BREAST CANCER NOW The research & support charity

We're here

CLEARING THE PATH TO DIAGNOSIS

Improving referral pathways in England for people with secondary breast cancer

Inside this report

Executive summary

Secondary breast cancer is when breast cancer spreads to other parts of the body, such as the bones, liver, lungs or brain. It's also known as metastatic, advanced, stage 4 breast cancer or secondaries. Secondary breast cancer is currently incurable, but it can be treated, and symptoms can be managed. The length of time that people will live with secondary breast cancer varies hugely, and it will depend on the biology of the cancer.

One of the main challenges that people with secondary breast cancer face is getting a prompt diagnosis in the first place. In our 2019 report, we spoke to people living with the disease about the potential barriers to them getting a prompt diagnosis.[1] People had to make repeated trips to the GP before they got their diagnosis and felt like their symptoms weren't taken seriously enough. There were also challenges around recognising signs and symptoms of the disease – particularly among primary care professionals.

In addition to this, people who had previously had primary breast cancer weren't given enough information about secondary breast cancer. Secondary breast cancer symptoms can often be vague, and are sometimes mistaken for other conditions or side effects of primary breast cancer treatment. This adds further to delays in diagnosis.

But we know that the faster people are diagnosed, the faster they can access treatment and tailored support. This can have a dramatic impact on quality of life. So, it's vital that all healthcare professionals can:

- Identify secondary breast cancer symptoms promptly
- Make use of pathways that can speed up diagnosis – including those for vague symptoms
- Refer patients on to those pathways effectively

Since 2019, local NHS systems in England (known as cancer alliances) have been introducing a non-specific symptom (NSS) pathway. This pathway allows healthcare professionals to refer patients quickly for further tests that confirm or exclude a cancer diagnosis.

Using these pathways could improve the speed and experience of diagnosis for some people with potential symptoms of secondary breast cancer - particularly those who haven't previously had primary breast cancer. But we need to go further.

Underpinning all of this is the need to make sure that both healthcare professionals and patients are given the information they need to rapidly identify symptoms and take appropriate action.

> "PEOPLE HAD TO MAKE REPEATED TRIPS TO THE GP BEFORE THEY GOT THEIR DIAGNOSIS AND FELT LIKE THEIR SYMPTOMS WEREN'T TAKEN SERIOUSLY ENOUGH."

Summary of recommendations

Recommendation:
NHS England must continue to work with cancer alliances to make sure local services are supported to meet the faster diagnosis standard targets for NSS pathways. These targets are 75% by March 2024 and 80% by 2025/26.

Recommendation:
By March 2024, NHS England should update the list of core criteria for NSS pathways to include:

- Past diagnosis of cancer
- Abnormal bloods
- Pain that does not ease with pain relief

Recommendation:
As part of its current review, NICE should update its recommendations on clinical follow-up in its early and locally advanced breast cancer guideline. It should give clearer guidance for healthcare professionals on:

- The importance of making sure that patients completing treatment for primary breast cancer know about the possibility of recurrence, including secondary breast cancer
- What information to give patients, including: signs and symptoms to look out for, how to report any concerns, and who to report them to

Recommendation:
GatewayC should continue to work with key stakeholders, including Breast Cancer Now, to determine the effectiveness of the breast cancer recurrence course, increase uptake, and promote its use among healthcare professionals.

Recommendation:
The secondary breast cancer audit should collect data on routes to diagnosis for those people diagnosed with secondary breast cancer. The audit should work with NHS England and other stakeholders to explore the possibility of linking NSS referrals to diagnoses, to monitor the impact of this pathway.

Recommendation:
Cancer alliances should use funding to develop resources for healthcare professionals, highlighting when the NSS pathway can be used.

Recommendation:
NICE should consider updating its suspected cancer guideline to reflect the NSS criteria, to support use of the pathway.

Recommendation:
NHS England should continue to support the sharing of best practice among cancer alliances, particularly those that have been given additional funding to support the establishment or improvement of NSS pathways.

Recommendation:
Cancer alliances, integrated care system leads and providers should work together to make sure there is enough capacity and the right mix of skills within community diagnostic centres (CDCs) to see patients on the NSS pathway.

Recommendation:
To make sure there is enough workforce capacity, NHS England should urgently work with providers and cancer alliances to find solutions to workforce shortages.

Recommendation:
NHS England should set out a dedicated cancer workforce plan, detailing the number of staff needed to diagnose and treat cancer now and in the future.

Introduction

When it comes to secondary breast cancer, getting a prompt diagnosis can make sure that people have timely access to treatment and care. This can make a huge difference to their quality of life. However, there are often delays in getting diagnosed, which can cause further anxiety at an already challenging time. Making sure people are diagnosed as soon as possible helps to minimise this uncertainty and anxiety.

There are many challenges associated with getting a prompt diagnosis. One of the biggest reasons for a delayed diagnosis is patients and healthcare professionals not recognising the signs and symptoms of secondary breast cancer. We've consistently highlighted this issue and it needs to be addressed. At the same time, it's important to be clear on how patients with vague symptoms are referred for further tests.

It can be difficult for people to know who they should speak to if they're worried about new and persistent symptoms. Patients who've had primary breast cancer may continue to be monitored for a set period, known as follow-up. During follow-up, patients can seek help with any symptoms via their treatment team. But follow-up procedures often vary depending on what is available locally, and on how likely the patient's cancer is to return. This can mean that some patients find themselves seeking help in general practice.

Similarly, people who haven't previously had primary breast cancer, and people who have been discharged from follow-up, may also find that general practice is the most likely route to getting further advice.

In our 2019 report, most people who responded told us that their secondary breast cancer was first diagnosed after some form of engagement with their GP.[2] As this is often the first port of call for people experiencing symptoms, it's crucial that referral pathways used in primary care work effectively for people with potential secondary breast cancer symptoms.

