# GP Referrals

## Part 1 – The referrals black hole

Healthwatch England
April 2023

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# Foreword

There has been a lot of media and policy attention since the pandemic on the issues people face accessing NHS services, including media coverage of record hospital waiting lists.[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 care[2].

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

Throughout 2022, around one million[3] referrals were made every month from GPs to consultant-led hospital teams. Many of these patients go on to have good experiences, both in terms of their journey through the health system and their outcomes.

But as this report highlights, this is unfortunately not the case for everyone. People we've spoken with have faced issues getting GP appointments. When they do get appointments, some are reporting they are rushed or are in a format that doesn't suit their needs. And when referral decisions are made, people are left feeling unclear as to why.

The impacts are many: ongoing health anxiety, frustration, needs going unmet and, in some cases, patient harm. All of which leads to people re-joining the queue for another GP appointment, or trying to get help for their condition from hospital teams, including those working in A&E.

That is why it is so important to understand the experiences and the expectations that people have when visiting their GP team with a medical issue. Because when expectations are not met, explained, or managed, there are knock-on impacts both on patients and on other parts of our strained healthcare system.

To address these many challenges, Government should look at investing in clinical staff in the long term, to ensure NHS capacity can meet public demand. But in the short term, there are immediate pressures. In the shorter term, investing in care navigators who can support people through their care pathways, improving the electronic systems enabling patients to track their own referrals, and expanding routes for self-referral and direct access can help improve people's experience of the referrals process.

## 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 these groups.

**The figures quoted in this briefing are based on the 626 patients who fall into the first group - those who either expected or requested a referral for tests, diagnosis, or treatment, but didn't get one**. Fieldwork was completed October 2022. We also shared our survey via the Healthwatch network (1,825 respondents overall, of which 357 respondents were in the "not referred group") and **comments from both surveys are used to support the analysis and provide quotes for this briefing.**

From national data, we know that GP referrals to hospitals are back to around pre-pandemic levels. However, as outlined below, more referrals are being rejected by hospital teams and waiting lists have grown in the last three years leading to an increase in waiting times.

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

- For those who thought they needed a referral, expected to be referred, asked for a referral, or were told to ask by another clinician, barriers to getting that referral included referrals getting lost, feelings that symptoms were not taken seriously, and issues in the first instance with access to GP teams.
    - "Had some referrals lead nowhere and never head back from some places, not even being told if I'd been rejected or not." [Male, aged 25 to 49]
- Those expecting a referral to mental health services from their GP practice are less likely to receive it compared with those expecting to be seen by other health service.
    - "Despite being suicidal and having open wounds for self-harm nothing was available to help." [Female, 25-49 years]
- Nearly three in five (57%) of those that failed to get a referral had asked their GP for the referral. Around a third (34%) had been told to ask their GP for the referral by a medical professional at another medical setting.
    - "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." [Female, 25 to 49 years]
- Nearly three quarters (73%) of those that failed to get a referral were repeat visitors (had seen their GP about symptoms or condition before).
- One in five (21%) who of those who expected to get a referral but failed to get one had previously been referred and fallen into the "referrals black hole" meaning they didn't hear anything further about the referral, the referral appointment was

cancelled, they got taken off the waiting list or they were referred to the wrong medical setting.

  - "I have wasted 2 months waiting for the wrong referral and now I have to somehow see a doctor to be referred to the correct hospital and there is a 10-months waiting list." [Female, 25 - 49 years]

- Respondents could choose from a list of multiple reasons why they believe they weren't referred and combining all the reasons selected, just under half (47%) of reasons were clinical, while just over half (53%) of reasons could be described as non-clinical. For example, the top non-clinical reason, selected by just over one in four (26%), was that they only had a phone appointment with their GP, which they felt meant their GP didn't fully understand their symptoms or condition.

  - "Only phone appointments allowed told to discuss 2 things I had to have an appointment for each." [Female 65 – 79 years]

- Nine in ten (91%) patients experienced consequences as a result of failing to get a referral, some relating to their condition, but many others relating to their life in general such as ability to work or mental health.

  - "I had to give up driving, and my car. I gave up cycling (balance probs) and resigned from a good job." [Female, aged 65 – 79]

- Over four in five (82%) patients failing to get a referral, tried alternative ways to get help. Attempts to get help elsewhere can place an additional burden on other areas of the NHS such as A&E or out of hours GPs. In some cases, patients have no choice but to visit these services when their condition reaches crisis point.

  - "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 – 24]

# Background

When people need help with a health condition, the first place they usually 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 or 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.

In England, we can track the number of people referred every month using several official NHS data collections. Where we refer to statistics from these collections, we have used national statistics from the period our research was in the field, i.e., October 2019 up to October 2022. This is data which can also be compared to pre-pandemic levels, so we compare October 2022 data with October 2019, rather than the latest April 2023 data with April 2020.

The monthly referral return (MRR) [3,4] captures the number of referrals for first consultant-led outpatient appointments. These are hospital appointments where the patient doesn't stay overnight or need to take a bed.

The NHS e-RS open data dashboard[5] also captures weekly data on the total number of referrals made through the e-referral service (e-RS) for consultant-led outpatient appointments. The e-RS dashboard also shows the total referrals accepted, booked, or rejected.

We can also track NHS referrals by looking at the number of people joining the waiting list for planned hospital care[1] and cancer care[6].

- Using the MRR[3], we can see that 1,046,764 referrals were made by GPs in October 2022, compared to 1,225,463 in October 2019 – a drop of 15%.
- Using the e-RS dashboard[5], we can calculate that in November 2022, 535,118 referrals were booked and 376,442 were rejected. In contrast, in November 2019 791,529 referrals were booked and 252,369 were rejected.

[4] MRR data is collected based on referring professional. We refer to GP referral data which is grouped with GPwER and general dental practitioner data. Data on referrals by other staff in primary care is grouped with referrals from urgent and emergency care, secondary care and screening programmes, and therefore difficult to separate for analysis.

