



# **GP Referrals**

## **Part 3 – Cancer Referrals**

July 2023

## Introduction

According to the NHS “one in every two people in this country will be told they have cancer at some point in their lives.” So, the NHS rightly outlined strong ambitions for cancer care within their Long Term [Plan](#) delivered in January 2019:

- By 2028, 55,000 more people each year will survive their cancer at least five years after diagnosis.
- By 2028, the proportion of patients diagnosed at stage one and two will rise from just over half to three quarters.

But cancer is not just about facts and figures and medical treatment. Research by [Maggie's](#) in April this year found that “three in five find the mental challenge of cancer harder than the physical”. Moreover, around half of those with cancer “felt there was support for the physical impact of cancer, but not the emotional effects”. The struggles people can face in being listened to, diagnosed, and treated quickly can add to the strain on mental health.

The [NHS](#) themselves identified that “shorter waiting times can help to ease patient anxiety and, at best, may lead to earlier diagnosis, quicker treatment, a lower risk of complications, an enhanced patient experience and improved cancer outcomes.”

This point came across clearly in our research, along with the idea that small changes could make a big difference to people during an incredibly difficult time in their lives.

Reassurance could go a long in alleviating fear of the unknown. [Bexley, male, aged 25-49]

## About our research

We conducted an online survey with over 2,000 adults in England between September and October last year to understand people's experiences of getting a GP practice referral and we received a further 1,825 responses to the survey via our local Healthwatch network.

This research takes a closer look at **385 cancer patients** from our referrals research who went to their GP practice and got a referral, or those that expected or requested a referral but didn't get one.

Our analysis paints a worrying picture that suggests the NHS still has much to do to ensure cancer is flagged at the earliest opportunity and pathways to proper diagnosis and treatment are swift and smooth.

It also illustrates the importance of seeing the person behind the cancer and considering the impacts cancer or just the fear of cancer has on them.

This briefing aims to highlight some of these qualitative experiences, alongside key findings from our surveys. For more information on our quantitative findings, please see Appendix 1.

# Challenges faced by people who need cancer referral

## People can struggle to get a GP appointment.

GPs are the gateway to referrals and cancer care, yet we know from our [evidence](#) that one of the biggest challenges for any patient is to get a GP appointment. For people who fear they may have cancer, this delay can cause significant stress and have devastating outcomes.

Couldn't see GP at first - took 6 weeks of ringing every morning at 8 and breaking down crying on phone to receptionist. [...] nurse practitioner who told me my symptoms were normal. [...] she wanted bloods which I had to go back in again for then unscheduled telephone consultation with a GP to go over everything again 6 weeks later, then referred to ultra sound, then after results came in finally referred under 2 week rule to gynaecologist oncology (GP didn't make the referral for a week so took 3 weeks) oncology did biopsy, then after I saw them sent for urgent MRI a month later, (under 2 week rule) [...]. [Cumbria, female, aged 25-49]

For conditions that may require clear visual inspection, patients wanted to be given the option of a face-to-face appointment with their GP, however, in some cases, phone calls and photographs were relied upon for diagnosis.

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 [GP] said it wasn't that from the photographs they'd asked me to send them. I was unable to see a GP face to face even when I requested this. [Norfolk, female, aged 25-49]

## Getting to see a GP is still no guarantee of a timely referral for further tests, or indeed getting a referral at all.

Of the 334 respondents who got a referral, just over half were referred at their first appointment. For almost one in six, it took a month or longer between their first GP practice appointment about their symptoms and being told they were going to be referred.

In some cases, the GP wanted to try other treatment or medication first, but in other cases the reasons were more concerning, such as people not feeling they were taken seriously, the appointment being too rushed, or patients struggling to make themselves heard or understood.

Three in four took some kind of alternative action while trying to get a referral from their GP practice such as making additional appointments or even going to A&E.

Patients also suggested that some GPs may lack the specialist knowledge required to spot the red flag symptoms of cancer and this can lead to delayed diagnosis.

I had itching and a lump in my breast. I explained to the GP I'd already tried ointment for thrush after this was suggested. GP then said to apply for another week. [...] Then after a total of 3 weeks of GP calls, I got the 14-day referral. [Birmingham, female, aged 50-64]

The government's 10-year cancer plan call for [evidence](#) echoes these findings.

