

**Secondary.  
Not second rate**

**breast  
cancer  
care**

**Setting the standard for care:  
Current best practice in  
secondary breast cancer  
March 2018**



No one understands the support, care, and information needs better than patients, and we would like to thank everyone who volunteered their time to this project.

This report is supported by a charitable donation from Pfizer Limited.

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<b>Contents page</b>	
<b>Executive summary</b>	<b>4</b>
Key findings	
<b>Recommendations</b>	<b>6</b>
Diagnosis	
Data collection	
Support and nursing care	
<b>Introduction</b>	<b>8</b>
Methods	
<b>Diagnosis</b>	<b>10</b>
Introduction	
Diagnosis best practice	
Patient information at the end of primary treatment and open access follow-up approaches	
Signs and symptoms visual resources	
Signposting to other services and links with community services	
Information at the point of diagnosis for secondary breast cancer	
Multidisciplinary diagnosis centres (MDCs)	
Supporting GPs	
Trends and key takeaways	
Recommendations to enable dissemination of best practice	
<b>Data collection</b>	<b>19</b>
Introduction	
Data collection best practice	
Improving data infrastructure and collection methods	
Improved services and patient outcomes	
Learnings	
Multidisciplinary team meetings dedicated to secondary breast cancer	
Trends and key takeaways	
Recommendations to enable dissemination of best practice	
<b>Support and nursing care</b>	<b>25</b>
Introduction	
Support and nursing best practice	
Service redesign to handle increasing demand in numbers of secondary breast cancer cases	
Enhanced information and support offer	
Coordinated care	
Information made accessible	
Improving outreach services	
Clinical Nurse Specialist (CNS) training in secondary breast cancer	
Further support for nurses	
Patient insights into support and nursing best practice	
Tools and resources	
Trends and key takeaways	
Recommendations for dissemination of best practice	
<b>Conclusion</b>	<b>34</b>
<b>References</b>	<b>35</b>

## Executive summary

Breast Cancer Care's **Secondary. Not Second Rate** campaign gathered evidence and highlighted a number of inadequacies in the care and support of people living with secondary breast cancer. These were in four key areas of diagnosis, data collection, support and impact, and nursing care. Based on our findings, we put forward recommendations to enable improvements in these areas.

This report aims to put forward potential solutions to the challenges identified in our campaign by presenting work around the UK and internationally in secondary breast cancer that demonstrates better care and support.

A number of stakeholders across the cancer landscape, including both healthcare professionals and people living with secondary breast cancer, were involved in the collation of best practice for this report. This has allowed us to develop a richer understanding of the current best practice benchmarks.

Areas of best practice we searched for included:

### Diagnosis

- awareness of the possible signs and symptoms of secondary breast cancer
- improving routes to diagnosis
- having support at the point of diagnosis for secondary breast cancer

### Data collection

- ability to collect rich information about the patient population in order to improve services
- infrastructure such as data management and clinical systems that enable a wider breadth of information to be recorded
- processes in place to support data collection within the hospital setting

### Support and nursing care

- enhanced information and support offer
- coordinated care across whole care pathway
- Clinical Nurse Specialist training in secondary breast cancer

## Key findings

The following best practice trends were all found to have a positive impact on patient experience and care and should be considered by NHS organisations looking to improve services in secondary breast cancer.

### Diagnosis

- Open access follow-up services that allow patients easily to return to their breast care team with any concerns.
- Information booklets at the end of primary treatment that have clear secondary signs and symptoms information, referrals to courses like Moving Forward, and contact information for follow-up concerns.
- Resources and infographics that demonstrate secondary signs and symptoms.
- Information booklet at point of diagnosis for secondary breast cancer that includes a named key worker and their contact information, a breadth of information covering the full impact of the diagnosis, and signposting to appropriate support and emotional services.
- Helplines such as Breast Cancer Care's free Helpline, which provides information and support over the phone.
- Accessible information in the form of different languages and information appropriate for people with literacy or learning difficulties.
- Development of Multidisciplinary Diagnostic Centres to improve the route to diagnosis for patients.

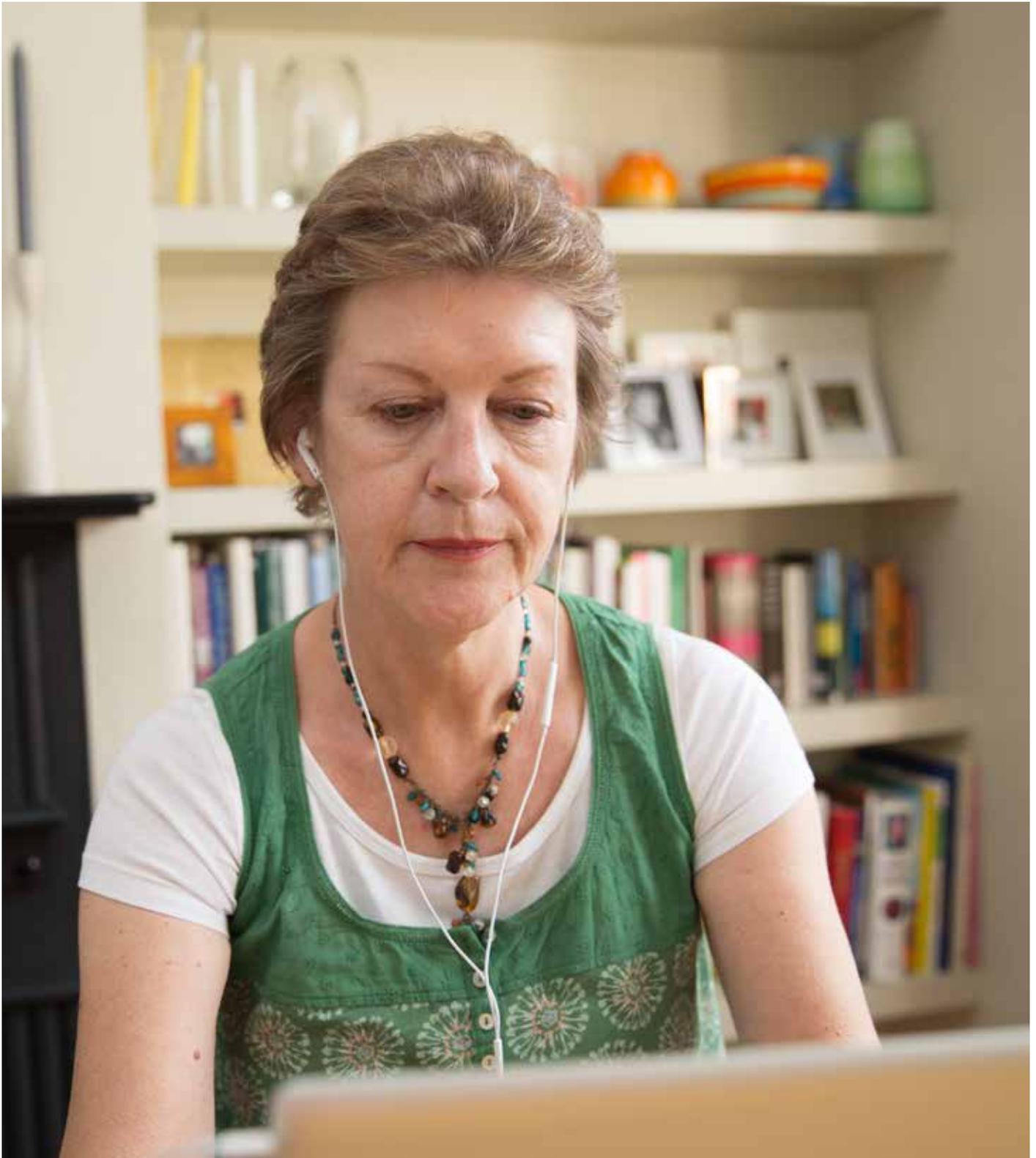
### Data collection

- The link between clinical and administration is pivotal in recording data. More thorough, accurate data is able to be collected through close working relationships.
- A support worker role to assist with data input, especially during initial set-up phase. This relieves administrative burden from clinical roles, who are often left with data collection responsibilities.
- Dedicated secondary breast cancer multidisciplinary team (MDT) meetings aid accurate data collection.
- Data infrastructure that supports efficient input and export of data is crucial to successfully collecting data.

## Support and nursing care

Breast care teams who:

- take a pro-active approach to providing patients with important information, support and care
- maximise resources through nurse-led care and stratification of patient follow-up based on level of need
- work collaboratively with supportive care teams to ensure a wider, holistic level of support for the patient
- have innovative outreach models such as satellite sites, hub and spoke models and mobile units as well as links to community services
- undertake ongoing education and training



# Recommendations

## Diagnosis

- Written information is critical to patients' understanding of their diagnosis and where to seek help. All NHS organisations should provide written information at both:
  - the end of primary breast cancer treatment with information on signs and symptoms of secondary breast cancer
  - the point of diagnosis for secondary breast cancer with information on diagnosis and signposting to supportive services both within and external to the hospital.
- The NHS should ensure every breast cancer patient has access to a health and wellbeing event that meets the criteria outlined in the respective national cancer strategies, such as Breast Cancer Care's Moving Forward course, to ensure they are better informed to spot the signs and symptoms of a recurrence.
- NHS organisations should consider open access approaches to follow-up, which allow immediate self-referral back to the breast care team should a patient have concerning signs and symptoms.
- GPs need to be supported to feel confident in referring back to the specialist team when patients present with concerning signs and symptoms.
- The results of the Accelerate, Coordinate, Evaluate (ACE) programme's multidisciplinary centre work (see page 16) should be used to inform future planning of cancer diagnostic pathways and support for GPs.