[5] NHS e-RS open data dashboard

[6] NHS cancer waiting times

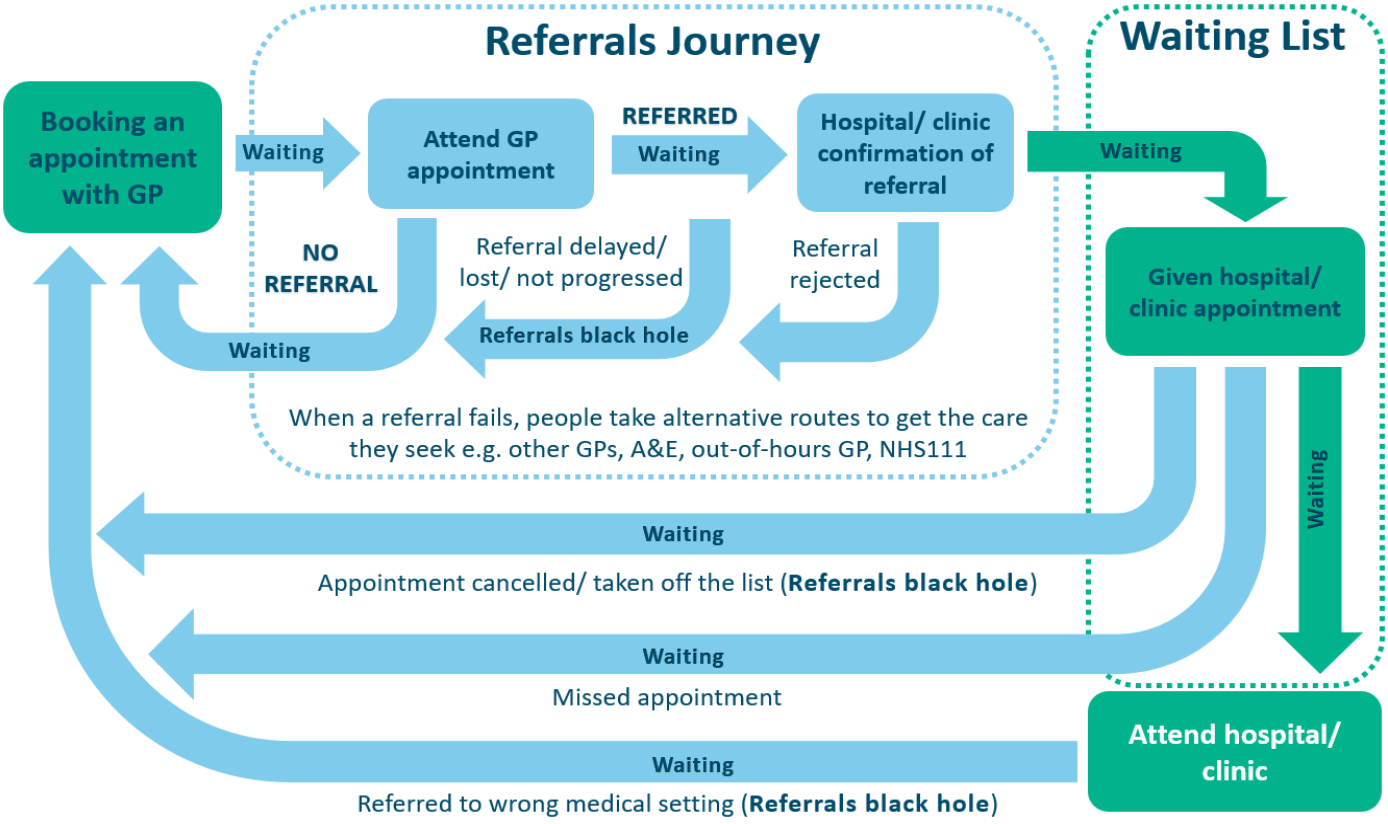
- Using the cancer waiting list data[6], we can see that 220,304 urgent two week wait referrals were made by GPs for first consultant appointments in October 2019 compared to 239,180 in October 2022.
- And using elective care data[1], we can see the total waiting list increased from 4.44 million in October 2019 to a record 7.21 million in October 2022. In October 2019, 92% of people on the waiting list were waiting 23.7 weeks for their first appointment. By October 2022 this figure had risen to 46.5 weeks.

When comparing 2019 to 2022, we can see that although GP referrals to hospitals are back to around pre-pandemic levels, fewer referrals are booked (-32%) and more referrals are rejected (+49%). Added to this, the elective waiting list grew to record levels every month from May 2020 until October 2022, with average waits for diagnosis and treatment also getting longer (+62%).

These numbers are important, but they don't cover issues such as patient outcomes, or how many people are re-referred for a condition they'd previously been referred for. For example, a decrease in referrals in a particular specialty might be a troubling sign of fewer people being referred for treatment and diagnosed, or it could mean that more people are progressing directly to treatment, reducing the number of re-referrals.

So, it is important to look beyond national figures 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.

There is a lot of focus on getting waiting lists down, however, that is only part of the problem. This research shines a light on the part of the patient journey that is not well known – getting a referral. And in particular, **this briefing focuses on understanding why some people expect referrals but are not referred by their GP.**



People are waiting longer for hospital care, but the time taken to get onto a waiting list can also be long and frustrating. And even for those that get onto a waiting list, they may find themselves right back at the start of the journey, if their original referral failed to progress through no fault of their own.

We carried out a nationally representative 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**. This **briefing reports on the experiences of the first group** which represents 626 patients. We heard from 2,144 people in all. We also shared our survey via the Healthwatch network (357 respondents in the "not 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.

We have also published a separate briefing, covering respondents who successfully got a referral following their GP appointment. That briefing focuses on how long it took participants to get a referral, and their experience of the process.

# Findings

## Getting a GP appointment can be the first hurdle

We already have a significant amount of evidence[7] on the struggles that people have faced when trying to access their GP team. This is important context, as GP services are usually the first port of call for people who need care and GP teams can arrange for tests or appointments with other specialist services.

So, when people are expecting or wanting to ask for a referral, falling at the first hurdle due to issues getting a GP appointment can be incredibly frustrating, increase people's anxiety about their health, and in some cases cause harm.

"Trying to get a GP appointment was a nightmare, 60-minute waits to get through then being told have to ring at 8.00 the following am. By the time I got through no appointments left. When finally, did see GP… they would not refer me. Was told to learn to live with pain." [Female, aged 50-64]

"… endless recorded messages and waiting times in a queue. The recorded messages encourage you to contact 111 or to go to A&E. When you do finally get through, receptionists act as medical filters… The whole process is incredibly stressful…" [Male, aged 50-64]

## Some people are less likely to get referred than others

We spoke to 626 people who either expected or requested a referral for tests, diagnosis or treatment, but didn't get one. These expectations may exist because patients had previously been referred for the same condition, or even because another healthcare professional had told them to ask their GP for a referral.

