



Closing referral black holes

How to improve experiences and reduce NHS workload
December 2025

healthwatch

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Executive summary

Over 20 million referrals from general practice were made between October 2024 and October 2025, with people sent to community and hospital teams for specialist tests and treatment. In 2023, our research highlighted how difficult the process of getting a referral can be for patients, with people describing how they ended up trapped in 'referral black holes' and left without updates from their NHS team.

Since our last report, there have been national changes to referrals. These include more visibility of referral journeys through the NHS App, pharmacy referral pilots for suspected cancer and a greater drive to increase referrals into community rather than specialist services.

In this follow-up report, we set out to understand if experiences of referrals have improved. Our results reveal a mixed picture, and we propose constructive changes to ensure referral processes work for patients and NHS teams alike in future.

Key findings

Our nationally representative survey of 2,622 people with an experience of a referral in the past 12 months found:

- **Over six in ten (62%) were satisfied with the referrals process.** While 62% said they were satisfied, our key findings below highlight simple actions that drive increased levels of

satisfaction. Only 7% of those experiencing a referral issue were satisfied with the process. Almost one in four (23%) were not satisfied with the current process.

- **One in seven (14%) people ended up in a 'referral black hole'.** We define the referral black hole as when a referral is either delayed, lost, rejected, or not sent. This marks an improvement from 21% affected when we ran the research in 2023. However, seven in ten (71%) of those experiencing referral black holes had to chase for updates themselves, so the total figure could be higher. Three in four people (75%) who had an issue with their referral reported at least one negative impact on their health and wellbeing, compared with 36% of those who had no referral issues.
- **Earlier referral leads to better experiences.** 59% of respondents were referred during their first GP appointment, with 71% of this group going on to be satisfied with the referral process. However, almost one in five (18%) people required three or more appointments before the GP referred them. Satisfaction was 67% when people were referred between their first and third appointment. Only 47% of those needing more than three appointments were satisfied with the overall process.
- **Quicker referral confirmation leads to better experiences.** Over one in ten (12%) people we spoke to were still waiting for confirmation of their referral, while more than one in three (36%) had waited longer than one month. Fewer than

one in five (19%) had confirmation within one week, but satisfaction for this group was high at 88%.

- **The right information and choices lead to better experiences.** Satisfaction rose to 83% when people were given all the information they needed along with a referral. Additionally, satisfaction jumped from 62% to 77% when any element of choice (for example, choice of location, consultant, or appointment time) was introduced at the point people were told they were to be referred. Unfortunately, one in four (24%) weren't given any choices or information.
- **Regular updates and support after referrals lead to better experiences.** Nearly half (47%) said that clear communication was among the top three important aspects of a referral. Just under one-third (32%) of people said that regular communication from GPs and hospitals/community clinics was important, as well as knowing who to contact with referral queries (31%). Regular communications after a referral, including updates, clear points of contact, and different types of support all increased satisfaction. But overall, not enough people agree they are given all the help they need.
- **Earlier referral, with quicker confirmation and better information and choice leads to almost universal satisfaction.** Satisfaction rose to 98% for those who were referred between their first and third GP appointment, had

their referral confirmed within a week, said they were given enough information, and were given patient choice.

Key recommendations

- **The NHS should introduce a referrals checklist with clearly marked responsibilities for different NHS teams.** Our research clearly shows the drivers and barriers to a good referral experience. The upcoming NHS minimum standards on waiting for elective care provide an opportunity for this, with resources for NHS staff to deliver the care people need.
- **Elective minimum standards must be expanded to cover all referral pathways.** Currently, the standards are planned to help those referred for non-urgent elective pathways. To ensure consistency, these standards should be expanded to cover other pathways too, including cancer, mental health, and neighbourhood referrals.
- **The 10 Year Workforce Plan must invest in trained admin staff to support people's referrals journeys.** The [elective reform plan](#) promises more training for non-clinical staff. However, recruitment, training and support of administrators, navigators and coordinators must be increased to support better delivery of patient communications and updates.
- **Jess' Rule must be implemented quickly and consistently.** The recently announced rule encourages GP teams to consider second opinions or referral after someone has three appointments for the same unresolved health issue. Support must be provided alongside this to help teams

meet potentially increased demand and waiting list support.

Background

Since 2023, the Government and the NHS have taken steps to improve the referral process. These changes include:

- Using the NHS App to give patients greater visibility of their referral
- Piloting the use of pharmacies to refer people with suspected cancer
- Enabling GPs to get expert advice before making a formal referral to help direct patients to the right care they need more quickly

There is evidence that some of these changes are already having a positive effect, while others carry some risks. These background details were vital to the scoping of our research and are explored in more detail in Appendix 1.

Two years on from our [last report on referrals](#), this report explores what impact national changes have had on people's experiences.

In that time, we have continued to hear from people who feel forgotten during their referral. This report tells some of their stories and aims to help decision makers, referrers, and providers understand what makes a good referral. We hope that this, in turn, will help ensure people get the right information and support in future, with better experiences of referrals and improved outcomes for patients.

Methodology

We commissioned YouGov to run polling for us about people's experiences with GP referrals. Although nurses, pharmacists, hospital consultants, and other healthcare professionals can refer people for specialist care, this research focuses on referrals from general practice to hospital teams.

The polling was a targeted survey of people whose GP has referred them for specialist care in the last 12 months.

- The targeted survey was carried out online between 7 – 23 March 2025.
- The total sample size was 2,622 adults. The figures have been weighted and are representative of all adults in England (18+) who were referred by their GP for specialist tests/treatment.
- In this report, we will call this “**our poll**”.

All the demographic breakdown statistics have been significance tested to 95% confidence level.

We also conducted our own self-selecting survey throughout March 2025 to collect qualitative insight.

- In total, we received 710 completed responses from adults living in England aged 18 or over.
- In this report, we will call this “**our survey**”.

The referral journey

How easy is it to get a referral?



**Three in five people were referred by their GP
at their first appointment**

In our poll, we asked people how many GP appointments they had before they were referred.

Number of GP appointments before being referred	Percentage of total sample
1 – Referred during the first GP appointment	59%
2 – Referred during the second GP appointment	18%
3 – Referred during the third GP appointment	9%
More than 3 – More than 3 GP appointments before being referred	9%

Most people were referred by their GP at their first

appointment. This marks a large increase from 39% in our research from 2023.

However, although down from 18% in 2023, nearly one in ten still needed more than three appointments before their GP referred them.

It is important to note that there are valid clinical reasons for treating a condition before referring someone. People frequently said that their GPs ordered “in-house” tests (i.e., further tests carried out at the GP practice) (42%), suggested using medication (34%), and monitoring their condition or symptoms (30%) before referring them. One in ten (10%) were told the GP was waiting on ‘advice and guidance’ from a hospital specialist. Without looking into every case individually, these can all be taken as clinically relevant decisions.

However, the number of people who needed more than three appointments before being referred may be a concern, particularly when serious illness is suspected. This has been highlighted recently with [Jess’ Rule](#), which would see patients either being referred or seen by a different GP for a second opinion, after three appointments about continuing and unresolved symptoms.