## Data collection

- The NHS should put targets and/or incentives in place for trusts and health boards to ensure data is being collected about people diagnosed with secondary breast cancer. This would mirror the situation for primary breast cancer, where several targets are already in place to ensure data is recorded.
- Senior management must support and provide impetus for accurate data collection within their trust or health board.
- Public Health England must ensure that trusts are aware of the user guidance<sup>1</sup> for the updated (v8.0) Cancer Outcomes and Services Dataset (COSD), so that trusts know what is expected of them<sup>2</sup>.
- The NHS needs to support the adoption of improved IT systems to allow trusts and health boards to record data more effectively and thoroughly.
- In order for healthcare professionals to improve patient care and understand complex caseloads, data should be collected on:
  - date of diagnosis
  - sites of metastases
  - when progressions occur
  - lines of treatment received
  - responses to treatment
  - referrals made to other healthcare professionals and teams
  - discussion outcomes at MDT meetings
- MDT meetings should discuss and record all new secondary breast cancer diagnoses to aid accuracy of annual diagnosis figures.

## Support and nursing care

- Specialist nurses working in secondary breast cancer must be supported to receive the appropriate skills and knowledge, including:
  - secondary breast cancer biology and pathophysiology
  - treatment options for secondary breast cancer
  - assessment and management of common symptoms, including bone pain and fatigue
  - supportive care communication skills
  - knowledge of local and national support services available
- Health Education England urgently needs to make continued professional development (CPD) funding available to NHS trusts to ensure the current workforce is always equipped with the right skills and knowledge to support their patients.
- Information should be accessible to everyone. This includes being available in multiple languages and suitable for people with limited literacy or learning difficulties as well as vision and hearing impairments.



## Introduction

For many years Breast Cancer Care has campaigned for improvements in the treatment and care of people living with and affected by breast cancer.

However, patients living with secondary breast cancer regularly tell us they feel isolated and forgotten. This, combined with inadequate evidence on patient experience and need, led us to believe that the current care and experience of people living with secondary breast cancer is second rate.

Our recent **Secondary. Not Second Rate** campaign included research that helped to build a UK-wide picture of current need in the areas of diagnosis, data collection, support and impact, and nursing care. We conducted in-depth research in these four key areas that were published in four respective reports:

1. Part one: Diagnosis
2. Part two: Who's counting? (data collection)
3. Part three: Support and impact
4. Part four: Nursing care

Our research found:

- many people living with secondary breast cancer experience delays in diagnosis, leading to a delay in receiving vital treatment and care
- in England, fewer than a third of hospital trusts are collecting data in full on their patients with secondary breast cancer, despite it being mandatory since 2013
- people living with secondary breast cancer are often not getting the care and support they need
- the current availability of specialist nursing for people with secondary breast cancer is well below the level of need. There is also a marked disparity between the level of specialist nursing support for people with primary breast cancer compared to people who have a secondary diagnosis, despite the latter often having very complex emotional and supportive care needs

These findings led us to make a number of calls to action to address these issues for people living with secondary breast cancer. Our recommendations can be summarised by the following calls for action.

1. **EVERY** breast cancer patient and all relevant healthcare professionals to be aware of the possible signs and symptoms of secondary breast cancer
2. **EVERY** patient to be fully supported from diagnosis through treatment and as they approach the end of life
3. **EVERY** person diagnosed with secondary breast cancer to have access to a specialist nurse with the right skills, knowledge and experience
4. **EVERY** hospital trust and health board to collect data on their patients with secondary breast cancer and for this data to be published nationally

Full findings and recommendations can be found in our report *The case for change*<sup>3</sup>.

## Taking the campaign forward: best practice

This report aims to put forward potential solutions to the challenges identified in our campaign by presenting best practice work in the UK and internationally in secondary breast cancer that can be adopted by other healthcare professionals to support service improvements.

## Methods

A wide range of stakeholders in the UK cancer landscape contributed to the identification of best practice for this report. Strong relationships established with oncologists, specialist nurses, allied healthcare professionals, managers, other national charities, Cancer Alliances, NHS health boards and trusts, Cancer Vanguard, and Public Health England allowed a range of perspectives.

This group came together for the Secondary Breast Cancer Advisory Committee to discuss and debate best practice in the areas of diagnosis, data collection, support and impact, and nursing care. The nature of the round-table discussions allowed for members of the group to bring their own knowledge and experience to the committee. We also searched for teams, services and initiatives that have received awards or accolades for innovation in secondary breast cancer, or have had their service improvement work published in peer-reviewed academic journals.

Most importantly, best practice around the support and care for people living with secondary

breast cancer was driven by people living with this incurable disease. Patients attending Breast Cancer Care's Living with Secondary Breast Cancer service were able to have focus group-style best practice discussions and helped to identify key specialist nursing qualities crucial to

this role. A number of people living with secondary breast cancer also attended the Advisory Committee and were vital to assessing current benchmarks for best practice.



# Diagnosis

## Introduction

Our research shows that people can experience delays in diagnosis of secondary breast cancer which can prevent timely access to vital treatment and care.

It is vital that both patients and healthcare professionals are supported to understand the signs and symptoms of secondary breast cancer. Our research indicated that 58% of patients did not know the signs and symptoms of secondary breast cancer, and a fifth (21%) of respondents who had a previous primary breast cancer diagnosis were initially treated for another condition by their GP, leading to a delay in diagnosis.

While these delays may not lead to a different clinical outcome for the patient, it is important that patients with secondary breast cancer are diagnosed quickly so that they receive the treatment and care they need to live well, for as long as possible.

We therefore collated best practice in the area of diagnosis for secondary breast cancer that addresses these challenges. Areas of best practice include:

- awareness of the possible signs and symptoms of secondary breast cancer
- improving routes to diagnosis
- having support at the point of diagnosis for secondary breast cancer

## Diagnosis best practice

### Patient information at the end of primary treatment and open access follow-up approaches

It is vital that patients receive information on the signs and symptoms of secondary breast cancer and who to contact if they experience any of these after finishing treatment for primary breast cancer.

We found that open access approaches that allowed easy follow up with any concerns, information booklets, and visual signs and symptoms resources support and empower patients to know signs of recurrence.

The Royal Marsden NHS Foundation Trust (Royal Marsden) established an open access patient-led follow-up service in 2011, which provides patients with extensive information and support at the end of their primary breast cancer treatment. This involves an end-of-treatment consultation with a specialist nurse to ensure patients are aware of signs and symptoms of secondary breast cancer. This follow-up service runs for five years and allows patients to easily return to the team if they need to.



## Royal Marsden secondary signs and symptoms information

Royal Marsden NHS Foundation Trust secondary breast cancer signs and symptoms information includes:

- a lump or swelling in your breast, in the skin after a mastectomy, above your collarbone or in the neck area, or under your arm
- any skin changes including dimpling, puckering, redness or raised spots on your breast or mastectomy scar
- nipple discharge
- lymphoedema
- any new, ongoing pain in any part of the body, especially in back or hips, that does not improve with pain killers and which is often worse at night
- pins and needles and/or loss of sensation or weakness in your arms or legs
- unexplained weight loss and loss of appetite
- a constant feeling of nausea
- discomfort or swelling under your ribs or across your upper abdomen
- a dry cough or a feeling of breathlessness
- severe headaches – usually worse in the morning

Although the signs and symptoms of secondary breast cancer are discussed at the end of primary breast cancer treatment consultation at the Royal Marsden, some patients are not emotionally ready to hear about their risk of recurrence. The nurse then directs the patient to the relevant information in the follow-up booklet to read when they feel ready.

## Royal Marsden open access patient information booklet

Each patient receives the booklet during the end-of-treatment consultation, which includes:

- individualised treatment summary
- signs and symptoms to report to the team or the patient's GP
- being breast and body aware
- information on how to contact the team if any new symptoms, worries or concerns arise with a full list of useful contact numbers



We also found a number of our best practice case studies produce individualised treatment summaries for patients at the end of their primary treatment. These contain a summary of the person's clinical treatment and care plan as well as detailed signs and symptoms of secondary disease, risk of relapse (personalised), and important contact numbers for advice.

Other hospitals, including Ipswich Hospital NHS Trust (Ipswich), make use of the wide range of easily accessible information resources provided by Breast Cancer Care. This includes information designed specifically for different stages of breast cancer care and treatment, such as at the end of primary breast cancer treatment, where comprehensive information and advice about recurrences, including secondary breast cancer, are available.

### Signs and symptoms print and visual resources

A National Cancer Institute (NCI) study in the US investigated the effectiveness of hearing and accurate recall. It found that patients recall just 14% of their conversations with healthcare professionals in a non-life-threatening situation<sup>4</sup>