We explored our results by different characteristics to understand who was failing to get a referral. Compared with the group who got a referral, those that failed to get a referral tended to be younger and there was a higher incidence of carers, LGBQ+ and neurodivergent people.

The percentage of people seeking a referral for **mental health and wellbeing** (11%) and **brain, nerves, and spinal cord issues** (7%), was significantly higher in the non-referred group compared to the referred group. This might in part be related to the huge increase in demand for NHS mental health services[8].

Those expecting a referral to mental health services from their GP practice are less likely to receive it compared with those expecting to go to other health service destinations.

"I was told the referral would be rejected, so go through school… Schools are not equipped, and GP's seem to just wash their hands of any responsibility, so parents are just left to fight for anything and EVERYTHING. Leaving us stressed and making us

[7] Healthwatch England. GP access review must be part of NHS Covid-19 recovery. March 2021

[8] NHS England » NHS expands mental health crisis services this winter

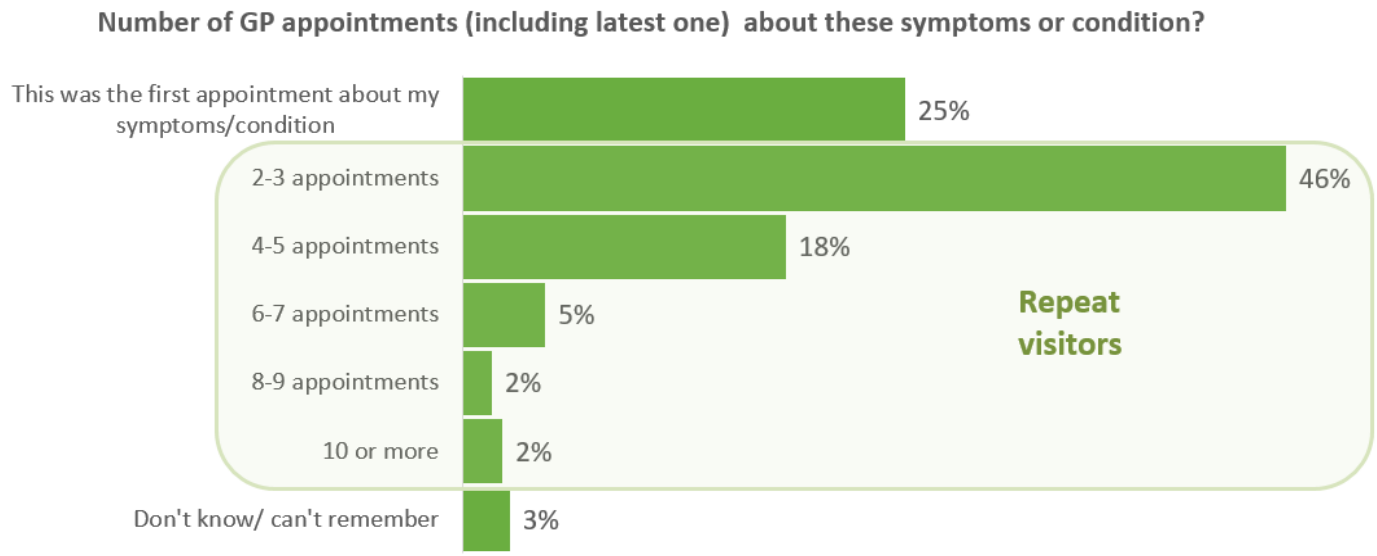
unwell." [Parent carer trying to get Autism/ADHA referral for child for over 2 years, mum is aged 25-49]

"I have been sent round in a circle. I was told to self-refer to a mental health support worker. I wanted to see a psychologist for PTSD… He then referred me to Community Mental Health Services… I said I needed a psychological assessment. He said I had to go back to my GP… I am now waiting to see my GP again." [Female, aged 65-79]

## Many people who failed to get a referral had already tried to deal with the issue before

Nearly three quarters (73%) of those that failed to get a referral were repeat visitors.

Patients who fail to get a referral are more likely to be **repeat visitors** meaning they have seen their GP about these symptoms or condition in the past. Those that got a referral previously are more likely to have returned to their GP because the referral did not progress through issues out of their control, such as referral letters being lost or missed.




One in five (21%) who of those who failed to get a referral had previously been referred and fallen into the "referrals black hole".

The relief of feeling listened to and securing a referral at a GP appointment, can turn to disappointment and frustration when time passes, and they hear nothing more.

Patients don’t always know if their referral letter was written, lost or it arrived at the right destination; if they were put on a waiting list or not’ whether their referral or appointment was cancelled; or when they might expect to hear something.


This process can feel like a **referral black hole** and leads to many patients returning to their GP. We have heard that patients often only learn about their initial referral not progressing after contacting their GP or the medical setting where they should have been referred to.

