

GP Referrals

Part 2 – The hidden waiting list

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Foreword

Since the pandemic, there has been a lot of media and policy attention on the issues people face accessing NHS services, including coverage of record waiting lists for hospital appointments.¹ Healthwatch have heard from people struggling to see their GP team, attending crowded A&E departments, and more generally about people's experiences of waiting for care².

But far less is understood about people's experience of the referral process from general practice to a hospital or community clinic.

Throughout 2022, around 1 million³ referrals were made every month from GPs to consultant-led hospital teams. So, we know that lots of people are being referred for more specialist treatment, but we don't know how long they are waiting before the referral is accepted. This report highlights that before people get the help they need from specialist teams, **there are four stages of waiting:**

- People wait for a GP appointment,
- they wait for their GP to tell them they will be referred,
- they wait for the hospital or clinic to confirm that referral, and
- then they finally join a waiting list.

This hidden waiting list is a blind spot for the NHS, and our report found that people waiting longer for a referral often do so without any other support from the health and care services. This includes information about the referral process, a copy of their referral letter, estimated timescales, or choice of appointment location, appointment time, or consultant.

And when people aren't given any of this support, their referral is less likely to progress directly to either an appointment or joining a waiting list, meaning patients either bounce back to their GP, go to A&E or suffer in silence.

It's vital that the NHS does more to understand hidden waiting lists and to improve the current referral processes. Not doing so simply moves demand for healthcare around a busy system. Not only is this inefficient, but it can also put people's health at risk.

It's crucial that support is put in place to ensure that everyone who needs treatment can access it as quickly as possible, in the right setting, and in a way that meets their needs.

Louise Ansari, Chief Executive, Healthwatch England

¹ [NHS Consultant-led Referral to Treatment Waiting Times Data 2022-23](#)

² [Healthwatch England. Health Disparities: waiting for planned care. June 2022](#)

³ [NHS Monthly Referral Return \(MRR\)](#)

Overview

We commissioned Panelbase to carry out an online survey covering two distinct groups who had an appointment with their GP practice in the past 12 months. **Firstly, those who either expected or requested a referral for tests, diagnosis, or treatment, but didn't get one, and secondly, those who were referred for tests, diagnosis, or treatment.** We heard from 2,144 people overall. We set quotas for ethnicity and financial status to ensure that we could make meaningful comparisons across different demographics.

The figures quoted in this briefing are based on the 1,518 patients who fall into the second group – those who were referred for tests, diagnosis, or treatment. Fieldwork was completed in October 2022. We also shared our survey via the Healthwatch network (1,825 respondents overall of which 1,458 respondents were in the “referred group”) and **comments from both surveys are used to support the analysis and provide quotes for this briefing.**

Using the NHS Monthly Referral Return³ we know that GP referrals to hospitals are almost back to pre-pandemic levels, with around 1 million GP referrals made every month. However, hospital teams are rejecting more referrals, and waiting lists have grown in the last three years leading to an increase in wait times.

Considering how long it can take for a patient to be told they are being referred, combined with the time it takes to get onto a waiting list, the total time the patient has been suffering from their symptoms or condition can be much longer than official waiting time statistics would suggest. There are gaps in measurement for some parts of the referrals process – creating a **dangerous blind spot.**

This briefing shares people's experiences and the impact behind these figures.

- Two in five (39%) patients are referred during their first GP appointment, and nearly four in five (79%) are referred within their first three visits, but nearly one in five (18%) require four or more GP appointments.
- Over one in ten (11%) waited over four months from their first GP appointment to being told they were to be referred and over one in ten (11%) waited over four months between receiving their GP referral and having that referral confirmed by a specialist team. So, patients can wait weeks, months or even years before joining NHS waiting lists for specialist appointments. These waiting times are not captured in NHS statistics.
- Two in five (42%) sought medical care from other parts of the NHS while trying to get a referral from their GP practice.
 - Those experiencing three month or longer waits at each stage were twice as likely to seek medical care from other parts of the NHS, compared to those who experienced waits of less than a month.

- Some go private out of desperation – whether they can afford it or not.
- As well as negative impacts for the patients themselves such as worsening physical and mental health, reduced ability to work and damage to relationships, delays in the referrals process can also impact those around them. Some patients needed additional care from friends and family and some needed social care support.
- Patients can be referred in different ways. Just under two in three (63%) were referred by their GP practice via a referral letter sent to the hospital/community clinic, while 16% were told to call or go online to book their own appointment directly with the hospital/community clinic and 12% had their referral appointment booked while at the GP practice.
 - The use of a referral letter may make the process take longer, but those who were referred in this way were more likely to progress to the waiting list or referral appointment itself. The mode of referral used varied depending on the profile of the patient.
- At the point of referral, advice, choices, and information were rarely given to patients, and in fact around one in seven (15%) were not given any advice, choices, or information at all.
 - The most common support offered was advice on how to manage symptoms while waiting (39%) and information on why people were being referred (31%).
 - Fewer were given information on how the referral process works (16%), estimates of when to hear back about the referral (15%), a copy of their referral letter (12%), or a choice of appointment times (8%).
 - Those highly educated **and** better off financially were given more advice, information and choices at the point of referral.
- Chances of a referral progressing smoothly vary greatly. Around 7 in 10 (71%) patients progress directly to an appointment or to join a waiting list, while others experienced problems along the way, such as not hearing anything further about their appointment (10%), finding out from the GP practice that the appointment hadn't been made (5%), discovering the hospital/clinic had no record of the referral (2%) or the GP had no record of it (2%), the referral was rejected (2%) or they were referred to the wrong clinic (1%).
 - Mental health referrals were less likely to lead directly to an appointment or waiting list (only 60%) than other conditions like cancer (90%).
 - People aged 18-24 (66%), those really struggling financially (63%), LGBTQ+ people (59%) and neurodivergent people (58%) were less likely than the total for all respondents (71%) to experience their referral progressing directly to an appointment or joining a waiting list.
- We asked patients whether they agreed with a range of statements about their referrals experience to understand the quality of those experiences. While there is room for improvement in all aspects of the referrals process, those who reported

having a poorer experience were more likely to be younger, of ethnicity other than white British, neurodivergent, less well off or lower educated.

- For some patients, getting through the referrals process is arduous and it erodes their faith in the NHS. When the NHS gets it right, however, patients really appreciate it, and it can positively affect their health outcomes⁴. This should be everyone's experience.

⁴ [Being listened to: what difference does it make? | Care Opinion](#)

Background

When people need help with a health condition, their first point of contact is their general practice team. A range of skilled healthcare professionals work in general practice, but most commonly people will see their GP. GPs can diagnose and treat a wide range of conditions. They can also order tests and interpret results, and in some cases, they can refer people to a local hospital or other medical setting for more specialist or urgent care.

Some people visit their GP with symptoms and have no idea what is wrong with them nor have any expectations of what might happen next. Others have an idea before contacting their GP that they need a referral. It could be that this is a long-standing or recurring issue which they have seen their GP about before, that a clinician at another medical setting told them to ask their GP for a referral, they are experts in their own long-term condition or simply that they have some prior knowledge and clear expectations.

It is important to understand the overall patient journey, which starts with attempts to get a GP appointment, and, if clinically necessary, progresses to getting specialist medical tests or treatment at a hospital/clinic.

We know from [our evidence and official statistics](#) that it can take time to get an initial appointment with a GP and that once referred, many patients spend long spells on a waiting list. However, the part of the referrals journey that is not currently measured is the time it takes to get that referral, or for the referral to be confirmed by the other medical setting. We also know that once a referral is given, this is not a guarantee of moving onto the next stage of the journey and getting the care needed. **This briefing looks at how long it took patients to get their referral, what happened next and how patients rated their experience.**

We carried out a representative online survey using [Panelbase](#) covering two distinct groups who had an appointment with their GP practice in the past 12 months. **Firstly, those who either expected or requested a referral for tests, diagnosis or treatment, but didn't get one,** and **secondly, those who were referred for tests, diagnosis or treatment.** This **briefing reports on the experiences of the second group** which represents 1,518 patients. We heard from 2,144 people in all. We also shared our survey via the Healthwatch network (1,458 respondents in the "referred group") and comments from both surveys are used to support this analysis.

This was a quantitative survey; however, respondents were given the opportunity to share more about their personal story through free-text responses. This has added depth and clarity to our understanding of the issues faced. The fact that so many respondents chose to tell us much more about their experiences, makes it clear that this is a very important and emotive issue.

Findings

Who is getting referred?