Respondents felt that healthcare professionals, particularly GPs, could benefit from more training on the signs and symptoms of cancer, and mechanisms to keep informed of the latest research and developments in this space. In turn, respondents believed this would help speed up diagnoses and referrals, so that treatment is started as early as possible.

### The relief of finally getting a referral can turn to frustration and worry when, after the two-week- wait, patients haven't heard anything back.

One in seven waited a month or more before getting confirmation from the hospital or community clinic that the referral was accepted. For all conditions, this can cause frustration and confusion. But for cancer referrals, poor administrative processes or communication between teams can have dire consequences if it means a delay in a cancer diagnosis.

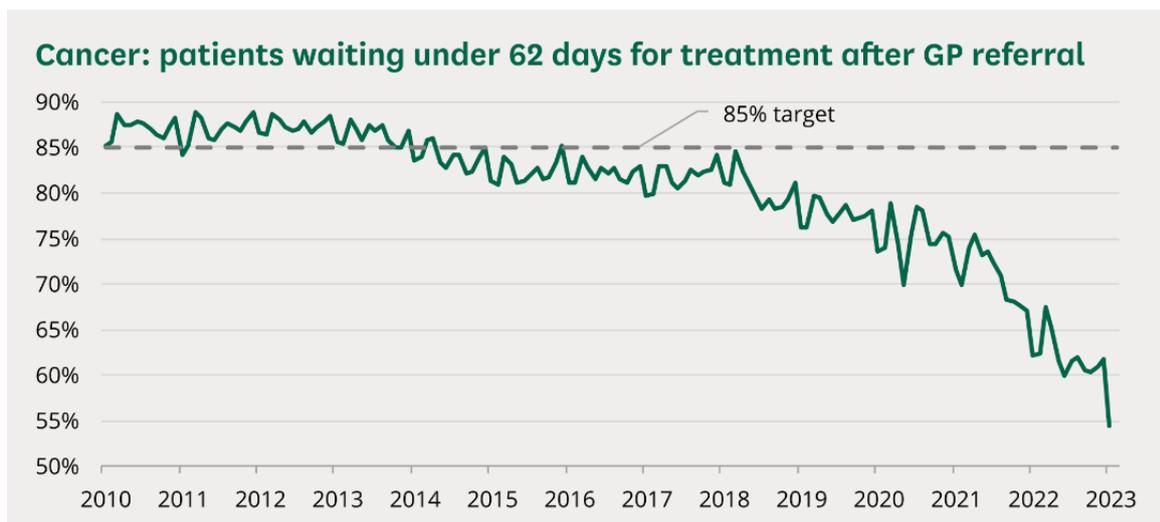
I had a red flag symptom - a new lump in my breast. He said I'd be seen in two weeks. After the 2 weeks wait elapsed, I rang the breast clinic. They didn't have a referral for me, so I then had to chase my GP Surgery because I was told I had been referred. They then sent through the referral, and I was seen in 2 days. I don't know if he forgot to do the referral, or something went wrong in the system. [Warwickshire, female, aged 50-64]

Patients we spoke with had to chase the GP practice or the medical setting where have been referred to themselves. Some found the promised referral never happened at all or it was stalled, refused, or cancelled altogether. This caused additional stress for the patients, and likely put additional pressure on other areas of the NHS when patients look for alternative routes to care, for example from a different GP, NHS111, an out of hours GP, A&E, or pharmacy.

Found out myself by phoning the hospital. I am on the waiting list but a massive backlog - waiting over 4 weeks now for 2-week estimated referral by GP. [North Yorkshire, female, 65-79]

### Further delays to get scans and treatment.

It can take some time to get the 14-day referral, and thereafter many are waiting longer than the [standard 62 days for treatment](#).



These delays can include last-minute cancellations.