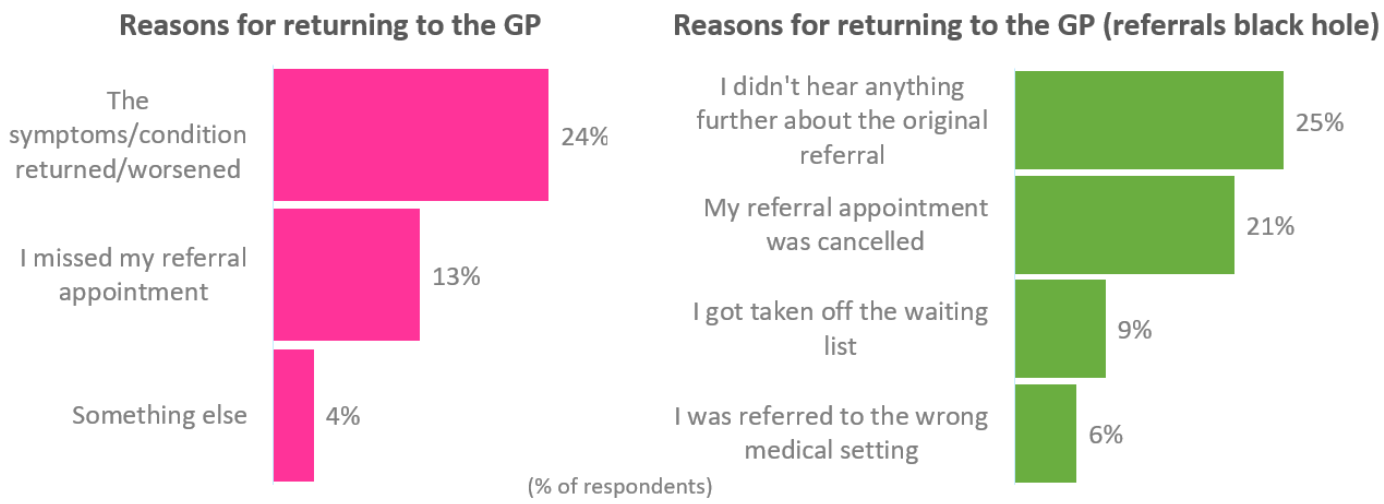



Figure 1: Q7. Why did you want to talk to your GP practice about the issue again? Base 259 non-referred respondents who had previously been referred.

"The GP submitted the referral without sufficient information and when I asked about updates on it, I was told it had been submitted. But in reality, it was rejected and only after 6 months of trying to get an answer [did] they check the status of the referral." [Man, aged 25-49]

"They told me I was referred to the hospital, then when I rang back up after not hearing from anyone, they had not referred me to anywhere so had to start the process again." [Parent on behalf of child, Male under 18]

Based on these responses, many of these referral issues seem to be related to workload and workforce issues, either at the general practice end or at the hospital.

"After doing all the research myself, I expected a referral. I tried to chase this on numerous occasions. My own GP told me not to contact him, the secretaries have a backlog of 900 letters and referrals 'due to Covid." [Female, 65-79 years]

"I have wasted 2 months waiting for the wrong referral and now I have to somehow see a doctor to be referred to the correct hospital and there is a 10-month waiting list". [Female, aged 25-49]

Patients miss appointments for many reasons. Some are not notified about their appointments via their preferred communication method, some simply forget, and for others it may be for reasons such as being ill, having caring responsibilities, or not being able to travel to their appointment. Patients can try and fail to reach someone to cancel the appointment, and even if they manage to cancel – it can still be recorded as DNA (did not attend).

"The hospital I was referred to did not check my contact details on the referral. A letter was sent to my old address and resulted in me missing the appointment that I knew nothing of." [Female, aged 25-49]

This can increase already high workloads in primary care by causing an **unnecessary bounce-back to the GP to be re-referred**. Making it easier for patients to cancel and reschedule directly with the clinic/hospital could reduce the number of patients having to go through the referrals process again (which is costly to the NHS) and reduce the delay to care/treatment and stress for the patients. The language commonly used around this issue is **"failure to attend"** which assumes blame on the part of the patient, when in fact it could be the "system" that is at fault or personal circumstances beyond the control of the patient.

Nearly three in five (57%) of those that failed to get a referral had asked their GP for the referral.

Considering that 34% of those that requested the referral had been told to ask their GP for that referral by a medical professional at another medical setting, it's easy to understand why patients could be even more frustrated.

"Referrals were not done; consultants have requested further testing and my GP does not even read follow up letters. Have had to fight for every single piece of care." [Female, aged 25-49]

"When I was diagnosed with aortic stenosis in 2018 my results letter specifically stated I was to have repeat echo in 3 years, unfortunately it was refused by a new GP at my practice." [Female, aged 50-64]

## People often perceive they are not getting referrals because they are not listened to.

Respondents could choose from a list of multiple reasons why they believe they weren't referred and combining all the reasons selected, just under half (47%) of reasons were clinical, while just over half (53%) of reasons were non-clinical.

The NHS Constitution for England formally states that:

- People have the right to access NHS services
- People will not be refused access on unreasonable grounds
- People have the right to receive care appropriate to their needs and preferences

There is a broad variety of both **clinical and non-clinical reasons** why patients think they were not referred and for many there is a mixture of both. The top reason, selected

by a third of patients in this group, was that "**the GP wanted to try medication/other treatment options first**". Like other clinical reasons, in most cases **reasonable** clinical decisions are made by expert clinicians who have decided that a referral wouldn't lead to the best outcome for patients.

However, the second reason chosen by just over a quarter of the group, was "**I was only given a phone appointment**". Like other non-clinical reasons, this is an example of people feeling like their **care wasn't appropriate to their needs and preferences** which contributed to **unreasonable** grounds for refusing access to specialist services via a referral.

"Appts were mostly on the phone. I struggle to get my thoughts across speaking on the phone and need a f2f appointment to make it easier, but couldn't get a f2f appt. [Female, aged 18-24, neurodivergent]

"An acquired brain injury can impair my ability to discuss complex medical matters, especially over the phone." [Man, aged 65-79, survey completed by a family member]

The Covid pandemic accelerated the use of remote appointments which was necessary to reduce the spread of the virus, however, in May 2021, GP practices were issued a letter[9] from NHS England saying patients should be **offered** face-to-face appointments ('unless there are good clinical reasons to the contrary', such as the patient displaying Covid symptoms). The latest data from the NHS Appointments in General Practice data[10] shows the level of telephone appointments has dropped from around a third to a quarter in a year (to November 2022).

The answer to the question "which is better – telephone or face-to-face?" – is probably "it depends", where patient choice, ability to communicate and clinical need[11] should be the driving factors. GPPS 2022[12] data shows that patients who had a face-to-face appointment, were more likely to be satisfied with the appointment they were offered (85%), than those offered a telephone appointment (64%), however the survey also found that year-on-year there was a small, but significant decline in the number of patients being offered a **choice of type of appointment** (24% in 2021 vs 22.3% in 2022).

