

**Secondary.
Not second rate**

**breast
cancer
care**

**Secondary breast cancer
Part four: Nursing care
April 2017**



only 21% of organisations had one or more Clinical Nurse Specialist dedicated to secondary breast cancer



With thanks to Apteligen who undertook this research on behalf of Breast Cancer Care.

We thank Novartis Oncology for providing funding and support throughout this project, which we have collaborated on while maintaining editorial independence.

We are particularly grateful for the contributions of staff, patients and their families from the hospital sites that took part in this research.

Thanks to the women living with secondary breast cancer who are pictured in our photos: Vicki, Claire and Dawn.

For more information on our policy work and campaigns, contact:

Danni Manzi, Head of Policy and Campaigns

campaigns@breastcancercare.org.uk

Contents

Section 1: Introduction	4
Section 2: Context	5
What is secondary breast cancer and why are we focusing on it?	
Making the case for change in secondary breast cancer	
What is a specialist nurse?	
Current policy in the nations	
Section 3: Methodology	10
Research design and development	
The UK-wide mapping survey	
The site visits	
Meetings with staff	
Patient group sessions and interviews	
Limitations of research	
Section 4: Findings and recommendations	14
Coverage and value of the CNS role for secondary breast cancer	
The role of the 'support worker' for people with secondary breast cancer	
Enhancing the community support offer accross the whole care pathway	
Section 5: Conclusion	35
References and notes	36

Section 1: Introduction

For many years, Breast Cancer Care has led the way in driving significant improvements in care for people living with and affected by breast cancer, including secondary breast cancer.

We know through feedback from patients and staff working in breast cancer that the quality of care for people with secondary breast cancer is often not as good as for people with a primary breast cancer diagnosis, especially when it comes to access to suitably trained specialist nurses.

Because of a lack of evidence surrounding nursing provision, and as part of our ongoing focus on secondary breast cancer, we have studied the provision of specialist nursing in England, Scotland and Wales for patients living with breast cancer that has spread to other parts of the body and is no longer curable. This is the first study of its kind that robustly maps current nursing provision and proposes practical suggestions for improvement.

Not only is this information invaluable for Breast Cancer Care's campaigning, influencing and service provision in this area, but we also hope multidisciplinary breast care teams, commissioners and provider organisations will use it to plan for and respond to the needs of their patients.

This report continues our series looking at secondary breast cancer, following our previous reports **Secondary breast cancer – Part one: Diagnosis;** **Secondary breast cancer – Part two: Who's counting (about data collection in England's hospital trusts);** and **Secondary breast cancer – Part three: Support and impact.**

It highlights the issues faced by breast care teams and patients across the UK: that patients with secondary breast cancer do not always have access to specialist nursing that may improve their quality of life and emotional wellbeing from the point of diagnosis.

The integration of hospital care into a wider system of holistic care for people with a life-limiting disease, including timely access to social care and support for families and carers, is also suffering from limited investment in many areas.

Underlying much of this is a lack of good-quality data on the number of people with secondary breast cancer, their support needs, and their experiences of the system – all of which denies commissioners and service providers the information they need to plan services that meet patients' needs effectively.

The next and final report will identify practical solutions and examples of best practice in the four core areas our previous reports have focused on in relation to secondary breast cancer: diagnosis, data, support and impact, and now, specialist nursing.



Section 2: Context

What is secondary breast cancer and why are we focusing on it?

Secondary breast cancer – also called metastatic, advanced, or stage four breast cancer – occurs when breast cancer cells spread from the breast to other parts of the body, such as the bones, liver, lungs and brain.

Secondary breast cancer is not curable but it can often be treated. Median survival is 2–3 years. However, the disease trajectory varies significantly according to site(s) of spread and response to treatment. Some people live for many years while others survive just a few months.

There are an estimated 36,000 people living with secondary breast cancer in the UK and each year around 11,600 die from the disease¹.

Breast Cancer Care offers comprehensive and unique support to people living with or affected by secondary breast cancer. We run monthly Living with Secondary Breast Cancer group-based peer support sessions across the UK. They are led by a therapeutic facilitator and help people to cope with the physical, social and psychological impact of a secondary breast cancer diagnosis and treatment.

In addition, we run an annual residential event for women aged 45 and under providing tailored information and support for younger women diagnosed with secondary breast cancer.

We have an online forum and facilitated web-based live chats, enabling people to come together to share experiences and get support from others in similar situations. Our telephone Helpline and Ask Our Nurses email services provide information and support not only to the person with the diagnosis but also to families and friends.

All these services are underpinned by our free, award-winning² **Secondary Breast Cancer resource pack**³ and a series of information booklets covering diagnosis and treatment of the most common secondary breast cancer sites.

Along with the information on our website, these are written by our own team of specialist breast care nurses, and reviewed by volunteer independent healthcare professionals and people affected by breast cancer. Our patient information is externally assessed by NHS England's Information Standard as being up to date and trustworthy.

In partnership with charity Breast Cancer Now, we deliver the Secondary Breast Cancer Pledge in England and Wales. This is a service improvement initiative working with hospitals to deliver patient-led improvements to care and treatment for people with secondary breast cancer.

We also support nurses who care for patients with secondary breast cancer through our Nursing Network and Secondary Breast Cancer Nursing Forum. Through sharing best practice and clinical updates, we aim to improve the Standards of Care for people diagnosed and living with secondary breast cancer.

All our services are free and involve people affected by breast cancer in both their development and delivery.

Making the case for change in secondary breast cancer

In 2006, Breast Cancer Care set up and coordinated the Secondary Breast Cancer Taskforce. A two-year initiative, the Taskforce was established because we recognised that people with secondary breast cancer were not receiving the best possible standard of care.

A national coalition of Healthcare professionals, charities, policymakers and people with secondary breast cancer, the Taskforce identified gaps in the treatment, support and care of people living with secondary breast cancer, through a series of meetings, a survey, other research and expert consensus. Among other things, the Taskforce identified that people with secondary breast cancer were far less likely to have a clinical nurse specialist to help coordinate care and provide emotional support as part of their care and treatment, in direct contrast to the experience of many primary breast cancer patients.

However, since the Taskforce findings were published over eight years ago⁴, and despite commitments made by governments to improve this situation, little has changed and problems with inadequate care and treatment persist.

Information from people who use Breast Cancer Care's services highlights that there are still significant gaps, and that access to a clinical nurse specialist is variable. This means that patients are often not getting support to live with the impact and side effects of their diagnosis and treatment.

Furthermore, we still don't have accurate, up-to-date figures on the number of people diagnosed or living with secondary breast cancer today. We addressed this issue in our previous report on data⁵.

In January 2013, it became mandatory for data to be collected by NHS hospital trusts in England on the number of people diagnosed with secondary breast cancer. However, we found that only a third (33.6%) of trusts in England are meeting this requirement in full. In Scotland, although data collection is not mandatory, progress is being made, with the Scottish Cancer Registry identifying an estimated 4,090 patients with secondary breast cancer in 2013. In Wales, there is a commitment to collect data but little progress has been made and there is still no national dataset available.

This lack of data, coupled with poor understanding of the experiences of people with secondary breast cancer, makes it enormously difficult for

commissioners to plan for and implement services that fully and effectively meet the needs of people with secondary breast cancer, such as specialist nursing provision.

These gaps in information and intelligence add to a widely shared experience: that people with secondary breast cancer feel forgotten or invisible, and that the care they receive is inferior to the care that is greatly valued by people treated for primary breast cancer. It is therefore timely that Breast Cancer Care has commissioned this study, the first of its kind to robustly map and analyse the current provision of specialist nursing in England, Scotland and Wales.

What is a specialist nurse?

The role of the specialist breast care nurse has become an established discipline in UK oncology since the 1980s⁶. However, the role of the Clinical Nurse Specialist (CNS) doesn't have a clear, unified UK-wide definition. The current debate on the future of specialist nursing practice and definitions led by Health Education England favours the more recent definition of Advanced Nurse Practitioner (ANP), a title that might well replace the CNS name in the future. However, both roles continue to exist, together with the broader title of Breast Care Nurse (BCN) and various key worker/support worker roles across both health and social care.

The NHS generally places the CNS role in the **NHS Agenda for Change** salary band 7, with responsibilities both in expert clinical advice, and service development and improvement. However, in practice CNSs may also be employed at bands 6 and 8, highlighting the variation in the level of specialism within the CNS role, and the growth of increasingly complex roles, which include proactive case management and the provision of psychological support and specialist symptom control. It highlights the importance of providing information to patients regarding their disease and its treatment, and facilitating their clinical choices.

The Royal College of Nursing (RCN) defines a specialist nurse as a nurse 'dedicated to a particular area of nursing; caring for patients with long-term conditions and diseases such as cancer, diabetes, Parkinson's, chronic heart failure and dementia'⁷.

The RCN goes on to say that specialist nurses 'provide direct patient care and can play a vital role in educating patients on how best to manage their symptoms, as well as offering support

following diagnosis' and should be educated to degree level or above⁸. Specialist nurses work in both hospital and community settings and may hold additional qualifications in their area of clinical practice, such as a diploma or Masters Degree.