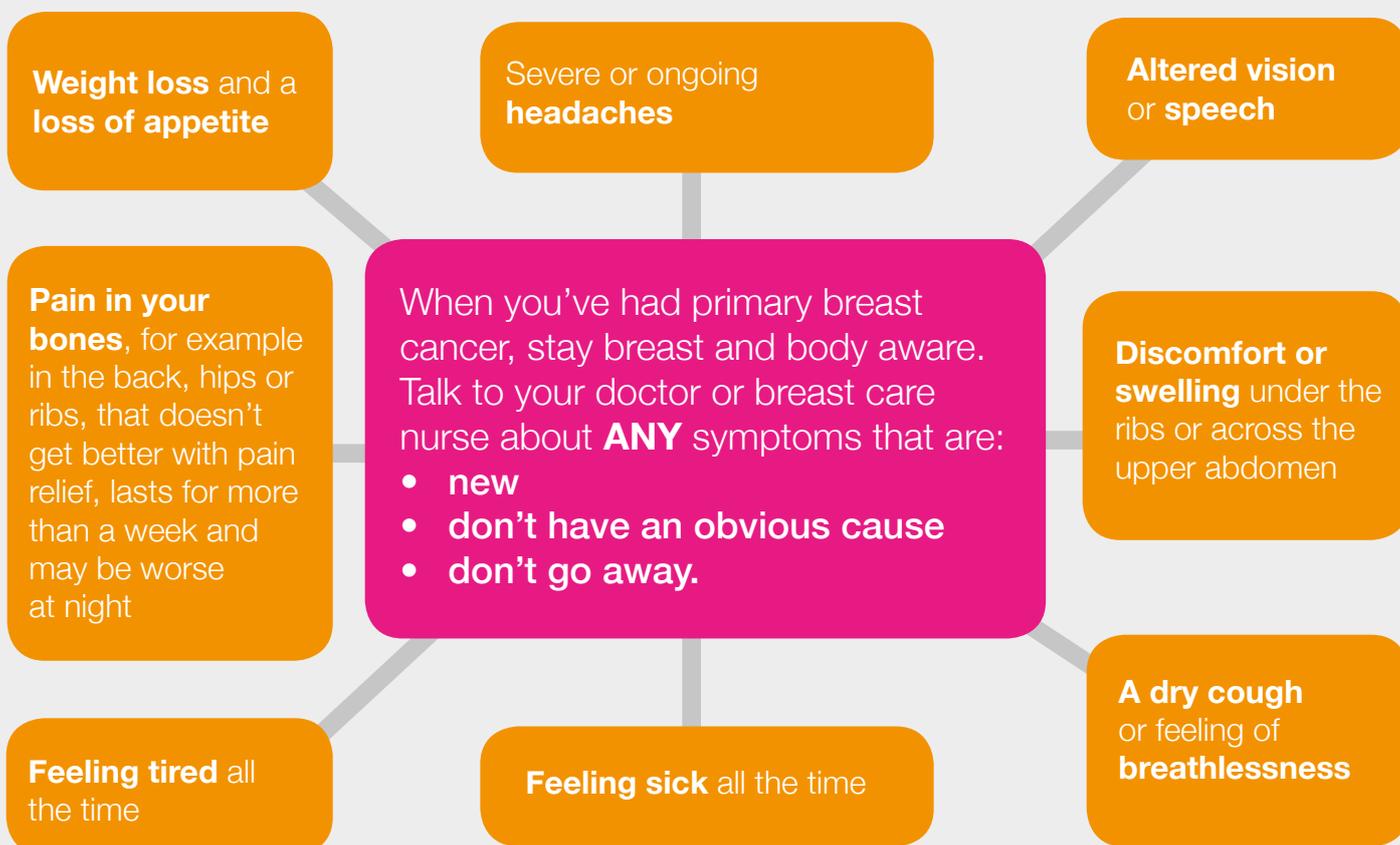
let alone when diagnosed with incurable cancer. However, in studies using visual cues such as infographics and pictographs, this recall level reached a mean of 80% for populations with average literacy<sup>5</sup>.

The following resources are free and may be given to patients as guides to recognise the signs and symptoms of secondary breast cancer.

### Breast Cancer Care's publications

All publications are free to download and order by post.

- After breast cancer treatment: what now?
- Moving Forward: for people living with and beyond breast cancer. This includes a chapter on continuing to be breast aware, types of recurrence, who to contact if you have a concern and coping with fear of recurrence.
- Secondary breast cancer visual guide to symptoms (shown below)



## Secondary Breast Cancer

Also known as metastatic or advanced breast cancer

If you have survived primary breast cancer be aware of these **RED flags\*** for secondary breast cancer. There are 5 main areas that secondary breast cancer can appear.



**BRAIN**  
Frequent headaches, vomiting (first thing in the am), dizzy, visual disturbance, fits, impaired intellectual function, mood swings, balance, fatigue. Family members and friends may say you are not your normal self.

**BONE**  
Pain in bones — commonly thigh, arm, ribs and back. Can be dull ache or sharp shooting pain. Bone pain with no obvious cause or haven't fallen over, report any new, unusual and increasing pain.

**LYMPH NODES**  
Swelling or lumps and pressure in chest/armpit/neck areas, dry cough.

**LUNG**  
Sharp pain on breathing in chest and back area, non productive cough, fatigue, blood clots can also cause shortness of breath.

**LIVER**  
Bloating, affected appetite, weight loss, fatigue, weak, pain near ribs on right hand side.



Please visit: [abcdiagnosis.co.uk](http://abcdiagnosis.co.uk)  
Twitter: @abcdiagnosis  
Facebook: [facebook.com/abcdiagnosis](https://facebook.com/abcdiagnosis)

**\*RED FLAG SYMPTOMS NEED TO BE REPORTED TO YOUR ONCOLOGIST**

### ABC Diagnosis' guide to red flag symptoms

Created by Jo Taylor, who has been living with secondary breast cancer since 2014, this resource aims to signpost people to information and resources. The infographic is reproduced above and is also available to download at [www.abcdiagnosis.co.uk/about-abcd/secondary-breast-cancer/](http://www.abcdiagnosis.co.uk/about-abcd/secondary-breast-cancer/)

### Signposting to other services and links with community services

Signposting to other services and resources is essential both as ongoing support and to raise awareness of secondary breast cancer signs and symptoms at the end of primary breast cancer treatment. There are a number of services available outside the immediate breast care team that patients should be referred to for information and support.

### Breast Cancer Care's Moving Forward courses

A number of NHS organisations refer patients to one of Breast Cancer Care's 200+ Moving Forward courses, which are run annually in partnership with NHS trusts and health boards. The courses are designed specifically for people finishing their primary breast cancer treatment and aim to empower and inform, improve wellbeing, connect and signpost as well as ensure patients are

confident in spotting possible signs and symptoms of recurrence.

Breast Cancer Care commissioned two independent pieces of research in 2017<sup>6</sup>. This research found that:

- side effects, long-term effects and late effects vary by cancer tumour site. As such, patients with breast cancer should have access to a breast cancer specific course following treatment
- Moving Forward significantly improves quality of life of participants
- the concerns of participants are reduced and emotional wellbeing is improved following attendance at a Moving Forward course
- Moving Forward increases activation levels of participants, empowering and enabling people to be self-managers of their own health and wellbeing
- Moving Forward offers real value to women who have experienced breast cancer, and to society

## NHS Greater Glasgow and Clyde Fear of Recurrence service

The Fear of Recurrence service was established to help people in Glasgow at the end of primary treatment who are worrying about their breast cancer recurring by teaching practical and emotional coping techniques to manage 'what if' worries. Information is also provided on how to cope with presence of new physical symptoms following cancer treatment, signs and symptoms of recurrence and lifestyle strategies for reducing risk of recurrent cancer. The service runs as a six week course with weekly two hour sessions and is funded by the charities Breast Cancer 2000 and the Beatson Cancer Charity.

### Information at the point of diagnosis for secondary breast cancer

Our research found that only half (51%) of patients fully understood their diagnosis of secondary breast cancer, with almost a third (30%) saying they were not given any additional information. It is essential that patients have a clear understanding of their diagnosis in order to make informed, confident treatment decisions and know where to access support.

### Patient information booklets

Ipswich Hospital NHS Trust provides a patient information document of important information resources and contacts (see Table 1). A patient information document is an easy way to ensure all patients receive a comprehensive guide to understanding their diagnosis, who they can contact and what other services are available to them. This type of active information sharing helps patients to feel confident, informed and supported to seek resources available to them.

The University Hospitals Bristol NHS Foundation Trust also provides a secondary breast cancer 'sources of information and support' leaflet. This provides financial support advice, a list of resources, information on Macmillan Grants, exercise and healthy eating information, and information on the benefits of palliative care and hospices in providing symptom control and support.

In addition to information files, having a small information centre space in a hospital can also be a really useful way for hospitals to keep a wide range of information and signposting resources, including materials such as Breast Cancer Care and other charities booklets.

**Table 1: Ipswich Hospital NHS Trust patient information**

Important contacts	Contact numbers including their named key worker (usually the Breast Nurse Specialist).
Clinical information	Information about secondary breast cancer, including the common physical signs and symptoms they may experience.
Emotional support	Common feelings experienced at the point of diagnosis are covered, as well as information about accessing cancer counsellors who have experience caring for people with secondary breast cancer.
Signposting information	Contacts for local and national support services. In addition, a list of complementary therapies, including six free sessions for massage and/or aromatherapy.

### Palliative care

A key worker should highlight the importance of discussing the benefits of palliative care at the point of diagnosis, explaining how the palliative care team specialises in pain and symptom management, psychological support and support for family and friends. A palliative care consultant based at a local hospice regularly visits Ipswich Hospital to run pain and symptom management clinics, ensuring all patients receive timely support. Patients then know the benefits and who to contact if they need to seek further support.



### The Metastatic Breast Cancer (MBC) Alliance's dandelion

The MBC Alliance in the US has produced a Communications Toolkit<sup>7</sup> to support healthcare professionals to communicate a secondary breast cancer diagnosis. The core aims include communicating in a time-effective manner as well as being accessible to patients of various literacy levels.

The toolkit is currently being piloted in a number of international settings with plans to publish findings in mid-2018. They then hope to distribute the toolkit more widely.

Their dandelion visual metaphor (above) was created as a familiar and approachable way to help describe the stages of cancer progression to patients, where patients are told to think of a cancer cell as a dandelion turned to seed.

### Multidisciplinary diagnosis centres (MDCs)

The ACE (Accelerate, Coordinate, Evaluate) programme in England<sup>8</sup> is an early diagnosis programme that supports the NHS to improve early diagnosis of cancer.

It was developed in response to the Independent Cancer Taskforce's Cancer Strategy for England<sup>9</sup>, which recommends a national ambition to achieve earlier diagnosis and required a shift towards faster investigative testing for patients presenting with symptoms. An ambition was set for 2020 to

have 95% of patients referred for testing by a GP to be definitively diagnosed with cancer, or to have cancer excluded, with this result communicated to the patient, within four weeks.

The MDC concept was recommended for patients with non-specific but concerning symptoms, with these patients often falling through gaps, resulting in delays to diagnosis.

This is often the case with secondary breast cancer, where our research highlighted that many people experience delays in diagnosis for secondary breast cancer, which can prevent timely access to vital treatment and care. The MDC is a single testing location where a patient may undergo multiple tests relevant to their presenting symptoms.