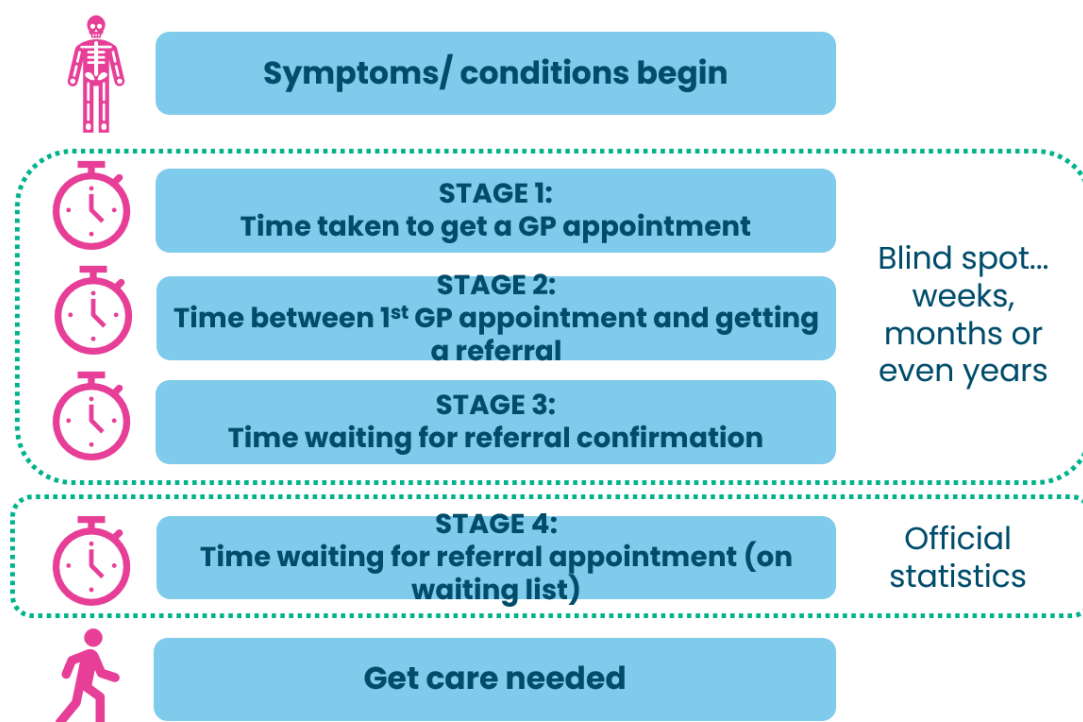
We heard from 1,518 people who received a referral for tests, diagnosis, or treatment from their GP practice and 626 who expected or requested a referral but did not receive one. This analysis focuses on those who **got a referral**.

We found people over 65 (or 65+) were more likely to have received a referral, however the opposite was true for both LGBTQ+ and neurodivergent people. We looked at other characteristics, but no notable differences were found.

"I also asked for a referral to be assessed for autism. My GP refused on the grounds it would take too long to get assessed." [Female, aged 25 to 49 years]

The journey to getting a referral can be a long one

Considering how long it can take for a patient to be told they are being referred, combined with time taken to make it onto a waiting list, the total time the patient has been suffering from their symptoms or condition, can be much longer than official waiting time statistics would suggest. There are gaps in measurement for some parts of the referrals process – creating a dangerous blind spot: "what is not measured cannot be improved"⁵.

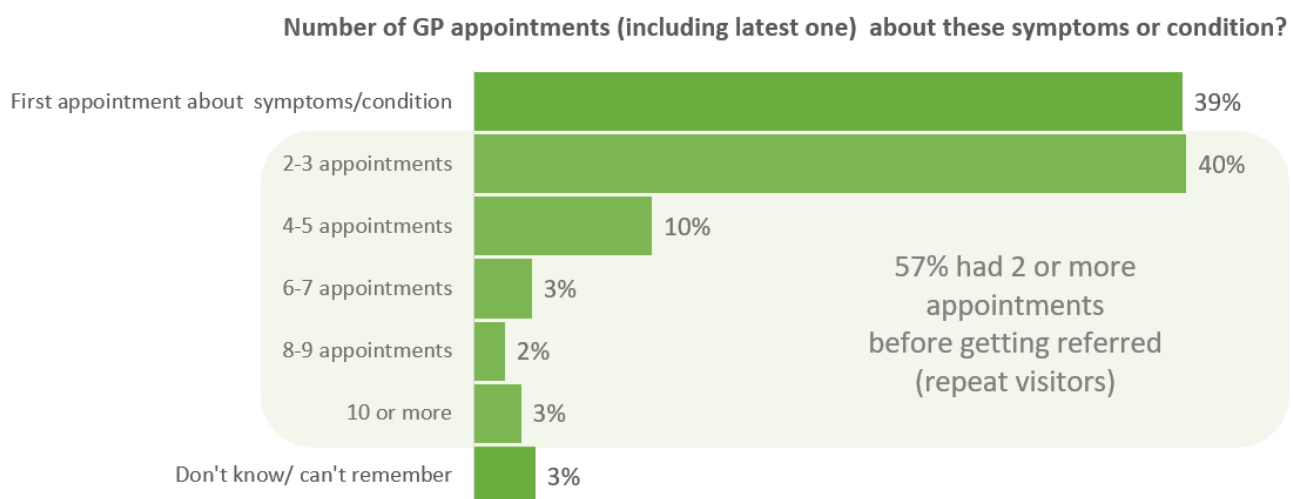


⁵ Patient Experience: Putting the Patient Front and Center - The Beryl Institute - Transforming the Human Experience in Healthcare

Two in five (39%) of those referred got their referral on their first GP appointment.

For the rest, it took multiple GP appointments over the course of weeks or even months to get a referral. There can be legitimate reasons why patients are not referred straight away, for example the GP wishes to try medication or lifestyle changes first, but this is not always the case, as we reported in [briefing one](#).

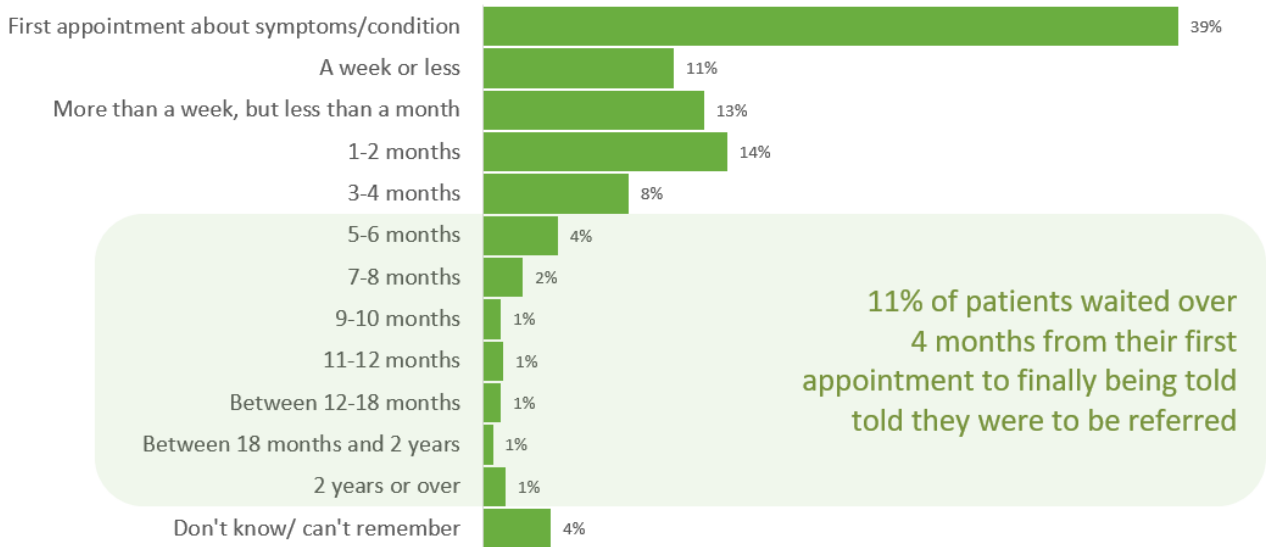
Figure 1: Q5 Base 1,518: All referred



One in ten (11%) patients took more than four months to get a referral and for few, it took over a year or even two.