This briefing looks at the new non-specific symptom (NSS) pathway, how it fits within the wider rapid diagnosis landscape, and how we can make sure it works effectively for people with potential symptoms of secondary breast cancer who could benefit from it. We also look at what more can be done to raise awareness of the symptoms of secondary breast cancer, both among patients and healthcare professionals.

> "...ONE OF THE BIGGEST REASONS FOR A DELAYED DIAGNOSIS IS PATIENTS AND HEALTHCARE PROFESSIONALS NOT RECOGNISING THE SIGNS AND SYMPTOMS OF SECONDARY BREAST CANCER."

What pathways are used to refer people with possible signs and symptoms of secondary breast cancer?

There's a lot of variation in the referral pathways used for people with potential signs and symptoms of secondary breast cancer. Different factors such as the symptoms that a person has, and what referral pathways are available locally all play a role.

Patient self-referral

Patients that have had a previous primary diagnosis may seek help directly from their multidisciplinary team (MDT). For example, patients can raise concerns by calling their MDT during follow-up. Even after treatment, people should feel empowered to contact a member of the team, such as a clinical nurse specialist or breast care nurse to flag new and persistent symptoms. This is known as open access and is provided in some areas, but not all. In areas where this isn't available, people may still present at their local GP.

> "EMPOWERING PATIENTS WITH THIS INFORMATION IS SOMETHING THAT IS INCREASINGLY IMPORTANT AS THE NHS CONTINUES TO CHANGE."

While open access can make it easier for people with symptoms of secondary breast cancer to talk to a member of their MDT, patients will need to learn the signs and symptoms in the first place and feel confident enough to get in contact.

Empowering patients with this information is something that is increasingly important as the NHS continues to change. With increasing demand for NHS services, fewer face-to-face appointments and potentially less familiarity among primary care professionals of a person's medical history, it will be vital that people feel they can advocate for their own health. We have free, downloadable resources, such as our **After breast cancer – what now** booklet that can help explain the follow-up process, and what people can do if they think their cancer has returned.[3]

Direct GP referral back to MDT

If a GP has concerns about the symptoms of a patient that has had a primary diagnosis they can refer them back to their MDT. Direct referrals by a GP can take place both during and after follow-up.[4] For most patients who have had a previous diagnosis of primary breast cancer, this is an ideal referral route. It means that people can seek advice about their symptoms from specialists who already have knowledge of their medical history and know how to assess symptoms. This can speed up the diagnostic process.

Other routes

In research we commissioned this summer (2023), we found that the urgent suspected cancer pathway was the most used referral route - GPs and practice nurses refer on average 65% of their patients with suspected symptoms of secondary breast cancer through this route.[5]

Others use advice and guidance (A&G) as a means of securing referrals for people with signs and symptoms that could be secondary breast cancer. A&G allows a "requesting clinician" (such as a GP) to seek advice from a "responding clinician" by forwarding documents like diagnostics test results. The responding clinician is then able to decide whether the request should be turned into a referral.[6] Patients who haven't previously had primary breast cancer could benefit from A&G. They may also benefit from non-specific symptom pathways.

When talking about the potential benefits of the NSS pathway in supporting the rapid diagnosis of some secondary breast cancer patients, we acknowledge that it won't be the most effective route in many cases. The ideal route for patients with suspected secondary breast cancer is to be able to access their MDT as soon as possible – whether via a GP or open access. But this may not always be possible in practice and won't be relevant to those who haven't had a previous primary breast cancer diagnosis.

The NSS pathway is not specifically set up to identify potential secondary breast cancer patients. But it could potentially serve the purpose of determining or ruling out cancer for people who can't be placed on other pathways.

How the non-specific symptom pathway could help

Since 2019, cancer alliances in England have been creating non-specific symptom (NSS) pathways. They're designed to support the rapid diagnosis of patients whose symptoms don't *"fit clearly into a single 'urgent cancer' referral pathway.*[7]" Some examples of these symptoms include tiredness, unexplained weight loss and nausea.

As part of its commitment to achieving faster diagnosis, NHS England (the body that has strategic oversight for health systems in England) is supporting the wider roll-out of NSS pathways across England. Their goal is for NSS pathways to cover the whole of England by March 2024.

At the time of writing, there are **108** NSS pathways in England. Primary care networks (PCNs) are required to deliver 7 national service specifications, one of which is supporting early cancer diagnosis. The 2023/24 specification includes the need to review the use of NSS pathways and take appropriate action to increase referrals.

We welcome the wider expansion of the NSS pathway. It could fast-track people with potential signs and symptoms of secondary breast cancer to have further tests. It could be particularly helpful for people who don't have direct routes into MDT services.

> "IN ITS LONG-TERM PLAN, NHS ENGLAND LAID OUT AMBITIONS TO IMPROVE DIAGNOSIS. HOWEVER, REFERRAL PATHWAYS ARE NOT ALWAYS CLEAR, AND IT CAN BE DIFFICULT FOR HEALTHCARE PROFESSIONALS TO KNOW WHICH PATHWAY TO USE."

But for these benefits to be realised, it must be clear to healthcare professionals which referral pathways they can use to aid faster diagnosis. The NSS pathway itself should also include symptoms of secondary breast cancer.

This is highlighted in our commissioned research of healthcare professionals, which show mixed opinions about the NSS pathway. The majority (**37%**) either agreed or strongly agreed that they have found the NSS pathway faster and easier when referring people with non-specific symptoms that could be secondary breast cancer. But a minority (**13%**) either disagreed or strongly disagreed. A further **25%** neither agreed nor disagreed with **2%** not sure. An additional **23%** were not able to answer the question due to not having used the NSS pathway.[8]

When asked what the barriers are that prevent them from using the NSS pathway, healthcare professionals pointed to several things including the use of other pathways, but also not being clear on when the NSS pathway can be used and what the criteria are.