The MDC concept comes from Denmark's cancer pathway for patients with serious non-specific symptoms, with the Danish health system similar to the UK. Core aims of the ACE programme include a decrease in cancer diagnoses via emergency presentation – which often happens with secondary cancers because of vague symptoms – and improvements to overall patient experience.

# The Danish Model

The Danish cancer pathway for patients with serious non-specific symptoms<sup>8</sup> is an initiative introduced in Denmark to improve the long diagnostic interval and poor survival of Danish cancer patients.

This model recognises the majority of patients have a symptomatic presentation of disease which is diverse and may change according to stage of cancer development, and that delays to treatment are often due to delay in diagnosis. As such, patients are referred to a centre to undergo multiple diagnostic tests in the one location.

The model sees the role of GPs as ‘gatekeepers’ to ensure appropriate referral of patients into more specialised health services such as re-referral to the breast clinic team.

The first Danish Cancer Patient Pathways (CPPs) for suspected cancer were implemented in 2008 for ‘alarm symptoms’, with additional CPPs implemented in 2011 for patients with serious non-specific symptoms and signs of cancer.

Patients referred to the diagnostic centre must undergo further investigations based on their presented symptoms and clinical findings (blood tests, endoscopies and biopsies, diagnostic imaging). Based on these results, patients are referred to a specific hospital department or back to their GP. A study of the impact of this service<sup>10</sup> found that 16.2% of all patients presenting with serious, non-specific symptoms to their GP had cancer.

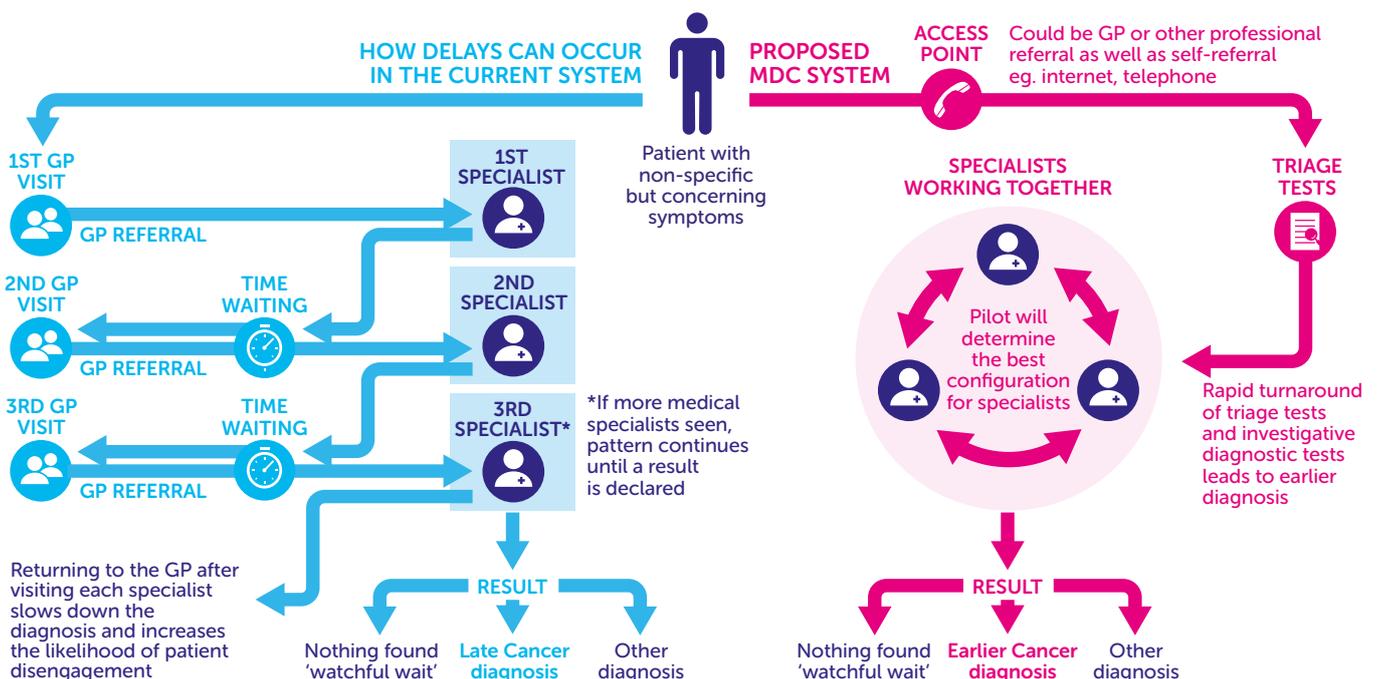
## Early Results

MDCs are currently being piloted across the NHS in England to test the feasibility of this referral route. Based on the data received so far (at December 2017), 1,022 patients have gone through the MDCs. Main symptoms are weight loss, nausea and loss of appetite and abdominal pain. Seventy-three cancer cases have been confirmed so far with upper gastro intestinal, lung

and haematology being the three most frequent broad categories. Five breast cancers were diagnosed including four with previous history of breast cancer – the recorded symptoms were weight loss, anaemia and pain.

An interim report will be published in April 2018 at: [cruk.org/ACE](http://cruk.org/ACE)

## HOW MDCs COULD IMPROVE EARLY CANCER DIAGNOSIS



## Supporting GPs

### Treatment summaries

As well as being a resource for patient information at the end of primary treatment, individualised treatment summaries must contain a summary of clinical treatments, risk of recurrence and contact numbers for referral back to a specialist team in order to support GPs to refer patients with symptoms requiring assessment back to their specialist team.

### Cancer Decision Support Tool

The Cancer Decision Support Tool<sup>11</sup> is designed to support GPs in clinical decision-making by displaying a risk prompt for a patient on their clinical system based on information from their patient record including symptoms, medical history and demographic data.

The tool is currently embedded within GP clinical systems EMIS and INPS Vision, with Macmillan Cancer Support working with TPP SystemOne to integrate the tool into their system to be available free of charge.

There is currently a symptom template for primary breast cancer within the tool and we recommend that secondary signs and symptoms are added to this.



## Trends and key takeaways

Best practice reflects breast care teams using a range of methods to ensure patients are aware of secondary breast cancer signs and symptoms at the end of their primary treatment and feel adequately supported at the point of diagnosis of secondary breast cancer.

Methods for doing this can be summarised as follows:

- Open access follow-up services that allow patients to easily return to their breast care team with any concerns.
- Information booklets at the end of primary treatment that have clear signs and symptoms information, referrals to courses like Moving Forward and contact information for follow-up concerns.
- Resources and infographics that demonstrate signs and symptoms.
- Information booklets at point of diagnosis for secondary breast cancer with a named key worker and their contact information, a range of accessible information covering the full impact of the diagnosis and signposting to appropriate support and emotional services.
- Helplines such as Breast Cancer Care's free Helpline, which provides information and support over the phone.
- Accessible information in the form of different languages and information appropriate for people with literacy challenges and learning difficulties.
- Initiatives such as the MDCs and the Cancer Decision Support Tool are also being developed to improve the route to diagnosis for patients.

## Recommendations to enable dissemination of best practice

- Written information is critical to patients' understanding of their diagnosis and where to seek help. All NHS organisations should provide written information at both:
  - the end of primary breast cancer treatment with information on signs and symptoms of secondary breast cancer;
  - the point of diagnosis for secondary breast cancer with information on diagnosis and signposting to supportive services both within and external to the hospital.
- The NHS should ensure every breast cancer patient has access to a health and wellbeing event that meets the criteria outlined in the respective national cancer strategies, such as Breast Cancer Care's Moving Forward course, to ensure they are better informed to spot the signs and symptoms of a recurrence.
- NHS organisations should consider open access approaches to follow-up, which allow immediate self-referral back to the breast care team if a patient has concerning signs and symptoms.
- GPs need to be supported to feel confident in referring back to the specialist team on patients' presentation of concerning signs and symptoms.
- The results of the ACE programme's MDC work should be used to inform future planning of cancer diagnostic pathways and support for GPs.



# Data collection

## Introduction

Data collection on the number of people diagnosed with secondary breast cancer has been compulsory for NHS trusts in England since January 2013. However, our research showed that fewer than a third of hospital trusts in England are collecting data in full on their patients with secondary breast cancer<sup>12</sup>.

The collection of data should take place within the trust, ideally through an MDT meeting, and be submitted to the Cancer Outcomes and Services Dataset (COSD). Collecting data on diagnosis and treatment of secondary breast cancer allows trusts to understand the incidence and prevalence of secondary breast cancer in their local area. This in turn enables services to be planned and developed to meet the local population's needs. Furthermore, it helps to build a national picture of secondary breast cancer diagnoses.

Data collection is a challenge across the NHS. In order for effective data collection to take place, there needs to be an awareness of what data needs to be collected, available resources to support this collection and buy-in from leadership that ensures responsibility for collection is assigned.

There are a number of best practice examples that demonstrate an improvement in the collection of data for secondary breast cancer by enabling easier data management and increased capacity to record information routinely.

We collated best practice around data collection for secondary breast cancer that demonstrates this as well as utilising data to plan and deliver better care and support for patients.

Areas of best practice include:

- ability to collect rich information about the patient population in order to improve services

- infrastructure such as data management and clinical systems that enable a wider breadth of information to be recorded
- processes in place to support data collection within the hospital setting

It is important to note that staff leading data collection improvements had a number of key learnings from this process that are provided in this report to help ease the transition into better data management for other NHS teams.

## Data collection best practice

### Improving data infrastructure and collection methods

#### Collection methods

In order to collect data efficiently, it is essential that proper collection methods are in place. We found that NHS organisations with systematic processes and software in place to assist data collection were able to collect data routinely and efficiently.

Maidstone and Tunbridge Wells NHS Trust has a large oncology centre at one of its sites where there are currently 190 people living with secondary breast cancer and receiving treatment. To deal with a large, complex caseload, the nurse clinician created an in-house system called KOMS (Kent Oncology Management System) in order to record a significant amount of information.