Figure 2: Q18 Base 1,518: All referred

Time between 1st GP appointment about the symptoms/condition... and being told by the GP you were going to be referred (stage 2)



“I’m getting concerned that by the time I will be diagnosed and treated it may be too late and I may need to have a major surgery to fix all the damage made by my disease. I am still alive and coping now, but only just about and this is affecting my quality of life. I pay NI like everyone else and yet I feel like I’m not getting my money’s worth. I refuse to go private if I’m paying towards the NHS. I shouldn’t have to pay for private care.” [Male, aged 25-49]

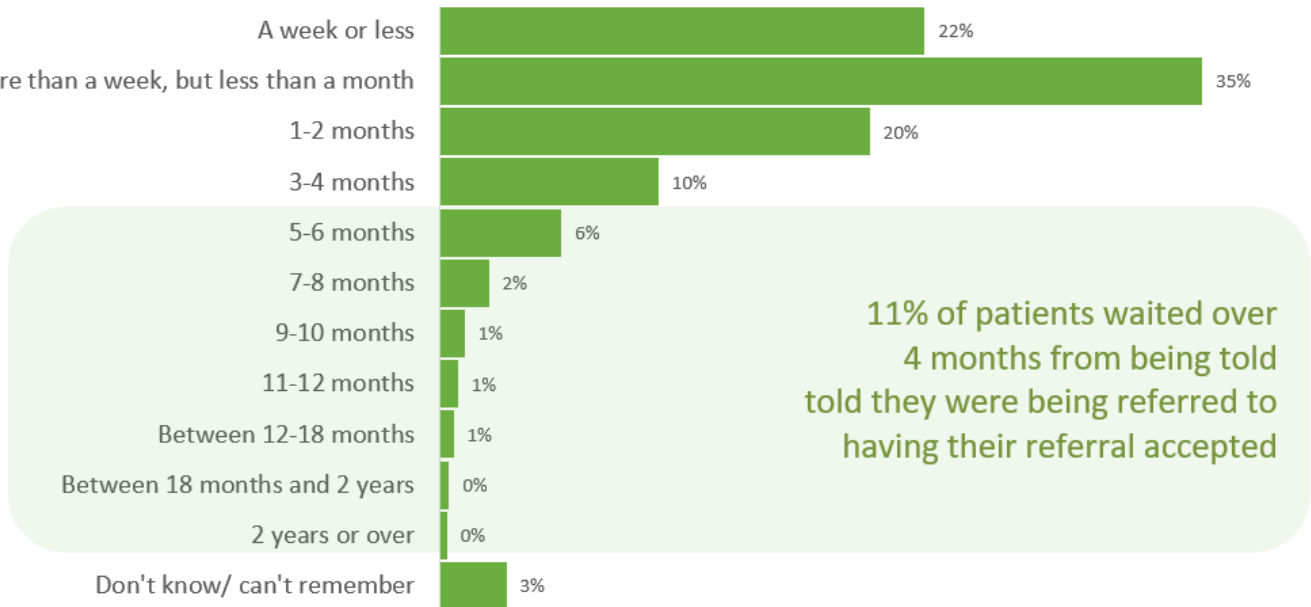
“Think it’s disgusting when a GP has now taken nearly a year to refer my mum to a cardiologist and they haven’t monitored her in that time, but she suffers greatly with breathlessness and pain. [Female, aged 25 to 49]

Also, one in ten (11%) patients took more than four months between the GP telling them that they were being referred and confirmation from the hospital or clinic that the referral was accepted.

“I was referred by my GP nearly 18 months ago to gynaecology, 12 months ago checked with the surgery that the referral had gone in and it had. I have still heard nothing from gynaecology, not even recognition that the referral has been made.” [Female, aged 25 to 49]

Figure 3: Q18 Base 1,155: Those referred and were on a waiting list or had an appointment

Time between GP saying that they were referring you... and receiving confirmation from the hospital/community clinic that the referral was accepted (stage 3)



The combined waiting time from the point of experiencing symptoms and seeking care to actually receiving that care can be long, but it's not being monitored. These hidden additional waiting times add to patient misery.

“Everything has been very slow. Eventually had an X-ray on my spine. Took 9 months to get to that stage after referral. After another three weeks I was contacted, and an appointment made for a telephone conversation to discuss results. Appointment was made with a delay of another 5 weeks. Still don't know what is causing the pain in my lower back. Now a year since referral.” [Female, aged 65 and over]

“Due to the massive backlog waiting list dermatology dept. I was advised to get GP practice to expedite my appointment. Asked the practice twice, but they've not done an urgent referral yet! Don't know why. Should have been seen in under 2 weeks [cancer referral]. It's 4 weeks now and it was a 6 week wait to see a GP initially. So, 10 weeks wasted, and nothing done. Not happy at all with this. I have sent a letter of complaint to the Practise Manager but she is away on holiday so nothing will happen very quickly. [Female, aged 65-79]

And even getting a referral is not a guarantee of getting care when needed.

“Some appointments were delayed by months, as the department would cancel and rebook for later in the year.” [Female, aged 18-24]

“Rejections need to be quicker; referrals need to have more updates, departments need to actually look at what a GP is saying before rejecting. My kid was rejected because she's got a diagnosis. Doesn't matter to them that it might be a wrong diagnosis. [parent on behalf of child, aged under 18]

But there may also be opportunities to reduce the time delays people face, as one in five (22%) of referred patients had been sent to their GP to ask for a referral by a health professional at another medical setting.

Consultant-to-consultant referrals could in some cases be appropriate - taking out the additional step of the patient having to go back to the GP time and reducing delays and frustration for the patient.

Delays in the referrals journey can drive patients to other areas of the NHS

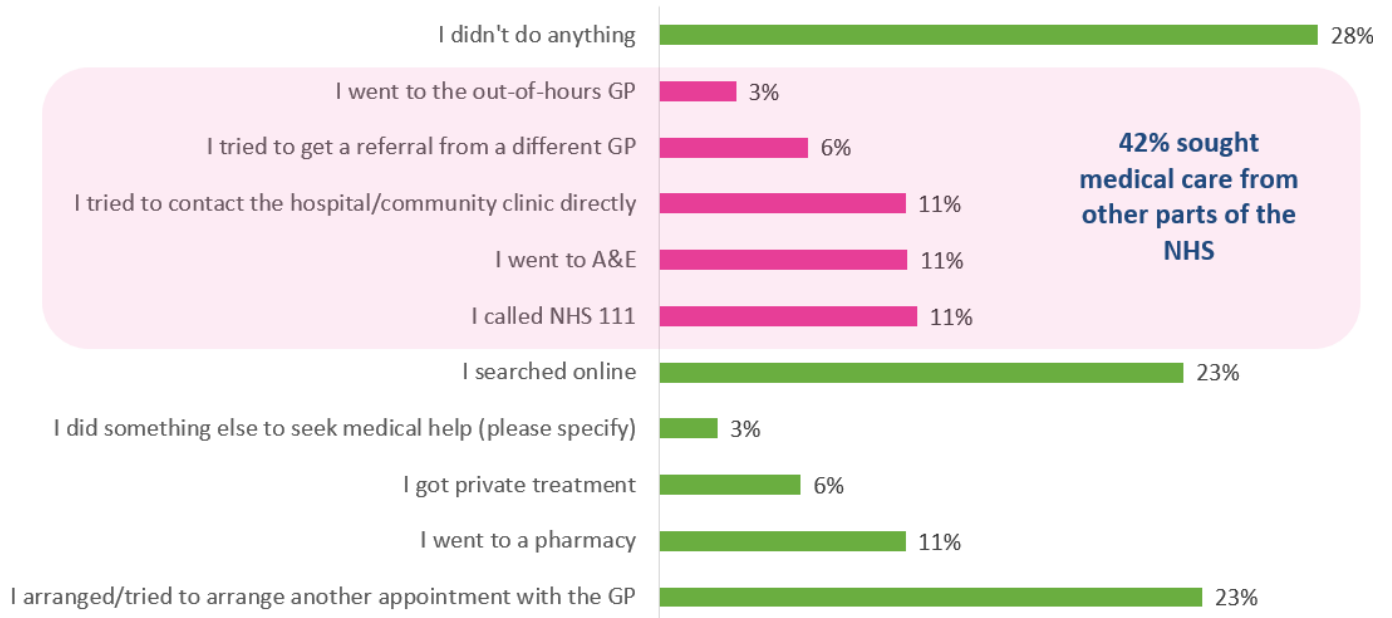
Two in five (42%) of those not referred at their first GP appointment sought medical care from other parts of the NHS, including A&E and out-of-hours GPs, while trying to get their referral.

This increases to three in five (60%) for those that had fallen into the referrals 'black hole' previously and four in five (81%) for those who had been instructed to ask their GP for the referral by a medical professional at another medical setting. This suggests that where patients feel they have been let down or ignored by the “system”, they are more likely to seek help from other parts of the NHS.

