healthwatch

Personalisation: giving people power to control their own care and have shared responsibility for achieving better health

April 2022-May 2023

Introduction

We know that patients and the public want as much control as possible over their care, and they want it to be appropriately tailored to their needs. The NHS Long Term Plan made personalised care a key principle for the NHS and set out an action plan for rolling out personalised care across England.

Patient rights to make choices about where they receive healthcare has always been central to the NHS and has been increasingly enshrined in legislation and the NHS constitution over time. The legal rights covered in the NHS Choice Framework include:

- Choosing a GP and GP practice
- Choosing where to go for a first appointment as an outpatient
- Asking to change healthcare provider if maximum waiting times are exceeded
- Choosing to have a Personal Health Budget.

The Comprehensive Model of Personalised Care sets out six components of personalised care, including shared decision-making, enabling choice, and social prescribing.

In this briefing we will share some of the evidence we hold about the kinds of choices people want and how the power to choose can give people more control over their own health. We will highlight the positive impact of cases where people are currently given these choices and demonstrate that these choices are not currently always available to people.

Our evidence shows that giving people flexibility and control over how they receive care leads to better patient experience. We also highlight how giving people the right information and technological tools can support people to make informed and empowered choices.

Yet people are not always aware of their right to choose healthcare providers or participate in shared decision-making about their own treatment. They are not always supported to take a lead in decision-making about their own care. Crucially, even when people are offered these choices, they are not always meaningful. A choice may exist on paper, but not be genuinely accessible to people. This includes examples where people are offered a choice of provider, but cannot access appointments at any of them.

While personalised care and choice remain important to people, in many cases a baseline quality of care or access to services are more important than having a choice of provider. In many areas of the NHS, a laudable ambition to provide personalised care is not being delivered due to wider staffing shortages, for example in maternity care, where targets to provide universal continuity of carer were suspended due to staffing problems. Improving access to health services across the board should underpin NHS policy on personalisation and choice going forward.

Methodology

This briefing is based on:

- an analysis of 4,350 pieces of feedback received in 2022/23 from 53 Healthwatch relevant to the theme. We used a variety of search terms to come up with the dataset.
- seven reports relevant to the theme researched by Healthwatch representing the views of 39,413 people
- Insights from our previous research projects on access to GPs, elective care waiting times, referrals, maternity care, maternal mental health and urgent and emergency care waiting times and experiences.

Key findings

The key messages around personalisation emerging from our evidence review across all service areas include:

- People want **flexibility in appointment types, times, and type of professional**. This is often not a matter of personal preference but essential to access due to communication requirements or work or caring commitments.
- People are **open-minded about seeing different services or professionals**, as long as they are informed about their options and these options are genuinely accessible. More could be done to **increase awareness of alternative services** like NHS 111 First.
- While **choice in service provider** is helpful, this is usually motivated by the desire to access care more quickly and is not meaningful if there are significant barriers to access at all possible services. Commitment to **patient choice must be underpinned by improvements to access** across the system.
- **Continuity of care** is more important to some than others but is essential in some areas like maternity care. Continuity of care does not always have to mean a single professional if there is a sense of a continuous service.
- **Good communication** and being supported to make decisions about their own care **is the most important contributor to personalised secondary care**, especially while long waiting lists for care are a reality.
- Making choices about their own care is empowering to patients, but these **choices need to be meaningful**. Private care is not a choice for many, and neither is being given the option of different providers if none have capacity to treat them.
- **Online tools,** such as referrals trackers or texting with GP practices **can give people a more personalised and continuous experience of care**, **as long as they are joined up** and two-way, allowing for escalation to live communication where needed.

The choices people want – primary care

Choice of GP

Registering for a GP is an initial patient decision which can lead to later impact on many other choices. The NHS Choice Framework sets out patients' right to choose which GP practice they register with, although GP practices have a right to refuse registration if they are at maximum capacity, or if they decide not to accept registrations from outside their practice boundary.

We hear from hundreds of people every week on their experiences of GP care. Despite many people being dissatisfied with their experiences, many patients remain with the same GP. In many areas of the country **patients may have little or no choice over which GP they register with** if other practices are not accepting new patients.

We hear about **people getting de-registered** if they move catchment areas, even if they still live very close by. This can have a major impact for people whose GPs may have long-term knowledge of their families or conditions going back many years. We've heard this particularly impacts rural areas:

Someone new to the Buckinghamshire area only had the choice of one GP practice that was able to accept them and their family. This GP didn't have any urgent appointments. Unfortunately, they are stuck without the choice to change as there are no other GPs accessible in the area.