The benefits of the specialist nurse have also been well documented, and include the combination of improved one-to-one yet highly specialised care, with efficiencies and cost savings likely where specialist nurses can be freed from routine and non-specialist nursing work⁹.

The National Cancer Patient Experience Survey in England also demonstrates that people affected by cancer across many different tumour sites value the support and input of a CNS. Patients who have been allocated a CNS are more positive about their experience of care, while the CNS is viewed as playing a valuable role in decision-making and as a trusted source of information¹⁰. In the Wales Cancer Patient Experience Survey 2013, 'patients with a CNS gave more positive answers than did those patients who did not have one; and these differences are statistically significant.'¹¹ This is also reflected in the Scottish Cancer Patient Experience Survey 2015.

For the purpose of this study, we are following the general role definitions described below when using these job titles throughout this report. However, it is important to recognise that there remains variation in how these job titles are used in practice:

- **Clinical nurse specialist:** a nurse working in either the hospital or community setting with the job title Clinical Nurse Specialist, and who holds specialist expertise in either primary or secondary breast cancer. This role is usually graded a band 7.
- **Breast care nurse:** a nurse working specifically with breast cancer patients, most typically those with a diagnosis of primary breast cancer. This role is usually graded as band 6 and some are used as training posts in preparation for a more senior clinical nurse specialist role.
- **Combined clinical nurse specialist role:** a clinical nurse specialist with responsibility for both primary and secondary breast cancer patients as part of their agreed job role. Some combined clinical nurse specialists will have specialist expertise in secondary breast cancer but others will not, and this will vary by organisation and local need.
- **Advanced nurse practitioner:** a nurse who works at an advanced level in a specialist area, usually with responsibility for diagnosis, prescribing,

and admission and discharge of patients, in line with the RCN's guide to advanced nursing practice¹².

- **Specialist nursing provision:** nursing care provided to patients with a diagnosis of breast cancer, by any one or more of the above nursing roles.
- **Support worker:** Typically a non-specialist role, not usually a registered nurse, who provides care coordination, education and self-management support for patients with care needs assessed as non-complex. This is sometimes also called a non-nurse key worker. We're using the term support worker here to minimise confusion of responsibilities¹³.

Current policy in the nations

England

In England, the **Clinical guidelines for the diagnosis and treatment of advanced breast cancer** published by the National Institute for Health and Care Excellence (NICE, 2009, updated 2014 and reviewed in 2015)¹⁴ place specific emphasis on assessing each patient's needs for 'physical, psychological, social, spiritual and financial support' and that this should be undertaken at key points, including at diagnosis, commencement of treatment, at relapse, and when death is approaching. NICE also recommends that mechanisms should be in place to 'promote continuity of care, which might include the nomination of a person to take on the role of "key worker" for individual patients'.

The national **Cancer Strategy for England** (2015)¹⁵ published by the Independent Cancer Taskforce, while placing relatively little emphasis on the assessment and treatment of patients who may live for a number of years with secondary cancer (that is, patients who are not undergoing curative treatment nor nearing end of life), recommends that work is needed to develop clear, multidisciplinary pathways of care for people with metastatic cancer.

The strategy also advocates for the systematic provision of a CNS or other key worker to help coordinate patient care. Among other benefits, this would help to shift the NHS in England towards a culture that values patient experience as much as clinical effectiveness and safety.

Consistent with valuing patient experience, **A Review of Choice in End of Life Care** (2015)¹⁶ is concerned with patient experience at the end of life. It makes the case for earlier access to specialist palliative care services in the community and earlier planning for end-of-life care needs, including greater choice around place of death.

Scotland

The main cancer strategy in Scotland, **Beating Cancer: Ambition and Action**¹⁷ released by the Scottish Government in 2016, does not appropriately address the needs of people with secondary breast cancer or other secondary cancers. The only relevant action in the strategy is around data collection and prevention of secondary disease.

Given the focus of survivorship for people with primary breast cancer, and the number of people living with secondary breast cancer in Scotland¹⁸, this is a missed opportunity to address the gaps in nursing provision for this patient group.

Breast Cancer Care would like to understand more from the Scottish Government about how nursing provision will be improved in light of our recommendations in this report.

Wales

Breast Cancer Care supports and welcomes the recently refreshed **Cancer Delivery Plan for Wales (2016–2020)**¹⁹. The plan states that services should meet the different needs of the population and outlines the need for patients with secondary cancer to be quickly identified, have data collected and full access to services and support to meet their specialist needs through improved collection of information on the care provided, and peer review delivered by the Wales Cancer Network.

We recognise this commitment to improving support and care services for people with secondary breast cancer in Wales and look forward to working with the Wales Cancer Network on their key actions.

New policy direction in the UK

More recently, the UK Oncology Nursing Service (UKONS) and the RCN published the first formal career and education framework for cancer nursing²⁰. The framework was developed in response to patient feedback showing that cancer experience is greatly improved when patients have access to a CNS, and a recognition that there was previously no succession plan for CNSs and no official career and education framework for cancer nursing. The framework provides, for the first time, an extensive description of the skills and competencies needed by nurses who might be responsible for patients with secondary breast cancer, and takes a significant step forward in providing a common language across the UK for role titles, levels of practice and cancer-specific nursing outcomes. These will help to guide cancer nursing education, training and practice in the future.

Finally, the **Macmillan one-to-one support pilot evaluation** (2015)²¹ is one of the most comprehensive evidence-based studies into new delivery models. In line with most scientific literature on specialist nursing and the CNS role, its findings suggest that both patient experience and finances can benefit from a collaborative division of tasks (inside one integrated service) between the medical and the more social aspects of care for cancer patients.



Section 3: Methodology

The purpose of this research was to identify and explore the different models of specialist nursing provision in place within the NHS for people with secondary breast cancer, and further our understanding of the value and impact the different approaches offer from a variety of perspectives (patients, family and carers, Healthcare professionals, and healthcare organisations).

With these aims in mind, the research focused on two main areas:

1. Mapping, for the first time, the existing specialist nursing provision for people with secondary breast cancer in every healthcare organisation with breast services in England, Scotland and Wales.
2. Gathering both qualitative and quantitative data about service delivery models and benefits of the CNS role from clinical staff, patients and family members. This was done through a survey and in-depth interviews with staff and patients in eight different hospital sites (six in England, one in Scotland and one in Wales).

This research was undertaken in three main phases. The work was largely exploratory in nature, designed to fill gaps in the existing evidence base and to provide new insights about the value of specialist nursing provision for people with secondary breast cancer. With this in mind, it is important to note that we did not, therefore, track changes in particular measures or indicators at the level of individual patients or services, nor did we assess the quality or performance of individual organisations.

Research design and development

The project began in December 2015 with an initial phase of work to design the overall approach and the specific research tools. This included a half-day design workshop in January 2016, attended by approximately 20 stakeholders including Healthcare professionals and colleagues from NHS in England, Scotland and Wales, and Breast Cancer Care.

The workshop provided valuable insight and material for the design of this study, and in particular the design of the mapping survey, selection criteria for the in-depth site visits and current thinking about the value of the CNS role for people with secondary breast cancer to inform the areas to explore during the site visits.

The UK-wide mapping survey

The second phase began in February 2016 and involved the distribution of a survey of specialist nursing provision for people with secondary breast cancer. The survey was sent by email to all acute NHS trusts with breast care services in England (137 NHS trusts), Scotland (12) and Wales (6), and the Velindre NHS Trust. For each organisation, we approached CNSs, lead cancer nurses and, in some cases, directors of nursing where no other cancer nurse contact was known. The survey sample excluded Community NHS Trusts.

The survey consisted of approximately 30 questions and covered the following areas:

- information about the type of specialist nursing provision for primary and secondary breast cancer in that organisation, and the amount of time dedicated to secondary breast cancer patients
- the number of CNSs for secondary breast cancer (where these exist) and how long those roles had been in place
- the size of the consultant oncologist workforce
- the number of new patients diagnosed per year
- perceived value and benefits of the CNS role
- details of documented clinical pathways for metastatic breast cancer
- whether or not the organisation employed non-nurse key workers to work alongside the breast care team
- the use of patient forums and nurse-led clinics.

The initial email contact was followed up with regular reminder emails (and in some cases direct telephone calls) over a period of six months. There was a 100% completion rate across Scotland and Wales, and a 99% completion rate for England, giving a total of 155 responses.

These high completion rates mean that it has been possible for the first time to develop a robust and representative national picture of the number of specialist nurses supporting people with secondary breast cancer.

The profile of respondents by role is shown in Figure 1, p11. In England and Wales the highest proportion of respondents were BCNs/CNSs with responsibility for both primary and secondary breast cancer patients. A fifth of respondents from England and Scotland were lead cancer nurses.

It should be noted that the chart shows all responses to the survey – this is higher than the number of organisations across the three nations as we received more than one response from

some organisations. For the analysis presented in section 4 of this report, the responses have been synthesised into a single response for each NHS trust or health board.