[9] NHS England orders GPs to offer face-to-face appointments to all patients - Management In PracticeManagement In Practice
[10] Appointments in General Practice, November 2022 - NDRS (digital.nhs.uk)[10] Appointments in General Practice, November 2022 - NDRS (digital.nhs.uk)
[11] David Nash inquest: Student 'likely to have lived' if seen in-person by GP - BBC News
[12] GP Patient Survey (gp-patient.co.uk)

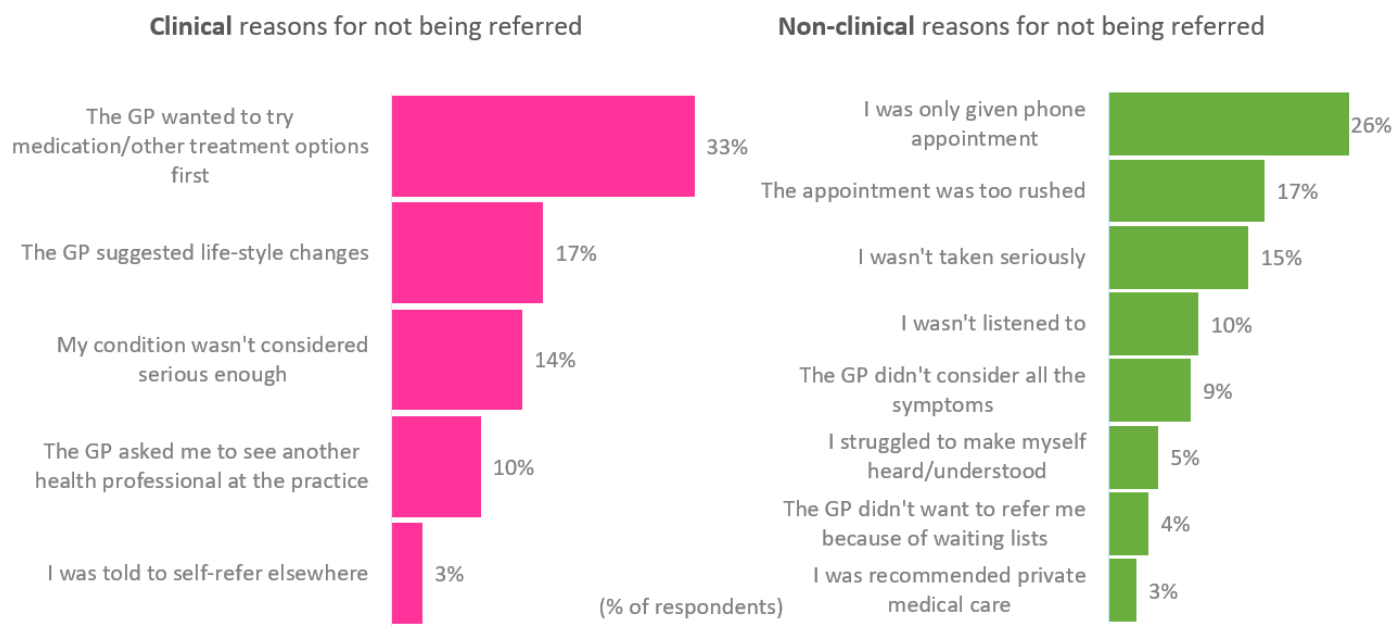



Figure 2: Q12. Why were you not referred for your symptoms or condition? Base 626 non-referred respondents

Some of these non-clinical reasons are of course subjective, but they do suggest experiences of care which were inappropriate to their needs. Given the volume and variety of non-clinical reasons for non-referral, it's easy to understand why some patients will feel frustrated and disappointed when they leave their GP surgery without the expected or requested referral.

"I struggled to make myself heard because no one was listening to me, they listened to me when my condition got much worse and intolerable for me…" [Female, aged 25-49]

Some feel driven to pay for private medical care…

"…I was upset at being told to pay privately… I returned to GP surgery 2 days later to reiterate I wanted to be on NHS waiting list. This was met with great resistance; told I could only be referred on 2 weeks wait if the basal cell carcinoma was on my face…Referral secretary spent an hour trying to explain why I was advised to go private. She informed me they are suggesting this to avoid waiting referral times… I am on the verge of paying privately as I want to know what I am dealing with… This has caused me so much distress which is why I am looking at paying…" [Female, aged 65-79]

…whether or not it is affordable for them.

"I have now been in agony for 12 weeks and am going to have to go private for more extensive physio…., causing financial hardship as I am a pensioner…" [ Female, aged 65-79]

"I had to pay privately (could not afford but was so ill). I paid for an MRI scan which proved I had a serious infection, a following CT scan by a private doctor following an endoscopy proved exactly the extent of infection." [Female, aged 50-64]

The State of Health and Care report 2022[13] by the Institute for Public Policy Research reported that for those who found it difficult to access NHS healthcare during the pandemic, 12% used private healthcare and a further 25% considered it. When asked what they would do if the wait for treatment was longer than 18 weeks, 59% said they would wait because they cannot afford it.

Previous Healthwatch polling from 2021[14] also highlighted these issues. Eight per cent of people we spoke to who were waiting for an elective care appointment had gone private due to long waits, with 14% considering private care. However, for 65% of respondents, going private was not an option due to cost.

## Not getting a referral results in significant consequences to health and wellbeing.

Nine in ten (91%) patients experienced consequences as a result of failing to get a referral.

Whether people were not referred due to clinical or non-clinical reasons, when patients go to their GP expecting to get a referral and fail to do so, the health problem they wanted help with does not just go away. Some of the consequences of failure to get a referral relate to the symptoms or condition they are suffering with, while others have wider implications to their lives and those around them. It can have implications for their partner, family, carers, employer, government (in terms of sickness benefits), and the NHS (for example, by leading to more costly treatment down the line).