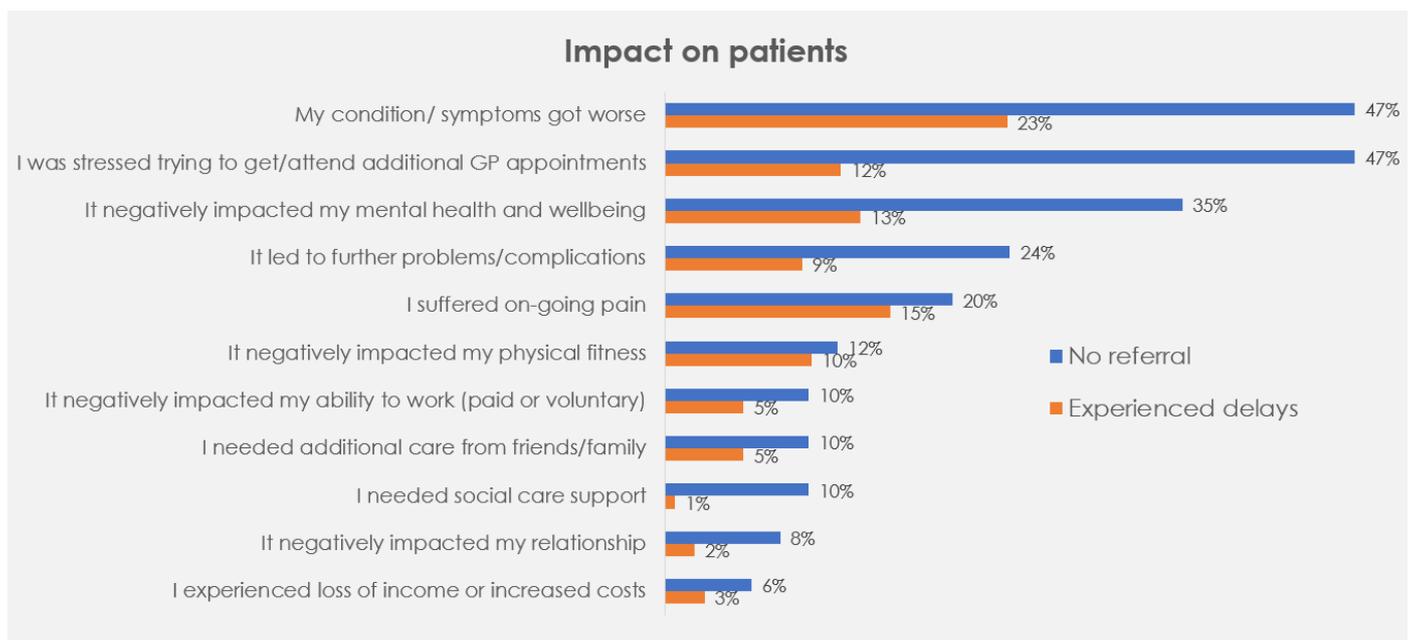
My hospital scan (referral) was cancelled twice due to incorrect staff being present and the ultrasound equipment needing to be fixed [Shropshire, male, 25-49]

But these statistics don't reflect the full picture in terms of overall timescales some patients experience. Before even being referred, we know patients already wait for a GP appointment, for GPs to tell them they will be referred, and for hospitals to confirm that referral before joining waiting lists.

To be told you're on a 2-week cancer pathway and then wait 11 weeks for the CT scan to be read is appalling and nobody cared except one receptionist. [Kent, male, 50-64]

## Impacts of delayed referrals to cancer care

**Failure to get a referral or a delay in the process can have serious consequences for people's lifestyles and medical conditions.**



No referral: Base 51 patients who requested or expected a referral related to cancer.

Experienced delays: Base 150 patients who got a cancer referral, but not on their 1<sup>st</sup> visit to their GP about their symptoms.

One nurse, two Advanced Nurse practitioners, and one GP- all of whom I saw face -to- face advised it was nothing to worry about. I asked a third ANP [...] she made an urgent referral to Dermatology at the local hospital where I 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 the cancer. [Lincolnshire, female, aged 65-79]

## **Sometime patients feel they have no choice but to go private.**

For any condition, the difficulty of getting a diagnosis or treatment can be hard, but when the suspected condition is cancer, it can feel like going private is a life-or-death decision.

I was told by GP I had pre-cancerous basal cell carcinoma on my face. After 2 weeks of waiting and hearing nothing, I went to the GP surgery and asked for a copy of the referral letter. At the top it said 'To Dermatology' but did not state which hospital. The letter itself was clear, but I suggest it was never sent out. After 2.5 months, with the BCC growing, I have been forced to go private. [Richmond upon Thames, female, aged 65-79]

And some patients told us that their GP had actively encouraged them to go private because of waiting lists.