“After begging for a referral for 2 years it took being admitted to hospital with my symptoms to get a proper referral for which there is a year waiting list for an urgent appointment. My GP decided that all my symptoms were in my head and didn't believe I was in pain. [Female, aged 18 to 24]

Figure 4: Q21: Base 919: Referred (but not referred at 1st appointment about symptoms/condition)

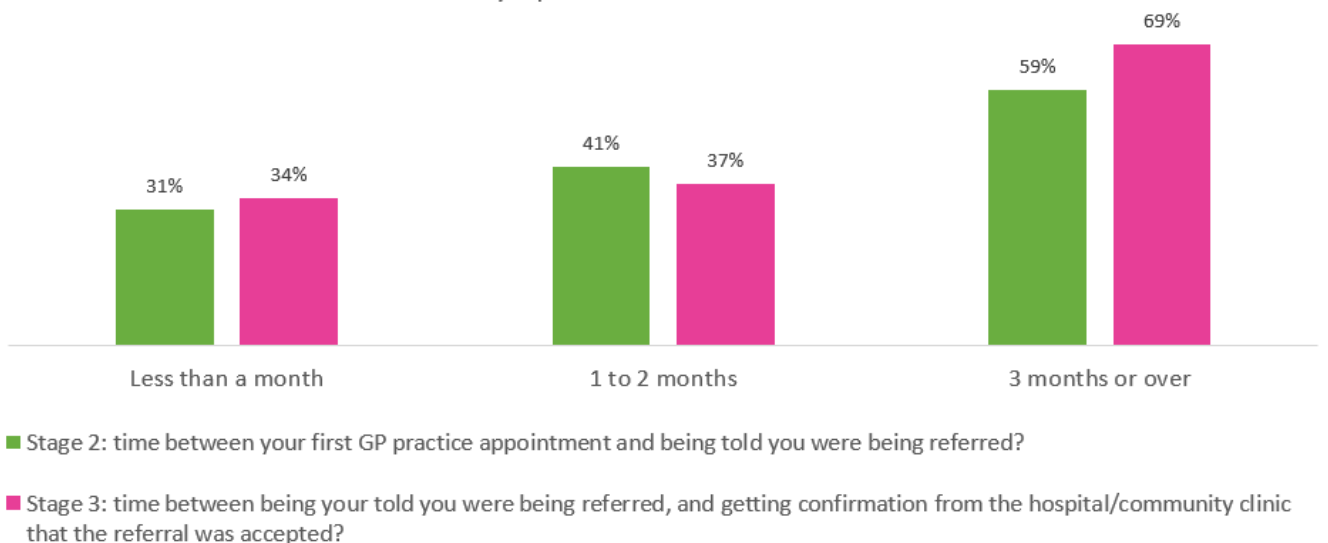
While trying to get a referral from your GP practice for your symptoms or condition, did do anything else to get medical help for your symptoms or condition?



This is the case both for stage 2 (waiting time between their first GP practice appointment and being told they were being referred, and stage 3 (the waiting time between being told they were referred and getting confirmation of the referral from the medical destination). The longer these waiting times are, the more this puts pressure on other areas of the NHS.

Figure 5: Q21, Q18 and Q26 Base 919: Referred (but not referred at 1st appointment about symptoms/condition)

Sought medical help from other parts of the NHS to get medical help for your symptoms or condition



Wait times of over three months double the likelihood that patients will seek medical care from other parts of the NHS, compared to those waiting less than a month (increasing from around 30% to around 60%).

Time spent waiting creates additional pressures for other areas of the NHS, but patients also experience a wide range of consequences:

Delays or referral issues drives patients to go private

Desperation can drive patients to private care, whether they can afford it or not.⁶

“Please sort out this ridiculous business of telling everyone that the NHS will allow referrals to any hospital when a GP surgery refuses to follow the rules. I had to write to my MP and liaise with my County Councillor on this issue. Then I had to pay thousands of pounds to get to the right consultant for the right treatment – it has been immensely stressful and expensive and caused the extension of my chronic pain to go on for years longer than it should.” [Female, aged 65 to 79]

“Was told by GP I had pre-cancerous basal cell carcinoma on my face (5 July). After 2 weeks of waiting and hearing nothing, I went to the GP surgery and asked for a copy of the referral letter. At the top it said 'To Dermatology' but did not state either Queen Mary's or Kingston derm. depts. The letter itself was clear, but I suggest it was never sent out. After 2.5 months, with the BCC growing, I have been forced to go private and have just had an operation with a private Dermatologist (costing a lot of money). I am awaiting the histology.” [Female, aged 65 to 79]

Delays in the referrals process can also have serious consequences for patients and those around them

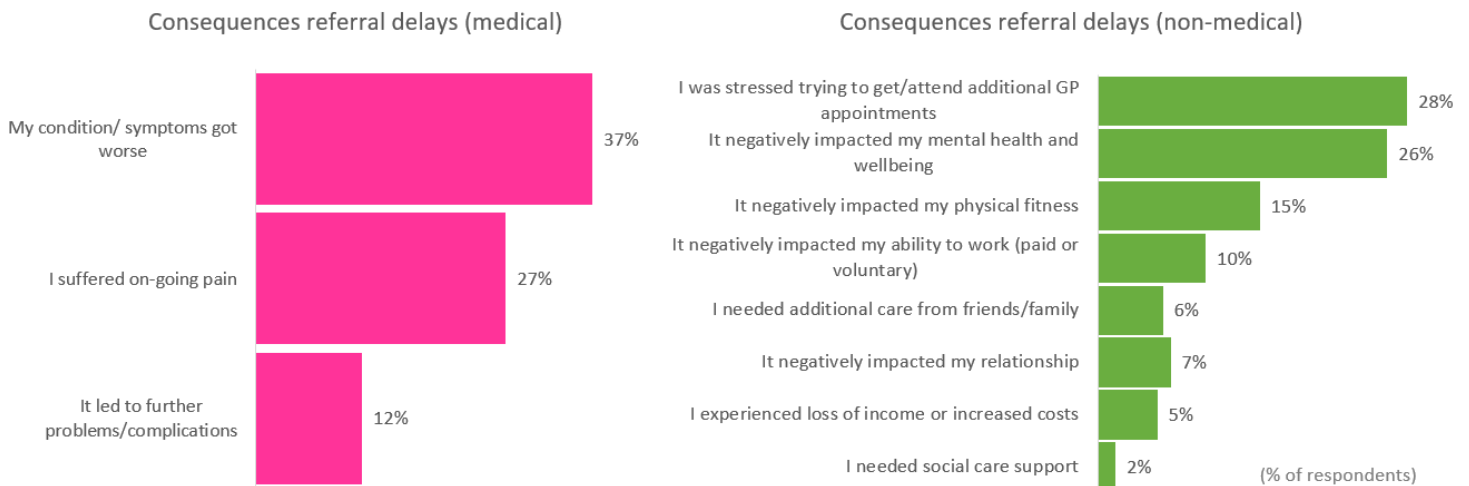
78% experienced negative consequences because of the delay in getting referred for their symptoms or condition

⁶ [Healthwatch England. What are people telling us about delays to hospital care and treatment? November 2021](#)

Many patients experience a multitude of serious consequences because of delays in getting care.

"I gained 6 stone
 My mental health deteriorated
 My relationship was ruined
 I lost my physical wellbeing/strength
 I felt forced to see a private GP
 Symptoms changes/worsened
 Ended up having to change my job and work less."
 [Female, aged 18 to 24]

Figure 6: Q22 Base 919: Referred (but not referred at 1st appointment about symptoms/condition



Referral delays mean many require additional help from friends or family.

"My daughter has been bedbound since November 2021, as a result of their poor care and lack of referral. She is slowly making a recovery with the support of the pain clinic and the community physios. But she is on the waiting list for CFS/ME support." [Female, aged 25-49]

Getting a referral can be a relief for patients, particularly for those who've already had a difficult and long journey to get to that point. Unfortunately, the onwards journey is not necessarily an easy one.

Referral methods vary and may affect the outcome

Just under two in three (63%) are referred by the GP practice via a referral letter to the hospital/community clinic

The GP contract⁷ states that teams must use the NHS e-Referral Service⁸ when referring patients. Practices and hospitals can use this system to book appointments using a range of methods.

The referral method used appears to depend on some degree on who the patient is and it also has a bearing on the outcome.



63% overall were referred by referral letter and this increased to 73% of over 65s and to 76% of those waiting over 3 months between being given the referral and having that referral accepted - suggesting referral letters could make the referral process longer.



16% overall were told to call or go online to book their own appointment directly with the hospital/ community clinic. This increased to 26% of under 25s and 21% of males.