"Worsening symptoms cause me extreme anxiety, particularly as I am sole carer of severely disabled son…" [Female, aged 65-79]

"The GP has not got a clue… My symptoms were visibly obvious. Blatant GP refusal… No explanation when asked… I referred myself to the hospital now undergoing several diagnostic tests for a serious life-threatening condition… For me this has been devastating at the highest level leaving my life destroyed." [gender unknown, aged unknown]

[13] The state of health and care 2022 | IPPR

[14] What are people telling us about delays to hospital care and treatment? | Healthwatch Data

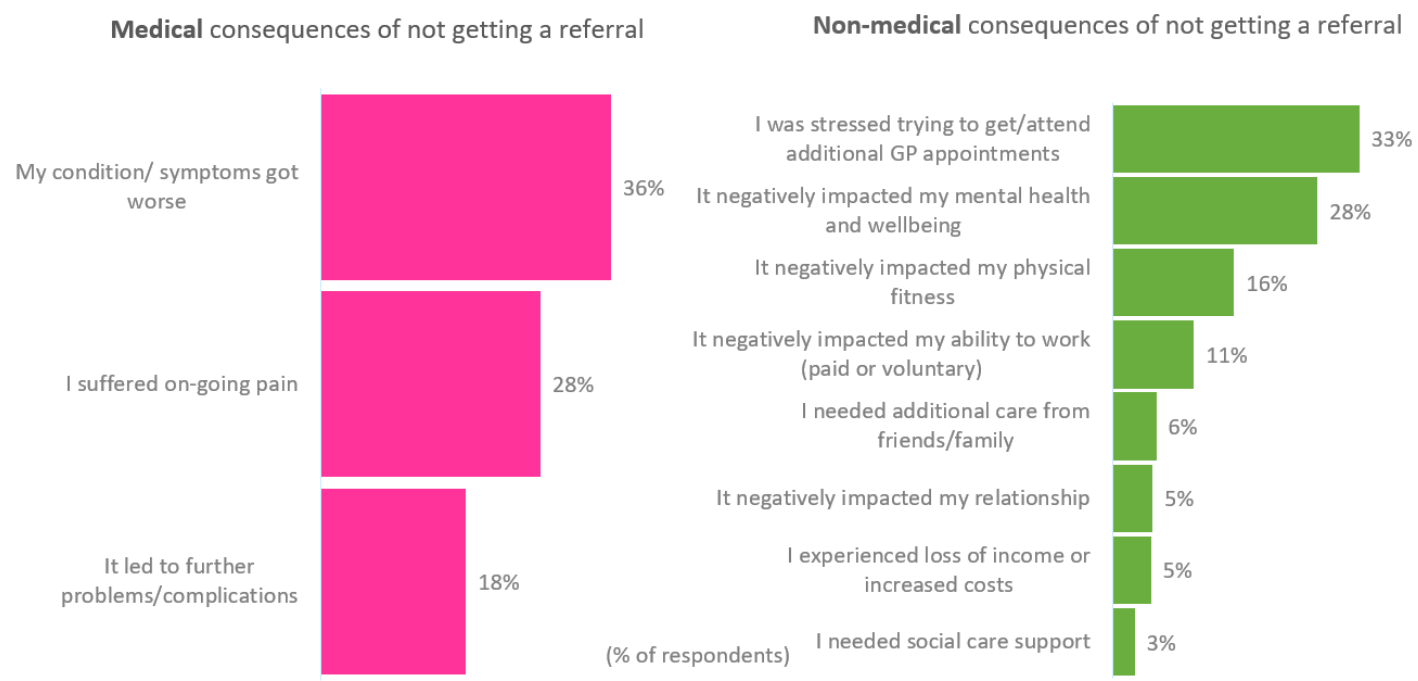



Figure 3: Q16. What were the consequences of not getting a referral for your symptoms or condition? Base 626 non-referred respondents.

One of the stand-out emotions expressed by patients, is **fear of the ticking clock**, because patients know delays to their treatment may have very serious medical consequences.

"This is worrying. I am not being heard. I have symptoms which could be bowel cancer and time is of the essence…" [Female, aged 65-79]

"If I had waited for the NHS appointment, I would have been dead by now. A 10 month wait! [Female, aged 65-79]

Just over a third of patients who failed to get a referral had already waited more than four months between their first GP practice appointment about their symptoms or condition and their most recent appointment. Earlier referral, and tackling the causes of the referrals black hole, could reduce these impacts in many cases.

# Not getting a referral can lead to people seeking alternative treatment, putting extra pressure on the system.

Over four in five (82%) patients failing to get a referral tried alternative ways to get help.

When patients expect a referral and fail to get one, it's easy to understand why so many will try alternative routes to medical care, especially given the consequences they might have experienced. The likelihood of trying alternative routes is significantly greater for those who had been asked by a healthcare professional at another medical to ask their GP for the referral. Given their expectation of getting a referral was likely to be higher and therefore the disappointment greater, this is unsurprising. Repeat visitors, particularly those who'd already had four or more appointments about their condition, are also more likely to take alternative routes to care, and in particular go to A&E or an out of hours GP.