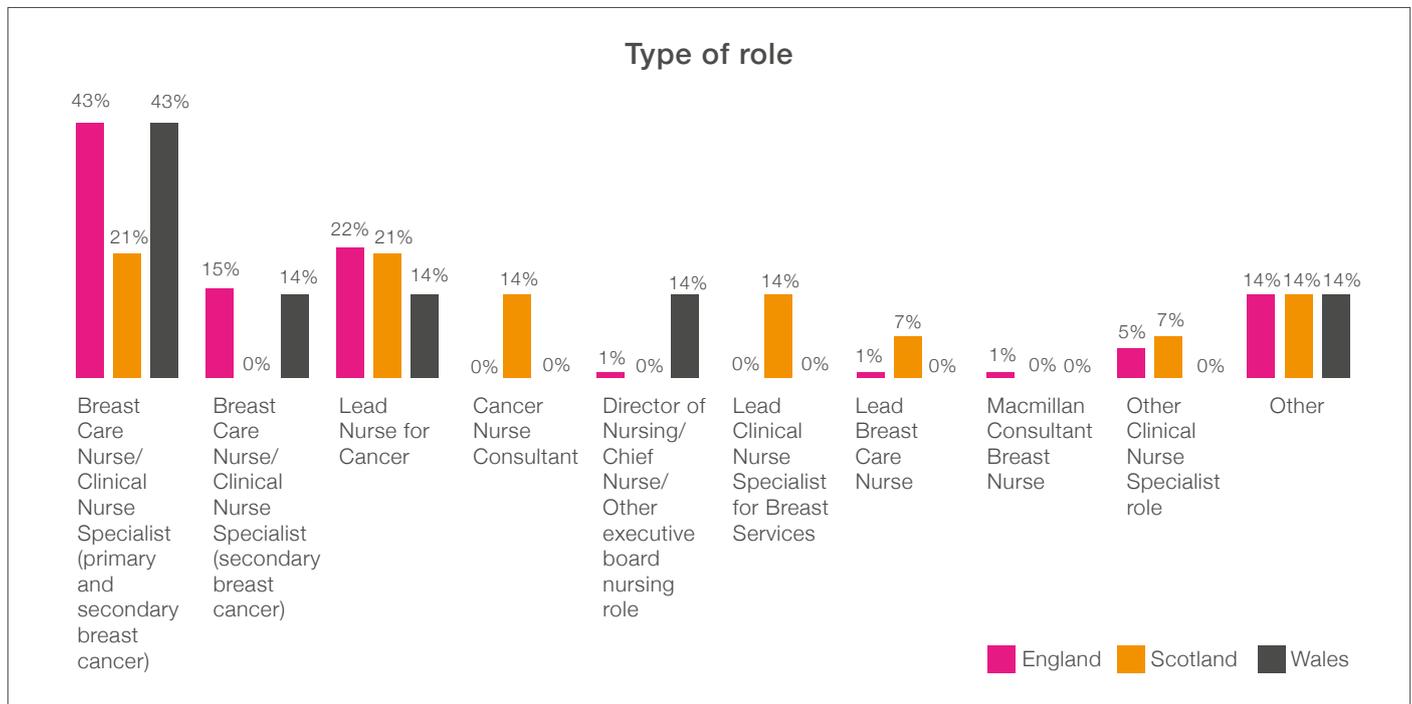


Figure 1: Survey responses by role in England, Scotland and Wales

The site visits

Phase three of the research involved a one to two-day visit to eight hospital sites across England, Scotland and Wales, usually meeting with both patients and staff. The purpose was to gather insight into how the whole range of needs of secondary breast cancer patients could best be met, and how different models of care and management arrangements support this. This was achieved through semi-structured discussions covering five broad topic areas:

- typical patient pathways
- processes for assessing patients' medical and non-medical needs
- resource allocation
- staffing and management structures
- arrangements for referral to services in the community.

It was important that the sites visited included a mixed profile across various characteristics that might impact on service delivery and patient experience. This included ensuring there was representation across regions in England, Scotland and Wales. Additionally, sites to visit were selected to ensure there was a mix across those serving

a rural, urban or semi-urban population, a range of caseload and overall trust sizes, and that sites with different models of care for secondary breast cancer patients were included.

Finally, it was also considered important to include at least one specialist cancer centre within the research.

An initial long list of preferred sites was developed and a named individual was contacted to seek their agreement to be involved in the research, and to identify a lead individual within the organisation who would help coordinate staff interviews and recruit patients. Each of the sites had different processes and governance requirements that needed to be met in order to coordinate the visits. Unclear management and governance structures, combined with limited levels of staff time to help organise and attend interviews, meant that it was not possible to visit all of the intended sites. However, given the longer initial starting list, it was possible to include enough of the sites in the research to give the breadth of coverage across the key characteristics identified.

The visits took place between June 2016 and February 2017.

At some sites it was not possible to meet all the staff or patients on site, and several follow-up telephone calls were arranged. In total eight sites were visited, which included six in England, one in Scotland and one in Wales, as detailed in Table 1, below.

NHS Trust	Number of visits	Number of staff interviewed	Number of patients interviewed
Northumbria Healthcare NHS Foundation Trust	1	7	6
Nottingham University Hospitals NHS Trust	1	5	6
Royal Cornwall Hospitals NHS Trust	1	7	1
The Christie NHS Foundation Trust	1	5	8
United Lincolnshire Hospitals NHS Trust	2	5	7
Velindre NHS Trust	1	13	7
Raigmore Hospital Inverness - NHS Highland	1	9	7
Homerton University Hospital NHS Foundation Trust	1	4	*
Total	9	55	42

*Homerton was selected to be one of the sites to be visited to ensure a site with a non-nurse keyworker was represented in the sample. However, the trust had recently introduced a new care pathway, meaning that most patients with secondary breast cancer now receive treatment at St Bartholomew's Hospital, and as such no patient meetings were set up.

Table 1: Number of staff and patient interviews undertaken

Meetings with staff

Meetings with staff were undertaken in either a group session or on a one-on-one basis, depending on what the site felt was most practical. While the exact roles and range of staff interviewed at each site varied according to staff availability and the different configurations of breast cancer services, at least one Secondary Breast Cancer Nurse was involved in all sites where the role existed. Other staff interviewed included individuals in roles such as Breast Care Nurse, Lead Cancer Nurse, Oncologist, Clinical Psychologist, Director of Nursing and Quality, Macmillan Community CNS and Macmillan Information Manager.

The interviews were semi-structured discussions which centred around developing an understanding of where specialised knowledge

and expertise existed, particularly where there was no CNS, and the extent to which there were established care pathways, multidisciplinary working and integration with services outside the hospital. The discussions explored the processes for keeping up-to-date with evolving treatments, identifying local networks used to share knowledge, and building an understanding of the patient journey. This included:

- whether and how patients are allocated a CNS
- how psychological and emotional needs are assessed
- processes for ensuring the right priority is given to the treatment of secondary breast cancer patients
- the use of documented care pathways.

Finally, specific challenges and solutions in more rural areas, where secondary breast cancer

caseloads were small (for example, hub and spoke models, pooling of resources, use of digital technology and out of hours cover) and challenges in relation to costs and resourcing were also discussed.

Following the visits some sites provided additional information to support areas covered in the discussions (such as policy documents, patient survey results, audit assessments and job descriptions). However, given the varied nature of the information available it was not possible to undertake a systematic review of this information across all sites.

Although it had been hoped that the visits could also be used to gather anonymous patient activity data at each of the sites, it quickly became clear that many data systems do not provide the ability to identify secondary breast cancer patients so this information was not available for the research. The issue of data collection in England and its impact on resource provision and patient experience is covered extensively in our previous report, **Secondary breast cancer – Part Two: Who’s counting.**

Patient group sessions and interviews

The site visits also involved patient interviews to develop an understanding of the patient experience, including in particular the support they had received, who had provided this and the impact of having or not a dedicated CNS. The patient sessions were structured discussions which involved the patient completing an activity designed to map their journey since their diagnosis of secondary breast cancer, what elements of their care had been particularly helpful, and what they would have liked at different points.

Limitations of research

Capacity for staff and patients to engage with the research

A number of organisations from the initial sample were unable to take part in the research, despite enthusiasm from nursing teams to be involved. Barriers to involvement included:

- internal concerns/agreement over the governance arrangements and level of clearance needed for the site visits to take place
- challenges identifying the right person to act as a main contact
- an internal reorganisation at one site

- internal capacity to organise and take part in the site visit in the face of significant staff workloads.

In addition to this, bringing patients together for group interviews proved difficult, in part due to the absence of existing patient groups in some organisations.

This meant that our sample was slightly smaller than originally planned, including the number of patients we were able to interview. However, we found a high level of consistency in the feedback we received from staff and patients across the sites we visited and therefore we can be confident in the findings presented in this report.