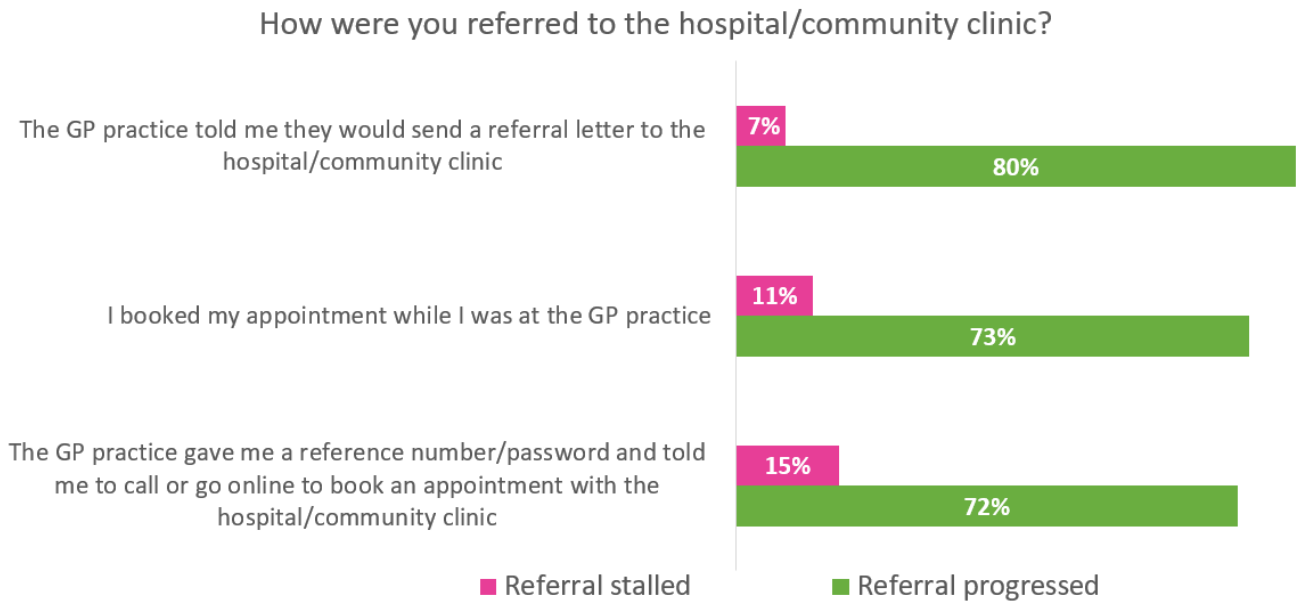
12% overall get their referral appointment booked while at the GP practice and this increased to 20% for under 25s.

The use of a referral letter may make the process take longer, but those who were referred in this way were more likely to progress to the waiting list or referral appointment itself.

⁷ [NHS England. Standard General Medical Services Contract. November 2022](#)

⁸ [NHS Digital. Joint Guidance on the use of the NHS e-Referral Service. 2018](#)

Figure 7: Q23 Base 1,518: All referred



Few people are getting comprehensive advice, choices, and information

Around one in seven (15%) were not given any advice, choices, or information when they were referred

Many things could be offered and in fact should be expected at the point of referral to make a patient’s ongoing referrals journey better, but for many this just isn’t happening. The NHS talks about “empowering people in their care”⁹ through the “comprehensive model of personalised care”¹⁰ however it seems like these principles are not being put into practice.

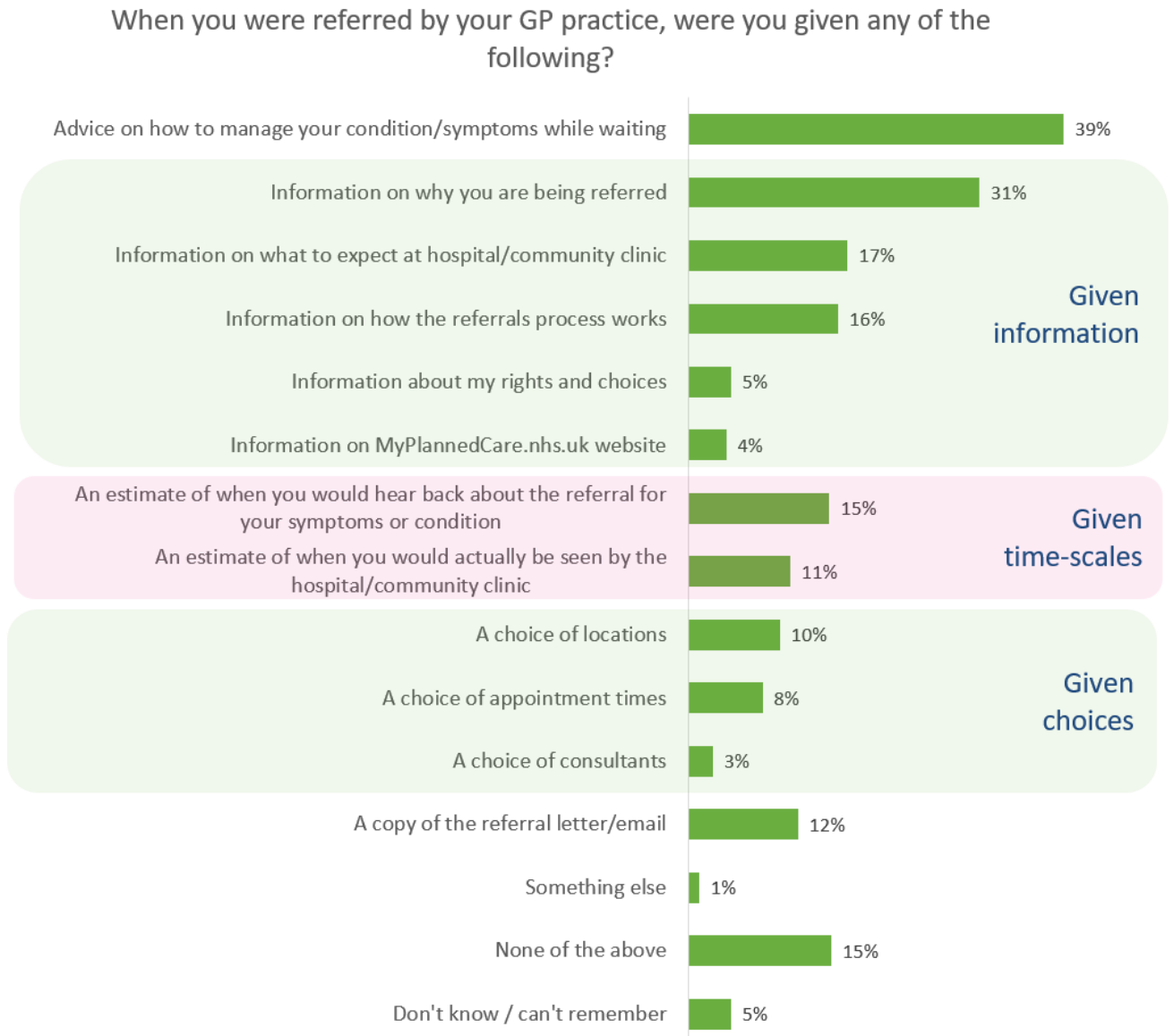
“I was not offered any support in the way of advice or medication whilst waiting for the referral appointment.” [Female, aged 50-64]

“Referrals for cancer investigations need to be managed with a full explanation not to be fobbed off to consultants! Without this, patients are not informed, feel rushed, feel frightened and stressed. I admire the consultant who rang me. GP relationships with patients are dire since covid. They still treat patients like numbers. I dislike my health centre but have no choices.” [Female, aged 65-79]

⁹ [NHS England » Empowering people in their care](#)

¹⁰ [NHS England » Personalised care operating model](#)

Figure 8: Q24 Base 1,518: All referred



Providing patients with information and setting their expectations could reduce confusion and opportunities for things to go wrong.

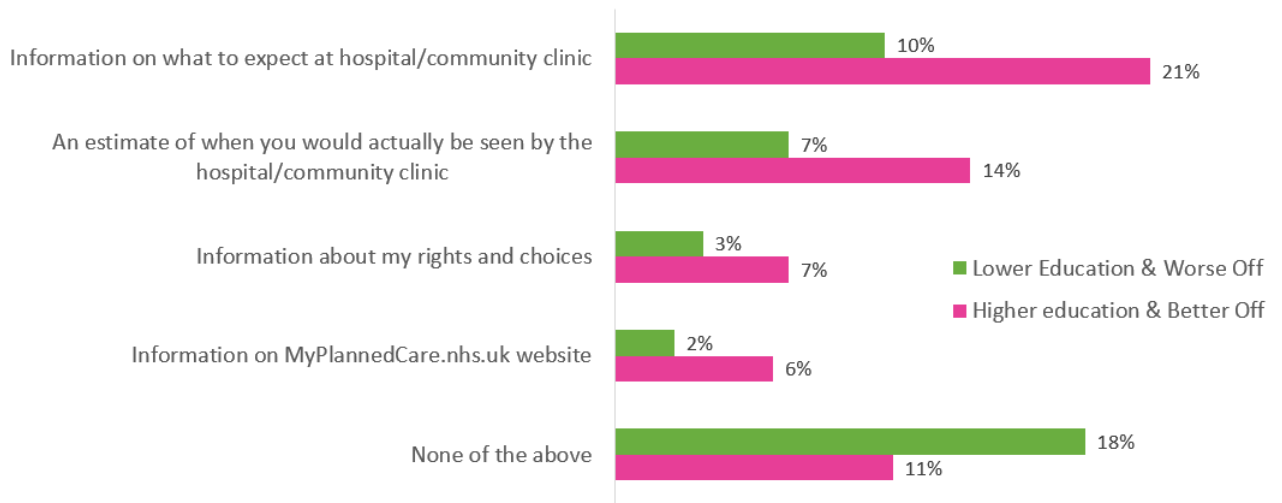
"I was confused because I thought I would simply get a letter with an appointment from the hospital, but I then received a blood test form and form for urine test from the hospital with no information as to where I had to take the urine sample to - also have no container so have still got to sort that out." [Female, aged 65-79]

What GPs offer patients at the point of referral varies by patient.