Healthwatch Bucks

Someone told us their mother has been forced to transfer surgeries, despite being informed that it was no longer necessary to move surgeries, the Practice Manager decided that their mother, a 95-year-old lady, who has been at the surgery for over 50 years, has to transfer. She is only just over the border and needs the familiarity. (White British woman aged 65 -79)

Healthwatch Birmingham

Choice of appointment times and types

Every patient is in a different situation, and ability or desire to take up phone or remote appointments will be mediated by work schedule, family responsibilities, digital literacy and access needs. Varying requirements call for flexible times and types of primary care appointment.

In our 2020 report The Doctor Will Zoom You Now and our 2021 report Locked Out, we highlighted the importance of giving people choice over the kind of appointment that is right for them, and the importance of quality communication no matter the type of appointment.

For many people, **phone or virtual appointments can offer much-appreciated flexibility** and allow them to avoid taking time out of work or traveling to a physical appointment. Where this suits patient needs, it can improve patient experience:

Positive feedback by daughter about her mother's GP practice in London - if you are in a queue for a call they will call you back which is fine if you can carry a mobile phone about with you - and she has been able to get a next day appointment. They have also made home visits. (Black British/Caribbean woman aged 65 -79)

Healthwatch Bath & North East Somerset

Since 2021, NHS England guidance has emphasised that GPs should give patients a choice over the type of appointment they want, unless there is a clear clinical justification for one appointment type over another. Yet we still **hear from people about the lack of choice they are given over the type of appointment** they have with their GP practice.

Not being given a **choice over the time of a phone appointment** can cause difficulties for people with work or family commitments, or people in areas with inconsistent mobile phone signal.

I had a blood test on Thursday and then had a message that I needed to phone the doctors, I rang at 8:30 and arranged for the doctor to call. I asked for a call after 9:30. I waited for the call but it didn't happen so I contacted the GP and they told me that the GP had tried to ring me at 9:24 but I had no missed calls. They said somebody would ring me back which they did but I was in the middle of helping my granddaughter use the toilet and couldn't get to the phone. I rang straight back but was told that I have to ring again in the morning at 8:30 to arrange another call. I can't take calls at work (I work in a hospital and am not allowed to have my phone with me), I only have one day when I can take calls during the day. Why can't they ring me back today.

Healthwatch Shropshire

Similar circumstances and requirements can also impact on people's ability to book an appointment in the first place:

The nurses are lovely. They always have time for you and they listen and if I was rating the service based on my experience with the nurses I would give it 5 out of 5. However everything else would be 0. It feels like the doctors don't care. The surgery seem unable to make any adjustments for patients' individual circumstances. Where I live there is a very poor mobile signal and I don't have a landline so when I am told the doctor will ring back I miss the call. I can't even make an appointment. I have told them this. Once I had

seen the doctor face to face and was asked to make a follow up appointment in 2 weeks. I asked at reception while I was there and was told I couldn't make the appointment in the surgery and would need to phone in even though I told them about the poor phone signal. I have been told by reception that if I can't call I can't have an appointment. It is so hard to get to see or speak to a doctor. I was also told by a doctor that my time was up and I would have to go even though I still had things to talk about. It seems like they don't care.

Healthwatch Norfolk

It is positive that many GP practices are using e-consult systems to allow people to book appointments or submit queries out of hours or without waiting in phone queues. However, we have heard from people that these systems are sometimes turned off out of hours or when all appointments for a certain time period are booked,

Online systems can also lead to one-way communications from GP practices by text message or email, which then do not allow patients to choose appointment type or time. To avoid creating additional barriers to access, **e-consult and online booking systems need to be freely available to use and lead to personalised responses**.

"New system online isn't working. There are many complaints that all the appointments are gone. The practice stated before it was rolled out that it would be an improvement. However, patients are not able to get appointments. Although people can use NHS 111 or the Urgent Treatment Centre, these services cannot refer them for treatment which means they have to go back to GP. What a wasteful system."

Healthwatch Sandwell

Preferences for virtual of face to face appointments are **different in rural and urban areas**. Research carried out by eight London Healthwatch shows that 67% of their 37,957 respondents prefer face-to-face appointments over virtual ones; this makes sense as majority of these patients live within 15 minutes of their surgery. However, a report by Healthwatch Norfolk indicates that patients in rural areas welcome the option of virtual appointments, particularly out of hours, as they find it harder to reach the surgery quickly. This highlights the importance of personalised choice to meet different needs in different contexts.

Access needs such as aphasia, autism, mental health difficulties, speech impediments or deafness **can also be a reason for requiring a specific appointment type**, or **requiring a longer appointment** to allow for interpreting or additional support. These issues surrounding access needs and appointment type are also highlighted in our other briefing on primary cand community care and in our research on accessible information.