When someone is first diagnosed with secondary breast cancer their diagnostic and treatment information is registered on KOMS. The trust uses InfoFlex as its recording tool to feed into its COSD submissions, which is led by the MDT coordinator, who extracts the information from the KOMS. However, these two systems do not interface, meaning that two databases for secondary breast cancer are being maintained, albeit for different purposes.

## Kent Oncology Management System records

For each patient at Maidstone & Tunbridge Wells, records are kept on KOMS for:

- date of diagnosis
- sites of metastases
- when progressions occur
- lines of treatment received
- responses to treatment
- referrals made to other healthcare professionals and teams
- discussion outcomes at MDT meetings

Frimley Health NHS Foundation Trust is able to collect data routinely on their secondary breast cancer patients by dedicating time within their team to collate and analyse cancer data from a variety of sources. Patients who are diagnosed with secondary breast cancer as their first diagnosis are captured via histology<sup>13</sup> or radiology<sup>14</sup> reports, which are then recorded weekly. For people who have previously had a diagnosis and treatment for primary breast cancer, the relevant data are captured when the patient is referred to either the clinical nurse specialist or Breast MDT. This referral system is helped by good working relationships across the

different MDTs and departments. The data are then submitted to the national datasets, including COSD, every month. Moreover, the trust has infrastructure in place to ensure that data can be collected. The Somerset Cancer Register (SCR) is used to record patient data.

### Data and IT infrastructure

The SCR is a software application developed by the NHS and designed to collect relevant data throughout the patient's cancer journey. This data collection, in addition to supporting patient care, supports national clinical audits including COSD.

The SCR supports the collection of secondary breast cancer data through its ability to record local, regional and distant, or metastatic recurrences. There are several ways that the data can be found using SCR, including a new code that is specific to any patient with metastatic breast cancer and a 'date of diagnosis' indicator.

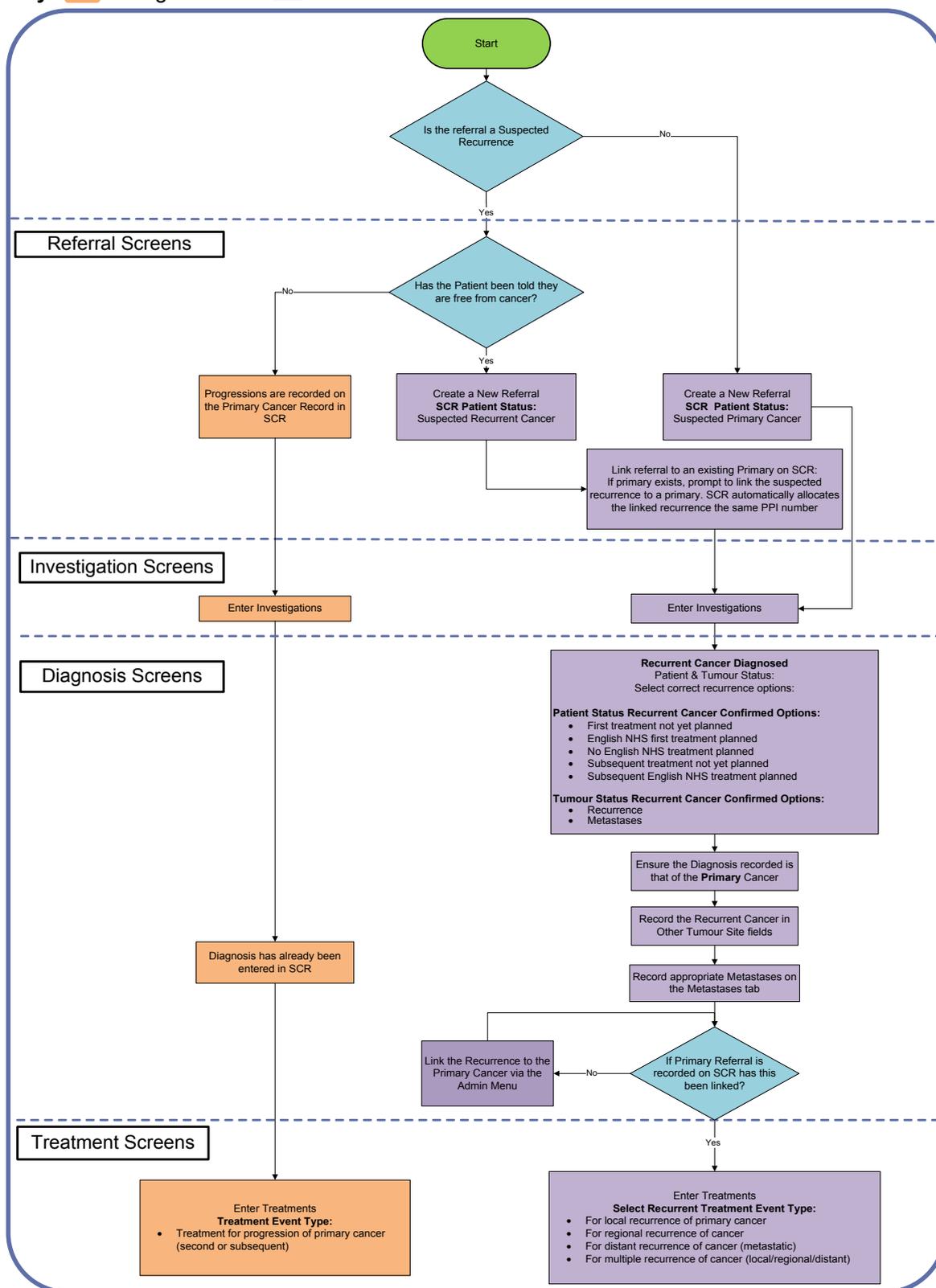
When a recurrence occurs, a new referral is made, which is linked to the existing primary diagnosis (unless secondary breast cancer is the first diagnosis) with SCR linking the recurrence to the original Positive Patient Identification (PPI) number. The recurrence is then marked as metastases where specific metastases sites such as liver, bone, brain and so on can be recorded.

Diagnosis	Staging	Metastases	Additional Info
Adrenal Metastases		None	Bone marrow
Bone (excluding bone marrow)		None	Brain Metastases
Liver Metastases		None	
Lung Metastases		Certain	Distant Lymph Node Metastases
Skin Metastases		Uncertain	Unknown Metastases
Other Metastases		None	Other Metastases

In addition, a treatment section of the system allows the lines of treatment for secondary breast cancer to be recorded as well as their respective treatment responses. For example, for each anti-cancer drug regimen, there are items such as cycles versus planned, disease response, treatment outcome and regimen modifications. Clinicians are able to extract from the SCR all patients on the system that are undergoing the same line of treatment to manage their caseload by line of treatment effectively.

The SCR offers training and support to providers with a dedicated learning management system with an eLearning module solely on recording recurrent cancers. There are also in-depth 'How Do I?' guides for both recording recurrence and progression of cancer as well as flow charts available to help recording these scenarios on the system.

**Key:**  Progression  Recurrence



## Improved services and patient outcomes

Secondary breast cancer specialist nurses must manage acute and chronic physical and psychosocial conditions associated with secondary breast cancer as well as act as patient advocates. Effective data collection helps practitioners to understand patient caseload and their complex, unique needs.

### Benefits for the hospital and patient outcomes

There are a number of benefits of robust data collection.

- Ability to demonstrate how many patients are diagnosed each month and the extent of continued support required for those living with secondary breast cancer. This may be pivotal to securing ongoing funding for the secondary breast cancer specialist nursing role.
- The healthcare team is able to identify local patient population groups, allowing for the development of a local clinical trial portfolio.
- Ability to extrapolate insightful real world data about their patient population and their first-line treatments and responses to treatment. This is particularly useful as a new generation of drugs for HR+ and HER2- are introduced.
- At Maidstone and Tunbridge Wells NHS Trust, the data is starting to show that secondary breast cancer patients are living longer so is being used to inform service developments that are more sustainable.
- The healthcare team is able to answer key feasibility questionnaires for pharmaceutical clinical trials.

### Learnings

Maidstone and Tunbridge Wells NHS Trust found two main challenges in establishing the in-house data system; the time required for initial set-up, and ensuring data collection becomes standard practice. They have shared their learnings which may be useful for other breast care teams (see Table 2).

The employment of a support worker role was also a crucial step in relieving the administrative burden placed on the secondary breast cancer nurse clinician to input data, so that this role could focus on providing patient care. In addition, ongoing developments in e-prescribing are also expected to provide opportunities for collection of data on secondary breast cancer.

**Table 2: Maidstone and Tunbridge Wells NHS key learnings from establishing in-house data system**

Challenge	Key learning
The main cost to setting up and maintaining a patient database using an in-house system has been the time required by the secondary breast cancer nurse clinician to input patient records, particularly given that she is a lone practitioner in essence	A business case was put forward for a support worker role for metastatic breast and colorectal cancer, which was initially funded by Macmillan Cancer Support. This role has been fundamental in helping to input the data. The secondary breast cancer nurse clinician demonstrated the complexity of the caseload using the KOMS in the business case for this position
Ensuring data collection processes are followed and become standard practice	Support and buy-in from the trust management has been integral to the success of improving data collection processes

The team believe that it is important to recognise that although recording patient numbers diagnosed with secondary breast cancer is important for service planning, understanding the complexity of their condition is also crucial. In addition, they recommend targets and/or incentives for trusts to ensure that adequate data collection is taking place, complementing the bottom-up pressure that comes from many nurses who wish to have such data readily available to help them in their roles. These incentives would mirror the situation for primary breast cancer where several targets are already in place and demonstrates that such targets can have a demonstrable impact.

Finally, Frimley Health NHS Foundation Trust attributes the links between clinical and administrative staff to their ability to collect and record data. In particular, communication between the CNS and the MDT Coordinator is paramount to their success. Patient data can be inputted and monitored using the expertise of both roles.