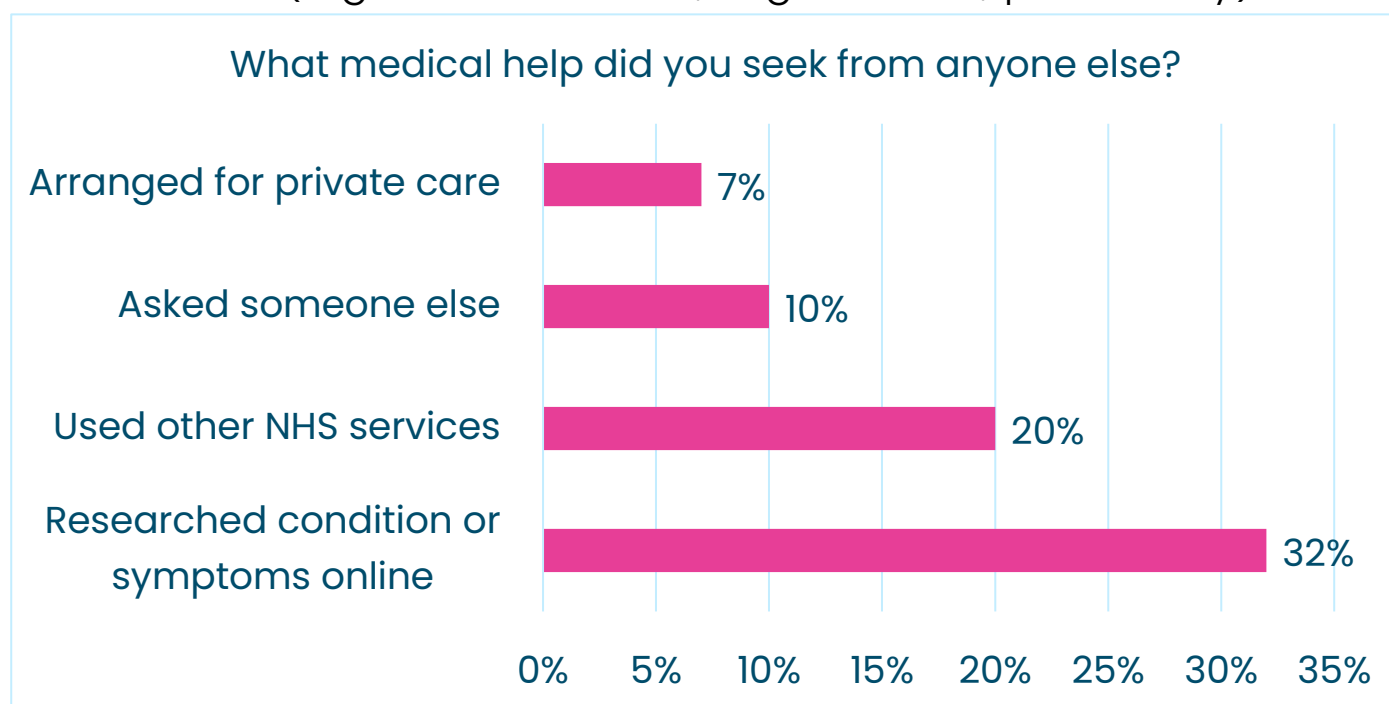
One challenge with using number of GP appointments as a marker for ease of referral is the time it takes people to get a GP appointment. Currently, national statistics do not capture the wait between GP appointment booking and eventual referral.

According to the [2025 GP patient survey](#), over one in three found it difficult to contact their practice over the phone, on a website, or using the NHS App. Furthermore, one in six people did not know what the next steps would be when they last contacted their GP practice. One in three waited longer than one week to see their GP. Another one in three felt they waited too long for their appointment.

This suggests that people, including those with potentially serious long-term conditions, may be waiting weeks or months between the onset of symptoms and eventually being referred.

Seeking medical help while getting a referral

More than half (53%) of the people in our poll told us that they had sought medical help or advice while waiting for their referral, including one in five (20%) who accessed another NHS service (e.g. a different GP, urgent care, pharmacy).



These results suggest that referral delays may increase pressure on other NHS services.

Information and choice

Healthwatch analysis of the [GP Patient Survey](#) shows a direct correlation between people being offered various choices over their GP appointments, and overall satisfaction with care from their GP. [Recent Healthwatch research](#) supports this, while also finding a gap between the choices people want and those they are offered.

We explored this as part of the referral process, finding that when they get it, people value information and choice at the point of referral. Unfortunately, our results show that people don't always receive this support.

One in five (21%) people were not given all the information they needed about their referral. Fewer than 40% of people said they had enough choice to be able to book appointments at a convenient time and place.



One in four people weren't given any of the listed choices or information

Almost one in four (24%) did not receive **any** of the information or choices that we asked about.

We also asked respondents how helpful they found the information and/or the choice they received. The majority of people who received a type of information or choice found it helpful.

Information/choice	Percentage who said it was provided	Percentage who rated it helpful
Information on why you were being referred	37%	94%
A copy of the referral letter/email	27%	93%
How long it would take to get referral confirmation	18%	92%
Waiting list estimates for tests or treatment	16%	81%
What to expect during referral journey	16%	98%
Choice of location	15%	95%
Choice of appointment times	12%	93%
Choice of hospital consultant	5%	95%

It is concerning that no single option was ticked by more than 40% of people, highlighting the poor provision for some of even basic information like why people are referred.

Waiting for a referral confirmation

National waiting list rules consider a referral as being from the point a hospital accepts a new appointment. However, many patients consider the point of referral to be when the GP first notifies them of an intention to refer. Quick confirmation of a referral is therefore important.

Of most concern are the people who are yet to have their referral confirmed. People with unconfirmed referrals do not show up in any official waiting list data, which is a blind spot for the NHS and leaves people in 'limbo', often not knowing what has happened to their referral. Over one in ten people (12%) in our poll were still waiting for confirmation of their referral (i.e. they had been told they'd be referred but had not yet booked a specialist appointment or been told they were on a waiting list).

Of the people who had received confirmation, more than one in three (36%) had waited longer than one month. This shows a slight improvement on 2023 results, when 41% waited over a month.

Fewer than one in five (19%) had confirmation of their referral within one week. This represents a slower confirmation rate than in 2023, when 22% waited a week or less.

Generally, people who were still awaiting referral confirmation had been waiting longer than those who had their referral confirmed. Nearly three in five people (58%) in this group had been waiting for a month or longer, including over one in ten (12%) who had been waiting for longer than six months.

Given the findings above on referral communications, there is a chance some of our unconfirmed cohort are actually on waiting lists, but that their NHS teams have not provided them with details on this.

Referral wait time	Percentage with confirmed referral	Percentage with unconfirmed referral
A week or less	19%	11%
More than a week, but less than a month	29%	25%
1-2 months	16%	22%
3-4 months	9%	19%
5-6 months	3%	5%
More than 6 months	8%	12%

Referral journey impacts

In our poll, we asked people if their health and wellbeing had been impacted by their referral journey. We asked about a range of both positive and negative impacts.

Encouragingly, over seven in ten (72%) reported at least one positive impact, though one in four (25%) said that they did not experience any positive impacts.

We found that almost half of the sample (43%) experienced at least one negative impact. The responses to our survey demonstrated that the negative impacts were particularly detrimental to people's health and wellbeing.

Positive impacts

The most frequently reported positive impacts relate to support and understanding. The positive impacts reported by respondents were:

- Feeling as though progress was being made relating to diagnosis and treatment (36%)
- Feeling listened to (29%)
- Feeling as though there was a better understanding of symptoms and/or condition (26%)
- Feeling as though there was a better understanding of the next steps in getting a diagnosis and/ or treatment (25%)