I am Autistic and have Selective Mutism but the practice insists on phone appointments. (Female, aged 18-24)

An acquired brain injury can impair my ability to discuss complex medical matters, especially over the phone. (Male, aged 64-79)

Healthwatch Kent

Choice of type of professional

In our engagement with the public on primary care, people generally tell us they are **open to seeing different kinds of primary care professionals**, including practice nurses and pharmacists. As NHS policy has moved in the direction of diversifying the 'front door' to the NHS and giving more prescribing rights to pharmacists, people are increasingly getting used to this as an option. Yet **booking systems and triage processes do not always offer people information about these options** or allow them to request to book in directly with their preferred professional.

This is particularly frustrating for patients with chronic conditions who are very familiar with the system and the help they need. It is also an inefficient use of GP time and resource. More consistent choice and information at an early stage of the booking process can help alleviate pressure on GPs.

From our referrals research, we also know that patients, particularly those with long term conditions, know who they need to speak to about their condition, but are often made to go through a long and convoluted process to get there. Giving people **more choice to go directly to the appropriate medical professional** could save time for the system.

Mother contacted your surgery last Tuesday as she was in considerable discomfort from pain patches she has been prescribed to help treat the pain she endures from her issues with her kidneys, she asked to speak with a doctor and was told she would receive a phone call. On Wednesday, I rang the surgery to see what has happening regarding the phone call she had been expecting as she hadn't heard anything, I was told the in house pharmacist would ring her on Friday morning- not a doctor as she had wanted to speak to. She was still in considerable pain due to the reaction. I spoke to our local pharmacist and they suggested antihistamine medication to help until mother managed to speak to a doctor. I understand the surgery is struggling under the current pressures, but she asked to speak to a doctor rather than try to get an elusive appointment - she is elderly with considerable health issues which needed and still needs addressing. When will a doctor will be able to speak with her, either by phone or in person, although she feels that she's not important enough for an appointment! If your surgery are unable to offer care to my mother-in-law, please can you advise us of one which can? (aged 80+, Woman)

Healthwatch Gloucestershire

Diagnosis and continuity of care

Related to a choice of type of professional is the importance of feeling supported throughout a diagnosis pathway. While **continuity of care** is important to many, it is important for some groups of patients than others. Some patients will choose speed of access over ensuring they see the same professional each time.

It is also possible for GP practices to explore new ways of providing **continuity of care without necessarily having to provide continuity of care giver in a single individual**. This could include things like text message conversations with patients, where all professionals in a practice can have access to the conversation history, and can provide fast track routes into an appointment if problems occur. **A sense of a continuous service** is often what patients are looking for rather than the concept of having an appointment with their family doctor. When this is put in place it has a positive impact on patients:

I received a text from my surgery to book an appointment for a long-term health condition review. The text gave a link to a full page letter explaining the new set up. Instead of attending various clinics at different times at the surgery for monitoring of long term health conditions, they were now encompassing them all into one annual appointment to be reviewed in your birth month. The appointment included blood pressure, full blood test (covering cholesterol check, kidney, liver function), weight. I was also offered the Pneumonia immunisation which I had at the appointment. Results were posted on my Patient Access account. I received a text 3 days later advising of cholesterol and diabetes reading with links to information and Nurse at the surgery for further advice. It was a definite improvement on several different appointments, the appointment was very relaxed and the nurse had time to answer questions. Overall a good experience.

Healthwatch Surrey

Opportunities

To continue making the best use of remote care technologies without creating additional barriers to access, GP practices should respect patient preferences for appointment types. Giving people the agency to say what is right for them is not just about giving people what they 'want', but a vital way for the system to manage people's varying needs more effectively, and to ensure no one is excluded from accessing care.

Making effective use of technology can allow practices to provide a continuous experience of care, without people necessarily speaking to the same person every time. However, in the longer-term, giving people flexibility and consistent access to the choices set out in the NHS Choice Framework will require longer-term investment in the primary care workforce and growing primary care capacity.

This can be done through a variety of mechanisms, including training more clinical care staff, but also by investing in care navigators, admin staff, and cloud telephony or electronic triage systems to support better patient experience and free up GP capacity.

The choices people want – elective and maternity care

Elective care

The Covid-19 pandemic had a major impact on waiting lists and response times for elective care; this has been slowly but steadily improving in the past two years. However, **waiting times are not the only thing relevant to patients, and aspects of 'personalisation' can often be more importan**t. In 2019 Healthwatch England undertook some exploratory work to support NHSE's Clinical Review of Standards. This work indicated that while the length of time people wait for elective treatment and having choices over the provider that treats them are important, these factors actually rank lower when compared to good communication around their healthcare.