Lack of service and activity data

Our initial aim was to obtain data from the case study sites on overall patient numbers, caseloads for individual nursing staff, staffing costs, hospital admissions and outcomes. This would have enabled us to explore the potential of quantifying, in financial terms, the monetary value of the CNS role in different settings. However, despite elements of this information being available in some of the organisations we visited, we were unable to obtain sufficient data for this type of analysis to be undertaken with accuracy.

We do, however, have considerable learning and analysis from our discussions with staff and patients. Where possible, we have also tested the learning from the site visits with the survey responses, so as to draw conclusions about the likely picture across the NHS as a whole.

Providing a snapshot in time

This research presents a snapshot of specialist nursing provision for secondary breast cancer in England, Wales and Scotland, and makes recommendations for how services can be improved nationally and at a local level. We did not set out to evaluate individual services or to track the care received by individual patients over a period of time. This means that the findings presented in this report may be more relevant to some breast care teams than others, particularly as local services continue to evolve.

We have attempted to draw out key learnings that will be useful for all breast care teams, whether they currently have specialist nursing provision for secondary breast cancer or not, as well as for the wider health and care system, in relation to how services are commissioned and designed, and how services across the statutory and voluntary and community sectors work in partnership with one another.

Section 4: Findings and recommendations

Coverage and value of the CNS role for secondary breast cancer

The findings from this research show that the current level of specialist nursing available to support people with secondary breast cancer is well below the level of need. Furthermore, the evidence suggests 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.

Our survey showed that only 21% of organisations that responded had one or more CNS dedicated to secondary breast cancer. See Figure 2, p15. A further 33% of organisations reported that they had one or more CNSs employed to provide support to people with either primary or secondary breast cancer. These are referred to as combined roles, which means that these nurses are responsible for both primary and secondary breast cancer patients as part of their agreed job role.

However, we found that 47% of these combined roles spend less than a quarter of their time with people with secondary breast cancer. While it is important to recognise that the number of people with primary breast cancer is greater than the number with secondary breast cancer, this result highlights that many nurses in a combined role have much less time to devote to secondary breast cancer patients.

‘We have limited time to spend with patients with secondary breast cancer, as primary breast cancer tends to be the main focus.’

Survey respondent

‘Difficult to achieve [the benefits of the CNS] fully within the constraints of a combined role – the primary breast cancer role always takes precedence in practice.’

Survey respondent

The survey also showed that 42% of organisations across England, Wales and Scotland have no specialist nursing provision solely responsible for people with secondary breast cancer, excluding roles that are combined.

This is in stark contrast to the level of specialist nursing provision for people with primary breast cancer. According to the **Cancer Patient Experience Survey 2015** in England²², 95% of patients with primary breast cancer were given the name of a CNS who would support them through their treatment. At the time of writing, data provided specifically on non-primary and patients with secondary breast cancer was not immediately available from existing patient experience analyses for Scotland or Wales. We note that the most recent Welsh Cancer Patient Experience Survey included questions on patients with secondary breast cancer, and we look forward to viewing this data on release in May 2017.

Of those who completed our survey, 76% indicated that the amount of specialised nursing provision for secondary breast cancer is not enough. Even in just those organisations that do have a dedicated specialist provision, over half (59%) said that the amount of specialist nursing provision was not enough. This finding was supported by our interviews with staff and patients.

Despite around 90% of the patients we interviewed being assigned a nurse specialist (these were sites with one or more dedicated CNSs for secondary breast cancer), many told us that these nurses were under incredible pressure, were often difficult to contact, and were often reacting to issues as they arose rather than being in a position to regularly review and plan

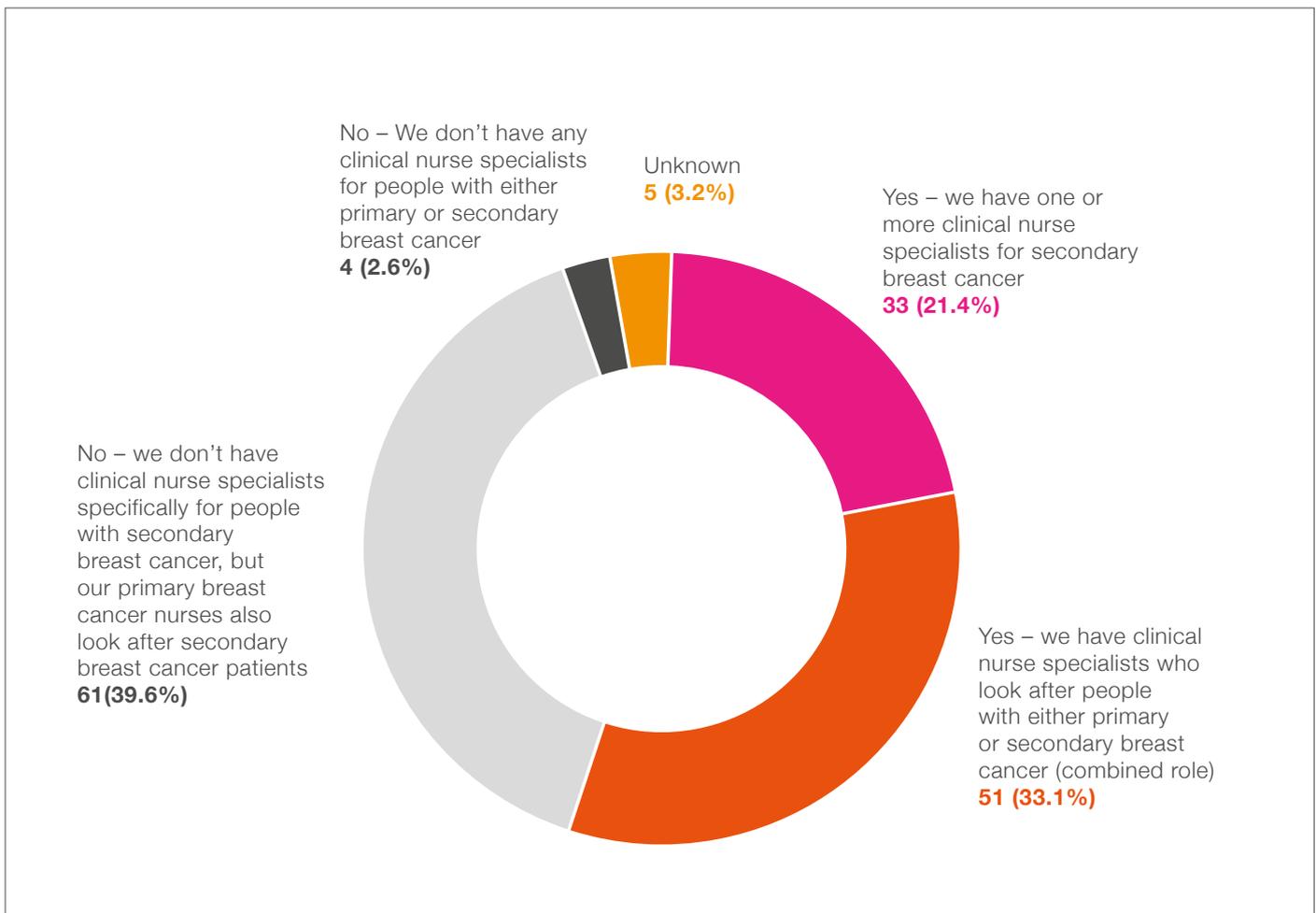


Figure 2: Coverage of specialist nursing provision for secondary breast cancer in England, Scotland and Wales

patients' ongoing support needs. This is reflected by the fact that only 40% of patients said they had received help for social needs, 17% had undergone an assessment of their psychological needs, and just under half (49%) had been referred to services in the community.

While we do not expect that all patients will need a psychological assessment or additional support at home and/or through community-based services, these results seem particularly low within the context of what might be expected for this patient group. For example, one source estimates that the prevalence of psychological distress among breast cancer patients is around a third (32.8%)²³.

The staff we spoke to estimated that each full-time CNS for secondary breast cancer might typically be able to reach around 20–30% of patients with secondary breast cancer on the caseload for that organisation²⁴.

Despite this limited national coverage, and limited reach into the population of people with secondary breast cancer, the value of the CNS role for patients with secondary breast cancer has been well documented in previous research²⁵. Our research supports these earlier findings and provides additional insight into the key features of a high-quality service for patients with secondary breast cancer. For example, around two thirds of respondents to our survey identified the main benefits of the CNS role for breast cancer as:

- supporting patients to make decisions relating to their treatment and care (66%)
- giving patients the information they need to distinguish potential disease progression and side effects of treatment (63%), and
- supporting patients to access symptom control to maximise quality of life (62%).

Other benefits included ensuring patients know how to access help out of hours, and ensuring patients are informed about the health and social care services available to them. See Figure 3, p16.