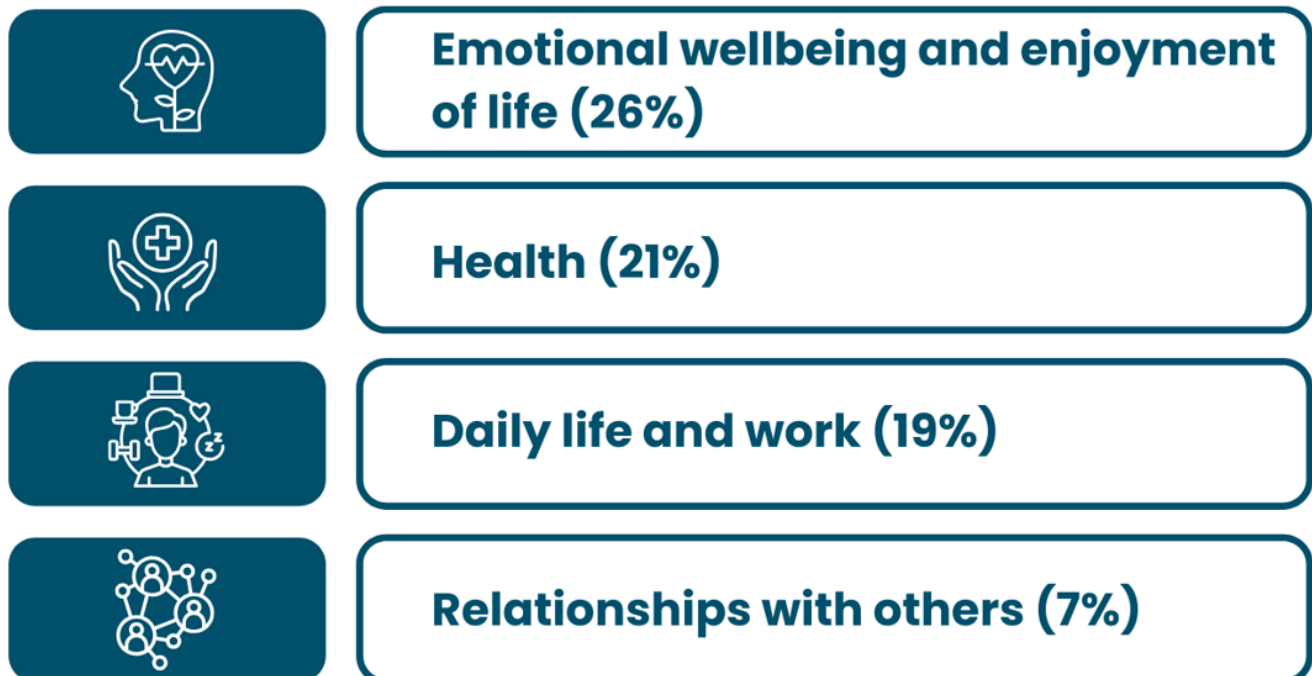
People also said that they felt supported with their symptoms and/or condition (23%) and better able to talk about their symptoms/condition with friends and family (11%).

Negative impacts

The negative impacts varied more than the positive impacts, but particularly affected people's wellbeing and their ability to go about their daily lives.

We asked people about the impact on 12 areas of their lives. The infographic overleaf summarises the negative impact across four key issues.

Negative impacts of referral journeys



People who were experiencing referral issues described how severely their health and wellbeing was affected in our survey. For some, the impact was all-encompassing and touched upon every aspect of their lives.

"It's affecting every aspect of my life. I can barely cope with day-to-day things. I don't feel like I'm living life, I'm just existing."

Female, aged 25 to 49 years, referred for bone, muscle or joint problems

Some people were left unable to live independently while waiting for their referral confirmation. These people would rely on others to support them, or would have to adapt to be able to carry out everyday tasks (e.g., household chores).

"I'm existing not living life. Even washing up takes me an hour as I have to keep sitting down due to pain. My general health is deteriorating. I retired last year and can't do any of the activities I wanted to do in retirement."

Female, aged 65 to 79 years, referred for bone, muscle or joint problems

Though less frequent, people told us about difficulties finding and maintaining work, leading to financial strain. For some, difficulties obtaining state support without a formal diagnosis compounded the financial impacts. Though private diagnosis was an option for some who could afford it, this was not the case for all.

"I have continued to deteriorate, had time off work and the rest of the time been working very limited hours. I am therefore struggling financially and have had to apply for benefit support which is difficult without a diagnosis. I had to pay for private medical appointments but can't afford a private MRI so remain waiting for the scan."

Male, aged 25 to 49 years, referred for nervous system problems

What makes a good referral?

In the [elective reform plan](#), the Secretary of State recognised that long waits for care have left many people worried when they get a referral. As the previous chapter shows, this is undoubtedly the case for some, while for others, getting a referral in itself can have a positive impact on people.

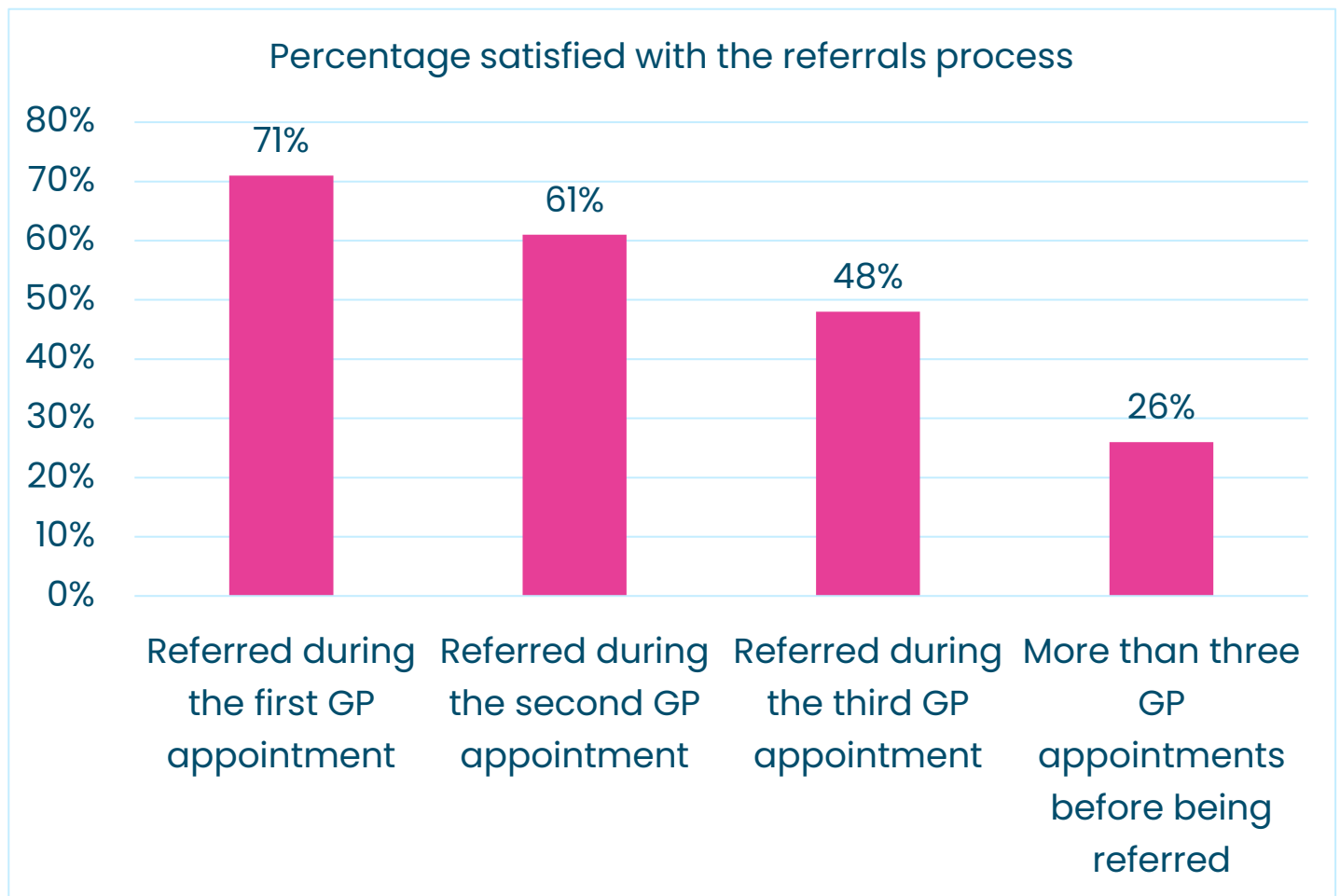
When looking at our full sample, 62% were satisfied with the referrals process, compared to 23% of people who were not satisfied. But it is also important to understand what additional support can help people after they're referred.