As part of a nationally representative poll, we asked the public to consider the 18 week RTT target and how much this mattered to them.

- The NHS "working to a target to diagnose and treat all people within a specific timeframe" scored a net positive score of 74%, and "being able to choose a service to handle your referral" at 72%
- Factors which scored more highly relate more to the relationship people have with services, in particular good communications:
    - Ensuring patients have the opportunity to discuss all treatment options (94%)
    - Ensuring the process of referral is simple and accessible (94%)
    - Prioritising diagnosis of patients to reassure people they will be seen in an appropriate timeframe for their condition (93%)
    - Waiting lists to be easily adjusted should a patient's condition change (93%)
    - Different services working together post treatment to help patients recover (93%)

Nevertheless, **choosing to go to a different provider** can help people to access care faster or more conveniently. However, through our recent referrals research, we found that **few people were given choices at the point of referral**. Choices could and should be offered when a GP refers a patient which could make their ongoing referrals journey better, but for many this isn't happening. Only 10% of

respondents were given a choice of locations, 8% a choice of appointment times and just 3% a choice of consultants.

Of those that were offered a choice of location, time, or consultant, **the options were often not meaningful.** For example, patients may be given a choice of provider, but the services might still have little capacity to provide the treatment.

A patient under a consultant at Hospital X for spinal treatment. They have advised her that the treatment required is no longer available at Hospital X through ICS. The consultant has mentioned two other hospitals who have funding to do the treatment, but they do not currently have any consultants to carry it out. She is wondering what her rights are to having the treatment carried out somewhere else, for example in a London hospital.

Healthwatch Cambs & Peterborough

This patient was offered a choice, but was not able to actually access the care she needed, and was not given information on how to proceed. This issue crops up repeatedly in our feedback:

I was referred for two separate issues. One I received an e-referral letter which have me 3 hospitals to choose from. I tried all three and none had appointments available. I tried the phoneline and they said they would manually refer me. And I haven't heard anything since. The second referral I didn't hear anything, requested a specific mental health service via my right to choose which has now apparently been sent but I haven't heard anything. The wait time in Sheffield is apparently 4 years. [Woman aged 25 – 49)

Healthwatch Sheffield

Choice in maternity care

Personalised care is a key objective for the NHS in maternity care, as set out in the March 2023 three year delivery plan for maternity and neo-natal services, which draws on previous reviews including Better Births and the Ockenden review.

When parents are given **comprehensive advice and support to make informed choices** about their maternity journey, it can make a huge impact:

The consultant was good and informative very much all of the medical side of things, but very much you know, let me make my choice of what I wanted, heard that I wanted the planned Caesarean, took me through different risks and everything spoke through my birth before. Yeah, so she was very good. (Woman, aged 27, White British)

Healthwatch Cambs & Peterborough (Maternal Mental Health research)

However, we have heard lots of people's maternity experiences over the last few years which suggest that **personalisation remains an ambition rather than a reality for many**. This has been acknowledged by NHS England, which last year removed

the national target date for continuity of carer in light of the unprecedented workforce challenges faced by maternity services.

Many of these stories tell us that **women and birthing parents are not given the guidance they need to make informed choices** about birth, and feel a lack of control over their maternity experience, causing excess stress. This has a particular impact on first time parents.

"[I chose the] one that was closest to me. They did not give me any information about the hospitals available. I was new to the country so was not aware I could choose any hospital." (Woman, Black)

Healthwatch Birmingham

Research by Healthwatch Birmingham, on the experiences of Black African and Black Caribbean women in maternal care indicates **mothers were not made aware of the support and choices available to them**. This lack of awareness was exacerbated by limited continuous care, meaning mothers could not discuss their options. Some of this support that was missed out were antenatal classes; this was also not necessarily a meaningful choice as language and timing barriers caused access difficulties for many. One woman quoted in the report said:

"On choice of delivery – they kind of say you have a choice but then they take the choice away."

Other issues of choice for Black African and Black Caribbean Women in maternal care centred on the birth and delivery process. They didn't feel that that they had real choice about where to give birth, and what type of birth to have.

These experiences collected by Healthwatch Birmingham further corroborate findings Healthwatch England gathered in 2022-23 research on maternal mental health, highlighting that that **many new mothers were not getting the mental health support they needed**, as well as in-depth interviews showing the impact and importance of continuity of care during maternity.

Going private – a false choice

Other organisations have tracked the increase in patients seeking private treatment in recent years due to NHS services not having capacity to meet their needs. Examples of this appear across many areas, ranging from buying items which should be available via prescription...