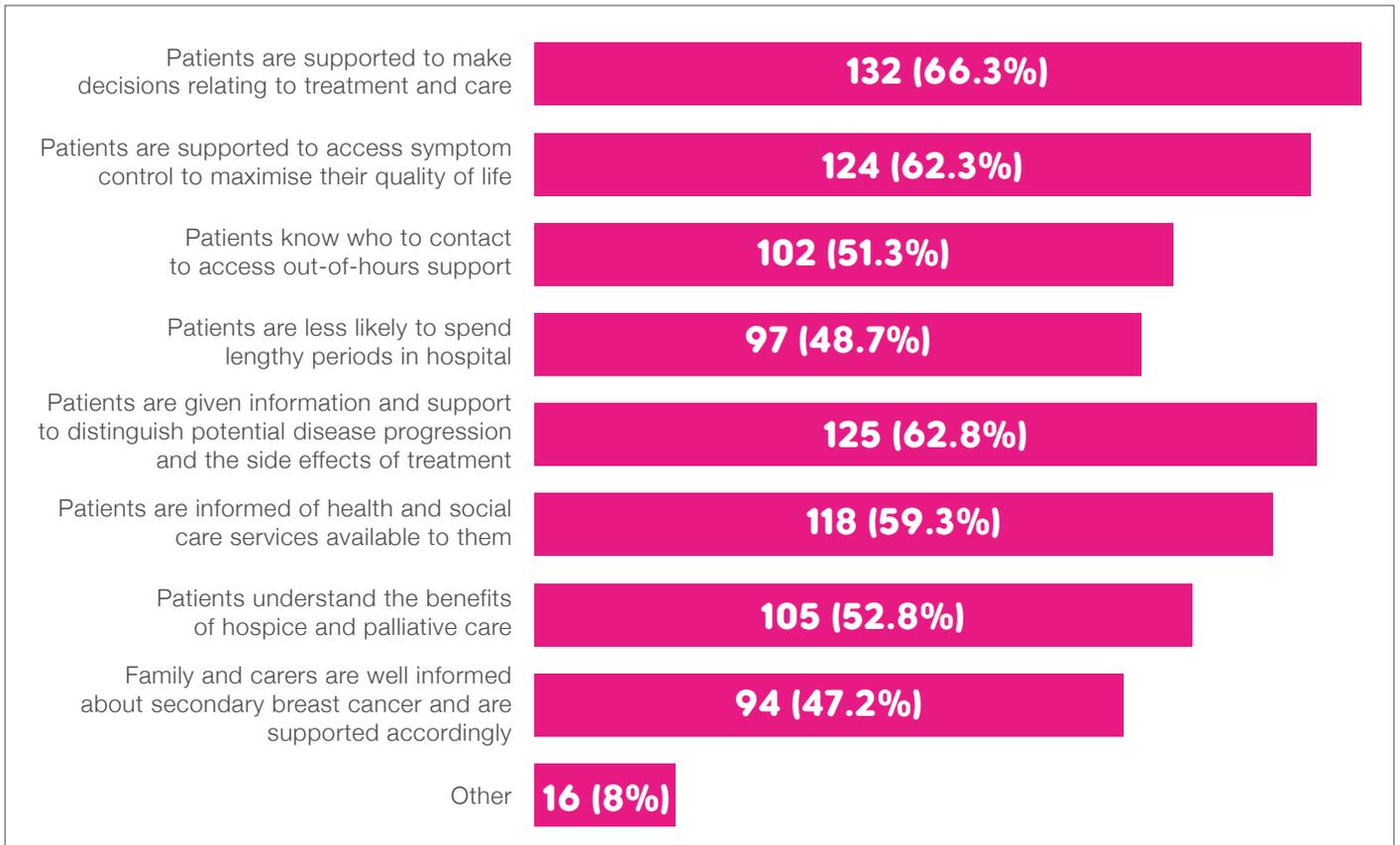


Figure 3: Staff reported benefits of the CNS role for breast cancer



Maximising CNS value through nurse-led care

Organisation: The Christie NHS Foundation Trust, Manchester, England

Type: Specialist Cancer Centre

The Christie is an internationally recognised centre for the treatment of cancer, providing services to 3.2 million people across Greater Manchester and Cheshire. It also provides services to patients from across the UK.

The Christie is the largest single site cancer centre in Europe, treating more than 44,000 patients a year. This case study highlights how it has maximised resources through nurse-led care and stratification of patient follow-up, which may be an adaptable approach for other sites.

The Macmillan Secondary Breast Care Nursing team at The Christie provides a service for approximately 300 newly diagnosed secondary breast cancer patients per annum. The team has 2.5 whole-time equivalent CNSs dedicated to secondary breast cancer.

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

The team has recently introduced a nurse-led clinic for all new patients with secondary breast cancer. Newly diagnosed patients attend a 45-minute appointment with the CNS around four weeks after their diagnosis. The team feel this time allows patients to focus on their initial medical treatment plan and therefore to

be in a better position to raise questions and concerns, and think about the additional care and support they need at the time of the first nursing assessment.

The CNS carries out a holistic needs assessment (HNA), which includes using a modified version of the Hospital Anxiety and Depression Scale and concerns checklist, and patients are allocated a follow-up pathway according to their disease burden, level of psychological support required and results of the HNA. The team is currently working on a stratification model for appropriate follow-up.

The service tries to 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. The team has developed and now delivers biannual health and wellbeing days to help empower people living with secondary breast cancer and enable them to act on issues early.

The team feels that this is a more 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 the nursing resources they have 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.

Our interviews with staff also highlighted that specialist nurses for secondary breast cancer play a vital role in the wider multidisciplinary team, supporting other healthcare professionals and acting as a key source of advice, information and support for patients.

The staff we spoke to felt that the CNS was often best placed to carry out a truly holistic needs assessment with people who have very complex medical and non-medical needs. They felt that having a CNS for secondary breast cancer would likely contribute to reducing unplanned emergency admissions, reducing A&E attendances, improving clinic utilisation (including chemotherapy clinics) and reducing the number of outpatient attendances needed. However, we were unable to quantify these potential benefits in any of the sites we visited due to the limited data available on patients with secondary breast cancer. Just under 50% of the respondents to the mapping survey said that patients were less likely to spend lengthy periods in hospital when they had access to a CNS.

The patients we interviewed reported improved patient experience from having a named professional, and someone they felt they knew well and could talk to about their treatment and/or social circumstances. However, even among those who did have access to a CNS for secondary breast cancer, or a CNS that supported both primary and secondary breast cancer patients, less than half said that they agree or strongly agree that (see Figure 4, p19):

- they knew where to go to for information and support outside the hospital (47%)
- they had someone to help coordinate different treatments, help and support for themselves and their family (42%).

Based on our discussions with patients during the interviews, these feelings were most commonly due to delays in being assigned a specialist nurse or due to difficulty making contact with the CNS who had been assigned to them.

‘Assigned a specialist nurse only after six months.’

Patient with secondary breast cancer

‘I self-referred to services in the community... I also self-referred to a support group, received help to manage better at home through [a cancer charity], and via my workplace for help at work. I met lovely people at a patient focus group, and was referred via my oncologist.’

Patient with secondary breast cancer

‘Nurse specialist wasn’t available at beginning.’

Patient with secondary breast cancer

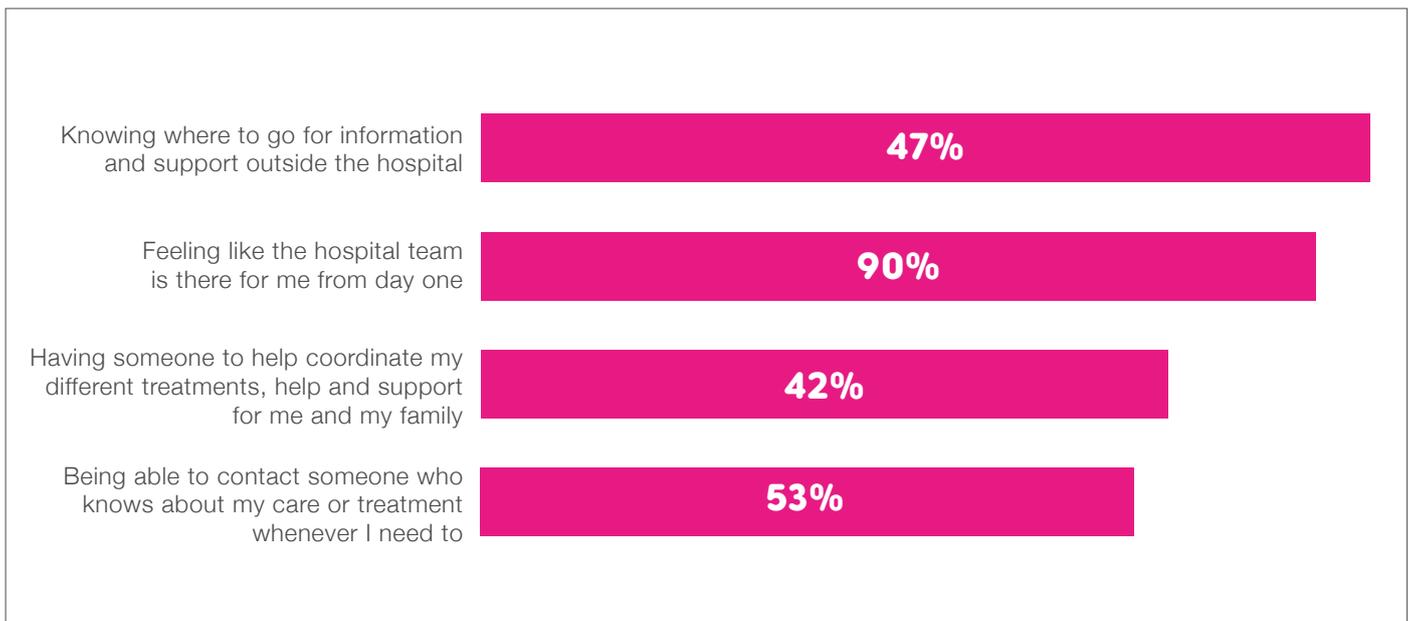


Figure 4: Extent to which patients agreed or strongly agreed with statements about their care

We found considerable variation locally in the way in which breast care teams work to deliver the best care they can for patients. These differences are often driven by local factors such as the physical location of staff (for example, breast care services may be provided across a number of sites), the number of specialist nurses for breast cancer available in the team and the availability of support services in the local community (such as a local hospice or other voluntary sector organisation).