**Over six in ten were
satisfied with the referrals
process**

In this chapter, we will revisit overall referral experiences alongside some aspects of the referral journey and explore which types of support may be considered the drivers of a good referral.

Early referral drives good experiences



People referred during their first GP appointment were significantly more likely to be satisfied with their referral journey. Inversely, people who needed more than one GP appointment before they were referred were significantly less likely to be satisfied.

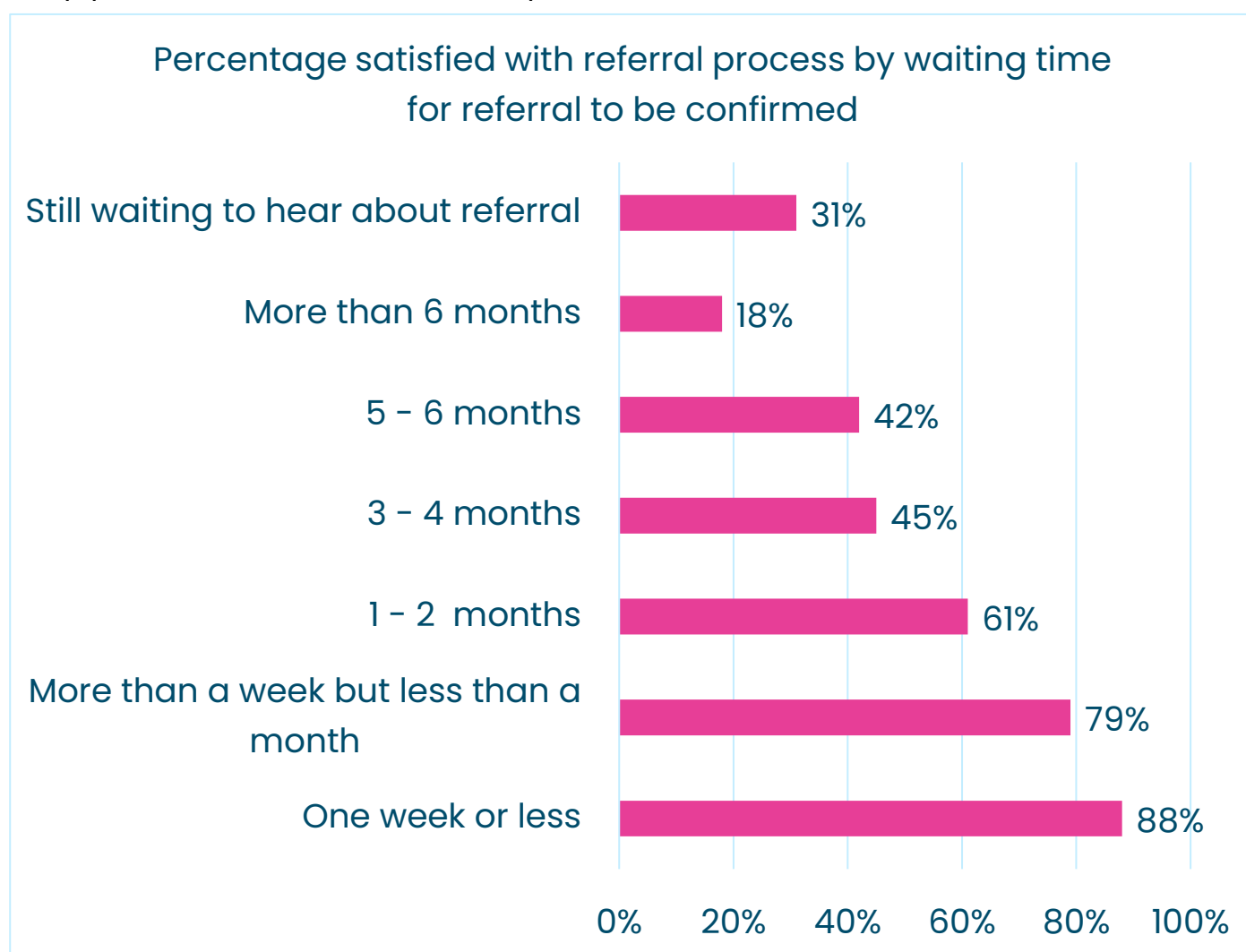
Although the sample sizes were small for some categories, there was an inverse relationship between the number of GP appointments before being referred and referral process satisfaction.

"I was seen and treated very quickly at each stage of the process, and have nothing but praise for all the professionals I saw on my journey. My condition was diagnosed and treated successfully, and with amazing speed. I cannot fault anything."

Female, aged 65 to 79 years, referred for skin problems

Quickly confirming referrals drives good experiences

Unsurprisingly, we found that people who waited longer for a confirmation of their referral (defined as having booked an appointment or being told you are on a waiting list) were happier with the referrals process.



When we looked at the relationship between time waiting for referral confirmation and overall satisfaction, there was a clear cut-off point where people waiting for less than one month to receive confirmation of their referral were significantly more likely to be satisfied with their referral journey (83% to 46% waiting longer than one month).

The one-to-two-month cut-off also applied to those who were still waiting for a referral confirmation (54% less than a month to 17% more than a month).

“There were no issues at all. I received a call offering me an appointment for seven days later just 17 hours after seeing the GP...I can’t fault the service or my treatment.”

Female, aged 65 to 79 years, referred for skin problems

Giving people the right information and choices at the point of referral drives good experiences

Information and choice were key drivers of overall satisfaction.

People who received information and/or choice from their GP when they were referred were significantly more likely to report that they were satisfied with their referral journey.

Information/choice	Percentage satisfied with the referrals process
Any choice ¹	77%
Any information ²	70%
Any choice or information	70%

Of the choices we asked about, those people most strongly associated with satisfaction were being given information on why they were being referred and being given a copy of the referral letter.

But ensuring people get the right information is also key. In our survey, people told us that the waiting list estimates they were given were underestimated, with people often waiting longer than they were initially told by their GP. This may explain why waiting list estimates did not drive referral satisfaction.

¹ Choices listed: choice of hospital consultant, choice of appointment times, and choice of location.

² Types of information listed: information on what to expect throughout your referral journey, information on why you were being referred, information on how long it would take to get confirmation of your referral, waiting list estimates for the specialist tests or treatment that you needed, a copy of the referral letter/ email.

"I was told the current wait time is a few weeks...it is longer than four months now, and I am still waiting. I did message about this about a month after waiting, I am still waiting."

Male, aged 25 to 49 years, referred for bone, muscle or joint problems

People were significantly more likely to be satisfied with their referral journey if they felt they had all the information they needed and that they were given appropriate information on how to manage their symptoms or condition.

Similarly, people who felt that they had been given enough options to choose convenient appointment times and locations were significantly more likely to report being satisfied.

Statement	Percentage satisfied with the referrals process
I was given enough options to be able to choose hospital/community clinic appointments that were at a time convenient for me	85%
I was given enough options to be able to choose hospital/community clinic appointments that were at a location convenient for me	85%

I was given all the information I needed about the referral	83%
I was given appropriate information on how to manage my condition while I was waiting for the specialist tests or treatment that I needed	83%

"I received a [form] where I could book my own hospital. I chose [hospital deleted] because of the very short wait time compared to local NHS hospitals."

Female, aged 65 to 79 years, referred for bone, muscle or joint problems

Clear, timely communication and support after referral drives good experiences

There is a clear relationship in our data between communication, support, and overall satisfaction.

Feeling supported throughout the referral process and clear and timely communication are drivers of overall satisfaction. Inversely, our data showed that a lack of support and communication drives dissatisfaction.