Long waiting times following appointment being cancelled. Patient buying their own medication from abroad. (White – Other woman aged 25 – 49)

Healthwatch Cambridgeshire and Peterborough

...to paying for mental health care where limited NHS help is available...

"I was encouraged to hear of the new mental health nurse based at Holt. But despite experiencing relentless suicidal thoughts, the only help I was offered was to signpost to private therapy. I left feeling like I'd hit a brick wall in the system. There was little empathy or real understand of my genuine concerns. It seems unless you are currently in an unsafe crisis state, there are no options."

Healthwatch Norfolk

…to paying thousands to receive the correct diagnosis.

Lady called in considerable distress. Had mobility and pain in feet and had been trying to get diagnosis and treatment through GP and NHS. Could not get a GP appointment initially so client had paid to go privately. Had some treatment via private means but was still experiencing symptoms. Since then, she had seen GP and consultant at local hospital who referred her to another department. The referral had so far taken 6 months and client was not happy as she kept paying for private consultations in between and had spent upwards of £13k on treatment so far. Asked if she had spoken to GP practice regarding a complaint which she had but was not happy as they were rude to her when she met with them to discuss. She stated the GP was very rude and dismissive which really upset her and her husband. (Woman, Black Other)

Healthwatch Leicester

Although having the **option to seek private care exists, this is not usually a genuine choice**, but one that people are forced to make when NHS services cannot provide adequate care.

Further, it is **not a choice much of the population can afford to make**, and this erodes a founding principle of the NHS: healthcare being free at the point of delivery. Our national polling found that of people currently waiting for planned treatment, nearly one in five people(18%) have already gone private for treatment or are considering it, but going private wasn't an option for half (47%) of respondents who had their treatment delayed.

Ability to keep track of referrals and monitor their own pathway

Our recent referrals research shows there are a great many **barriers to being referred for elective care** – from the point of getting a GP appointment, to long waiting times for receiving an appointment. Referrals fail for a number of reasons, for example wrong information may be sent, patients are sent to the wrong location or their referral is rejected. Some people never get their referral at all. This can leave people feeling powerless and as though they have no degree of control over their own healthcare treatment or diagnosis, depersonalising healthcare experience.

The Commentator was referred for a chest X-ray by their GP and tried to book this. She was told she isn't a X patient, she has only been to Y hospital before so she wasn't

registered at X to book an x-ray. She asked them to book one in Y and was told the referral was for X and this was not interchangeable. She would have to wait until she was manually entered as a X patient to be able to book. She was under the impression the hospitals had merged but it seems the two booking systems don't communicate and her x-ray isn't a priority for admin, but it is to her. She has been trying to book this since 8th Feb - 3 days and 5 phone calls later she realised she was not on the system. (White British woman, aged 65 – 79)

Healthwatch Somerset

Currently people are falling through the cracks – getting specialist treatment often requires the patient to actively pursue a referral over a long period of time, returning to their GP repeatedly to discuss the same issue.

One tool which would greatly support patients to have more control over this process is an **online referral tracker**, where all information about a referral is logged from the point it is made, and which both patients and clinicians have access to. While online referrals systems do exist, it is not clear how universal these are, as most patients are still required to show a referral letter to book a specialist appointment, and patients do not have access to the referrals tracker until a referral is accepted by a specialist, meaning they cannot ensure the referral has been made and received.

Personalised Communication

Communication is key across both primary and elective care; many of the examples discussed in this briefing highlight everyone's communication needs are different and access to healthcare can be greatly improved by recording these needs and putting the systems in place to ensure those needs are met at every stage.

A **lack of personalised communication can contribute to increased health inequalities**. For example, in 2021/22 we carried out some research to support the elective care recovery plan, which found that women, people with disabilities and those from ethnic minorities all report longer waits for care. These groups also had a worse experience whilst waiting, resulting in greater impact on their mental health, their ability to work, their ability to care for loved ones. The majority of patients report that the amount of supporting information provided during their waiting period was inadequate, especially in helping them manage their condition.

Research we carried out in 2022 shows that **people who speak little or no English have difficulties at all points along their healthcare journey**, meaning that there is not sufficient provision of translation services at any point. This is greatly contributing to health inequalities for people from different backgrounds.

Access to healthcare is also difficult for people who have **specific communication needs such as communicating through British Sign Language (BSL)**. Despite the 2016 Accessible Information Standard setting out people's legal right to receive information about their health in alternative formats, our evidence suggests that this is still far from a reality. Personalised communication is a must for everyone to be able to access the healthcare that they need. **Choice is not meaningful if it cannot be communicated to patients** and

they cannot be made aware of their options. The case study below highlights the difficulties faced by a deaf patient in accessing gynaecological care.