The rapid diagnosis landscape in England

There's been a lot of progress over the years to support better outcomes for people living with cancer. Despite this, there's still more that can be done – particularly on speeding up diagnosis. In its long-term plan, NHS England laid out ambitions to improve diagnosis. But referral pathways are not always clear, and it can be difficult for healthcare professionals to know which pathway to use.

Breast Cancer Now commissioned research (August 2022) of 255 primary healthcare professionals in the UK to understand the barriers they face in diagnosing people with potential secondary breast cancer. In response to the question on what challenges they face in the timely identification and referral of patients with potential secondary breast cancer, we found that:[9]

38%
said that **urgent referral criteria are too specific** to primary breast cancer signs and symptoms

38%
said there was a **lack of urgent referral pathways** for general or non-specific symptoms.

35%
said there was **a lack of urgent referral pathways for lower or medium risk** symptoms

18%
said referral pathways were **unclear**

Through its faster diagnosis framework (2022), NHS England aims to give healthcare professionals a clearer understanding of how referral pathways for cancer fit together. It also highlights when healthcare professionals can use these pathways.

Different cancer pathways include:

1. **Urgent suspected** – patients can be referred via this pathway if they have symptoms outlined in the National Institute for Health and Care Excellence's (NICE) suspected cancer guideline (NG12).[10] These include breast lumps and changes to the nipple. The 28-day faster diagnosis standard (FDS) requires healthcare professionals to either confirm or rule out cancer within 28-days from the point of urgent referral
2. **Urgent breast symptomatic (cancer not suspected)** – this pathway is for patients who have breast symptoms but the clinician referring them doesn't suspect they have cancer. There's still an expectation for these referrals to meet the FDS
3. **Non-specific** – patients with vague symptoms that may indicate cancer can be referred via this pathway.[11] The FDS will apply to referrals made through this pathway
4. **Non-urgent** – referrals which aren't thought to be urgent, which can apply to patients with vague, as well as site-specific, symptoms

The NSS pathway could give people with potential secondary breast cancer symptoms (which are often vague and non-specific) access to a timed pathway that could speed up their diagnosis.

Recommendation:
NHS England must continue to work with cancer alliances to make sure local services are supported to meet the faster diagnosis standard targets for NSS pathways. These targets are 75% by March 2024 and 80% by 2025/26.

The development of best practice timed pathways guidance should also help cancer alliances meet FDS targets. These aim to support the management of cancer pathways and improve experiences of care. For NSS pathways, the aim is that best practice timed pathways will be developed by March 2024.

However, these pathways will only be effective, and work as intended, if services are supported in embedding them locally. This means making sure there is enough resource available for them to implemented.

How the NSS pathway works

People with new and persistent symptoms can be referred onto NSS pathways via their GP or from hospital – although this may differ depending on location.

From primary care:

1. A patient visits their GP or a primary care professional with non-specific symptoms that meet the core non-specific symptom referral criteria. Examples include unexplained and unintentional weight loss, fatigue, abdominal pain, nausea and GP "gut feeling" (annex 1)[12]
2. GP or primary care professional arranges for the patient to have a range of core filter function tests (annex 2). How long this step takes to complete will vary, and will depend on what tests are carried out and how these are organised locally
3. If test results are inconclusive, the patient is referred on for further tests via the NSS pathway
4. On referral, the FDS clock starts, and healthcare professionals will have 28 days to confirm a cancer diagnosis or rule cancer out

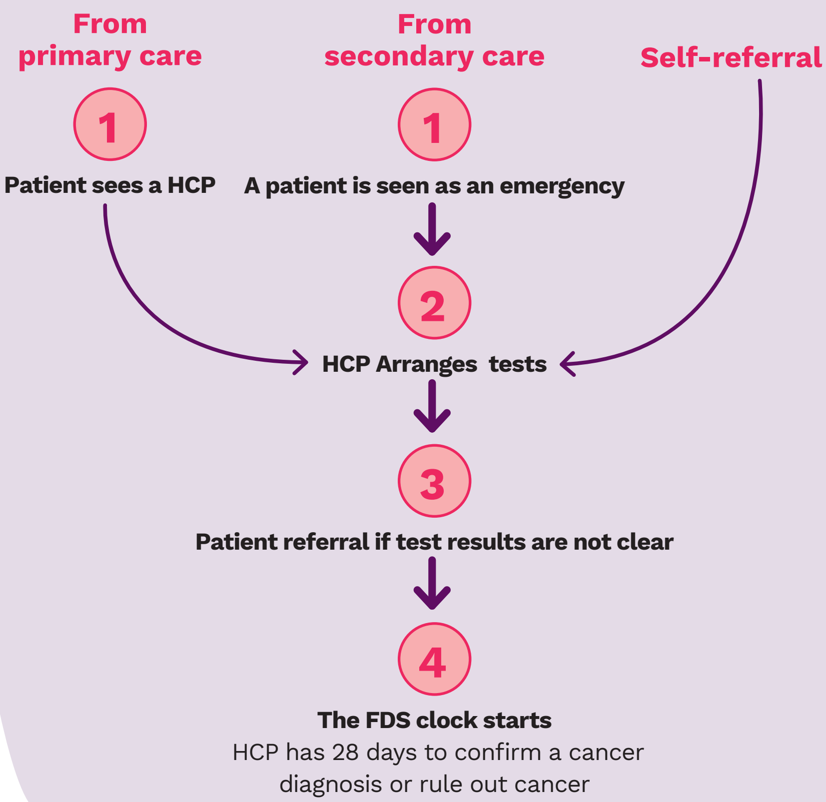
The same journey could also apply for patients who:

- Are seen as an emergency in secondary care
- Self-refer – this is currently only available in certain areas but can include, for example, patients being given access to cancer hotlines if they are worried about symptoms

In these instances:

1. A patient who presents as an emergency or self-refers with NSS core referral criteria can be referred for further investigation via the NSS pathway
2. On referral, the FDS clock starts, and healthcare professionals will have 28 days to confirm a cancer diagnosis or rule cancer out

The diagram below sets these routes out:



How can we make sure the NSS pathway works for people with potential secondary breast cancer symptoms?