Statement	Percentage satisfied with the referrals process
I felt supported throughout the referrals process	91%
I had clear communication from my GP and the hospital/community clinic about my referral	86%
I had confirmation of my referral from the hospital/community clinic quickly	85%
I know/knew who to contact about my referral	83%
The reasons for any delays to my referral were clearly explained to me	81%

"I cannot praise my GP...enough. She was very thorough, followed everything up in a timely manner and even telephoned the evening I was admitted into hospital to check how I was and whether she could help in any way. Without her care and attention, things would have been much more difficult to deal with."

Male, aged 80+ years, referred for digestive system problems

Hidden waits and referral black holes

Symptoms/condition begin

STAGE 1:

Time taken to get a GP appointment

STAGE 2:

Time between 1st GP appointment and getting a referral

STAGE 3:

Time waiting for referral confirmation

STAGE 4:

Time waiting for referral appointment (on waiting list)

Get care needed

Our previous work uncovered a hidden waiting list of people who are waiting for their referral to be confirmed (Stages 1-3 in the figure).

Too often, we found that combined with referrals left unconfirmed, people were also not given information they needed. This led to them experiencing what we call the referral black hole, where people are not involved in decisions about their care and left stuck between GP and hospital teams.

This report aims to further explore the time waiting for referral confirmation at stage 3. This stage represents the transition from GP care to hospital or community clinic care. Our previous work found that this time can be difficult for people, with referral issues leading to delays and further knock-on effects on people's health and wellbeing.

How do the data compare to our previous research?

As we updated our polling questions for this research, not all the data collected are directly comparable to our previous referrals work from 2023. This section focuses on the data that are directly comparable.

People are being referred sooner

Compared to our previous research, a greater proportion of people in our poll were referred during their first appointment (59% versus 39%). However, when combined with people referred during their second GP appointment, the proportions are similar (77% in our poll and 79% in the previous research).

In our previous research, a much greater proportion of people needed more than three GP appointments before being referred (18% versus 9%).

Fewer people seek medical help, but more search for information

Comparatively fewer people sought medical help, information, or advice in the current research than in 2023. In our previous research, 28% of people said that they did not seek medical help while waiting for a referral, compared to 46% of people in our poll.

Respondents to our poll also reported searching for information on their symptoms and/or condition online more than in the previous report (32% versus 23%). [Our work on Men's Health](#) echoed this, finding that men often sourced health information online, including social media and AI tools.

We also found that people reported using NHS 111 and A&E less in our most recent research (6% versus 11% for both).

More people are given no information with their referral

When comparing the information and/or choices we asked about across both polls, more people in the most recent research received information and/or choice.

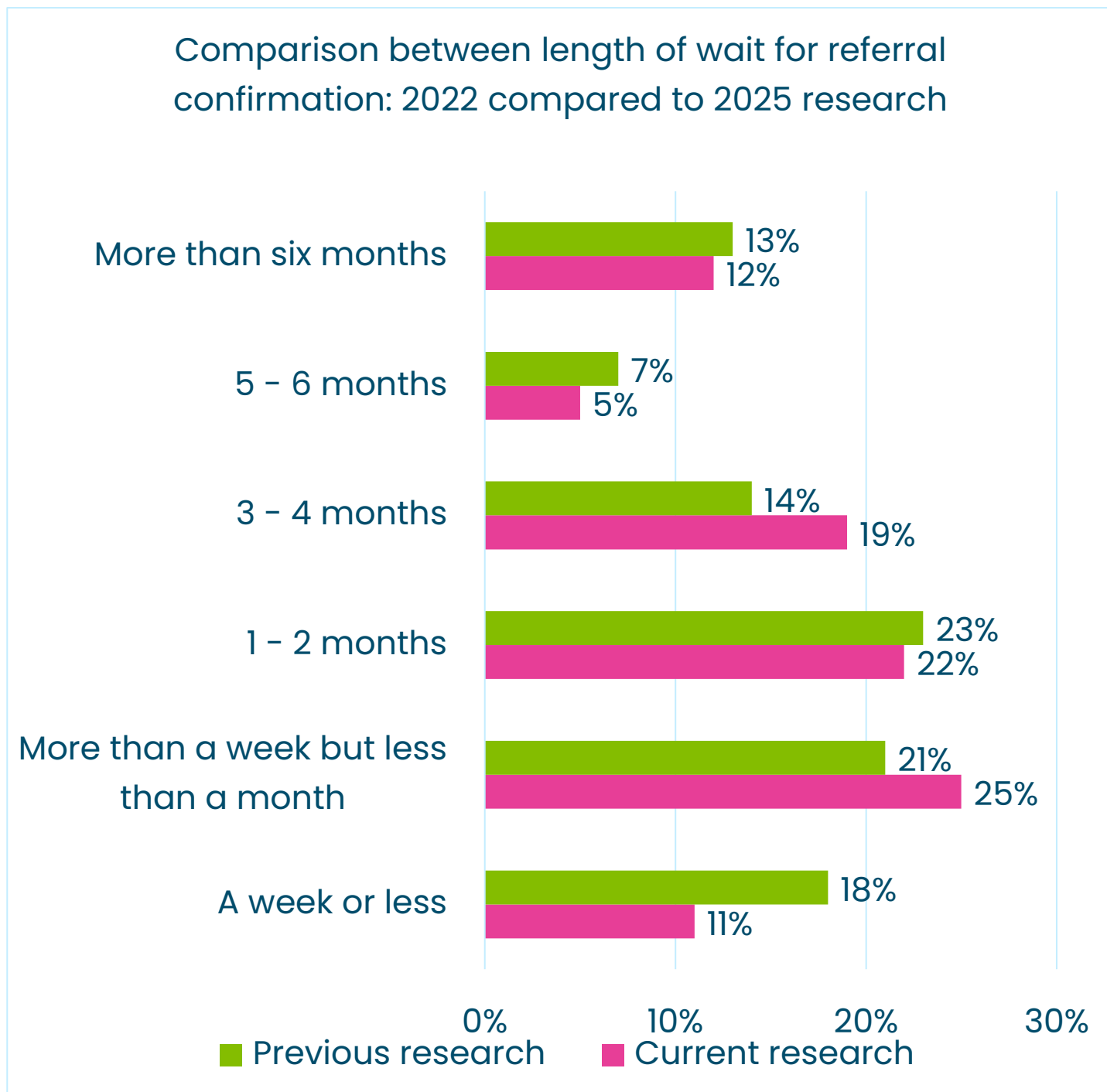
However, a greater proportion are also given no information. So, while provision has improved for some, it has gotten worse for others.

Information	Percentage who said it was provided in 2025	Percentage who said it was provided in 2023	Percentage change
Information on why you were being referred	37%	31%	+6%
A copy of the referral letter/email	27%	12%	+15%
How long it would take to get referral confirmation	18%	15%	+3%
Waiting list estimates for tests or treatment	16%	11%	+5%
What to expect during referral journey	16%	16%	No change
No information provided	24%	15%	+9%

Similarly, despite a greater proportion saying they were given all the information they needed (63% vs 58%), a smaller proportion felt supported throughout the process (47% vs 54%).

Getting a referral confirmation

The lengths of time waiting for a referral confirmation are broadly similar in this research compared to our previous work.³



³ Only people with a confirmed referral have been included in the current research figures.

Although consistently fewer people reported waiting for each time period, this is likely because in our 2025 research, we included an option for people to report that they were still waiting to hear from the hospital/community clinic about their referral. In our poll, we found that people with an unconfirmed referral generally have been waiting longer than those with a confirmed referral.

What did we learn?

Referral black holes

The current research has allowed us to gather additional insight into the issues people faced when waiting for referral confirmation. Specifically, people often had to be proactive and follow up with either their GP or the hospital/community clinic regarding the status of their referral.

We asked respondents to our poll whether they had experienced any issues with their referral (i.e. referral was delayed, lost, rejected, or not sent). This is what we refer to as the **referral black hole**, where people are initially referred, but have to return to primary care after sitting in limbo between a GP and hospital service without an update or confirmation.