In some organisations, staff described how the CNS for secondary breast cancer worked primarily alongside oncologists in the outpatient oncology clinic, whereas others described how the CNS engaged with patients through nurse-led telephone or outpatient clinics. In some organisations we observed close links between the surgical and oncology teams, which patients told us they felt offered them greater support at the point when they were diagnosed with secondary breast cancer. In those organisations with a greater distinction between the two teams, patients tended to report a greater feeling of being left to fend for themselves early on after their secondary diagnosis.



Empowering patients through strong multidisciplinary team working and access to supportive care services

Organisation: Velindre NHS Trust, Velindre Cancer Centre, Cardiff, Wales

Type: Specialist Cancer Centre

Velindre Cancer Centre is a specialist cancer centre providing services to over 1.5 million people across South East Wales and beyond. Each year the centre treats over 5,000 new patients. Delivering patient-centred care is a key part of Velindre's ambition, and Velindre NHS Trust has been asked by the Welsh Government to develop bold and exciting plans for patient-centred cancer services in South East Wales.

The breast care team is committed to delivering a truly multidisciplinary service for people with secondary breast cancer. The team introduced one of the first dedicated weekly multidisciplinary team meetings for secondary breast cancer following the trust's involvement in Breast Cancer Care's Secondary Breast Cancer Taskforce. Velindre employs five Breast CNSs: one Breast Oncology Clinical Nurse Specialist, three Advanced Nurse Practitioners, and one who specialises in bone health.

In addition to medical and nursing staff, a range of other professionals work as part of the team, including a clinical psychologist, physiotherapist, palliative care consultant, welfare rights officer and a lead professional for complementary therapies. One of the oncology team works two days a week as a GP associate to help bridge the gap between secondary (acute) and primary care, and support GPs to take on the role of care coordination for patients undergoing active treatment. All new patients are assessed

holistically by a CNS once a diagnosis of secondary breast cancer has been made.

In order to help improve care from diagnosis, patients also receive a treatment summary – a 'hand-held' paper summary of their treatment and care plan (as a four-page A5 size booklet) with detailed signs and symptoms of secondary disease and important contact numbers for advice.

Velindre also benefits from an on-site supportive care team, which brings together support workers, welfare rights advisors, chaplaincy, and a dementia nurse specialist. 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 supportive care team forms part of the multidisciplinary team, and is a key part of the whole care pathway. The team has developed strong links with a local hospice, as well as other local services, including family support.

The breast care team believes that the demand for ongoing non-medical support has increased because of its efforts to integrate this type of care into the team, and to reach out to patients earlier and in a more structured way. 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.

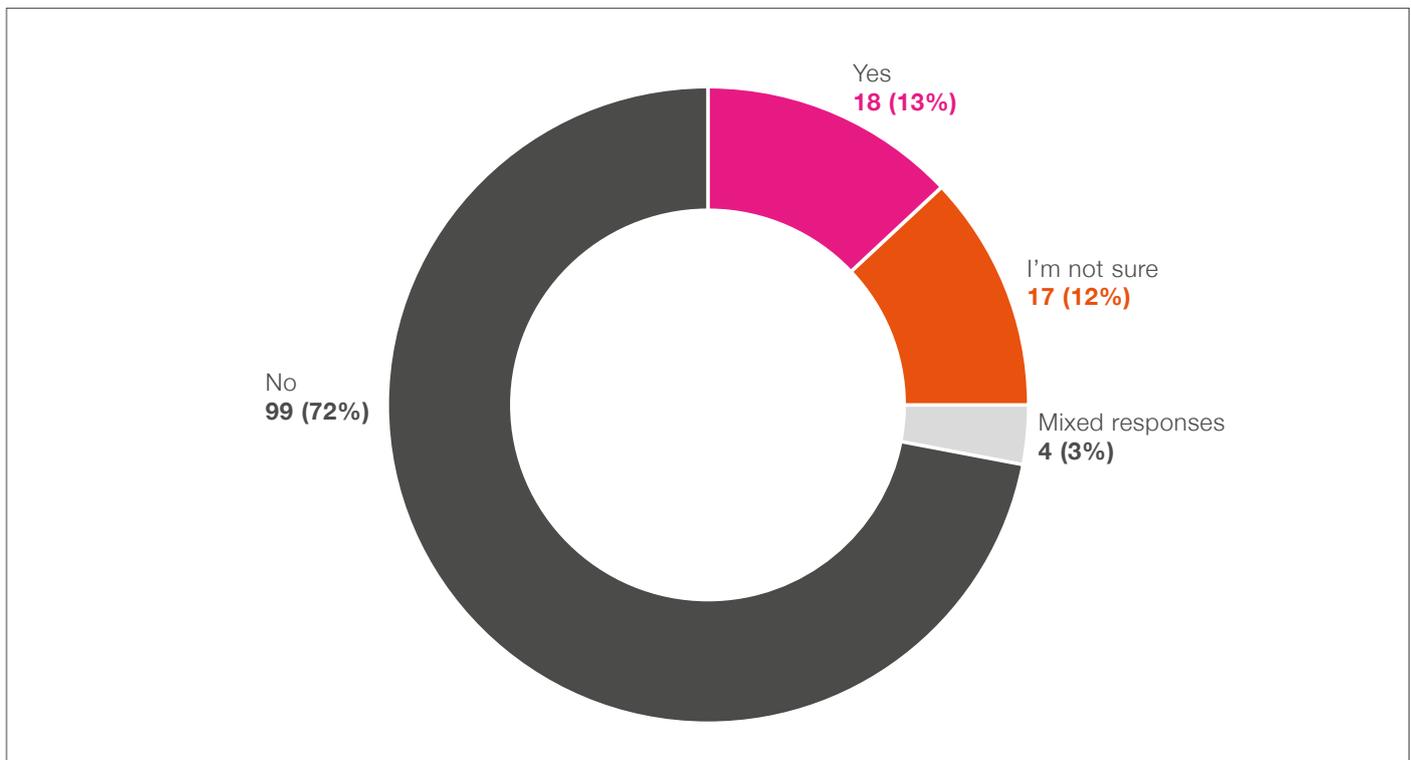


Figure 5: Proportion of organisations with a documented care pathway for secondary breast cancer

The extent to which community nurses and other community-based services link in with the hospital team also varies, in some cases being more formalised through their representation at multidisciplinary team meetings or regional networks, and in others being more informal through the connections and knowledge that individual staff have acquired over time.

There were also a number of common features in the way services are organised.

- Three of the eight sites we visited hold a weekly multidisciplinary team meeting specifically to discuss patients with secondary breast cancer, acting as the main mechanism for identifying patients needing specialist nursing or other non-medical input (for example, psychological assessment or signposting to community information and advice services). Two sites hold multidisciplinary team meetings that cover both primary and secondary breast cancer patients. Given that seven of the eight sites we visited have some specialist nursing provision for secondary breast cancer, the proportion of organisations with breast cancer multidisciplinary teams among our sample is likely to be much higher than the proportion nationally, and this ties in with anecdotal evidence.
- An initial assessment of non-medical needs is usually undertaken by a CNS, although this doesn't always follow a prescribed format and

may not always happen until some months after diagnosis.

- Documented care pathways are not yet adopted by hospitals across the UK as a meaningful tool to structure services for secondary breast cancer; 72% of nurses who responded to the mapping survey said that their organisation had no care pathway for secondary breast cancer patients²⁶. See Figure 5, above.

Where we received more than one response from a single organisation, and where the responses given were different, these have been recorded as mixed responses in Figure 5.

Our discussions with staff also highlighted that many services lack meaningful tools to monitor patient numbers and caseloads, which can leave teams without a robust evidence base for resource planning, and limited ability to track patients through the system.