Client was referred to the Enhanced Community Gynaecology Service (ECGS) by their GP. The first problem was that the ECGS contacted them by phone, and were unaware that the client is deaf, using BSL and TypeTalk to communicate. Once this hurdle was overcome, they were offered an appointment for early February. The client requested a BSL-interpreter be present for the appointment, but they said they couldn't arrange one at "such short notice". Client explained to them they can request to an interpreter see if they're available, one week is plenty of time to ask for BSL interpreter. [many appointments were then cancelled due to difficulties booking an interpreter]. Eventually the client received a text inviting them for an appointment with the ECGS (with an interpreter present) at the end of June. The client stated that they feel they would have been seen in February if they could hear, but instead because the service essentially couldn't organise an interpreter, they have had their appointment pushed back by 4 months. Client wrote to us again, stating that they have now had their appointment at the end of June cancelled with 2 days' notice. Client was despairing because they are in so much pain & discomfort and the service does not seem to at all appreciate that.

Healthwatch Hertfordshire

Interim support and having the tools to cancel/reschedule appointments

Another key area where patients need agency in is the ability to cancel or reschedule appointments if needed. There needs to be a recognition that external circumstances can impact patients' ability to attend appointments, and they should not lose their place in the system as a result. Giving patients the tools to reschedule appointments will also save the NHS time and resource in reducing missed appointments.

Man suffers with both physical and mental health conditions, they had an operation planned for December that they have been waiting 18 months for, however, the week before the operation service user contracted Covid-19, and following guidance they were unable to go ahead. The Hospital re booked it and told the user that it would take place in January and he would get a letter to confirm. When the user received the letter it had been re booked for the following week, and he was still too unwell. He informed the Hospital who cancelled the operation and said he will need to be re referred and could take up to 2 years once again. (White British man aged 18 – 24)

Healthwatch Solihull

Opportunities

Patients recognise that it will take time and systemic change to tackle long waiting lists. Good communication and support while people are waiting are the most important things to people in the meantime. Tools like online referrals trackers

can go a long way to empowering people to manage their own care and feel like they are receiving a connected, personalised services.

The choices people want – urgent and emergency care

Even in situations where patients need urgent attention, we have heard that they **still value choice of services**, and are **open-minded about using alternative services which may help to reduce pressure on A&E departments**. The NHS 111 First initiative is designed to ensure that people are directed to the right service for their needs. As we've previously shown, when this works well, people get the right treatment more efficiently:

The person called NHS 111 with an eye issue. They got a doctor to call back within an hour and were immediately prescribed medication and got them an appointment at the local optician the same day. They saw the optician who said they had a detached retina and sent them to the hospital immediately where they were seen on arrival. The whole experience could not have been better. The person felt cared for and that they got the right treatment very quickly. (White British man aged 50 64)

Healthwatch North Yorkshire

Healthwatch Rutland's visit to Oakham Urgent Care Centre highlighted that people they spoke to were unclear of the purposes of different urgent and emergency care services, but were pleased to have a local easy to access service that dealt with their needs quickly.

But the system is **not always good at offering that choice** or letting people know that there are options for seeking urgent care. Our national polling on NHS 111 suggested that 73% of people are **not aware that NHS 111 can reserve time slots at A&E**. Research by Healthwatch Shropshire and Healthwatch Telford and the Wrekin about people's experiences of urgent medical care found that over half of respondents weren't aware that NHS 111 could book appointments with GPs and Urgent Treatment Centres or give them arrival slots for A&E.

People **may not want to go to A&E when they are ill, but feel forced to** either because primary care can't resolve the issue or because the need occurs out of hours. For example, research by Healthwatch Blackpool, Healthwatch Blackburn with Darwen, Healthwatch Cumbria and Healthwatch Lancashire for Lancashire and South Cumbria Health and Care Partnership found that some survey respondents told them that they went to an emergency department or walk in centre as they couldn't get a GP appointment and wanted to be seen quickly.

This was particularly an issue for people who worked full time, who were self-employed or cared for young children.

People also **don't know about the availability of extended access GP** appointments because their GP hasn't told them about these appointments, as recent research by Healthwatch Warrington suggests.

Yet just because they need to go to A&E doesn't mean they need to go the moment they call 111 or 999. Waiting at home for a scheduled urgent care appointment is an option for many. However, our research in 2021 showed very few people knew about this option and qualitative feedback since suggests it is not being consistently offered. For example:

Waited.... and waited... and waited. There was a constant queue of people entering A&E. A gentleman came in with a badly cut hand, he collapsed in front of us. Later a young lady did so too, despite her mother asking for assistance. Mum was called for an X-ray at 6pm & I went to buy food and drink. Apparently someone came to call her name while we were out, but did not come to try again. We waited & waited! Around 8.45pm she was called… and prescribed diuretics.