One in seven people (14%) found themselves in this black hole, saying their referral had been delayed, lost, rejected, or not sent. This compares with 21% who fell into referral black holes and bounced back to general practice when we ran our research in 2023.

The most common issue was the referral being delayed, accounting almost two-thirds of referral issues.

Referral issue	Percentage of sample who experienced referral issues
Delayed referral	60%
Referral not sent	14%
Rejected referral	13%
Lost referral	12%

We also found that people were often not told of any issues.

Seven in ten (71%) of those experiencing the referral black hole **had to chase up the status of their referral** with either their GP or the hospital/community clinic.

Referral issue	Percentage told about the issue	Percentage who had to chase up
Delayed referral	36%	64%
Rejected referral	91%	9%

The one exception was where referrals were rejected: in these circumstances less than 10% of people had to chase up their referral to find that it had been rejected.⁴

This issue was also highlighted in our survey, where people told us about the additional burden chasing up their referral had on them.

“The mental health is worse than the pain. Waiting years to see someone and getting bounced from department to department and starting from the bottom of a list, do doctors not actually know how to communicate?”

Male, aged 50 to 64 years, referred for bone, muscle or joint problems

Referral issues, impacts, and satisfaction

We were also able to examine how referral issues and impacts interacted, and how they affected overall satisfaction with the referrals process.

Unsurprisingly, people who experienced a referral black hole (i.e. delayed, lost, rejected, not sent) were more likely to report negative referral journey impacts than positive impacts.

⁴ Note: referrals that were not sent or lost are not included, as these issues would not be known to GPs, hospitals, or community clinics, and therefore these issues could not be relayed to patients.

Three in four (75%) people who had an issue with their referral reported at least one negative impact on their health and wellbeing.

People who did not experience any referral issues were also more likely to report positive impacts than negative ones. However, one-third of this group still reported at least one negative impact, which suggests the experience of the referrals process is still difficult for people, even if goes smoothly.

We also found that people who had to chase up their referral were slightly more likely to also experience detriments to their health and wellbeing than those who did not have to chase up (79% compared to 72%).

“This has been unnecessary stress and anxiety. Being disabled I have limited resources and had to neglect other aspects of life and not maintain my health. For example, my house is a tip, housework has to take a lower priority, as it is hard to cope. This referral issue has taken time off me, and will indirectly affect my longevity, due to poorer quality of life. It is entirely counterproductive, I will go into care, or die, sooner because of these shortcomings, which will cost society more not less.”

Male, aged 50 to 64 years, referred for nervous system problems

Overall, 62% of people were satisfied with the referrals process. Only 7% of this group had experienced at least one

referral issue, with nearly nine in ten – 88% – of this group reporting no referral issues. The table below shows the proportion of people who had experienced different types of referral issues by satisfaction.

Referral issue	Percentage satisfied with the referrals process
Delayed referral	31%
Lost referral	27%
Rejected referral	27%
Referral not sent	26%

While people are less likely to be satisfied if they've had a referral issue, our research also shows that referral issues are not the only driver of dissatisfaction. Nearly one in five (18%) participants had not experienced any referral issues but still reported being dissatisfied with the process.

"It is worrying that I feel that the coordination of my healthcare is down to me... It is increasingly stressful for me as I age & likely to develop other health conditions, there is no coordination between hospitals and GPs."

Female, aged 65 to 79 years, referred for digestive system problems

As expected, people who experienced negative impacts were more likely to report that they were not satisfied with the referrals process. This effect was pronounced for impacts related to emotional wellbeing and the ability to live life fully.

Negative impact	Percentage satisfied with the referrals process	Percentage not satisfied with the referrals process
Emotional wellbeing and enjoyment of life	34%	49%
Health	31%	49%
Daily life and work	35%	47%
Relationships with others	32%	55%

"I received a text message nearly a month later saying my referral had been approved. I later saw on my NHS app that the neurology response approving me for a brain MRI was received in a few days but not actioned for several weeks. I was off work or working reduced hours with a big impact on my day-to-day life in terms of being able to look after myself and also... [a] huge financial impact on me."

Male, aged 25 to 49 years, referred for nervous system problems

Summary

Our current research builds upon our previous referral work to gain additional insight into the issues people encounter when waiting for referral confirmation (i.e. when on the “hidden waiting list”). Specifically, people need to be proactive in their care to feel informed.

People feel shut out by a system that fails to keep them updated and supported, leading to increasing frustration, stress, and anxiety.

We have also been able to link referral issues and the associated impacts to overall satisfaction. Where people feel heard, supported, and understood, they have a more favourable view of the referrals process.

These results tie into our findings around communication, specifically that clear and timely communication drives satisfaction. When taken together, a picture emerges: the referrals process, as it is, appears to be disjointed and difficult to navigate. Indeed, this was a recurring theme in our survey data.

“It’s a mess. No one seems to know the correct process for referrals, and GP’s/surgeries seem to just be winging it and hoping for the best – yet the reality is they are playing with people’s lives. Communication and follow-up is non-existent, leaving patients to fend for themselves...”

Male, aged 25 to 49 years, referred for nervous system problems

Public priorities to improve referrals

What is important to people?

We asked respondents to select the three aspects of a referral that were the most important to them.

Please note that we purposefully did not include wait times in the response options, as we know that these are already important to people.

"I don't mind waiting – everyone knows what pressure the NHS is under – but I would really have liked a progress report of how far up the list I was, and a bit of sympathy for my deteriorating eyesight."

Female, aged 65 to 79 years, referred for eye problems

Referral aspect	Percentage of total sample
Clear communication from your GP and the hospital/community clinic about your referral	47%
Being able to choose appointments that are convenient for you (e.g. at a convenient time, in a convenient place)	37%
Being given appropriate information on how to manage your condition while waiting for the specialist tests or treatment that you needed	36%
Regular communications from your GP and the hospital/community clinic updating you on the progress of your referral	32%
Knowing who to contact about your referral	31%
Being able to track and manage your referral online	31%
Being able to choose where you got the specialist tests or treatment that you needed	23%

"It is important to feel part of my treatment planning which I currently am not. Services are unfortunately good at doing to the individual and not with the individual."

Female, aged 50 to 64 years, referred for reproductive symptom problems

We also asked about what referral aspects were important to people in our survey, though we did not ask people not to include waiting. As expected, waiting times were considered important to people who completed our survey. However, there was a general acceptance of long wait times for NHS treatments, though unsurprisingly, people with life-limiting or life-changing conditions (e.g. cancer, glaucoma) valued the speed of treatment highly.

"Information, knowing what is happening is the most important. We all know there is issues within the NHS and everyone knows you will not be seen quickly but the fact there is not transparency, no one will take responsibility or even give you any information makes you feel like you are fighting a losing battle."