Improving the core and optional NSS referral criteria

While the NSS symptom pathway could help speed up diagnosis and access to treatment and care, there is still room for it to be improved. This includes expanding what symptoms will qualify a patient to be referred via the pathway (the core and optional NSS referral criteria). The current criteria doesn't reflect all the symptoms and past medical history that people with secondary breast cancer may experience, including:[13]

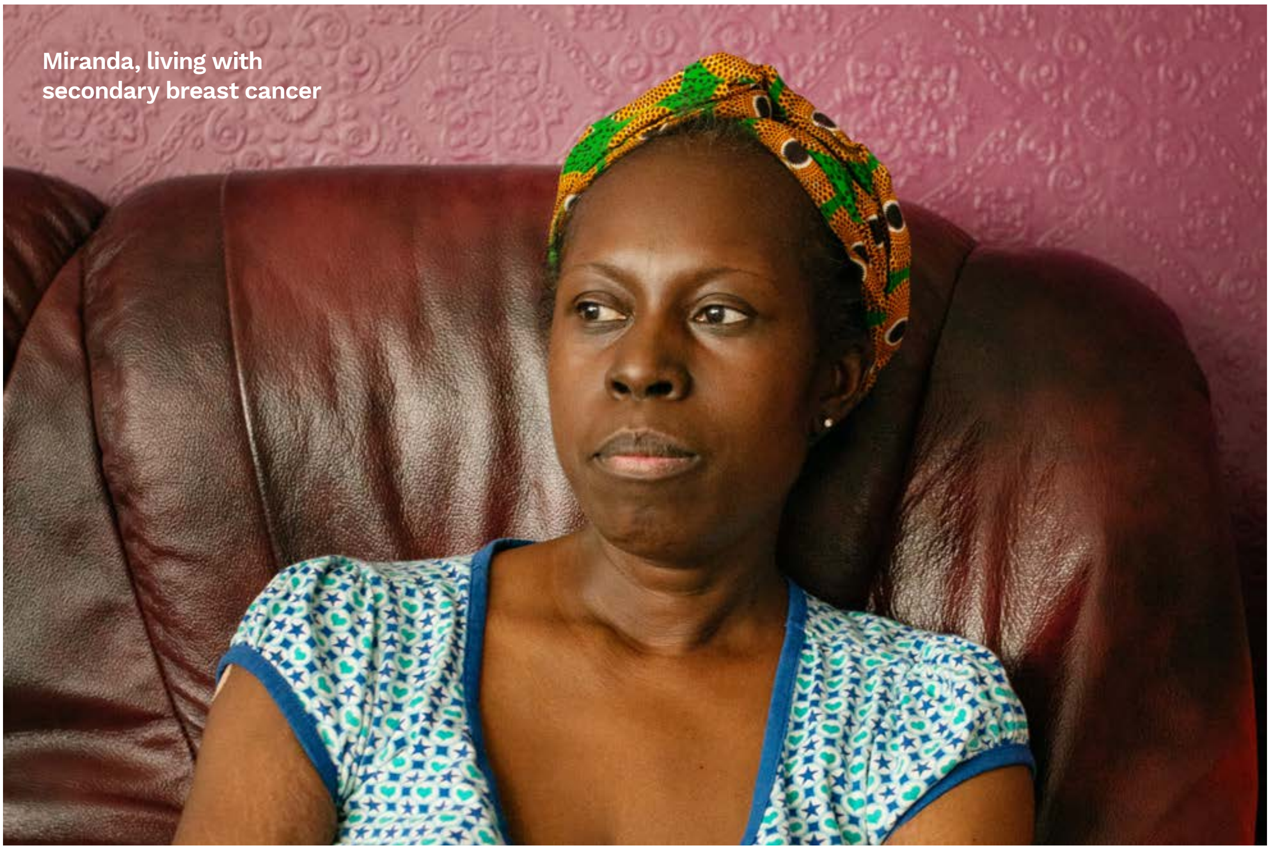
- A past diagnosis of cancer (including when and what type)
- Abnormal bloods
- Pain that does not go away with pain relief

This also means that the list of core and optional tests **outlined in the framework**[14] **doesn't include** some of the tests that could be done to help diagnose secondary breast cancer.[15]

Recommendation:

By March 2024, NHS England should update the list of core criteria for non-specific symptom pathways to include:

- Past diagnosis of cancer
- Abnormal bloods
- Pain that does not ease with pain relief


Miranda, living with secondary breast cancer

Improving awareness of secondary breast cancer

A potential benefit of the NSS pathway for people with secondary breast cancer is access to the FDS that confirms or rules out cancer within 28 days. However, this still requires patients and healthcare professionals to recognise which symptoms may be secondary breast cancer related.

We hear anecdotally from our secondary breast cancer nursing group that nurses are seeing more people presenting with advanced disease. They hear of people being frustrated both that they were unable to recognise signs and symptoms themselves, and that they were incorrectly treated for other conditions before they were diagnosed with secondary breast cancer. So, it's fundamental that both healthcare professionals and patients know how to identify signs and symptoms early on. As we mentioned earlier, this means that patients should feel equipped to advocate for their own health.