Breast Cancer Care has covered this issue extensively in our previous report **Secondary breast cancer – Part two: Who's counting** about data collection in England's hospital trusts. Our nursing research showed that as a result, some patients miss out on appropriate follow-up nursing assessment and review as their disease progresses. This lack of data is also hampering efforts to improve the quality of services locally.

Building connections within the hospital and with external partners to make best use of limited CNS time and improve patient experience across the whole pathway.

Organisation: United Lincolnshire Hospitals NHS Trust, Lincolnshire, England

Type: General Acute Trust

United Lincolnshire Hospitals (ULH) NHS Trust is one of the biggest hospital trusts in England, serving a population of over 750,000 people. The trust operates services from four main hospital sites: Lincoln, Grantham, Boston and Louth. Services are also provided in a range of community settings. ULH covers a diverse urban and rural population, characterised by high levels of deprivation in some parts of the county, and an ageing population. In more rural areas of the county, even accessing a GP can be a problem.

Trust-wide there are currently 4.6 whole-time equivalent specialist nurses for primary breast cancer. The breast care team also benefits from a Trainee Advanced Nurse Practitioner, although this role works largely with primary breast cancer patients. A 0.6 whole-time equivalent senior breast care support nurse attends the oncology outpatient clinic each week, working closely with the oncology consultants to identify and support secondary breast cancer patients with non-medical needs, often referring patients and their families to the services of a local hospice, which provides support for anyone living with a life-limiting illness, not just at the point when they have palliative care needs. However, this level of specialist nursing can only reach a fraction of the patients in need of support.

Within the context of an incredibly challenging financial position, the breast care team is focusing efforts on making the most of the very limited specialist nursing resource available

to support secondary breast cancer. This is happening by building links across teams within the trust and with external partners across the region. The aim is to foster greater inter-disciplinary cooperation between its own services and strengthen collaboration with those in the community. In particular:

- rolling out level 2 psychological support training for all specialist nurses in the breast team, enabling those working with primary breast cancer patients to provide additional emotional support for secondary breast cancer patients around the point of diagnosis
- increasing awareness of the value of the CNS role through regional commissioning groups and as part of the development of the local sustainability and transformation plan
- developing agreed care pathways and standard operating procedures to improve care coordination and information sharing between nurses in the breast care and chemotherapy teams, and with key services in the community
- reviewing the role of the on-site Cancer Information Service so that it becomes more embedded in the care pathway for people with secondary breast cancer and can play a role in reaching out to more patients with complex support needs.

Given its limited specialist nursing provision, with none specifically dedicated to secondary breast cancer, the trust believes these efforts will help to make better use of resources across the whole care pathway, with the CNS becoming more of a care coordinator and bridge between hospital and community.

Recommendations

We know that secondary breast cancer can have a dramatic impact on the quality of life of the person diagnosed, and that access to a CNS can greatly improve their ability to live well. As outlined in the **Cancer Strategy for England**, the support of a CNS is the most important contributing factor to people's positive experience of care. The strategy states that CNSs 'play a crucial role in providing information, enabling communication and in coordinating care'. It also notes that there is a current shortage of CNSs across all tumour sites and that they are sometimes used inefficiently, spending time on tasks other than providing specialist care. Scotland's key policy document for cancer, **Beating Cancer: Ambition and Action**, notes that a wide range of skilled staff are required to provide advice, support and targeted care to people with cancer.

It is clear from our findings that the current provision of specialist nursing for people with secondary breast cancer in England, Scotland and Wales is not enough, and that there is a great disparity between this provision and the care provided to people with primary breast cancer.

Despite our evidence showing the positive value of the CNS role, many organisations have no dedicated specialist provision whatsoever for people living with secondary breast cancer. More needs to be done to ensure that people living with secondary breast cancer have access to a specialist nurse to improve their patient experience.

Around two thirds of respondents to our mapping survey identified the main benefits of the CNS role for secondary breast cancer as the ability to provide care, specifically through supporting patients to make decisions relating to their treatment and care, giving patients the information they need to distinguish potential disease progression and side effects of treatments, and supporting patients to access symptom control to maximise quality of life.

We believe that the role of the CNS is integral to ensuring effective standards of care are met for every person living with secondary breast cancer as the CNS is responsible for ensuring that many of the above services are provided.

We recommend that our Standards of Care (see page 24) be adopted in each hospital trust/health board to improve the patient experience.

Standards of Care

To support the provision of care and support for people with secondary breast cancer, Breast Cancer Care developed Standards of Care for people with secondary breast cancer. These standards were developed in conjunction with people living with secondary breast cancer, healthcare professionals and other relevant stakeholders, and relate to three key areas: **information and support**, **treatment and care**, and **palliative and supportive care**. People living with secondary breast cancer should be able to expect the following.

Information and support

- Timely, high-quality information and support at diagnosis and onwards from a CNS who is skilled and knowledgeable in the treatment and care of people with secondary breast cancer.
- A CNS who will act as a point of contact, be an advocate, help coordinate treatment and care planning, and signpost/refer people to relevant support services (including those provided by Breast Cancer Care).
- A comprehensive assessment of emotional, physical and information needs at any time necessary, but especially when first diagnosed, if the cancer progresses and if treatment changes. This should include assessment of any symptoms of the disease and side effects of treatment.
- To be aware of and be referred to local and national supportive, health and wellbeing services to address problems and help improve quality of life. Services should include psychological support and a range of opportunities to meet or talk to others with secondary breast cancer.
- To be signposted or referred to specialist services for expert financial and employment advice. This should include information on benefits they may be entitled to and rights at work, as well as managing the impact of any loss of income.

Treatment and care

- To be given a clear and personalised plan of all aspects of their treatment and care in a way that is most useful to them. People living with secondary breast cancer should have the opportunity to discuss the aim of treatment with their specialist and, where available, the opportunity to participate in clinical trials. This discussion should include expectations of treatment, the goals of treatment, and how treatment may affect quality of life and wellbeing.
- Have the treatment and care reviewed when necessary by an experienced multidisciplinary team. This is made up of all the healthcare professionals who contribute to care including specialists in palliative and supportive care when required.
- Expect good communication between all members of the hospital and other healthcare teams, including the GP, ensuring that everyone is informed regularly about their condition and any changes in the care plan, so that the patient is provided with the support and care they need.

Palliative and supportive care

- Receive timely information on the benefits of local palliative and supportive care services for patients and the people closest to them. Be referred for specialist input as soon as needed for symptom control, and access to advice and treatment out of normal working hours.
- Support and guidance from a healthcare professional on talking to those closest to them about the impact of living with secondary breast cancer. Be offered support for family from a healthcare professional so that their current and possible future needs can be identified and addressed separately.
- Sensitive and timely advice and support for them and their family on planning end-of-life care. There should be the opportunity to discuss wishes with whoever they feel most comfortable with in the treatment team, meaning that all those involved with their care are fully aware of patients' wishes and the patient has control and confidence in the choices they make.

In order to address some of the problems we have found in providing this level of care through the absence of a CNS (or other structures that reduce their effectiveness), we also recommend that additional investment is provided to ensure that all hospital trusts in England and all health boards in Scotland and Wales are able to provide a CNS for people living with secondary breast cancer, either through dedicated or combined roles. Crucially, this person must have the right knowledge, the right skills, the right experience and enough time to care for people living with secondary breast cancer, ensuring they are provided with the Standards of Care on p24.

The level of provision should be determined by the trust and its clinical commissioning groups (CCGs) in England or by health boards in Scotland and Wales, depending on local variables (such as the number of people living with secondary breast cancer in the area, the style of care that may work best within that particular unit or the services already available in the community, and others). However, it must be sufficient to ensure that all people with secondary breast cancer have a holistic needs assessment (HNA) to identify patient needs at key stages throughout their treatment, as per our Support Package recommendation in our previous report **Secondary breast cancer – part three: Support and impact**. During this HNA, patients should be referred in the hospital or provided with comprehensive information about how to access care and support services in the community appropriate for their needs, as per our Standards of Care. As outlined above, our research has shown that the HNA and robust signposting are the two most important drivers of improving patient experience and maximising the value and impact of the CNS role.

The **Cancer Strategy for England** currently states that NHS England and the Trust Development Authority should encourage providers to ensure that all patients have access to a CNS or other key worker from diagnosis onwards, to guide them through treatment options and ensure they receive the appropriate information and support. Breast Cancer Care welcomes this position, but we also acknowledge that since the publication of the strategy there has been little published progress in this area.

Beating Cancer: Ambition and Action for Scotland states that the Scottish Government will put the 'necessary levels of training in place

to ensure that by 2021 people with cancer who need it have access to a specialist nurse during and after their treatment and care'. It also states that workforce planning for cancer will move to be undertaken on a national basis over time, and will ensure that workforce planning for cancer will span the entire cancer pathway, complementing **Everyone Matters**, another Scottish cancer policy document that states that the Scottish Government will strengthen workforce planning to ensure the 'right people, in the right numbers, are in the right place at the right time' to deliver seamless healthcare. Again, Breast Cancer Care welcomes this position, but we acknowledge that these terms are quite broad, and are not specific to any tumour site or to metastatic cancers.