When I was upset at being told to pay privately for my diagnosis [...] I returned to GP surgery 2 days later to reiterate I wanted to be on NHS waiting list. This was met with great resistance; even being told I could only be referred on 2-week wait if the basal cell carcinoma was on my face. Referral secretary [...] informed me they are suggesting this to avoid waiting referral times. This has caused me so much distress which is why I am looking at paying. [Devon, female, aged 65-79]

## **But regardless of outcome, how patients feel they are treated can help make the cancer journey a little more bearable.**

Many patients reported good experiences around the way they were treated and around speed of response. Given the fear factor of cancer, this is always very much appreciated.

Doctor and nurse were very supportive and took time to explain everything and were respectful and maintained my dignity. [Medway, female, aged 65-79]

I was referred to be seen within two weeks as the condition had a potential cancer risk. Everyone involved ensured that my treatment went ahead as planned and in a timely way both at the GP surgery and hospital. [Derbyshire, female, aged 50-64]

My GP was very attentive and answered all my questions fully. He put me at ease and focused on my anxiety! He also gave me a direct number to call me if I had any other questions and needed further information. [Greenwich, female, aged 50-64]

## Recommendations

[Official NHS data](#) shows a record 2.9 million people were referred for cancer checks from April 2022 to March 2023. However, the same NHS figures also show that targets for patients to attend their first hospital appointment within two weeks have not been hit since May 2021. And targets for first treatment within two months have been missed since December 2015.

So, while the increase in referrals is welcome, we know that some people are not being diagnosed or treated quickly enough.

We know the NHS has long term commitments to improving cancer diagnoses, and to helping services recovery from the impact of COVID-19.

And other initiatives may also provide people with quicker support closer to home, such as the community pharmacy diagnosis pilot and the introduction of more community diagnostic hubs. These services may also reduce demand on stretched GP teams.

But in the shorter term, NHS England must support GP teams to implement plans to improve GP access, so that people can get timely referrals. This should include vital plans to recruit and train more care navigators who can ensure life-saving cancer referrals don't go missing, and help patients know where they are in their wait for appointments.

First appointments in general practice must also work for patients, so they can communicate their conditions as effectively as possible.

<b>Our Recommendation</b>	<b>Why is this change needed?</b>	<b>Who is responsible for implementation?</b>
Train and hire more care navigators in general practice.	<p>The first barrier many people describe to getting a referral is getting a GP appointment in the first place.</p> <p>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 offline in evenings and over weekends.</p> <p>But patients' health needs can't be put on hold or switched off when they need support from their GP team.</p> <p>Care navigators can help this situation by managing increased demand over the phone and allowing 24/7 access to online triage systems.</p> <p>They can also work with clinical staff to help quickly communicate referral decisions and confirmations to patients.</p>	<p>NHS England</p> <p>Department of Health and Social Care</p> <p>Health Education England</p> <p>Integrated Care Systems</p>

<p>At the point of booking, give people choice of appointment types, times, place, and healthcare professional.</p>	<p>Our research highlighted a lack of personalised access choices as the reason for long waits for a referral.</p> <p>Research by Healthwatch and others shows that many people value remote appointments, while others prefer face-to-face consultations due to communication needs.</p> <p>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.</p> <p>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.</p> <p>And these preferences of appointment type, time, and professional can change.</p> <p>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.</p>	<p>NHS England</p> <p>Integrated Care Systems</p> <p>GP teams</p>
<p>Record people's communication preferences in e-RS or other care record systems.</p>	<p>Patient communications must be accessible. This not only ensures services meet people's needs under the Accessible Information Standard but can support people's understanding of and navigation through the health system.</p> <p>We have heard from people who have missed appointments and then either bounce back to general practice or go to A&amp;E because of referral letters being sent in the wrong format. So, by</p>	<p>NHS England</p> <p>Integrated Care Systems</p> <p>GP teams</p>