> "IT'S FUNDAMENTAL THAT BOTH HEALTHCARE PROFESSIONALS AND PATIENTS KNOW HOW TO IDENTIFY SIGNS AND SYMPTOMS EARLY ON"

Patients

Secondary breast cancer symptoms often present in the same way as other conditions, or the side effects of treatments for primary breast cancer. Symptoms can include pain in bones, fractures, breathlessness, weight loss, nausea, fatigue, and headaches, to name a few.[16]

Given that these symptoms can be vague, patients may not seek help earlier on. They're also not always aware of what to look for. Recent data from the National Cancer Patient Experience Survey (CPES) 2022 in England found that breast cancer patients were the least likely to say that they had been given information about the possibility and signs of their cancer coming back or spreading (**57.5%**).[17]

Similarly, in our 2019 report, we found that only **13%** of respondents who previously had breast cancer felt they were given enough information from healthcare professionals on the signs and symptoms of secondary breast cancer.[18] To help patients take early action, they must be given information on what to look out for, and know how and who to report their concerns to.

The National Institute for Health and Care Excellence's (NICE) guideline for early and locally advanced breast cancer[19] currently includes only a vague reference to "signs and symptoms to look out for and seek advice on" as part of clinical follow-up.

We believe that there should be more detailed guidance for healthcare professionals about informing patients about the signs and symptoms of secondary breast cancer. There should also be more guidance on how to report any concerns, including who patients should contact if they are concerned that their breast cancer has come back.

Recommendation:
As part of its current review, NICE should update its recommendations on clinical follow-up in its early and locally advanced breast cancer guideline. It should give clearer guidance for healthcare professionals on:

- The importance of making sure patients completing treatment for primary breast cancer know about the possibility of recurrence, including secondary breast cancer
- What information to give to patients, including: signs and symptoms to look out for, how to report any concerns, and who to report them to

Healthcare professionals

Healthcare professionals across the UK also struggle to identify the signs and symptoms of secondary breast cancer. In our 2019 report we found that:[20]

- Almost a quarter (**23%**) of respondents who had previously had breast cancer had seen their GP 3 times or more before getting a diagnosis
- Of those who had spoken to a healthcare professional about their symptoms, **41%** felt their symptoms were not taken seriously
- **11%** of respondents who had not been given a prior breast cancer diagnosis, and **6%** of respondents who had a previous primary breast cancer diagnosis were only diagnosed with secondary breast cancer after being seen as an emergency or in A&E

In research that we commissioned in 2022, we found the following challenges in identifying symptoms and referring patients with potential secondary breast cancer:[21]

> "WE FOUND THAT OVER HALF OF GPs (58%) AND PRACTICE NURSES (51%) HAD DIFFICULTY LINKING NON-SPECIFIC SYMPTOMS (E.G., FATIGUE) WITH SECONDARY BREAST CANCER."

24%

Almost a quarter of GPs and over one-third (**37%**) of practice nurses **highlighted late identification of signs and symptoms** among healthcare professionals.

37%

of practice nurses said there was a **lack of training provided to primary care professionals** on signs and symptoms of secondary breast cancer

Vague symptoms can also increase the risk of inappropriate referrals by healthcare professionals, or of not being referred on at all. In our research, on the question of what challenges are faced by healthcare professionals in timely referral of patients with potential secondary breast cancer, we found that over half of GPs (**58%**) and practice nurses (**51%**) had difficulty linking non-specific symptoms (e.g., fatigue) with secondary breast cancer.[22]

To make sure secondary breast cancer patients are not falling at the first hurdle, we must get to grips with these basics.

There's also a need to think about the role that other healthcare professionals could play in helping people recognise the signs and symptoms of secondary breast cancer. There have been conversations in the health service and beyond around expanding the role of pharmacists in primary care. Many primary breast cancer patients will be using adjuvant treatments such as hormone therapy over extended periods, which they collect from their local pharmacy. Health services could explore the possibility of raising awareness of the signs and symptoms of secondary breast cancer among pharmacists.

How we can support healthcare professionals

Our awareness campaigns

Throughout the year, Breast Cancer Now runs campaigns that help healthcare professionals identify secondary breast cancer symptoms. We contact both GPs and practice nurses across a variety of different channels including postal mailings, emails, magazine advertising and digital marketing, highlighting the ways that they can spot the signs and symptoms of secondary breast cancer quickly.

In our most recent campaign (Spring 2023), we provided healthcare professionals with information on how they can download resources for people who have finished treatment for a primary diagnosis. We used digital and magazine advertising to showcase our new tailored secondary breast cancer support landing page, made specifically with healthcare professionals in mind, with downloadable information and resources.[23]

> "... WE PROVIDED PROFESSIONALS WITH INFORMATION ON HOW THEY CAN DOWNLOAD RESOURCES FOR PEOPLE WHO HAVE FINISHED TREATMENT FOR A PRIMARY DIAGNOSIS."

GatewayC

We also work with key partners like GatewayC to raise awareness of secondary breast cancer symptoms among healthcare professionals working in primary care. GatewayC is a free online early cancer diagnosis resource for GPs, nurses, allied health professionals and other clinicians in England and Wales. It helps them to identify suspected cancer and to refer when needed. GatewayC is funded by the NHS.

We have worked with GatewayC and others to develop a course aimed at increasing healthcare professionals' awareness of potential symptoms of breast cancer recurrence. It also includes how and when to refer patients on for further investigation. The breast cancer recurrence course,[24] which was launched in 2021, is a useful resource that can help improve diagnosis for people with secondary breast cancer. However, we need to make sure that this course is well-known and routinely used among healthcare professionals.

Recommendation:
GatewayC should continue to work with key stakeholders, including Breast Cancer Now, to determine the effectiveness of the breast cancer recurrence course, increase uptake, and promote its use among healthcare professionals.

> "THE BREAST CANCER RECURRENCE COURSE, WHICH WAS LAUNCHED IN 2021, IS A USEFUL RESOURCE THAT CAN HELP IMPROVE DIAGNOSIS FOR PEOPLE WITH SECONDARY BREAST CANCER."