Those highly educated **and** better off financially were twice as likely to have been given information, advice and choice. When we look at those characteristics individually, however, the differences are not as stark, highlighting how intersectionality can create even greater disparity in patient experience. In this case, it suggests perhaps the more vulnerable patients are not getting the same level of support from their GP as others.

Figure 9: Q24 Base lower education and worse off 416, Higher education and better off 747

When you were referred by your GP practice, were you given any of the following?



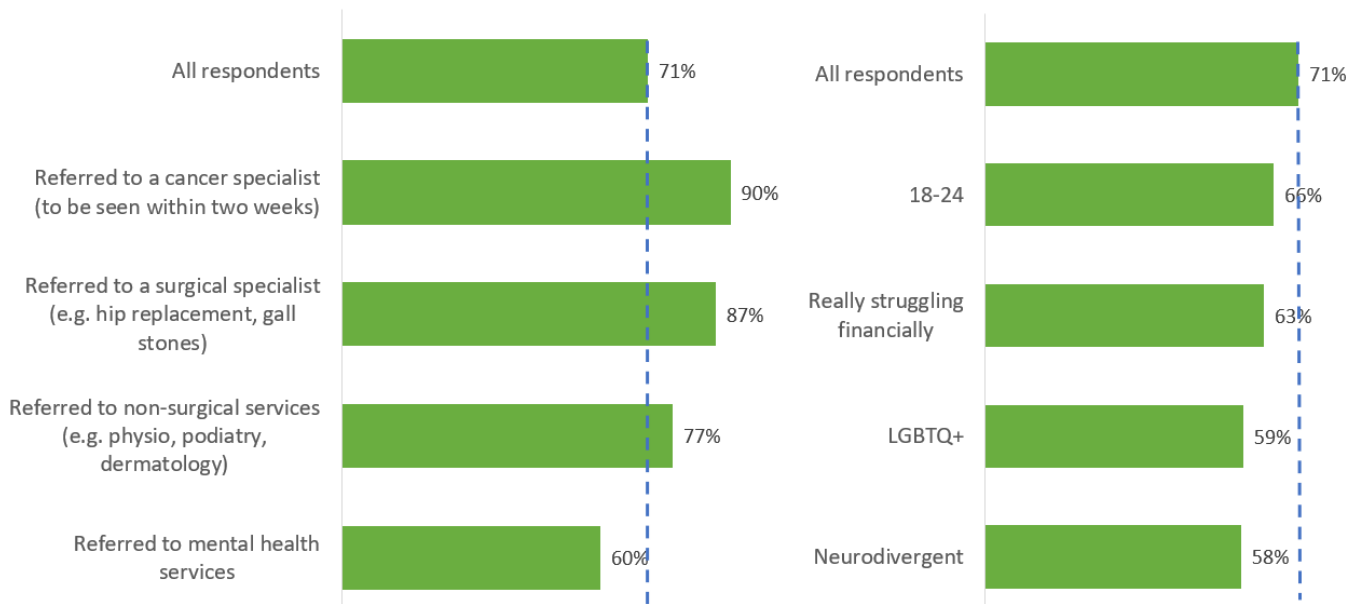
Chances of a referral progressing smoothly vary greatly

The referral progressed straight to an appointment or waiting list for seven in ten (71%) patients.

The path to a referral appointment or waiting list may be more direct for some patients depending on their referral destination and personal characteristics.

Figure 10: Q25 Bases vary for each bar (cancer 115, surgical 200, non-surgical 443, mental health services 128, age 253 18-24, Really struggling financially 150, LGBTQ+ 133, Neurodivergent 98)

Referral progressed directly to appointment or waiting list



Those referred to a cancer specialist were most likely to progress directly to the next stage, whilst those referred to mental health services were least likely to progress directly. It makes sense that cancer referrals have the best chance of progressing smoothly considering the life-threatening nature of cancer, but why should mental health services have the worst chance of progressing when compared to surgical or non-surgical referrals?

Additionally, patients not given any information or support with their referral were less likely to see their referral progress to an appointment or waiting list. Only 6 in 10 (59%) of those who received no additional support (as listed in figure 8) saw their referrals progress, compared with 3 in 4 (74%) of those who received at least one piece of additional support.

Those being referred to mental health services also have a different profile to those referred elsewhere. They tend to be younger, female, neurodivergent and/or LGBTQ+, and less well-off financially. This is a vulnerable group of people who suffer significantly higher self-harm and suicide rates^{11,213}. Research by Stonewall¹⁴ in 2018 reported that “LGBT people face widespread discrimination in healthcare settings and one in seven people (14%) avoid seeking healthcare for fear of discrimination”. They also noted high levels of suicidal thoughts.

“The CCG would not pay for my long-term mental health support despite this being recommended by a professional who had said I needed specialist help as I have autism and was suicidal” [Male, aged 25-49]

¹¹ [Death by Suicide Among People With Autism: Beyond Zebrafish | Autism Spectrum Disorders | JAMA Network Open | JAMA Network](#)

¹² [Undiagnosed autism might be contributing to suicides | MHT \(mentalhealthtoday.co.uk\)](#)

¹³ [Why is the LGBTQ+ community disproportionately affected by mental health problems and suicide? | News and Events | Greater Manchester Mental Health NHS FT \(gmmh.nhs.uk\)](#)

¹⁴ [LGBT in Britain - Health \(stonewall.org.uk\)](#)

“The clinic contacted me to fill in a questionnaire about my symptoms. I have not heard anything else from them, including not having heard that I am on their waiting list or when they will be able to see me. [Non-binary, under 25]”

For some the referrals journey is bumpy

Some patients experience a range of setbacks or delays on their referrals journey before getting onto a waiting list or being given an appointment – and some might not make it to their destination at all.

Some patients experience, not just one, but a multitude of problems such as delays, discovering there was no record of the referral at the GP surgery or hospital (lost, not made), or rejection when the referral is made to the wrong department, or with the wrong information.

“Doctor didn’t give correct information to hospital. I telephoned the hospital and was told that this had delayed my referral. I sent a letter to my doctor asking him to give correct information. Referral was made on 6/7/2022 and I have not received a date for hospital to today’s date.” [Female, aged 65 and over]

“The appropriate department forgot to add me to waiting list, lost my referral and I only found out because I enquired. I waited 6 months longer.” [preferred not to give demographic information]

“My referral was rejected due to a paperwork issue and has been re-referred, but I’m still yet to hear anything from the hospital” [Female, aged 25 to 49]