	<p>ensuring all patients are communicated with via their preferred method, the NHS can reduce the likelihood of demand presenting in the wrong settings.</p>	
<p>Offer longer appointment slots in general practice to those who need them.</p>	<p>Not all patients will need this, but for those who do, extra time during appointments would help give staff the space to assess patients holistically, and to share information about the referral process and where to go for help in the future.</p> <p>This would particularly help those with multiple long-term conditions and could potentially reduce the frequency of visits to general practice before onward referral.</p> <p>Only by understanding and managing demand can the NHS improve capacity at the right parts of the system.</p>	<p>NHS England</p> <p>Integrated Care Systems</p> <p>GP teams</p>
<p>Improve the online e-referrals tracker for patients.</p>	<p>We've heard from patients who have received no information along with their referral and had to chase the GP or hospital teams themselves.</p> <p>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.</p> <p>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.</p> <p>This should start from the moment a GP agrees to make a referral, not after the referral is accepted by specialist teams.</p> <p>Information should also be available and shared with patients via other preferred communication</p>	<p>NHS England</p> <p>NHS trusts</p> <p>GP teams</p>

methods where relevant, as noted  
in their care records

## Appendix 1

Data comes from an online survey about GP referrals of adults in England which was distributed via two methods.

Firstly, [Panelbase](#) was commissioned by Healthwatch England to host the survey (Data collected between 29 September to 20 October 2022).

Secondly, the survey was distributed by the Healthwatch local network. (Data collected between 22 August to 11 October 2022).

Our analysis of referral experiences for all conditions highlighted that one in ten cancer referrals did not progress directly to a hospital appointment or people joining an NHS waiting list.

We wanted to further understand people's experiences of cancer referrals, so this analysis is based on a subset of the referrals data related to cancer from both data sources:

- **Panelbase – 179 respondents**
- **Smart Survey - 206 respondents**

This was a quantitative survey, however, respondents also provided free-text responses.

Of the 334 that got a referral:

- 55% were referred at their first appointment
- For 28% it took up to a month to be referred after 1st appointment
- For 16% it took a month or over to be referred after 1st appointment

For those that weren't referred at their first appointment, we asked them why they were not referred at previous appointments.

<b>Why were you not referred for your symptoms or condition at previous GP practice appointments?</b>	<b>Count</b>	<b>%</b>
The GP wanted to try medication/other treatment options first	39	26%
I was only given phone appointment	25	17%
The GP didn't consider all the symptoms	18	12%
My condition wasn't considered serious enough	17	11%
The GP suggested life-style changes	16	11%
I wasn't listened to	14	9%
I wasn't taken seriously	13	9%
The GP asked me to see another health professional at the practice	11	7%
I don't know/ no reason was given	11	7%
The appointment was too rushed	9	6%
I was recommended private medical care	8	5%
I struggled to make myself heard/understood	5	3%
The GP practice refused to refer me for tests, diagnosis or treatment	4	3%
The GP didn't want to refer me because of waiting lists	3	2%
I was told to self-refer elsewhere	3	2%
None of the above	15	10%
Returned to GP because they were not referred perviously	150	100%

13% of those that received a cancer referral hadn't heard anything more about it when they participated in the research. Of those that had heard back (289), the time taken between being their GP practice saying that they were referring them and getting confirmation from the hospital/community clinic that the referral was accepted ranged from less than a week to over a year. For one in seven it was over a month.

How long did it take between being your GP practice saying that they were referring you and getting confirmation from the hospital/community clinic that the referral was accepted?	Count	%
A week or less	103	36%
More than a week, but less than a month	143	49%
1-2 months	16	6%
3-4 months	5	2%
5-6 months	8	3%
7-8 months	4	1%
9-10 months	1	0%
11-12 months	2	1%
Between 12-18 months	1	0%
Between 18 months and 2 years	2	1%
2 years or over	1	0%
Don't know/ can't remember	3	1%
Hear back about referral	289	100%

26% took no action to seek medical help while trying to get a referral, which means nearly 3 in 4 took some kind of action.

While trying to get a referral from your GP practice for your symptoms or condition did do anything else to get medical help for your symptoms or condition?	count	%
I searched online	19	13%
I arranged/tried to arrange another appointment with the GP	13	9%
I went to A&E	10	7%
I went to a pharmacy	5	3%
I tried to contact the hospital/community clinic directly	4	3%
I called NHS 111	4	3%
I got private treatment	4	3%
I went to the out-of-hours GP	1	1%
I tried to get a referral from a different GP	1	1%
I didn't do anything	39	26%
Total (not referred at first appointment)	150	100%