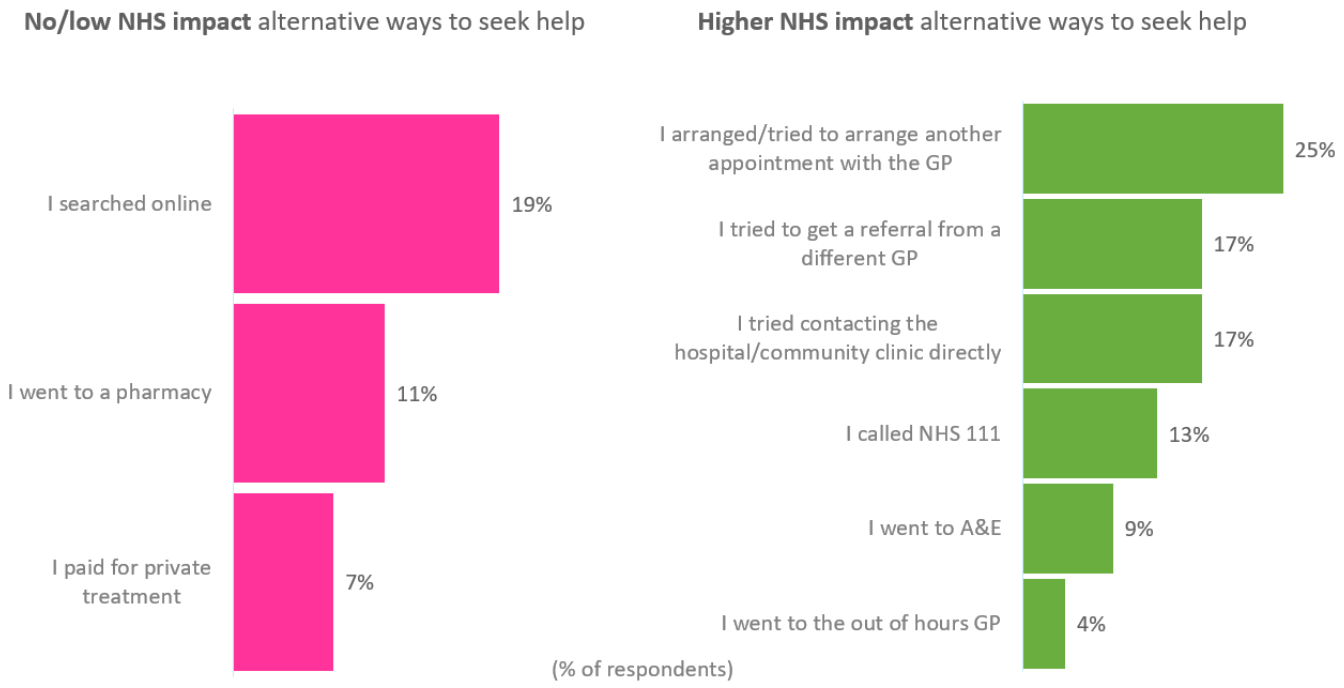



Figure 4: Q14. While trying to get a referral from your GP practice for your symptoms or condition, did you do anything else to get medical help for your symptoms or condition? Base 626 non-referred respondents.

To varying degrees patients' attempts to get help can place an additional burden on other areas of the NHS such as A&E or out of hours GPs and in some cases, they have no choice and end up in hospital anyway.

"...a non-healing lesion which I raised at several appointments at my GP practice [Jan 2021] ... advised me it was nothing to worry about. In April 2021... GP did not appear concerned... As time went on in 2021... I became increasingly concerned it could be skin cancer... When I asked a third ANP [advanced nurse practitioner] in August 2021 she looked at my nose and made an urgent referral to Dermatology... was seen within 2 days and told it was cancer... it impacted on my PhD studies and my part-time job. I had surgery but as it had gone undiagnosed for 8 months the op did not remove all of the cancer...". [Female, aged 65-79]

Or in this instance, barriers to accessing general practice and a subsequent misdiagnosis let to a patient's death.

"Could not get a GP appointment after 3 days of continual phone calls. Eventually saw a Nurse Practitioner. Given 3 days of antibiotics. Taken eventually to hospital in severe agony, then straight to a hospice. Died within 2 weeks of first getting to see a nurse practitioner. Never saw a doctor." [Female, aged 65-79 – referral to cancer specialist was refused, survey completed by someone else on patient's behalf]

For patients who sought alternative help by visiting A&E or out-of-hours GP, almost one in two (45%) got the medical care they needed.

"I went for a private skin lesion scan, and they said it was a basal cell carcinoma which is what I had told my GP I thought it was, but they said it wasn't from the photographs they asked me to send them. I was unable to see a GP face-to-face even when I requested this." [Female, aged 25-49]

"Spoke to my sister, who is a nurse. I only went to A&E when I became very ill, very suddenly, early one evening. I would not have gone if I hadn't been so poorly." [Female, aged 50-64]

## Quality of communication and feeling listened to make a big difference

The **quality of communication or complete lack of it** through all stages of the referrals process can cause significant frustration and stress for patients.

For those who feel comfortable using digital systems, access to an online system that allows them to check the existence of their referral, its progress through the system, then finally the outcome (whether it is rejection of the referral, being added to a waiting list or given an appointment) could significantly reduce patient anxiety and suffering. This would also reduce the need for some avoidable repeated contact from patients. The App would need to be accessible by the GP, the referral destination and the patient.

"It would have been helpful for me to be informed that my referral was at least being dealt with or I was on a waiting list as now, I have no idea if I have been forgotten. A simple note to say you are on a list would be a huge relief to me." [Female, aged 65-79]

Some comments made by patients suggest a **lack of faith** in the knowledge and ability of the GP team to correctly diagnose problems, including a limited knowledge of correct diagnosis pathways and processes.

"The GPs did not review medical notes and kept making mistakes including failing to follow their decided treatment plan, referring to the wrong speciality/department/clinic, repeating medication treatments that were only supposed to be used once." [Man, aged 65-79, survey completed by a family member]

"I asked for a referral as the orthotics dept required it in order to make a new splint/calliper for my leg. The surgery did not know what orthotics was and asked me to spell it. I later had a call from the surgery pharmacist asking me to elaborate about the "special medicine" I had requested earlier." [Woman, aged 65-79, completed by a carer]

In addition, some comments we received suggest pressures from commissioners to reduce referrals. It also seems that some doctors either feel there is no benefit to their patients joining long waiting lists, or that they are helping the NHS to reduce costs and waiting lists by avoiding referrals or suggesting private medical care.

"MRI scan too expensive, apparently." [Female, aged 65-79]

"Trying to cut down the NHS money can result in of death of so many people who are being ignored and didn't get treated… because of GP way of cutting the cost by doing half job." [Female, aged 25-49]

Many patients feel **hopeless and helpless** when they struggle every step of the way through the referrals process, from the very beginning in trying to access their GP in the first instance, failing to get a referral, or getting a referral and finding themselves in the referrals black hole. Their only option is to keep trying with multiple visits to the GP, other GPs, out of hours or A&E. Some simply give up and continue to suffer undiagnosed and/or untreated problems. The impact on their life can be devastating or even deadly.

"I have lost all faith in any level of care, advocacy or concern from GP. It upsets me greatly and makes me feel more unwell if I go to them and get no help, so I just stay home on my own steadily getting worse." [Female, aged 25-49]

"Different parts of the healthcare system don't seem to communicate well. When referrals don't go as expected, GP blames hospital, hospital blames GP, patient is caught in the middle. All the time health problem is worsening, patient feeling **lost** and **helpless** and not knowing who to go to or where to turn. Added **stress** and time making multiple phone calls and going round in circles. It seems each section of the healthcare system wants a different one to take responsibility for care of the patient. As a patient it is **exhausting** and **exasperating**" [Female, aged 25-49]

# Recommendations

We know that for the public, GPs and their teams are a trusted first port of call – even in instances where they may not be the right contact, such as for advice about social care.

But when patients attend GP appointments expecting to be referred for specialist care, it's vital we understand that they have these expectations for a whole range of reasons. They may be experts in their own long-term condition and understand when symptoms have become worse. They may not understand exactly what is wrong with them but be worried and anxious that there may be a serious problem with their health. And in some cases, they may have been told by another healthcare professional to ask for a referral from their GP.