Healthwatch Shropshire

Similarly, people may have more than one choice of where to attend, but little way of knowing which is the best choice for them. As we recommended in the Clinical Review of Standards work, it would be **useful to give patients real-time data on waiting times** in different departments to help with decision-making. This would also help spread demand across the system at peak times.

Opportunities

People are willing to use alternative services to reduce pressure on urgent and emergency care when they are informed about them, and often have a good experience. The availability of services like NHS 111 First need to be better publicised, and patients should be given as much information as possible about what they can expect at a service to support their decision-making.

Helping people make informed and empowered choices

Technology & independence

Most patients are **ready, willing, and able to embrace the benefits that technology offers** in supporting their health and interactions with the NHS.

In our work on remote monitoring, people told us that there are **many benefits to blood pressure monitoring at home**, including peace of mind, feeling in control, and convenience. People also said they would **consider using other forms of remote monitoring technologies** if the right processes are in place. Yet the systems to do this are not always in place or if they are, they are not optimised for a quality patient experience or efficiency of the NHS. For example, while people were encouraged to make use of blood pressure monitors at home, they were not always supported to submit blood pressure readings to the GP practice electronically, nor told what to do if they got an out of the ordinary reading.

If I had the equipment and appropriate knowledge to monitor anything about my health, I would do it. I believe we have to turn away from picking the phone up and ringing the GP and we need to take responsibility for ourselves through changing our lifestyles and doing some exercise. (Male, 70-79)

Healthwatch Gloucestershire

Our briefing on '*Prevention: allowing people to live longer, healthier lives*', delivered alongside this briefing, provides more detail on the place of technology in supporting patients' experience of access to care and supporting preventative health measures.

Empowering patients to make choices

Patients can only make choices about their care if they are made aware of them.

I was not told that the waiting list was two years to see a rheumatologist. I complained to Worcestershire Healthwatch who were very helpful and told me to ask for a referral at a different hospital with a shorter waiting list. I didn't even know I could do this so I phoned the GP surgery and now have an urgent referral at another hospital but that has gone

over the time allowed and still no appointment it is now eight months since the first referral from the GP and I have no appointment. The whole process is a disgrace. (Female, 50-64)

Healthwatch Worcestershire

Our referrals research shows that at the point of referral, only 5% were given information about their rights and choices.

Even where people are made aware of their right to choose alternative providers, not having seamless systems in place to track or share patient information can delay the process. Improving online referrals tracking systems so that patients and professionals can access all the same information, and ensure that all services are using the national e-referrals system, can support more seamless referral to different providers.

I researched where the X Practice could refer me to in Lincolnshire instead of having to travel to Addenbrooke's (the roads are notoriously unpredictable and there is never anywhere to park) so Grantham or Boston would be preferable. I then sought advice from X Health who replied immediately that they could book an appointment for me as soon as they have seen a copy of the GP referral letter and confirmation of the NHS waiting times. (Woman, aged 65-79)

Healthwatch Lincolnshire

Opportunities

Ensuring that technology provides a continuous and seamless experience throughout a patient pathway can allow people to have a personalised care experience, even if this is not always with the same professional or even the same provider.

Important steps forward have been made in recent years in this area, including giving patients access to their own health records through the NHS App, and encouraging the development of online referrals and patient records systems. Yet most patient referrals still require a referral letter, and incompatible electronic systems remain a key reason that information about people's accessibility needs are not passed between services on referral.

More work remains to be done in ensuring the full digitisation of NHS services to best support personalised care.

Appendix i: Recommendations

Recommendation	Why is this change needed?	Who is responsible?
Primary care		
Maintain traditional models of care alongside remote methods and support patients to choose the most appropriate appointment type to meet their needs.	We know that remote care has worked well for many and has even removed barriers to accessing care for some who would otherwise find it challenging. But we know that some people find it more difficult to access care through digital or remote methods for a variety of reasons, including affordability of technology, digital skill level and language barriers. For some people, remote methods aren't an option, and a lack of alternatives can mean they don't receive vital healthcare.	NHS England, ICBs, GP practices
Offer flexible appointment slots so people can book an extended appointment rather than multiple visits.	Extended appointment slots would give staff more time to provide patients with information about their referral, as well as more time to assess patients, potentially reducing the frequency of visits to general practice before onward referral. Extended appointment slots can also be essential for people with communication or access needs, to allow time for interpreting or explanation of their condition.	NHS England Integrated Care Systems General Practice Teams
In line with the General Medical Services (GMS) Contract for GPs, ensure that information is provided and maintained on all GP websites about how to contact the GP to book an appointment and ask for help.	Many people are struggling to access care from their GP, often because they do not know how or are confused by the variety of methods available. This is leading to people feeling that they should not seek care for their health issue because of the pressures the NHS is under. This puts people's health and wellbeing at risk and increases demand on overstretched hospitals.	NHS England
Secondary care		
Ensure all practices are using the e-referral services and improve the online referrals tracker for patients.	The GP contract states that GP teams must use the NHS e-referral service. However, the HSJ has recently found that 27 Trusts still do not have an electronic patient record system.	NHS England NHS Trusts General Practice Teams