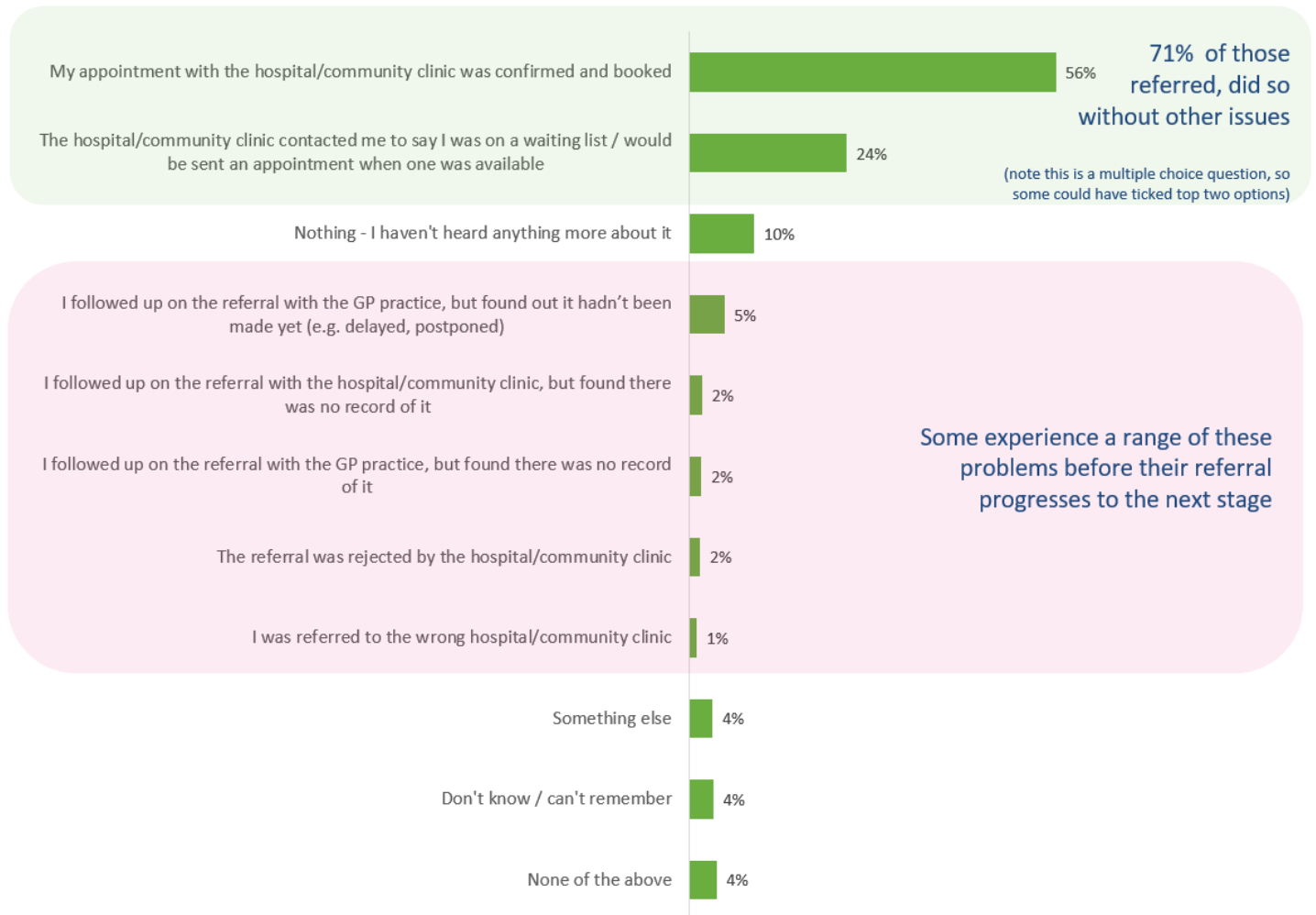
For many, the “not knowing” can be a major source of stress. Setting expectations could alleviate some of that stress.

“You are left in limbo with referrals. You are told to wait two months before chasing, then after the deadline has passed, they still can’t give you any indication of how long you will wait to be told when your appointment will be. There are no timeframes and the GP surgery leave you to chase it yourself. In the meantime, not only do your symptoms worsen, but the anxiety of no timeframe is miserable. I became so anxious that I now have another health condition to deal with.” [Female, aged 25 to 49]

“Not getting a confirmation that the referral has or hasn’t gone through is very stressful as a patient.” [Female, aged 25 to 49]

Figure 11: Q25 Base 1,518: All referred

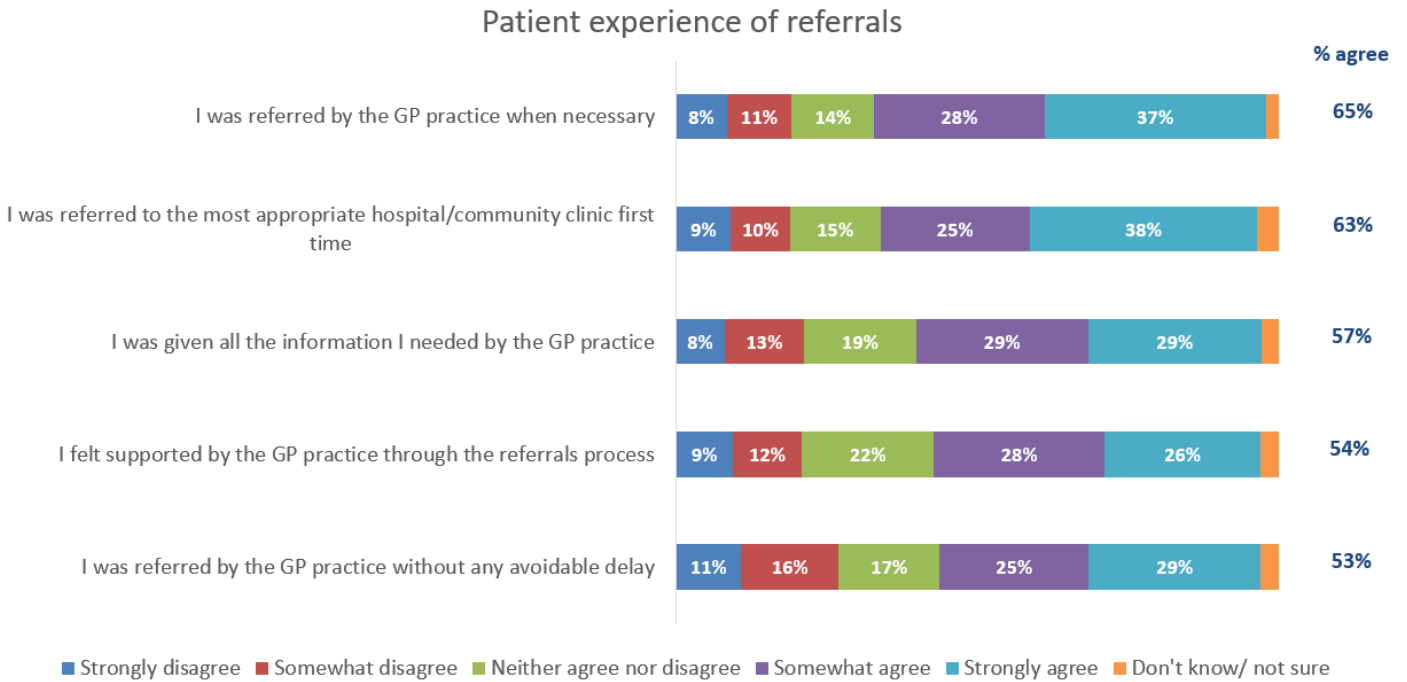
What happened after your GP practice said you were being referred for your symptoms or condition?



Experience of referrals has much room for improvement and more for some than others

We asked patients whether they agreed with a range of quality statements about their referrals experience to understand the quality of those experiences and we discovered that across all aspects, there is much room for improvement. There is also some evidence of disparity in how some people experience referrals. Those less likely to agree with these statements tend to be younger, of ethnicity other than white British, neurodivergent, less well off or lower educated.

Figure 12: Q27 Base 1,518: All referred



For some patients, getting through the referrals process is arduous and it erodes their faith in the NHS.

"It's exhausting having to fight for referrals often meaning having to jump through hoops before getting the referral. Often don't feel listened to and rushed out the appointment or not taken seriously. Feel very let down by the overall process and experience with my fibromyalgia diagnosis and treatment." [Female, aged 25-49]

"A&E had told me to ask my GP to refer for scan when I injured my knee, but they didn't refer me anywhere until I'd returned approx. 4 times in pain crying. I referred myself to physio who said "why haven't you been to the orthopaedic hospital first" due to the severity of my injury. Had a really hard long 6 months struggling to walk and work my mental health was badly affected and still waiting now. If I hadn't gone back to GP a few times I would not have been referred at all. Usually, I am happy with my GP, but this has made me feel less trusting of them." [Female, aged 25 to 49]

"I'm not confident that my referral will progress any further. I understand that the NHS is in crisis because as a heart attack survivor I would have expected concern over my sudden chest pain, yet I had to fight for a GP appointment and for referral to a consultant. I feel that we are witnessing the end of the NHS." [Male, aged 50-64]

When the NHS gets it right, patients really appreciate it, and it can positively affect their health outcomes¹⁵. Experience like this should be commonplace.

"My GP has been amazing through all my referrals; they are supportive and include me in the referral process so I can have a say in what is sent. They are also being extensive in investigating some high inflammation markers in my bloodwork and continuing with strong communication via text while I am having tests etc" [Female, aged 25-49]

¹⁵ [Being listened to: what difference does it make? | Care Opinion](#)

"The GP was really helpful, and up front about the waiting time likely to be like a year, because even though the pain is excruciating, I was not dying. Life stinks, but he's seen me (and helped me) work through some really dire times. He also did do some chasing up and reporting back and stayed professional and stayed human. He's got a good balance going within the confines of a structure that's not friendly really to either." [Female, aged 50 to 64]

"Despite difficulties faced, including initial difficulties to get an appointment and long wait times for referrals; I am very grateful that I am being seen and things are progressing. I have seen many different doctors at the same surgery and some of the doctors have been good by explaining where things are up to, empathy and referring when needed." [Male, aged 25-49]

Recommendations

We know that millions of people are referred by their GP every year. But current data can't help us understand the experiences of patients while they go through the referral process

The various stages of waiting are a blind spot for the NHS, and these hidden waiting lists can lead to a range of problems. We've heard from patients who are waiting months on top of the time they'll spend on long hospital waiting lists.