Understanding the population: the need for better data

To understand the potential impact of the NSS pathway on people with secondary breast cancer, we need better data. To date, there is still no definitive figure for the number of people living with secondary breast cancer in the UK. The best estimate we have is that there are over 61,000 people living with secondary breast cancer in the UK – with 57,215 people living with secondary breast cancer in England in 2020/21[25]. This is a huge increase on the previous estimate of 35,000.

If we don't know how many people are diagnosed with the disease, and the routes through which they are diagnosed, it will be difficult for us to know the ultimate outcome of those referred via the NSS pathway.

NHS England has commissioned a national clinical audit for secondary breast cancer, but given the lack of data to date, it will be some time before we see data being published that can improve patient outcomes.

Recommendation:
The secondary breast cancer audit should collect data on routes to diagnosis for those diagnosed with secondary breast cancer, working with NHS England and other stakeholders to explore the possibility of linking NSS referrals to diagnoses, to monitor the impact of this pathway.

> "TO FIND OUT HOW WELL LOCAL NHS SYSTEMS IN ENGLAND ARE MEETING RAPID DIAGNOSIS AMBITIONS, ROBUST DATA COLLECTION SYSTEMS MUST BE IN PLACE."

Measuring performance

To find out how well local NHS systems in England are meeting rapid diagnosis ambitions, robust data collection systems must be in place. This includes regular reporting on NSS pathways. In its faster diagnosis framework, NHS England said that non-specific symptom referrals will be introduced into cancer wait times guidance from July, and that NHS England will monitor the data to ensure compliance.

As set out in the most recent cancer waiting times guidance, the NSS pathway has been brought into the scope of the FDS and 62-day referral to treatment targets.[26] Data on NSS pathway referrals will therefore be publicly available and included in cancer wait times performance statistics. At the time of writing, we understand that the data is expected to be published imminently.

Cancer alliances have also regularly collated NSS pathway data through dashboards. A couple of cancer alliances have told us that these dashboards, which were initially supported by NHS England, were useful in helping local systems measure progress against their plans, and support ongoing improvements.

To make sure that the NSS pathway is working as intended, it's vital that cancer alliances and providers are supported in collecting high-quality data. This will help us understand whether programmes of work on faster diagnosis are effective.

While data on NSS pathways tells us how many people referred through them were diagnosed with breast cancer, it doesn't tell us whether they were diagnosed with primary or secondary breast cancer. This means that we don't currently know how many people referred on to the NSS pathway go on to be diagnosed with secondary breast cancer. There should be a way to link data on those referred through the NSS pathway to a confirmed secondary breast cancer diagnosis. This is something that should be incorporated, where possible, in the audit as highlighted above.

Funding

Cancer alliances have been given additional place-based funding for 2023/24 and 2024/25 to support the roll-out of the NSS pathway. After this, systems will need to use existing funding. The funding reflects NHS estimations for various programmes of work.

NHS England has given examples of how the money could be distributed, suggesting that for 2023/24, **6%** could be allocated to NSS pathways, and **3%** in 2024/25.[27] Funding can be used to expand or improve NSS pathways and can include, among other things:

- Recruiting, educating, and training staff
- Promotion of NSS pathways – such as among GPs

Cancer alliances can decide how they allocate this funding based on local need. Given that NSS pathways are still relatively new, it will be vital that funding supports the education and training of primary care professionals. This will include information on the instances in which NSS pathways could be used. In the survey that we recently commissioned on the NSS pathway, healthcare professionals told us the following:[28]

> "GIVEN THAT NSS PATHWAYS ARE STILL RELATIVELY NEW, IT WILL BE VITAL THAT FUNDING SUPPORTS THE EDUCATION AND TRAINING OF PRIMARY CARE PROFESSIONALS."

48%

would like clearer guidance on when to use the NSS pathway

40%

would like clearer guidance on criteria for referring through the NSS pathway

34%

would like guidance on NSS pathway criteria and how it differs from other referral criteria

Recommendation:

Cancer alliances should use funding to develop resources for healthcare professionals, highlighting when the NSS pathways can be used.

Recommendation:
NICE should consider updating its suspected cancer guideline to reflect the NSS criteria, to support use of the pathway.

> "IT WILL BE VITAL THAT FUNDING SUPPORTS THE EDUCATION AND TRAINING OF PRIMARY CARE PROFESSIONALS."

Introducing innovation

We're pleased to see potential for introducing innovation within NHS England's faster diagnosis framework. Some examples of what can be adopted by local systems include:

- Self-referral
- Triage hubs – these allow healthcare professionals to redirect referrals to the right pathway

Cancer alliances were also given the opportunity to bid for additional funding to introduce innovations locally. Work is being carried out to share key learnings. For example, cancer alliances and other interested groups like Academic Health Science Networks can join the National Cancer Programme Innovation Group, which is facilitated by NHS England.

This group acts as a forum for sharing learning and good practice. The national NSS delivery groups also allow the sharing of best practice pathways among cancer alliances. Data dashboards mentioned earlier have been created to visualise data and can also serve as an evidence base. A national economic and impact session was also held recently to support commissioning for 2024/25, and a case study report is under development.

Recommendation:
NHS England should continue to support the sharing of best practice among cancer alliances, particularly those that have been given additional funding, to support the establishment or improvement of NSS pathways.

> "COMMUNITY DIAGNOSTIC CENTRES (CDCS) ARE WELCOME ADDITIONS TO THE NHS LANDSCAPE"

Other innovations that support rapid diagnosis

Faster diagnosis ambitions may increase demand for scans, tests and checks in hospitals. This can lead to further delays and backlogs. To prevent this, NHS England has supported the creation of services, outside of acute hospital trusts, where people can have further investigations. This has led to the introduction of community diagnostic centres (CDCs). CDCs are described as "one-stop shops" that allow people to get tests more locally.[29]

These centres are still relatively new but are welcome additions to the NHS landscape. They offer a range of investigations and can reduce the number of locations and appointments that a patient has to navigate.