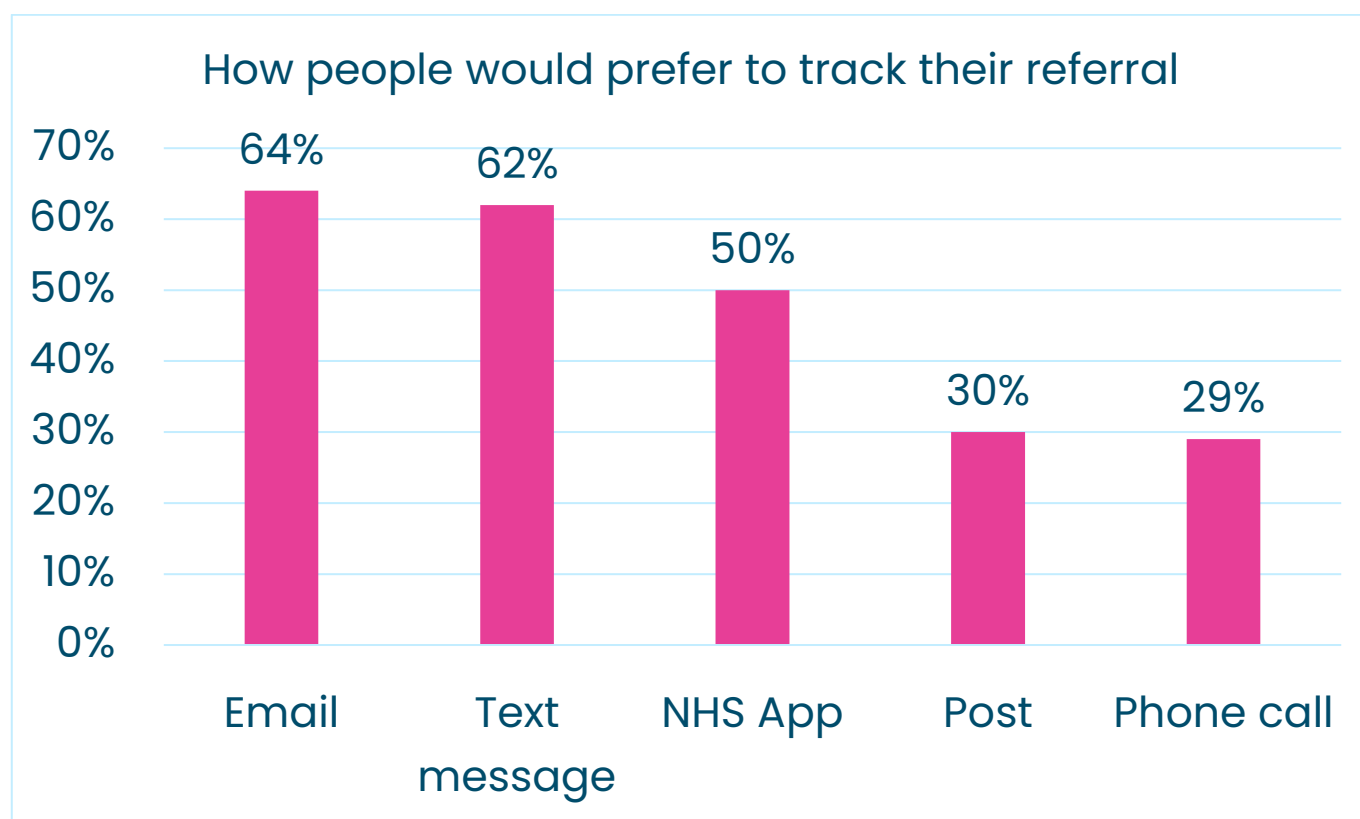
Female, aged 25 to 49 years, referred for digestive system problems

Referral tracking preferences

The elective reform plan promised expansion of both the NHS App and the Manage Your Referral website by March 2027.

Both channels aim to improve information and appointment management for people referred for elective care. However, at the time the plan was written in January 2025, only 8% of bookings were made via these channels.

We asked people which method of communication they'd prefer for referral updates, with over one in five preferring email and text.



Given the government's push to deliver more through the App, we also asked about people's confidence using it.

Almost nine in ten (89%) said they would be confident using the App for any purpose. However, this channel doesn't work for everyone.

Percentage who are not confident in using the NHS App for any purpose

Overall	11%
Really struggling financially	21%
Disabled	19%

Conclusions

Despite over twenty million referrals each year, the process people go through before getting a specialist appointment remains a blind spot for the NHS. There are no publicly available ways of tracking people's journey from first symptoms through to treatment, with measures instead kicking in only once a hospital accepts a referral.

This must change if we're to improve patient safety, experiences, and outcomes.

The government's shift to delivering more care closer to people's homes provides an opportunity to do this and shed current practices that don't work for patients or NHS teams.

Our report points the way to improvement, by highlighting what is already starting to benefit patients, and where NHS teams can go further.

Positively, two years on from our earlier research we can see improvements in how quickly people are referred for specialist care. We can also see that more people now get copies of their referral letters, along with waiting time estimates.

To support further improvements, this report also highlights the specific actions that increase patient satisfaction:

- Quicker referrals from GP teams

- Quicker acceptance and confirmation from specialist teams
- Better communications
- More information and choices

It's now vital that NHS decision makers ensure these types of support are given to everyone who is referred, so they know why, what comes next, what their choices are, and who to contact if they need more help.

Not only is this what patients want, it will address demand failure for the NHS, reducing instances of people going into referral black holes. This is where referrals are delayed, lost, or rejected without any communication, leading to people bouncing back to busy GP teams and beginning the cycle all over again.

By delivering targeted changes and measuring the referral process earlier in the patient journey, we can ensure nobody is forgotten when they need specialist care.

Recommendations

1. Support patients from the moment they are first told about their referral.

Recommendation	<p>The Department of Health and Social Care and NHS England should introduce a referrals checklist for NHS teams. The introduction of minimum standards of waiting for elective care provides an opportunity for this. The checklist should be visible to all teams involved in the referral as well as patients, and it should cover all the drivers of a good referral experience:</p> <ul style="list-style-type: none"> • Referring people as quickly as possible, between their first and third GP appointment. • Providing referral confirmation within a week. • Giving people all the information they need with their referral, including information on why they're being referred, a copy of their referral letter, expected confirmation and waiting time, and what to expect during their wait. • Giving people a choice of hospital consultant, location, and appointment time.
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Current policy	The elective reform plan (2025) promises the publication of minimum standards patients should expect to experience in elective care. This
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	was planned for September 2025 and is now expected Spring 2026.
Evidence	<p>Our qualitative findings highlight the importance of waiting times to patients.</p> <p>However, our research also found that earlier referral, quicker referral confirmation, better provision of information and choice, and regular communications all lead to better patient experiences.</p> <p>For those who received all this support, satisfaction with the referral process rose to 98%.</p>
How our proposal will help	Including a referral checklist will ensure everyone who is referred is given proactive information and choices, both of which have been shown through this report to improve experiences.
Recommendation	The Department of Health and Social Care and NHS England should expand the elective minimum standards to cover all referral pathways, including cancer, community, mental health, and other non-electives.
Current policy	The planned minimum standards will only cover elective pathways.
Evidence	Our research covered the drivers of good GP referral experiences for all types of care.

How our proposal will help	Expanding the minimum standards will ensure better experiences for people referred for cancer, community, mental health and other care – not just elective care.
Recommendation	The Department of Health and Social Care and NHS England should formally measure implementation of how the minimum standards of waiting for elective care are used, including referral checklists.
Current policy	The waiting for elective care minimum standards have not yet been published.
Evidence	Our research shows the drivers of a good referral, but to improve experiences, barriers to implementation of any referral checklist must be removed.
How our proposal will help	Measuring implementation of the checklist will incentivise referring and admission team to better support patients, while enabling policymakers to understand where support is helping patients and NHS teams.

2. Provide everyone with a referral with accurate waiting time estimates.

Recommendation	The Department of Health and Social Care and NHS England should upgrade the NHS Wayfinder and My Planned Care services to provide
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referred patients with an average (mean) and maximum (92%) expected waiting time measure.

Current policy The NHS App (through NHS Wayfinder) and My Planned Care websites currently only provide average expected waiting times for any given pathway.

Evidence Average wait times can differ substantially to maximum expected waiting times. Our survey showed the importance of waiting times to people, while our polling showed only 16% were given waiting list estimates. These estimates were only rated helpful by 81% of people given them, compared to over 92% helpfulness for all other options provided, suggesting room for improvement in this area.

How our proposal will help Providing people with more accurate waiting time estimates can manage expectations and improve experiences, while ensuring access to both average and maximum waiting times could improve the helpfulness of any information people are given.