When these expectations are not met, this can lead to a range of problems, many of which could be prevented by better communications, expectation setting and visibility of processes.

And problems with unmet health needs, poorly managed expectations, and barriers to accessing referrals can have knock-on effects on many other parts of the NHS.

## Experience of not getting a referral

These policy recommendations aim to bring about improvements in processes to help with the understanding and management of people's healthcare needs, and to improve people's experience of seeing a member of their general practice team when they have expectations of a referral to more specialist care.

| Recommendation | Why is this change needed? | Who is responsible for implementation? |
|---|---|---|
| Train and hire more care navigators to improve access to general practice. | The first barrier many people describe to getting a referral is getting a GP appointment in the first place.<br><br>People can currently book appointments in person, over the phone, or online.<br><br>But too often people experience situations where staff are too busy to speak in person, phone lines are keeping them on hold for long periods, and online systems are | NHS England<br><br>Department of Health and Social Care<br><br>Health Education England<br><br>Integrated Care Systems |

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| | offline in evenings and over weekends.<br><br>But patients' health needs can't be put on hold or switched off when they need support from their GP team.<br><br>Some people we spoke with went to A&E when they couldn't get a GP appointment and were subsequently treated.<br><br>Care navigators can play a vital role in ensuring people's needs are met in the right setting, first time.<br><br>With these staff acting as first-line support, the future of general practice could become one with fewer long waits on the phone and with 24/7 access to online triage systems like e-Consult.<br><br>This would help make sure that increasing demand for healthcare is managed properly by trained staff. | |
| 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.<br><br>However, the HSJ has recently found that 27 Trusts still do not have an electronic patient record system.<br><br>Trusts and GP practices should prioritise full transition to electronic systems, supported by appropriate resource from NHS England.<br><br>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 | NHS England<br><br>NHS Trusts<br><br>General Practice Teams |

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| | understanding of where someone is on the referral pathway.<br><br>It will also support improvements to online tracking and booking systems.<br><br>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.<br><br>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.<br><br>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.<br><br>This should start from the moment a GP agrees to make a referral, not after the referral is accepted by specialist teams.<br><br>Information should also be available and shared with patients via other preferred communication methods where relevant, as noted in their care records. | |
| Offer flexible appointment slots in general practice to give people more time with clinicians. | People have the right to access NHS services, and to not be refused access on unreasonable grounds.<br><br>But some people we spoke with said they felt they weren't referred | NHS England<br><br>Integrated Care Systems<br><br>General Practice Teams |

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|---|---|---|
| | as clinicians didn't listen to them, didn't consider all their health issues holistically, or they didn't have the time to explain their condition properly.<br><br>Making flexible or double appointment time slots more accessible can help patients, while also providing clinical staff the time and space to clearly explain to patients the reasons for either being referred or not.<br><br>This in turn can help to manage people's expectations, reduce the likelihood of them needing to return to general practice or A&E for more answers, and ensures they understand their rights are being met following an explanation of the grounds for being denied access to specialist treatment. | |
| At the point of booking, give people choice of appointment types, appointment times, and healthcare professional wherever possible. | Our research highlights that a barrier to getting a referral can be GP appointments which don't suit the needs of patients.<br><br>Research by Healthwatch and others shows that many people value remote appointments, while others prefer face-to-face consultations due to communication needs.<br><br>We also know that people need to organise travel, or alternative care arrangements for loved ones or children, and waiting on phone or online appointments without defined times can put their lives on hold.<br><br>Finally, sometimes people value speed of access, and others want to see the same healthcare professional, for example for a long-term condition like asthma or diabetes. | NHS England<br><br>Integrated Care Systems<br><br>General Practice Teams |

| | | |
|---|---|---|
| | And these preferences of appointment type, time, and professional can change.<br><br>This recommendation isn't about the proportion of appointment types being delivered or ensuring everyone has access to same-day appointments with a GP. It's about people being given meaningful choices, so their needs can be understood and managed appropriately. This will ensure people are seen in an appropriate way as early as possible, ensuring better outcomes and saving staff time. | |
| Increase awareness among patients of self-referral routes. | The NHS 2023/24 priorities and operational planning guidance also set out plans to expand self-referral routes to falls response, musculoskeletal, audiology, weight management, community podiatry, and wheelchair and community equipment services.<br><br>The aim is to empower patients to take control of their healthcare, streamline access to services and reduce unnecessary burden on GP appointments.<br><br>But more must be done to help patients to understand these potential options, including how to access services through self-referral. | NHS England |

# 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 **626 people who did not get 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 (REFERRERD) | | 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 LGBQ+ | 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% |

| 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) | |
|---|---|---|---|---|
| **Ethnicity** | | | | |
| Arab | 8 | 1% | 8 | 1% |
| Asian / Asian British: Bangladeshi | 59 | 4% | 23 | 4% |
| Asian / Asian British: Chinese | 32 | 2% | 6 | 1% |
| Asian / Asian British: Indian | 116 | 8% | 44 | 7% |
| Asian / Asian British: Pakistani | 119 | 8% | 46 | 7% |
| Asian / Asian British: Any other Asian / Asian British background | 34 | 2% | 14 | 2% |
| Black / Black British: African | 168 | 11% | 49 | 8% |
| Black / Black British: Caribbean | 62 | 4% | 28 | 5% |
| Black / Black British: Any other Black / Black British background | 12 | 1% | 7 | 1% |
| Gypsy, Roma or Traveller | 1 | 0% | 4 | 1% |
| Mixed / Multiple ethnic groups: Asian and White | 37 | 2% | 20 | 3% |
| Mixed / Multiple ethnic groups: Black African and White | 16 | 1% | 10 | 2% |
| Mixed / Multiple ethnic groups: Black Caribbean and White | 63 | 4% | 20 | 3% |
| Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic background | 37 | 2% | 11 | 2% |
| White: British / English / Northern Irish / Scottish / Welsh | 594 | 39% | 273 | 44% |
| White: Irish | 4 | 0% | 3 | 1% |
| White: Any other White background | 74 | 5% | 29 | 5% |
| Another ethnic background | 20 | 1% | 11 | 2% |
| Prefer not to say | 12 | 1% | 7 | 1% |

| | | | | |
|---|---|---|---|---|
| Don't know | 50 | 3% | 13 | 2% |

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