## Multidisciplinary team meetings dedicated to secondary breast cancer

It is important to have key people responsible for the collation of data on secondary breast cancer patients. The team at Frimley Health NHS Foundation Trust includes an analyst, a team leader, a performance lead, the Cancer Manager, and a dedicated MDT Coordinator. Having different roles embedded into the overall team responsible for the collection of data allows the data inputting process to be spread across several roles, allowing a more balanced approach to committing time and resources. This further alleviates pressure from the clinical nurse specialists and other clinical roles that are often left managing data collection on top of other duties and responsibilities, allowing them to focus their time on direct patient care.

Dedicated MDT meetings for secondary breast cancer allow enough time for the ongoing care and treatment of existing patients to be discussed as well as new diagnoses. This allows for more accurate data collection to take place on the annual number of diagnoses as well as a richer understanding of their existing caseload and looking at patient outcomes more closely.

## Trends and key takeaways

### Enabling data collection

- The link between clinical and administrative staff is pivotal in recording data. More thorough, accurate data is able to be collected through close working relationships.
- A support worker role should be considered to assist with data input, especially during initial set-up phase. This will relieve administrative burden from clinical roles, who are often left with data collection responsibilities.
- Dedicated secondary breast cancer MDT meetings aid accurate data collection.
- Data infrastructure that supports efficient input and export of data is crucial to collecting data successfully.
- Support and buy-in from senior management is integral to the success of improving data collection processes.

### Benefits of data collection

- Recording data allows a trust/health board to identify what the demand is for secondary breast cancer services and plan accordingly.
- Data can be used to provide the business case for further funding of specialist nursing posts within a trust/health board.
- Data can show local patient population groups allowing for the development of local clinical trial portfolios and answering feasibility questions.

## Recommendations to enable dissemination of best practice

- The NHS should put targets and/or incentives in place for trusts and health boards to ensure data is being collected on people diagnosed with secondary breast cancer. This would mirror the situation for primary breast cancer, where several targets are already in place to ensure data is recorded.
- Senior management must support and provide impetus for accurate data collection within their trust or health board.
- Public Health England must ensure that trusts are aware of the user guidance<sup>1</sup> for the updated (v8.0) COSD, so that trusts know what is expected of them<sup>2</sup>.
- The NHS needs to support the adoption of improved IT systems to allow trusts and health boards to record data more effectively and thoroughly.
- In order for healthcare professionals to improve patient care and understand complex caseloads, data should be collected on:
  - date of diagnosis
  - sites of metastases
  - when progressions occur
  - lines of treatment received
  - responses to treatment
  - referrals made to other healthcare professionals and teams
  - discussion outcomes at MDT meetings
- MDTs should discuss and record all new secondary breast cancer diagnoses to aid accuracy of annual diagnosis figures.



# Support and nursing care

## Introduction

A diagnosis of secondary breast cancer is life changing. Our research highlights that although people living with secondary breast cancer are greatly affected by the disease, they are often not receiving the care and support they need. In addition to this, our research indicates that the current availability of specialist nursing to support people with secondary breast cancer is well below the level of need, with a marked disparity between the level of specialist nursing support for people with primary breast cancer compared to people who have a secondary diagnosis.

Some of our key findings:

- three-quarters (76%) of NHS trusts and health boards across the UK said there was not enough specialist nursing care for people with incurable secondary breast cancer
- only 28% of patients were made aware of general palliative care services and only 36% were made aware of counselling or psychotherapy<sup>15</sup>
- fewer than half (44%) were made aware of local support groups or opportunities to speak to other people with secondary breast cancer

We found that the longer a person lives with secondary breast cancer, the less support they receive. As treatments improve, people with secondary breast cancer will live longer and the demand on secondary breast cancer services will continue to grow. It is therefore vital that patients are given the right information, provided with appropriate support and signposted to available services both locally and nationally. The benefits of a specialist nurse are well documented<sup>16</sup>, with the clinical nurse specialist acting as a key source of advice, information and support for patients.

Best practice that ensures excellent care and support for people living with secondary breast cancer demonstrates that a proactive approach to care, maximising resources and working alongside wider supportive care and community care teams enables a more holistic, well-rounded experience of care for the patient.

Best practice included:

- an enhanced information and support offer
- coordinated care across the whole care pathway
- clinical nurse specialist (CNS) training in secondary breast cancer

## Support and nursing care best practice

**‘It was particularly good to have contact with a service dedicated to secondary breast care as the issues faced can be so different to having an initial breast cancer diagnosis.’**

**Secondary breast cancer patient,  
Edinburgh Breast Unit**

A number of NHS trusts and health boards have undergone service redesigns in response to increasing demand for secondary breast cancer services and a lack of current resource capability. University College London Hospital (UCLH), as one of the three Cancer Vanguard sites in England, conducted a data analysis between December 2015 and September 2016 which indicated a 16% cumulative annual growth rate for the secondary breast cancer service. Similarly, The Christie in Manchester, another Cancer Vanguard site, the Edinburgh Breast Unit of Western General Hospital, and The Velindre Cancer Centre, Cardiff, have recognised that support for secondary breast cancer patients is often less systematic than that provided to patients presenting with primary breast cancer. All four hospitals (see Table 3) completed service redesign projects that have helped to improve the care and support for their patients significantly.

Site	Trust	Type	Location
UCLH	UCLH NHS Foundation Trust	Major hospital and cancer vanguard site	London
The Christie	Christie NHS Foundation Trust	Specialist cancer centre and cancer vanguard site	Manchester
Velindre	Velindre NHS Trust	Specialist cancer centre	Cardiff
Western General Hospital	NHS Lothian	Major hospital	Edinburgh

Common issues at the point of baseline included:

- time to discuss secondary patients at MDT meetings
- level of nursing resource available for secondary patients
- level of consultant resource available at clinics
- appointment waiting times
- increasing caseload with newly diagnosed patients per annum on top of their existing complex caseload

Service design should reflect patient need. Top reasons for contact with the CNS team have been listed in a patient satisfaction survey created by the Edinburgh Breast Unit of Western General Hospital, and include:

- information
- symptom control
- practical issues
- specialist referral
- emotional support

### Service redesign to manage increasing demand in numbers of secondary breast cancer cases

#### Secondary nurse-led clinic and stratified follow-up pathways at The Christie

The Christie is the largest single site cancer centre in Europe, treating more than 44,000 patients a year with 2,500 new breast cancer patients each year. The secondary breast cancer nursing team at The Christie provides a service for approximately 300 newly diagnosed secondary breast cancer patients per annum on top of their existing complex caseload. The team has 2.5 whole-time equivalent CNSs dedicated to secondary breast

cancer. The service originally supported both primary and secondary patients; however, the team recognised that the two groups of patients were not receiving the same level of care.

A new secondary breast cancer dedicated nurse-led clinic was introduced at The Christie in 2015, with newly diagnosed patients invited to attend a 45-minute holistic needs assessment (HNA) carried out by a CNS around four weeks after their diagnosis. This includes using a modified version of the Hospital Anxiety and Depression Scale and a Concerns Checklist.

Patients are then stratified to specific follow-up pathways according to their disease burden, level of psychological support required and results of the HNA. Patients also receive written information and a resource pack to ensure they understand their diagnosis and treatment options.

A co-production approach has been crucial to the clinic's success and continual learning approach, with a patient focus group meeting bi-monthly to discuss the service. The success of the clinic has been recognised, with the team receiving the Cancer Nursing Practice award at the 2017 RCNi Awards.

The team feels the nurse-led clinic and stratified follow-up (see Table 4) allows for a proactive rather than reactive way of working. This approach helps the team to provide better information for patients, helps to act on issues before they reach crisis point and uses their nursing resources more effectively. Medical appointments can focus on medical issues, and the CNSs can support the medical appointment but also focus on supporting patients in relation to their psychological and social needs. Working closely with palliative care, the team feels that the approach also facilitates earlier advanced care planning for the end of life.

Table 4: The Christie NHS Foundation Trust learnings

Challenge	Key learning
Identifying new secondary breast cancer patients across multiple consultants	Ensure close working alongside doctors and being very clear about referral criteria. Liaise with breast cancer nurses in peripheral sites and attend meetings to communicate service development at every level
Practical issues including ensuring administrative support is in place and proper data collection recorded to monitor success of clinic	Management and board level support imperative. Appropriate research and planning went into how to evaluate the service from the outset to ensure it could demonstrate it improved patient care  The team has recently employed a data analyst to help bring all the secondary breast cancer patients together in a database to improve the efficiency of the clinic and patient follow-up
Large complex caseload	In addition to the nurse-led clinic, a telephone clinic was established for follow-up appointments as well as bi-annual health and wellbeing days. Patients are being stratified to plan appropriate follow-up
Ensure all patients and relatives have access to appropriate support	The CNSs regularly liaise with GPs, local breast care nurses, community palliative care nurses, district nurses and local hospices to try to achieve high-quality care

### Designing a new efficient secondary breast cancer patient pathway at UCLH

UCLH Cancer Collaborative, one of three English Cancer Vanguard, has undergone a major secondary breast cancer redesign. UCLH was chosen as the pilot site owing to its significant metastatic service and challenges around increasing demand for secondary breast cancer services on its current resource capability.

A review of the current secondary breast cancer patient pathway was beneficial in pinpointing potential bottlenecks and areas of inefficiency.

### Imaging and reporting delays

Survey results indicated that a number of appointments were taking place without a relevant scan or report. This highlighted challenges around imaging and reporting, with 24% of patients either having a delay in treatment or requiring their appointment to be rearranged around scan availability. The project team equated this issue to an additional 167 outpatient appointments a year.

