared within the NHS also if for a hospital visit medical history is requested can the patient easily provide that information if they have access on the patient portal
- One concern is about self diagnosis. Patients might think everything is online so what's the point of seeing the doctor.

Appendix D – Focus Group Results

THEMES	**FOCUS GROUPS**		
	UNIVERSITY ATTENDEES	**SIXTH FORMERS**	**TRAVELLER COMMUNITY**
PRIVACY		**Parental access:** Differing opinions expressed about how much access they would wish parents to have. One participant commented there should be, *"parental controls, but for parents"* meaning the participant should be able to set the controls regarding what healthcare information their parent could and could not access.	Within the community, women don't share information regarding their own health with men unless it is deemed serious (even then will probably only share with husband); however the community is tight-knit and there is a lot of support for one another between women, *"travelling women don't share with their men folk".* Would be embarrassed to discuss health with their children and would not want to worry them. Mixed feeling on how long wish to see their children's healthcare records. 1 participant said *"forever",* consensus was until they are married. Older women in the community *"problem solve"* Women would prefer to see a female healthcare professional unlikely to fully disclose the problem if see a male/ may not attend if it is a male. Group reported this was not an issue for the men, men would see male or female healthcare professional.

SAFETY	Concerns over ownership of stored data. Included how personal data is stored and who may be able to access it (not limited to other family members more of a concern in terms of corporate companies and how such companies would use their health information). Safe transfer of results to another healthcare provider particularly in an emergency situation. One portal was considered a way of mitigating transfer of data between providers.	Lack of awareness of who owns their healthcare record.	Would prefer paper records such that they can be kept and filed in a safe place at home and referred back to. Lack of trust in knowing that the data on their health is safe and kept confidential. Mixed feelings in the group about how safe a digital record is, possibly ok to receive 'minor' information digitally. Serious illness, defined as, cancer, wish to see a doctor and be able to have someone they know with them, this was described as *"halving the pressure".*
ACCESSIBILITY	University students living arrangements are transient. Flow of information between providers is an issue, different from transfer of results above, linked to their own movement and living in different town to home town while at university and struggles to access information from 'home GP' when seeing 'university GP'. Significant variation noted amongst participants when discussing what/when/how they access their healthcare records.	Would like to see personalised records	Barriers to accessing devices that allowed them to use the NHS App and therefore their data e.g. with use of older model mobile phones that don't have app functions. Training on how to use the NHS App may be helpful but it is difficult to retain the knowledge unless immediately applied. However, mentioned that the next generation who are attending school and will have a higher level of literacy may not face the same barrier. PIN access issues even when there are no competency issues accessing apps. Wrong PIN/ unable to contact someone to get the right PIN. This comment made in relation to maternity services. Mention of maternity services becoming less and less accessible through the

			years (from bi-weekly visits made possible to intervals of months). Mention that for those with autism / difficulty expressing may find digital access more helpful. Timing and waits for appointments problematic if moving around. Compounded if unable to understand letters/results as have to wait again before can get another appointment to have them explained.
COMMUNICATION	Control over the information they receive, may not wish to either receive all the results digitally and/or wanted to be able to control the time when those results would be sent to them. One participant commented, *"why do patients not have the right to get their results?"*, another one commented on not needing the, *" full blown detail"*. The importance of access with understanding of what they are viewing Annoyance expressed at having to constantly repeat information when see different healthcare professionals. Lack of communication between primary, secondary care and also pharmacies was raised particularly when advocating for another person. Examples given where for a participants child and mother. Would like to have control over booking appointments and who they may see.	Several participants had access to their parents' healthcare records. They needed to navigate healthcare for their parents due to language barriers and health and digital literacy.	Believe that calling for an appointment will be the easiest and quickest way to access clinical attention. Low literacy (reading and writing) impacting on ability to understand the data even if digital access wasn't the issue – not being able to understand messages if came through an app / text / email – would much prefer to be able to receive results face-to-face and ask questions and can bring a companion to help comprehend. Not understanding the words in healthcare letters increases their worry and makes them *"feel stupid".* Having the function for the information to be read out may help but; • concern for privacy issues (others can hear it) • they have difficulty with apps being able to understand their accent

	Information required on the online form to get a GP appointment was considered excessive. One participant commented, *“you have to pretend you are dying”* to be seen.		• due to their literacy difficulties generally, and health literacy in addition they often are unable to pronounce words correctly from the doctors’ letters and therefore a read aloud function is not helpful. • Would like continuity, to see the same healthcare professional and not have to keep explaining their history/situation.
TECHNOLOGY		Use of an AI chat box for asking questions. Having sufficient data on mobile phones to download app (gaming apps taking priority). NHS App knowledge limited, only 20% of the group aware of the app, only 1 member had access information via it, this was a covid pass to enable travel. All saw relevance of being able to access their vaccination history.	Not feeling confident using digital technology by themselves. Sometimes looking up what it says in the letter on google is very worrying, it doesn’t help. Ok to get appointments sent via text. Thought a good feature of technology is the appointment reminders.
PHYSICAL & MENTAL HEALTH		One participant asked the question if the healthcare information recorded would be physical and mental. The whole group felt it important mental health was included, a general acknowledgment within the group of the significance of mental health issues.	