	Trusts and GP practices should prioritise full transition to electronic systems, supported by appropriate resource from NHS England. This will ensure that all referrals and appointment data is stored centrally, and is accessible to the relevant services, minimising risk of referrals being lost or different professionals having contradictory understanding of where someone is on the referral pathway. It will also support improvements to online tracking and booking systems. Currently, patients can book their appointments through the online 'Manage My Referral' system, but only after they have already received their booking number, which most receive via letter. This system should be improved to ensure that patients and teams in general practice, referral management centres, and hospital admissions teams should all have access to the same centralised information about which stage of the referral process the patient has progressed to. This should start from the moment a GP agrees to make a referral, not after the referral is accepted by specialist teams.	
Improve processes for patients to contact NHS teams about their condition following a referral.	More support should be given to help GP and hospital teams to reduce the numbers of people returning to general practice due to communication failures following a referral. As well as improving channels for the NHS to update patients about their referral, patients must also have access to care navigators in general practice and a single point of contact at their hospital (or another referral setting). This is so patients can give feedback about their condition while waiting for care, without needed to book a new GP appointment. This includes whether they need to cancel or reschedule appointments or quickly chase up a	NHS England NHS Trusts

	referral if they have not received information about its progress.	
Deliver the LongTerm Plan commitments on improving access to specialist community perinatal mental health services.	As part of the Maternity Transformation Programme, the NHS has invested in four additional mother and baby units since 2016. NHS England needs to continue its work to ensure every ICB has access to specialised community perinatal mental health services, including the development of new Maternal Mental Health Services (MMHS, referred to in the Long Term Plan as 'maternity outreach clinics') for women with moderate to severe or complex mental health needs arising from birth trauma or loss. This will need to be underpinned by longer-term systemic solutions to workforce and staffing issues and considered as part of the NHS Workforce Plan.	NHS England Integrated Care Systems
Improve the support people receive while they wait for treatment, such as better access to pain management, physiotherapy, and mental health support	Our insights highlight the impact waiting has on people's ability to carry out household tasks, the level of pain they're experiencing and their mental health. Greater access to support would allow people to wait in more comfort for their planned care and help ensure they are in the best possible shape to receive treatment when the time comes.	NHSE NHS Trusts Integrated Care Systems (ICSs) PCNs
Acknowledge that we don't just need more doctors and nurses to tackle the backlog, but more well trained and compassionate admin staff and care navigators to manage waiting lists better. These teams should be supported to implement and manage good patient communication. This includes serving as a single point of contact for patients to access information on their planned care proactively, so that they don't need to contact general practices for updates.	Good communication would reduce health inequalities and the potential for health anxieties. It would also help prevent people from feeling forgotten while supporting them to ensure they are not waiting in pain or struggling to pay household bills.	Department of Health and Social Care (DHSC) NHS England

Urgent and emergency care		
Publicise the availability of NHS 111 First, especially that this gives people the option to pre-book time slots at A&E or urgent treatment centres.	NHS 111 is a well-known service, and the new option of pre-booked time slots at A&E and other urgent appointments is useful to patients when it works well. But its full potential for improving patient experience can only be unlocked if more people are aware of the offer and if people consistently receive high quality care and advice through NHS 111.	NHS England
Conduct a patient experience evaluation of NHS 111 First.	Although we know that an additional £24 million was invested in NHS 111, most of which was allocated to hiring more call handlers and improving the ratio of clinical to non-clinical staff dealing with calls, it is not clear whether this will be enough to increase people's confidence in the service or cater for an increased demand. Greater transparency on how additional investment is being used, alongside modelling of the predicted increase in demand, would help the sector scrutinise whether the investment is sufficient.	NHS England
Support hospitals to publish A&E waiting times data in real time.	Live information about waiting times should be made availble to give people the maximum power to choose the best possible experience in A&E, and to support better distribution of patients across the system. Such initiatives have been trialled at some trusts but have yet to be rolled out more widely.	NHS England NHS Trusts

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