As such, it was concluded that continuing secondary breast cancer services in the current form was unsustainable. A number of recommendations for service redesign were made, including but not limited to the following:

- recruit an additional CNS
- review current CNS structure to ensure more time dedicated to secondary patients
- create dedicated secondary MDT meeting to ensure secondary patients have sufficient time and expertise to be reviewed and discussed
- review radiologist capacity for the breast care team
- implement a new secondary patient pathway
- review use of stratified follow-ups and CNS-led follow-up clinics
- ensure a complete data set is captured on all secondary patients
- ensure palliative care and nuclear medicine input into new secondary pathway and have attendance at secondary MDT meeting

### New secondary breast cancer patient pathway

A new secondary breast cancer patient pathway was proposed by UCLH in 2016. All new suspected cases should be seen by an oncologist or, where appropriate, go straight to the 'diagnostic test' stage of the pathway with these results being reviewed in a secondary designated MDT meeting. The new pathway also recommends a dedicated secondary clinic, rather than having secondary breast cancer patients attend the general breast oncology clinic. In order to manage increasing demand, the new pathway recommends closer links with other services such as palliative and community care, with a number of these services able to be run external to the clinic by other teams rather than the Oncology team alone.

A successful business case has since been developed and accepted for a new CNS post as well as reorganisation of the current staff team to ensure there is sufficient cover for leave. As a result of this increased capacity, a monthly Secondary Breast Cancer Support Group has been created, open to all patients within the UCLH Cancer Collaborative geography.

Palliative care staff now attend clinics as well as consultant weekly ward rounds (for inpatients) to provide enhanced supportive care for all new secondary patients and people at critical points in their care. Nuclear medicine now also attends the MDT meeting for discussion of relevant cases.

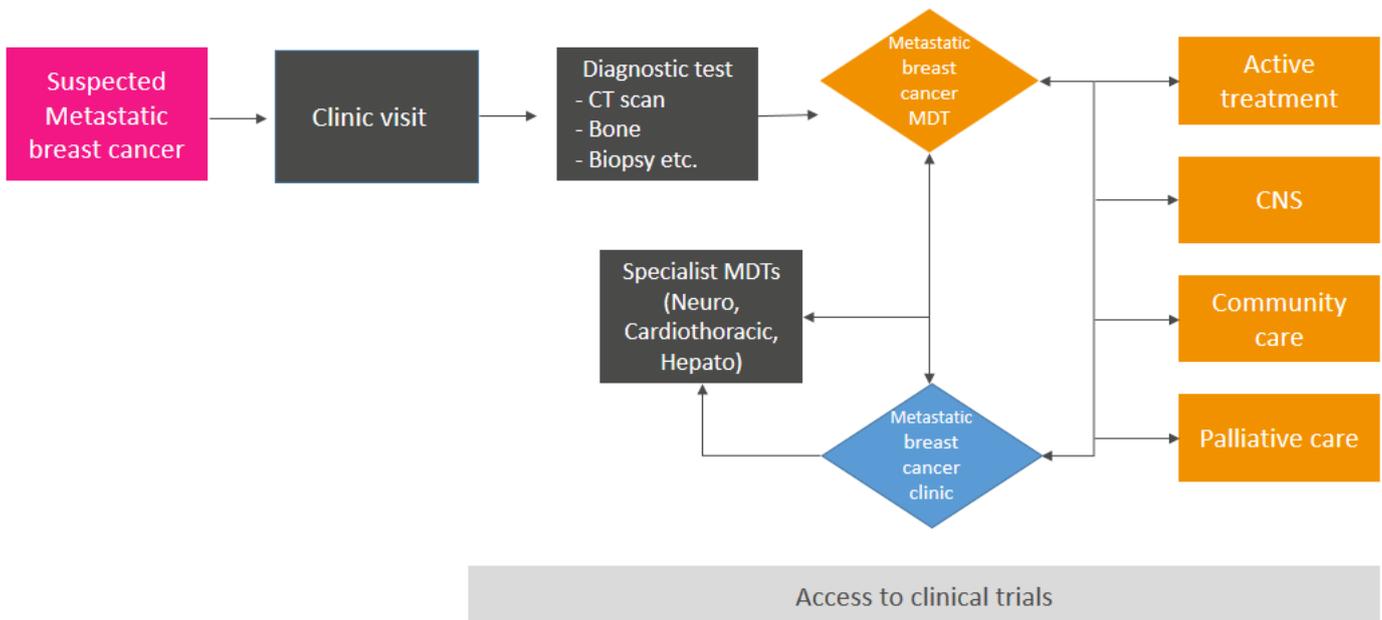
### Direct-to-oncology referral

Reviewing the current secondary breast cancer pathway also allowed a number of quick-win improvements in improving patients' initial entry into the pathway, such as developing a Direct-to-oncology referral for patients with suspected disease progression who usually had a two-week wait for referral and had to attend a surgical clinic before being progressed to the oncology clinic.

### Direct referral enablers

Required enablers for direct referral include:

- education for local GPs on the pathway
- internal arrangements for suspected secondary breast cancer patients to be offered oncology appointments
- more robust process of communication with the Acute Oncology Service (AOS) team for any suspect cases presenting through A&E



## Enhanced information and support offer

### Coordinated care

The Velindre Cancer Centre is a specialist cancer centre in Wales providing services to over 1.5 million people across South East Wales and beyond. It treats over 5,000 new patients each year. The team introduced Wales' first dedicated secondary breast cancer multidisciplinary team (MDT) meetings in 2010 for secondary breast cancer following the trust's involvement in Breast Cancer Care's Secondary Breast Cancer Taskforce.

The MDT Coordinator adds all newly diagnosed patients to the MDT meeting agenda as well as any patients who have had a query raised by a member of the team regarding their treatment after their consultation at the secondary clinic. In addition to medical and nursing staff, a range of other professionals work as part of the MDT team, including a clinical psychologist, physiotherapist, palliative care consultant, pharmacist, clinical trials nurse, radiotherapy practitioner, a lead professional for complementary therapies and members of the on-site supportive care team.

### Supportive care

The supportive care team at Velindre brings together welfare rights, chaplaincy, and children and family social care professionals. The team is integrated into the nursing structure at the trust, which helps to ensure early assessment and intervention for non-medical support needs, and signposting to other support services outside the hospital. The team has developed strong links with

a local hospice, as well as other local services, including family support. The Palliative Care team is also on-site and attends clinics for patients who have pain management and palliative care concerns.

The Supportive Care team assists the CNS with the HNA, as they will be called on to offer support for non-clinical concerns such as financial rights.

The team feels that this helps to give people with secondary breast cancer more control over their lives. Patients and their families are more able to spot a potential issue early, and to seek the appropriate help before the issue escalates or becomes more serious.

Similarly, the Edinburgh Breast Unit has been able to achieve a more structured approach to their assessment of emotional distress and concerns for patients by making use of Macmillan's Concerns Checklist framework. A key worker is also identified to provide individualised, coordinated care to meet the unique needs of each patient and to offer specialist advice and signposting.

### Breast Cancer Care's Living with Secondary Breast Cancer service

Breast Cancer Care's Living with Secondary Breast Cancer service currently runs in 33 locations across the UK and is designed to give people the chance to meet and share experiences with other people living with a secondary diagnosis, and get information and support.

Regular guest speakers cover a range of topics including:

- benefits and financial assistance
- cancer-related fatigue
- clinical trials
- pain management
- palliative and supportive care
- physical activity
- side effects of treatment

### Helplines and forums

Helplines allow people to call about a wide range of worries and concerns, especially when they do not have an open access service to call or are not currently a patient. Family, friends and carers are also welcome to call for information and support.

- Breast Cancer Care's Helpline – 0808 800 6000
- The Macmillan Support Line – 0808 808 0000
- Cancer Research UK – 0808 800 4040

All three helplines have trained specialist nurses and advisors.

Breast Cancer Care's online Forum has a dedicated section for people living with secondary breast cancer. Topic boards include treatments and medical issues, living with a secondary diagnosis, meet-ups, inspiring news and stories, and end of life.

### Information made accessible

#### Different languages

The 2011 UK Census classified 88 main languages other than English used in the UK<sup>17</sup>. It is therefore vital that people with language proficiencies other than English are able to access quality information about their cancer diagnosis. Macmillan Cancer Support has translated a series of cancer information booklets into different languages. Although there is not one specifically on secondary breast cancer, there are relevant titles on breast cancer, cancer for young people, treatments for cancer, living with cancer and end of life care. Breast Cancer Care's Helpline has a language interpreting service.

### Information for people with learning difficulties

CHANGE, an organisation for people with learning difficulties, has produced a series of booklets for people with cancer using simple language and pictures. Although none are specific to secondary breast cancer, most booklets are still relevant to overarching cancer themes. Topics include living with cancer, treatment for cancer, side effects of cancer treatment and end of life. Booklets are free to download on the Macmillan website.

### Vision and hearing impairments

All of Breast Cancer Care's publications are available in large print, Braille, audio CD or DAISY format on request by calling 0345 092 0909 or emailing [publications@breastcancercare.org.uk](mailto:publications@breastcancercare.org.uk). Macmillan Cancer Support also has British Sign Language (BSL) videos available about cancer and its treatment.

### Improving outreach services

The Christie operates on a hub and spoke model, linking in with breast care nurses and oncology teams across the region. Services are provided at The Christie hospital site in Manchester and in a number of community settings. These include a mobile chemotherapy unit, and outreach services to neighbouring non-specialist NHS trusts and in people's homes.

Innovative methods of outreach have helped maximise the resources available to trusts and health boards so that they are accessible to as many patients as possible, who often travel large distances for clinic appointments and treatments.

The Velindre has been asked by the Welsh Government to develop bold and exciting plans for patient-centred cancer services in South East Wales. This had led to a number of outreach services listed below.

- A new cancer treatment centre focusing on treatment services such as chemotherapy and radiotherapy and located just off a major motorway running through South Wales so it is easily accessible for patients.
- Increasing satellite units within other hospitals (with designated facilities) to increase community outreach. These services will include radiotherapy services for patients with a secondary diagnosis.