NHS England's faster diagnosis framework recognises that CDCs will support rapid cancer diagnosis with good coordination between themselves, cancer alliances and local NHS systems (known as integrated care systems). The coordination will include making the most of CDCs' capacity.

Rapid access to CDCs will also need healthcare professionals to recognise non-specific symptoms and refer on. It will therefore continue to be important that healthcare professionals have the information and tools they need to refer patients on for tests as quickly as possible.

Recommendation:
Cancer alliances, integrated care system leads and providers should work together to make sure there is enough capacity and the right mix of skills within community diagnostic centres (CDCs) to see patients on the NSS pathway.

Diagnostic and imaging workforce

An important part of improving timely diagnosis is making sure there is enough capacity in the diagnostic and imaging workforce. The review conducted by Sir Mike Richards on diagnostics (2020) stated that an additional 4,000 radiographers (including advanced practitioner radiographers), 2,000 radiologists and 220 physicists would be needed to meet demand.[30]

Recent projections made by the Royal College of Radiologists in its Clinical Radiology Workforce Census (2022)[31] suggest that by 2027:

- There will be an estimated **41%** shortfall in clinical radiologists in England
- An additional **3,365** clinical radiologists will be needed to meet demand

To make sure that people with secondary breast cancer get a quick diagnosis, it's vital that the NHS in England has:

- A sustainable diagnostic and imaging workforce
- Appropriate diagnostic equipment to meet both current and future demand

We're pleased that NHS England recently published its long-awaited workforce plan. Plans to increase the number of training places to help plug the projected shortfalls in the NHS workforce are welcome. However, we urgently need to understand what this will mean for medical specialities, including radiology. These developments will take time, and more must be done to improve diagnostic capacity now.

Recommendation:

To make sure there is enough workforce capacity, NHS England should urgently work with providers and cancer alliances to find solutions to workforce shortages.

Recommendation:

NHS England should set out a dedicated cancer workforce plan, detailing the number of staff needed to diagnose and treat cancer now and in the future.

> "PLANS TO INCREASE THE NUMBER OF TRAINING PLACES TO HELP PLUG THE PROJECTED SHORTFALLS IN THE NHS WORKFORCE ARE WELCOME. HOWEVER, WE URGENTLY NEED TO UNDERSTAND WHAT THIS WILL MEAN FOR MEDICAL SPECIALITIES, INCLUDING RADIOLOGY."

Annex

Annex 1

NHS England has full referral criteria for NSS pathways via its faster diagnosis framework.[32] We've outlined the core criteria below:

- New, unexplained and unintentional weight loss (either documented >5% in 3 months or with strong clinical suspicion)
- New, unexplained constitutional symptoms of 4 weeks or more (less if very significant concern). Symptoms include loss of appetite, fatigue, nausea, malaise, bloating
- New, unexplained vague abdominal pain of 4 weeks or more (less if very significant concern)
- New, unexplained, unexpected or progressive pain, including bone pain, of 4 weeks or more
- GP "gut feeling" of cancer diagnosis – reasons to be clearly described at referral
- Abnormal radiology suggesting cancer; not needing admission and not suitable for existing urgent cancer referral or cancer of unknown primary pathway

Annex 2

The full list of filter function tests that can be carried out for people with non-specific symptoms can be found via NHS England's faster diagnosis framework. We've listed the core tests below:

- Chest x-ray
- Urine
- FIT
- FBC
- ESR or CRP
- U&E with eGFR
- LFTs (including globulins)
- TFTs
- HBA1c
- Bone
- CA-125 (women)
- PSA (men)
- B12/ferritin/folate and iron studies (if anaemic)


WE'RE HERE FOR YOU
INFORMATION AND S
CONTACT OUR NURSES
SOMEONE LIKE
BECCA, THE BREAST CANCER SUPPORT APP

References

1 Until things change: Unsurvivors (2019), Breast Cancer Now

breastcancernow.org/sites/default/files/bcn_untilthingschange_final_30.09.20.pdf

2 This was highlighted in the data that fed into our 2019 report. In our survey data 43% of respondents said that their GP suspected cancer and referred them urgently and 11% of GPs started treating the respondent for another condition and referred the patient to a specialist for that condition.

3 This was highlighted in the data that fed into our 2019 report. In our survey data 43% of respondents said that their GP suspected cancer and referred them urgently and 11% of GPs started treating the respondent for another condition and referred the patient to a specialist for that condition. atment-what-now-bcc169

4 Ibid

5 Breast Cancer Now commissioned Synergy Healthcare Research to conduct an online survey with 250 primary care healthcare professionals (200 GPs and 50 practice nurses) in September 2023. A key objective of the survey was to identify which referral pathways healthcare professionals use for people with symptoms that could be secondary breast cancer and what prevents healthcare professionals using the NSS pathway.

6 NHS Digital, Advice and guidance overview for the NHS e-referral service (e-RS), available at:

digital.nhs.uk/services/e-referral-service/document-library/advice-and-guidance-overview

7 NHS England, Faster Diagnosis, available at:

england.nhs.uk/cancer/faster-diagnosis/

8 In the research we commissioned this year conducted by Synergy, we asked healthcare professionals to highlight to what extent they agree they have found referral of patients with non-specific symptoms that may suggest secondary breast cancer easier and faster via the NSS pathway.