3. Ensure all patients have a choice of referral tracking method.

Recommendation	The Department of Health and Social Care and NHS England should make changes to the GP contract to guarantee that all patients have a choice over how to track their referral journey.
Current policy	The elective reform plan promises an expansion of both the NHS App and Manage your Referral websites to improve information and appointment management by 2027 and make these channels the default routes for patient choice.
Evidence	Half of our respondents said they would be happy to track referrals through the NHS App, and 89% said they would be confident using the App for any purpose. However, one in ten (11%) would not be confident, including one in five (21%) who were really struggling financially and another one in five (19%) disabled people.
How our proposal will help	The 10 Year Health Plan promises partnerships with libraries, community organisations, and App ambassadors to support uptake of the NHS App. While this will improve confidence for some, everyone must be given people genuine and informed choice and not excluded due to preference, affordability, or digital confidence. Ensuring tracking is done in ways which work for

individuals could support better referral experiences and fewer examples of demand failure.

4. Invest in NHS admin staff to improve referral experiences.

Recommendation	The Department of Health and Social Care and NHS England should, through the 10 Year Workforce Plan, invest in the recruitment, training and retention of care administrators, navigators, and coordinators to support people on their referral journeys.
Current policy	There were no measurable or modelled commitments to admin staff in the latest workforce plan.
Evidence	One in seven people (16%) with a referral ended up in a referral black hole, with their referral delayed, lost, rejected, or not sent. In the majority of these instances, patients have to chase up themselves to find out an error has been made.
How our proposal will help	NHS admin staff could support proactive communication with everyone referred for specialist treatment. At nearly every stage of a patient's journey through the NHS, admin staff can support them to access the right services and navigate an often-confusing system. This is particularly the case at the interface of services, such as when going through a referral.

Increasing numbers of, and support for, NHS admin staff could improve delivery of referral checklists and reduce demand failure.

5. Implement Jess’ Rule quickly and consistently.

Recommendation	The Department of Health and Social Care and NHS England should provide support to NHS teams to implement Jess’ Rule.
Current policy	<u>Jess’ Rule</u> is a safety initiative rolled out across the NHS in England from 23 September 2025. It asks GPs to consider their options, including onward referral, if a diagnosis isn’t offered or symptoms have worsened after three appointments.
Evidence	Almost one in five people (18%) we spoke with required three or more appointments before being referred. Only 47% of four or more appointments were satisfied with the overall referral process.
How our proposal will help	Giving NHS teams the resources they need to manage potential increases in demand for specialist care will ensure consistent implementation of the rule in all parts of the country.

Recommendation	The Department of Health and Social Care and NHS England should formally track and make publicly available the number of GP appointments a person has for any single pathway of care, before a decision to treat, refer, or discharge.
Current policy	NHS data only covers episodes of care from the moment any referring clinician makes a referral, and separately where another NHS team accepts it. There is a blind spot for data collection related to an episode of care from the onset of symptoms to the decision to refer.
Evidence	Our data shows how many appointments people have before being referred. However, this is not formally collected or published at a national level.
How our proposal will help	Better data collection and publication will fix the current NHS blind spot and enable formal monitoring of the impact of Jess' Rule.

Appendix 1

In 2023, we published [two reports](#) looking at people's experiences of referral processes. This was a missing link in our evidence, sitting between the issues people have accessing GP appointments and their long waiting times for hospital care.

For non-urgent hospital care, there is a national target for 92% of people to wait no longer than 18 weeks from referral to starting their treatment. The clock for this 18-week period only starts once a hospital has accepted the referral.

Our 2023 research found examples of people experiencing hidden waits for care while sitting in 'referral black holes'. Since then, national data shows continued growth in demand for hospital care. This can be seen through:

- [Consultant-led referral to treatment \(RTT\) waiting times data](#)
- [Referrals data from the e-Referral Service \(e-RS\)](#)

Current data

RTT data shows the number of new clock-starts and completed treatments each month for elective care. Despite recent improvements, this data shows that the total elective waiting list at the end of August had grown to a total of 7.39 million appointments, with 6.24 million people waiting for care

(some people are waiting for multiple appointments). It is now almost a decade since the 18-week target has been met.

Additionally, [recent research from the Nuffield Trust and Health Foundation](#) suggests that modest list reductions seen in the past year have in fact been driven through 'unreported removals'. This includes list validation exercises, such as where patients are asked if they still need treatment and removed if they don't. These cases show up in official statistics as 'removals other than treatment' (ROTT). [Analysis](#) suggests that around 3% of the total waiting list is removed each month through ROTTs.

Data from the e-RS dashboard shows the number of total referrals, total bookings, and total appointment slot issues (ASIs) each week for elective, community, and cancer care. ASIs are delayed or deferred referrals and occur when no appointments are available for people to book through the e-RS system.

This data shows that over 20 million referrals were made in the last 12 months (up to 13 October 2025). The four-week rolling averages of total referrals made has increased from 378,990 in mid-September 2024 to 413,040 in mid-September 2025. For the same period, the four-week average of booked referrals has also increased from 133,819 to 152,424.

However, ASIs are also up, from 85,127 to 89,746.

National response

Data shows that demand for appointments consistently outstrips capacity, increasing pressure on both GP and hospital teams and leading to an over-reliance on ROTTs to reduce waiting lists. Meanwhile, increasing levels of delayed and deferred referrals leave people either in referral limbo or rejoining the back of a very long queue.

These challenges have led to various reforms and initiatives from the government. In [the 10 Year Health Plan](#), there is a commitment to shift finances and activity from hospitals to developing neighbourhood teams. There were also several key changes announced in the [elective reform plan](#):

- Meet the target for 92% of patients to wait no longer than 18 weeks from referral to treatment by 2029.
- Expand the NHS App and Manage Your Referral website to improve information and appointment management by 2027 and make these channels the default routes for patient choice.
- Provide more training to staff to support effective referral, booking and waiting list management processes.
- Expand use and increase activity from community diagnostic centres (CDCs), which will be open 12 hours per day, seven days a week from 2026.
- Expand use of Advice and Guidance (A&G), where GPs seek advice from specialists before referring (by 2026).

- Work towards all patients having informed conversations with their GP about their referral, including choice of where they would like to be seen via the NHS App.

These measures aim to improve experiences and reduce people's waiting times.

Impact and risks

There is already some evidence of impact. There were 7.2 million [CDC appointments](#) delivered from July 2024 to June 2025, including 1.6 million more tests and scans when compared against the same period the previous year.

And in the first three months after funding was provided through the GP contract to incentivise better use of A&G, [over 300,000 referrals have been diverted](#) with primary or community teams delivering care instead.

But these reforms carry some risks as well.

The same A&G data shows that diversions are slightly down on the preceding three months, and the same three-month period the year previous. And despite a steady number of diversions, the numbers of unprocessed requests are on the rise. This suggests that more patients are experiencing delays to their referral decision.

Additionally, waiting lists only shrinking due to funded validation exercises poses a risk to the public's confidence in the NHS and the Government's ability to return to statutory waiting time targets. [Healthwatch evidence](#) shows that people contacted as part of these exercises are offered no

updates or support while waiting, other than the request to confirm they still need treatment. This leaves people feeling forgotten and isolated following their referral.

And a recent private letter from NHS England to ICBs asking them to reduce referrals to hospitals and increase community activity where possible raises additional issues for people requiring specialist care.

The NHS Constitution sets out patient rights to receive care appropriate to needs and not being refused access on unreasonable grounds. Without the right protections, gatekeeping of care could run counter to these principles, while also posing a risk to patient safety.

Rationing of care also leads to failure demand, where people instead try and get their needs met by other busy NHS teams. As noted by the [BMA](#), the care these patients need does not disappear. Instead, these patients need to be cared for by GPs while they wait for hospital treatment. Our research also shows that people visit other teams, like those in pharmacy or A&E departments.



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