And while waiting, people have told us they are rarely given information, timescales, or choices about their referral. This leads to referrals not always progressing as quickly as possible, and patients bouncing back to extremely busy general practices.

Experience of getting a referral

These policy recommendations aim to support staff and bring about changes to the referrals process to improve people's experience of moving from general practice to the care of a team in a hospital or community clinic.

Recommendation	Why is this change needed?	Who is responsible for implementation?
Add questions on the referral process to the GP Patient Survey	<p>There is currently no published national data collection covering people's experiences of referrals, or the time people wait for a referral. Additionally, data isn't collected on where referrals fail and bounce back to general practice for a new referral.</p> <p>NHS England should work with Healthwatch England to add questions on the referral process to the annual GP Patient Survey.</p> <p>This would ensure a greater understanding of the current patient referral journey. And it would also support the development of baselines and KPIs for satisfaction over the longer-term</p>	NHS England

<p>Offer flexible appointment slots in general practice to give people more time with clinicians.</p>	<p>Almost three in five respondents who were referred were repeat visitors to general practice.</p> <p>Some of these patients will have required multiple appointments, but for others there may have been opportunities to refer more quickly.</p> <p>Additionally, 15% were given no information, timescales, or choice along with their referral. In some instances, this reduced the likelihood of referrals progressing directly to appointments or joining a waiting list.</p> <p>Both issues could be helped by the allocation of additional GP appointment time.</p> <p>This 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.</p>	<p>NHS England</p> <p>Integrated Care Systems</p> <p>General Practice Teams</p>
<p>Ensure all practices are using the e-referral services and improve the online referrals tracker for patients.</p>	<p>The GP contract states that GP teams must use the NHS e-referral service.</p> <p>However, the HSJ has recently found that 27 Trusts still do not have an electronic patient record system.</p> <p>Trusts and GP practices should prioritise full transition to electronic systems, supported by appropriate resource from NHS England.</p> <p>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</p>	<p>NHS England</p> <p>NHS Trusts</p> <p>General Practice Teams</p>

understanding of where someone is on the referral pathway.

It will also support improvements to online tracking and booking systems.

We've heard from patients who have received no information along with their referral. Some of these people have gone on to discover that the referral was never actually sent or received by specialist teams.

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.

Information should also be available and shared with patients via other preferred communication methods where relevant, as noted in their care records.

<p>Improve processes for patients to contact NHS teams about their condition following a referral.</p>	<p>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.</p> <p>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).</p> <p>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 referral if they have not received information about its progress.</p>	
<p>Review NHS guidance related to the referrals process.</p>	<p>Guidance on referral optimisation should be updated. Approaches such as 'advice and guidance' are currently being used across the country, but without shared decision making, patients can remain unaware that the process is underway and that they will either be contacted soon about a hospital referral, or treatment from the GP team. This leads to frustration, and their demand for healthcare moving elsewhere in the system.</p> <p>Consultant-to-Consultant referral guidance should also be updated.</p> <p>Over one in five people we spoke with had been told by another healthcare professional to ask their GP for a referral.</p> <p>This will include consultants in secondary care settings.</p>	<p>NHS England</p>

	<p>The latest guidance relating to consultant-to-consultant referrals was published in 2018. This guide suggests scenarios where hospital consultants should recommend patients return to their GP for a referral, to ensure a holistic approach to care.</p> <p>However, since this guidance was published, median waits have more than doubled, and the people waiting the longest for treatment are being affected disproportionately.</p> <p>Patients such as those we spoke with could wait weeks for a GP appointment, months to join a waiting list, and now almost a year for their hospital care.</p> <p>Where once a holistic approach may have been advised for some referrals, more timely access may now be preferred by patients.</p>	
<p>Review pathways for which additional roles in primary care can refer.</p>	<p>With the expansion of primary care teams to include more nursing staff, pharmacists, and physiotherapists, the NHS should review the roles and responsibilities of these staff.</p> <p>This includes which team members may be able to support integration of NHS services by referring patients for some conditions.</p> <p>We know that patients in some instances are happy to see the most appropriate health professional, and where possible, these teams (under the supervision of the GP) could support increasing demand for care by referring on.</p>	<p>NHS England Integrated Care Systems</p>

About the research

Survey 1	
Fieldwork	29 September to 20 October 2022
Supplier	Panelbase DRG
Methodology	Online survey
Sample	The sample size for the whole survey was 2,144, but the base for group covered in this briefing is 1,518 people who had been given a referral . We set minimum quotas for ethnic minority and financial status. The figures quoted in this briefing come from this survey.
Questionnaire design	The survey covered numbers of visits to the GP, including whether they were return visits for an existing condition and reason for the return visit. It explored why patients think they may have not got, or been refused a referral, the impact it had on them and what alternative actions they took to get the desired medical attention. The survey also explores the experience of getting a referral for those that got one, including what information they were given, wait times, impact of any wait, what alternative actions they might have taken for past failed referrals and what the outcomes were.
Survey 2	
Fieldwork	22 August to 11 October 2022
Source	Healthwatch England
Methodology	Online survey
Sample	The sample size for the whole survey was 1,825, but the base for group covered in this briefing is 367 people who did not get a referral . The comments quoted in this briefing come from this survey. The survey was distributed online by our local Healthwatch network, and respondents are self-selecting.
Questionnaire design	Identical to the Panelbase survey, except that the demographic questions are at the start of the survey to facilitate quota checks.

Sample Demographics (Panelbase dataset)

Over the last 12 months, which of the following has applied to you?	Referred for tests, diagnosis or treatment (REFERRED)		Expected or requested a referral for tests, diagnosis or treatment, but didn't get it (NOT REFERRED)	
All respondents	1518	100.0%	626	100%
Age				
18-24	253	17%	122	20%
25-49	829	55%	381	61%
50-64	254	17%	88	14%
65-79	165	11%	28	5%
80+	13	1%	6	1%
Prefer not to say	4	0%	1	0%
Gender identity				
Male	464	31%	203	32%
Female	1050	69%	417	67%
Non-binary	2	0%	5	1%
Prefer not to say	2	0%	1	0%
Gender identity the same as sex recorded at birth				
Yes	1501	98.9%	613	98%
No	11	0.7%	9	1%
Prefer not to say	6	0.4%	4	1%

Over the last 12 months, which of the following has applied to you?	Referred for tests, diagnosis or treatment (REFERRED)		Expected or requested a referral for tests, diagnosis or treatment, but didn't get it (NOT REFERRED)	
Sexual orientation				
Heterosexual / Straight	1358	90%	521	83%
Bisexual	75	5%	50	8%
Asexual	23	2%	12	2%
Lesbian / Gay woman	16	1%	8	1%
Gay man	10	1%	11	2%
Pansexual	8	1%	4	1%
NET LGBTQ+	132	9%	85	14%
Prefer to self-describe	3	0%	3	1%
Prefer not to say	25	2%	17	3%
Which of the following statements apply to you?				
I am a carer	177	12%	101	16%
I have a disability	176	12%	69	11%
I have a long-term condition	324	21%	124	20%
I am neurodivergent (Autistic, ADHD/ADD, Dyslexic, Tourette's etc.)	98	7%	62	10%
None of the above	879	58%	311	50%
Prefer not to say	35	2%	17	3%

Over the last 12 months, which of the following has applied to you?	Referred for tests, diagnosis or treatment (REFERRED)		Expected or requested a referral for tests, diagnosis or treatment, but didn't get it (NOT REFERRED)	
Current financial situation				
Very comfortable (I have more than enough money for living expenses, and a lot spare to save or spend on extras or leisure)	144	10%	72	12%
Quite comfortable (I have enough money for living expenses, and a little spare to save or spend on extras or leisure)	617	41%	254	41%
Just getting by (I have just enough money for living expenses and little else)	597	39%	228	36%
Really struggling (I don't have enough money for living expenses and sometimes run out of money)	150	10%	69	11%
Prefer not to say	7	1%	2	0%
Not known	3	0%	1	0%
Highest level of education completed				
None	10	1%	1	0%
Primary (left school before/ at 11)	1	0%	8	1%
Secondary (left school before/at 16)	219	14%	74	12%
A-levels, high school or equivalent	307	20%	141	23%
Post-secondary vocational/ technical	211	14%	84	13%
University (1st degree)	479	32%	211	34%
Postgraduate (2nd or further degree)	285	19%	105	17%
Prefer not to say	6	0%	2	0%


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