- Mobile chemotherapy units, funded by Tenovus cancer charity in Wales, have been introduced. This is a unique service, with members of Velindre's welfare rights and supportive care team attending these mobile clinics to ensure a holistic approach to care.

### CNS training in secondary breast cancer

#### Hospital training initiatives: Edinburgh Breast Unit

Edinburgh Breast Unit has a number of learning opportunities for their breast care team that are transferable to other breast care teams.

#### Rotation opportunities

Edinburgh Breast Unit offers rotation opportunities to CNSs from the early breast and adjuvant cancer service team, where they are able to join the secondary team for a fixed period or for one to two days a week with the aim of ongoing development of skills and competencies associated with caring for secondary breast cancer patients. Feedback from this programme has been extremely positive, with nurses reporting an increased knowledge base and the development of transferable skills.

#### Annual training day

Edinburgh Breast Unit holds an annual full-day secondary breast cancer training event which focuses on the patient experience and pathway from diagnosis of secondary breast cancer to treatment options, side effects and ongoing symptom control. This course is aimed at ward staff, community nurses, allied healthcare professionals, and anyone with an interest in understanding more about secondary breast cancer.

#### Psychology toolkit

An in-house course designed for CNSs and practitioners, which provides a 'toolkit' for psychological support strategies. Clinical psychologists also provide support for the CNS team in terms of advice and support strategies for complex patient needs and providing a framework to support patients.

### The Royal Marsden School: Principles of Metastatic Breast Cancer Care

Principles of Metastatic Breast Cancer Care is an annual five-day classroom-based module designed for nurses and allied healthcare professionals working with patients living with secondary breast cancer. This module advances students' knowledge and insight into the disease and its impact from physical symptoms to emotional support. Learnings from the module enable healthcare professionals to develop appropriate care, support and services.

Key topics include:

- metastatic (secondary) breast cancer biology and pathophysiology
- the impact of metastatic breast cancer on individuals and family
- treatment options for metastatic breast cancer and decision making
- assessment and management of common symptoms, including bone pain, fatigue and fungating breast wounds
- supportive care issues specific to secondary breast cancer patients
- identification and management of relevant palliative care emergencies
- supportive communication skills and strategies
- ethical, social, economic and political factors that may influence the care and treatment of patients with secondary breast cancer

Students at the MSc level will also propose innovative service and development ideas to improve or develop clinical care. The course was nominated for the Laing-Buisson Prize for education innovation in 2017.

The Royal Marsden School also hold a one-day free course 'What We Should Know About Metastatic Breast Cancer'.

For further information please contact The Royal Marsden School by telephone on 020 7808 2900, email at [school@rmh.nhs.uk](mailto:school@rmh.nhs.uk) or visit the Royal Marsden website, [royalmarsdenschool.ac.uk](http://royalmarsdenschool.ac.uk).

## Further support for nurses

Breast Cancer Care's Nursing Network<sup>18</sup> is a free network supporting nurses' professional development, with teleconference training sessions counting towards Nursing and Midwifery Council revalidation as well as a host of benefits and opportunities to share best practice with other nurses across the UK. As part of the Nursing Network, a Secondary Breast Cancer Nurses Forum is open to all members who are currently involved in providing specialist care to people with secondary breast cancer and who are interested in developing their clinical skills. Macmillan Cancer Support also has E-learning courses<sup>19</sup> that support continuous professional development hours for revalidation.

## Patient insights into support and nursing best practice

**'I can't imagine not having my clinical nurse specialist [CNS]; you would feel totally isolated from one appointment to the next.'**

Patient representative

Nobody can understand the support needs of someone diagnosed with secondary breast cancer more than the people who are themselves living with this incurable disease. It is therefore vital that best practice is driven by patients.

### The CNS role

Key characteristics of an excellent CNS have been described as:

- able to build a relationship based on trust with the patient
- 'kind but firm' and is able to tell the patient any bad news in an honest, open manner
- accessible and is available to be contacted outside of clinic appointment times via email or telephone
- will attend to clinic appointments and will have a debrief with the patient afterwards to explain results and answer any further questions

- provides continued emotional support as well as being a source of information about the disease
- refers the patient to outside support and information services
- is available at each stage of treatment and progression for added support and information on what the options are and what to expect next

From speaking to patients, it cannot be stressed enough how much the little things matter. Patient feedback has stressed that an approachable, positive point of contact can make a huge difference.

**'My CNS knows I have anxiety in between having my scans and finding out the results at my next clinic appointment, so she calls me straight after they've been discussed at the MDT meeting to discuss the main results and what to expect.'**

Patient representative

**'It was only when my CNS left that I realised how much I relied on her. I felt adrift without her.'**

Patient representative

## Tools and resources

A number of tools and resources have been identified to help breast care teams support patients.

- **Breast Cancer Care's Standards of Care**

The standards of care for patients with secondary breast cancer<sup>20</sup> may be used to support the delivery of excellent patient care.

- **Holistic needs assessments**

A guide for professionals providing HNAs can be downloaded from Macmillan Cancer Support's website<sup>21</sup>. It is recommended that an HNA should not occur directly after diagnosis, but rather within a few weeks to allow a person newly diagnosed some time to process and adjust to their secondary diagnosis.

- **Macmillan's Concerns Checklist**

This is a one-page checklist that should be given to a patient during their HNA. It covers physical, practical, family and relationship, emotional, and spiritual and religious concerns

as well as information prompts to different information needs. It is available to download online from Macmillan Cancer Support's website<sup>22</sup>.

- **Breast Cancer Care's Checklist**

The next edition of Breast Cancer Care's latest Secondary breast cancer resource pack, to be published in April 2018, will feature a needs and concerns checklist that is designed for review during an HNA or clinic appointment.

- **Hospital Anxiety and Depression Scale**

The Hospital Anxiety and Depression Scale<sup>23</sup> is commonly used in the NHS to determine the level of anxiety and depression a patient is experiencing. This scale can be beneficial for breast care teams to adequately assess the level of support required for patients at the point of diagnosis for secondary breast cancer.

## Trends and key takeaways

Excellent care for secondary breast cancer is marked by a few common trends in the service offering. This usually includes breast care teams with the characteristic listed below.

- Take a proactive approach to providing patients with important information, support and care.
- Maximise resources through nurse-led care and stratification of patient follow-up based on level of need.
- Work collaboratively with supportive care teams to ensure a wider, holistic level of support for the patient.
- Have innovative outreach models such as satellite sites, hub-and-spoke models and mobile units as well as links to community services.
- Undertake ongoing education and training such as training rotations, in-house training days and accredited continuing professional development.
- Have MDT coordinators who chair MDT meetings and ensure there is sufficient time for both treatment decisions and for support measures to be discussed.

## Recommendations for dissemination of best practice

- Specialist nurses working in secondary breast cancer must be supported to receive the appropriate skills and knowledge, including:
  - secondary breast cancer biology and pathophysiology
  - treatment options for secondary breast cancer
  - assessment and management of common symptoms, including bone pain and fatigue
  - supportive care communication skills
  - knowledge of local and national support services available
- Health Education England urgently needs to make continued professional development funding available to NHS trusts to ensure the current workforce is always equipped with the skills and knowledge to support their patients.
- Information should be accessible to everyone. This includes being available in multiple languages and suitable for people with literacy challenges or learning difficulties as well as vision and hearing impairments.

## Conclusion

This report highlights how maximising resources, both within and external to the hospital setting, results in more efficient, streamlined models of care and improved patient experience for people living with secondary breast cancer.

In order for patients to be diagnosed earlier and receive vital treatment and care faster, we found breast care teams using a range of methods to ensure patients are aware of concerning signs and symptoms at the end of their primary treatment. This runs concurrently with new, innovative models of improving diagnosis such as multidisciplinary diagnostic centres, which act as a 'one-stop' diagnosis centre for people with non-specific but concerning symptoms.

It is vital for effective service planning that trusts and health boards understand how many people are being diagnosed each year with secondary breast cancer and how many people are living with the disease in their local area. Teams who have taken active steps towards addressing key barriers – such as lack of awareness that data has to be collected, lack of available resources to support collection and a lack of buy-in from within the trust – have seen vast improvements in patient care and support.

Moreover, nursing teams that demonstrate best practice are maximising resources available to them. This is done through a combination of nurse-led care and stratification of patients,

strong links to supportive care available in the wider community such as palliative care teams, innovative outreach models and referral to support networks such as Breast Cancer Care's Living with Secondary Breast Cancer service for additional non-hospital based support.

It is encouraging that many hospitals are striving to improve their support and services for patients with secondary breast cancer. However, it is important to recognise that this is not the standard across the UK, with the care and support offered to people living with secondary breast cancer dependent on their geography and local NHS service available. It is therefore vital that best practice is spread across the UK so that all patients receive the support and care they need. The NHS, Health Education England and other government bodies must actively push for service improvements and support for secondary breast cancer patients.

Breast Cancer Care will continue to work with governments and the NHS to ensure best practice is disseminated to drive service improvements in the care and support of people living with secondary breast cancer.

## References

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- 2 For Wales: As part of the Welsh Government's review of the data collection of metastatic patients, data should be specifically coded for metastatic patients and must not be 'grouped' under recurrence. This should be implemented through the introduction of the single cancer dataset. For Scotland: The Scottish Cancer Registry should update the estimated number of patients with secondary breast cancer on an annual basis.
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- 12 Breast Cancer Care, Secondary. Not Second Rate Part two: Who's Counting? (2016).
- 13 Histology reports at the Trust include a code that determines the type of cancer. There is a specific number within this code that indicates metastatic disease, meaning that these reports can be used to quickly identify patient numbers.
- 14 Radiology reports are sorted manually, unlike histology reports. It is hoped that this will soon become an automated process but, in the meantime, it is possible that some secondary breast cancer patients slip through the net.
- 15 In Scotland and Wales, the picture is more positive, with 33% and 60% of Health Boards respectively reporting that there is not enough specialist nursing care for people with incurable secondary breast cancer.
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When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

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