9 Breast Cancer Now commissioned Synergy Healthcare Research to conduct an online survey with 255 primary care healthcare professions (204 GPs and 51 practice nurses) in August 2022. One of the key objectives of the survey was to identify key barriers to referring patients with suspected secondary breast cancer or recurrence. Question 11 asked what challenges, if any, healthcare professionals face in the timely identification and referral of patients with potential metastatic breast cancer.

10 National Institute for Health and Care Excellence guideline, Suspected cancer: recognition and referral [NG12]

nice.org.uk/guidance/ng12

11 NHS England, Faster Diagnosis

england.nhs.uk/cancer/faster-diagnosis/

12 A full list of core and optional referral criteria for NSS pathways can be found at NHS England's NHS Cancer Programme: Faster Diagnosis Framework, 28 November 2022, Annex 1, pgs. 29-30

england.nhs.uk/wp-content/uploads/2019/07/B1332-NHS-Cancer-Programme-Faster-Diagnosis-Framework-v5.pdf

13 Breast Cancer Now, Secondary breast cancer symptoms [accessed 14 June 2023]

breastcancernow.org/information-support/facing-breast-cancer/secondary-metastatic-breast-cancer/secondary-breast-cancer-symptoms

14 NHS England, NHS Cancer Programme: Faster Diagnosis Framework, 28 November 2022, pg.30

england.nhs.uk/wp-content/uploads/2019/07/B1332-NHS-Cancer-Programme-Faster-Diagnosis-Framework-v5.pdf

15 Breast Cancer Now, Secondary breast cancer tests [accessed 14 June 2023]

breastcancernow.org/information-support/facing-breast-cancer/secondary-metastatic-breast-cancer/secondary-breast-cancer-tests

16 A fuller list of secondary breast cancer symptoms can be found via the Breast Cancer Now's Secondary Breast Cancer Symptom page here:

breastcancernow.org/information-support/facing-breast-cancer/secondary-metastatic-breast-cancer/secondary-breast-cancer-symptoms

17 NHS England, National Cancer Patient Experience Survey, 2022 National Quantitative Report [accessed 20 July 2023]

ncpes.co.uk/latest-national-results

18 Breast Cancer Now, Until Things Change: Unsurvivors, (2019), pg. 9

breastcancernow.org/sites/default/files/bcn_untilthingschange_final_30.09.20.pdf

19 National Institute for Health and Care Excellence (2018) Early and locally advanced breast cancer: diagnosis and management, available at: nice.org.uk/guidance/ng101 [accessed 13 September 2023]

20 Statistics are UK-wide.

21 Breast Cancer Now commissioned Synergy Healthcare Research to conduct an online survey with 255 primary care healthcare professions (204 GPs and 51 practice nurses) in August 2022. Question 11 asked what challenges, if any, healthcare professionals face in the timely identification and referral of patients with potential metastatic breast cancer.

22 Ibid

23 Breast Cancer Now, Secondary breast cancer support for healthcare professionals, available at:

breastcancernow.org/information-support/healthcare-professionals/secondary-breast-cancer-support-healthcare-professionals [accessed 13 September 2023]

24 GatewayC, Breast Cancer Recurrence, available at:

gatewayc.org.uk/courses/breast-cancer-recurrence/ [accessed 13 September 2023]

25 Based on findings from Palmieri, C., Owide, J., & Fryer, K. (2022). Estimated Prevalence of Metastatic Breast Cancer in England, 2016-2021. JAMA Network Open, 5(12), e2248069

doi.org/10.1001/jamanetworkopen.2022.48069.

This paper estimates 57,215 people living with secondary breast cancer in England in 2020/21. Combined with requested data from Public Health Scotland (2022) estimating 3,945 people living with secondary breast cancer at the end of 2020.

26 NHS England, National Cancer Waiting Times Monitoring Dataset Guidance Version 12.0 August 2023

england.nhs.uk/wp-content/uploads/2023/08/PRN00654-national-cancer-waiting-times-monitoring-dataset-guidance-v12.pdf

27 In its Cancer Alliance Planning Pack guide, NHS England suggests that for 2023/24 local systems could allocate 6% of place-based funding for the NSS pathway and 3% in 2024/25.

28 In the research we commissioned this year conducted by Synergy, we asked healthcare professionals what additional information they would like to receive about referring patients via the NSS pathway.

29 NHS England, 40 community diagnostic centres launching across England, 1 October 2021 [accessed 29 June 2023]

gov.uk/government/news/40-community-diagnostic-centres-launching-across-england

30 NHS England (2020) Diagnostics: Recovery and Renewal – Report of the Independent Review of Diagnostics Services for England, available at:

england.nhs.uk/publication/diagnostics-recovery-and-renewal-report-of-the-independent-review-of-diagnostic-services-for-nhs-england/

31 Royal College of Radiologists, Clinical Radiology Workforce Census 2022

https://www.rcr.ac.uk/sites/default/files/documents/rcr_clinical_radiology_workforce_census_2023.pdf

32 NHS England, NHS Cancer Programme: Faster Diagnosis Framework, 28 November 2022, pg.29 and 30

https://www.england.nhs.uk/wp-content/uploads/2019/07/B1332-NHS-Cancer-Programme-Faster-Diagnosis-Framework-v5.pdf

Acknowledgements

We'd like to thank everyone who contributed to the development of this briefing, including cancer alliances, policy makers and healthcare professionals. Your experiences and insights helped to shape the recommendations we have made, and we thank you for taking the time to share them with us.

In particular, we'd like to thank:

- Tom Anderton - Lancashire & South Cumbria Cancer Alliance
- Kaye Davies - Lancashire & South Cumbria Cancer Alliance

DON'T FORGET

We're here if you ever need to talk.

Our breast care nurses and highly trained staff on our free Helpline are here for you, whatever you're going through.

We're ready to listen on 0808 800 6000 or you can find information and support online at breastcancernow.org

BREAST
CANCER
NOW The research & support charity

We're here