The **Wales Cancer Delivery Plan** states that a key worker (a person responsible for coordination of care that is usually a CNS) can make a significant difference in a person's experience of cancer services, acknowledging that the cancer pathway is complex, and that this person is fundamental to help the patient navigate the pathway and ensure a smooth patient journey. Breast Cancer Care welcomes this position and notes that a key service measure outlined in this document is the allocation of a key worker, who is usually a CNS. We would encourage the Wales Cancer Network, responsible for meeting the requirements of the Wales Cancer Delivery Plan, to ensure this deliverable is met.

In light of this policy context in England, Scotland and Wales, Breast Cancer Care recommends that the relevant responsible bodies take greater affirmative action in ensuring there is an equitable provision for metastatic patients in their geographical areas of jurisdiction. In England, the CCGs are responsible for ensuring that NHS trusts are appropriately resourced, while this responsibility rests with health boards in Scotland and Wales. These bodies should prioritise the allocation of appropriate funding relevant to patient need, to ensure that an appropriate level of specialist nursing is provided for people living with secondary breast cancer. In England, Cancer Alliances also represent a prime opportunity to ensure that there is a sufficient network of support provided for CNSs due to their ability to bring together local clinical and managerial leaders from providers and commissioners who represent the whole cancer pathway.

We also suggest, as per our recommendations in our previous report on data, **Secondary breast cancer – Part two: Who’s counting**, that data on the number of people living with secondary breast cancer be collected immediately to ensure that these bodies can plan and provide these necessary resources for their jurisdictions.

Our research also shows that despite the value of the CNS role being clearly recognised in improving the patient experience of people living with secondary breast cancer, many nurses are unable to spend enough time to care appropriately for their patients with secondary breast cancer. While we acknowledge that each NHS trust or health board has a different internal structure that may affect the way secondary breast cancer patients are dealt with, Breast Cancer Care recommends that breast care units in England, Scotland and Wales introduce a risk stratification process that aims to increase the value of the CNS role to people living with secondary breast cancer.

Breast care units could identify patients that require different levels of specialist nursing intervention around the point of diagnosis in a risk stratification process. This classification should, in part, be based on an HNA conducted at several stages throughout their treatment plan, as per our Support Package recommendation in our previous report; **Secondary breast cancer – Part three: Support and impact**. Based on this risk stratification process, limited specialist nursing resources can be focused on those most in need. Using a tool such as the HNA that is conducted not just at diagnosis but also as the cancer progresses, as the treatment changes and toward the end of life, changes in a patient’s level of need (or risk) can be picked up and more resources allocated as needed. Our case study on The Christie (p17) highlights how they have maximised the resources available to them through nurse-led care and risk stratification, which may be an adaptable approach for other sites.

In conjunction with a risk stratification process, we also recommend that more work is undertaken around care pathways for people with secondary breast cancer. Our research has shown that services aren’t structured around patient need, and often referrals occur informally rather than through a clear and structured care pathway that both the healthcare professional and patient are aware of. We feel that care pathways may be part of the solution as they may help to allocate resources at the right time, and also provide the patient with a clearer outline of what their cancer journey might look like, helping to resolve feelings of uncertainty and lack of coordination.

The role of the ‘support worker’ for people with secondary breast cancer

The results of our survey show that only four NHS organisations in England have a non-nurse support worker for people with secondary breast cancer. None of the organisations in Scotland or Wales indicated in our survey that they have this type of role. In all but one organisation, support workers worked alongside one or more CNSs for secondary breast cancer, typically providing emotional support and helping to coordinate appointments and multidisciplinary team discussions. One organisation described the role as being to ‘support patients emotionally and psychologically’ and to help patients ‘to learn to live with secondary cancer’. The support worker also has a coordination role in this organisation, including coordinating scans and appointments for patients, ensuring that multidisciplinary team discussions take place when needed, and liaising with the oncologists who are based at a different hospital site. The support worker also has a responsibility for running a monthly support group for patients with secondary breast cancer.

Staff in all the sites we visited were supportive of the idea that responsibility for the overall care coordination plan for some patients could be taken on by a non-nursing support worker role. This role would need strong administrative and communication skills, along with a good understanding of the local services available and how to access them. This is particularly important in light of current workloads for many CNSs, and evidence that care coordination is an important driver of improved patient experience for this patient group.

Providing an additional point of access and care co-ordination through the role of a non-nurse key worker

Organisation: Homerton University Hospital NHS Trust, London, England

Type: General Acute Trust

Homerton University Hospital provides general and specialist health services, both in hospital and in the community, across the London Borough of Hackney and the City of London. The trust's staff work out of 75 different sites. The local population is culturally diverse, and the trust serves a relatively young population, with only 18% of the population in Hackney over the age of 55. Around 45% of residents are from a black or minority ethnic background.

Services for people with secondary breast cancer are provided jointly with Barts Health NHS Trust, which means that medical oncology appointments and chemotherapy services for most patients are provided at St Bartholomew's Hospital in the City of London. However, the Homerton does continue to provide follow-up monitoring and support.

The breast care nursing team consists of two whole-time equivalent CNSs. They work closely with a cancer information and support manager, who acts as a non-nurse key worker and additional access point across all tumor-treating sites. This includes face-to-face work with secondary breast cancer patients.

Sharing responsibility for providing advice and information on a wide range of care and support needs alongside the nursing team, the information and support manager also liaises with services within the hospital and in the local community for individual patients and their families. This involves signposting patients to the correct services for support, and covering issues such as access to palliative care, family support, referral to community nursing and immigration (this is a particular issue within the local community).

By having a physical presence on-site, this non-nursing support role provides direct support to the CNS team, offering both telephone and face-to-face contact, especially when a CNS may not be available. The cancer information and support manager has a background of both nursing and working in community organisations, and is therefore well-placed to build new connections and provide advice for both staff and patients. This reduces pressure on the nursing team and enables them to focus on more specialist clinical work. The role has evolved to include more outreach work, rather than being a passive information point that people can approach, which directly supports the CNS role by reducing follow-up questions and improving general care.

Recommendations

It is clear from our field work that there are few examples of a support worker role, defined for the purposes of this discussion as a person enlisted to support the breast care team with non-clinical tasks, as opposed to a named key-worker that would coordinate the care of a person with secondary breast cancer, usually a CNS. Nurses and other healthcare professionals we spoke to agree that a support worker role could reduce the burden on the CNS, a role which we know is already stretched.

This is supported by a clear policy drive towards the use of support workers for patients with cancer. In England, the **Cancer Strategy** states that efforts should be made to 'systematise

patients having access to a CNS or other key worker to help coordinate their care', so that patient experience can be on a par with clinical effectiveness and safety.

The strategy describes the role of the CNS or other key (support) worker as guiding patients 'through treatment options and ensuring they receive appropriate information and support'²⁸.

While **Beating Cancer: Ambition and Action** does not make specific mention of the use of support or key workers, it does mention that the Scottish Government will invest to support access to health and social care services during and after treatment via, for example, the National Links Worker Programme that works in a similar way. A links worker is a person who works between

the primary care team in the hospital and the patient to enable better access to information, knowledge, skills, relationships and resources. The **Cancer Plan for Children and Young People** in Scotland also states that it is a priority for people with cancer to have an 'identified key worker at every stage of the care pathway'.

The **Wales Cancer Delivery Plan** makes reference to the role of the key worker, stating that 'the cancer pathway is complex and a named key worker is fundamental to help the patient navigate the pathway and ensure a smooth patient journey'²⁹. However the plan also recognises that the role of key worker will usually be undertaken by the CNS 'who as part of a wider multidisciplinary team coordinates treatment and care'³⁰. This is contrary to our suggestion of the support worker, who would be an additional role in the breast care team, taking on non-clinical tasks to support the CNS.

In 2012, Macmillan Cancer Support embarked on a project to pilot new workforce roles that provide one-to-one support for people affected by cancer. One of these new roles is the Macmillan Cancer Support Worker, providing emotional support and practical advice, signposting to a range of other services, and coordinating a person's care and support. The role

non-specialist, working with people who can largely self-manage their care. They work either directly with the CNS team or with community-based support teams. The evaluation of the Macmillan one-to-one support pilots found that the support worker role can 'help [the] CNS to manage a bigger caseload by taking on some of the less clinical and specialist areas of work as well as offering people a single point of contact and continuity'³¹. However, it is not clear from the evaluation report what proportion of patients in the pilots who were assigned a support worker had been diagnosed with a secondary cancer.

There is limited evidence available from our research as to how a support worker role might work alongside a breast care team to support patients with secondary breast cancer as part of the primary care services in the hospital as this role is yet to be embedded in NHS services. However, our findings show that staff and patients could gain significant benefits as the role may help to reduce the burden on CNSs and improve general access to a named professional, which is a key driver of improved patient experience. As per our Homerton case study (p27), the non-nurse key worker role could focus on care coordination, provide non-clinical advice, information and signposting about support services in the community, and patient advocacy.



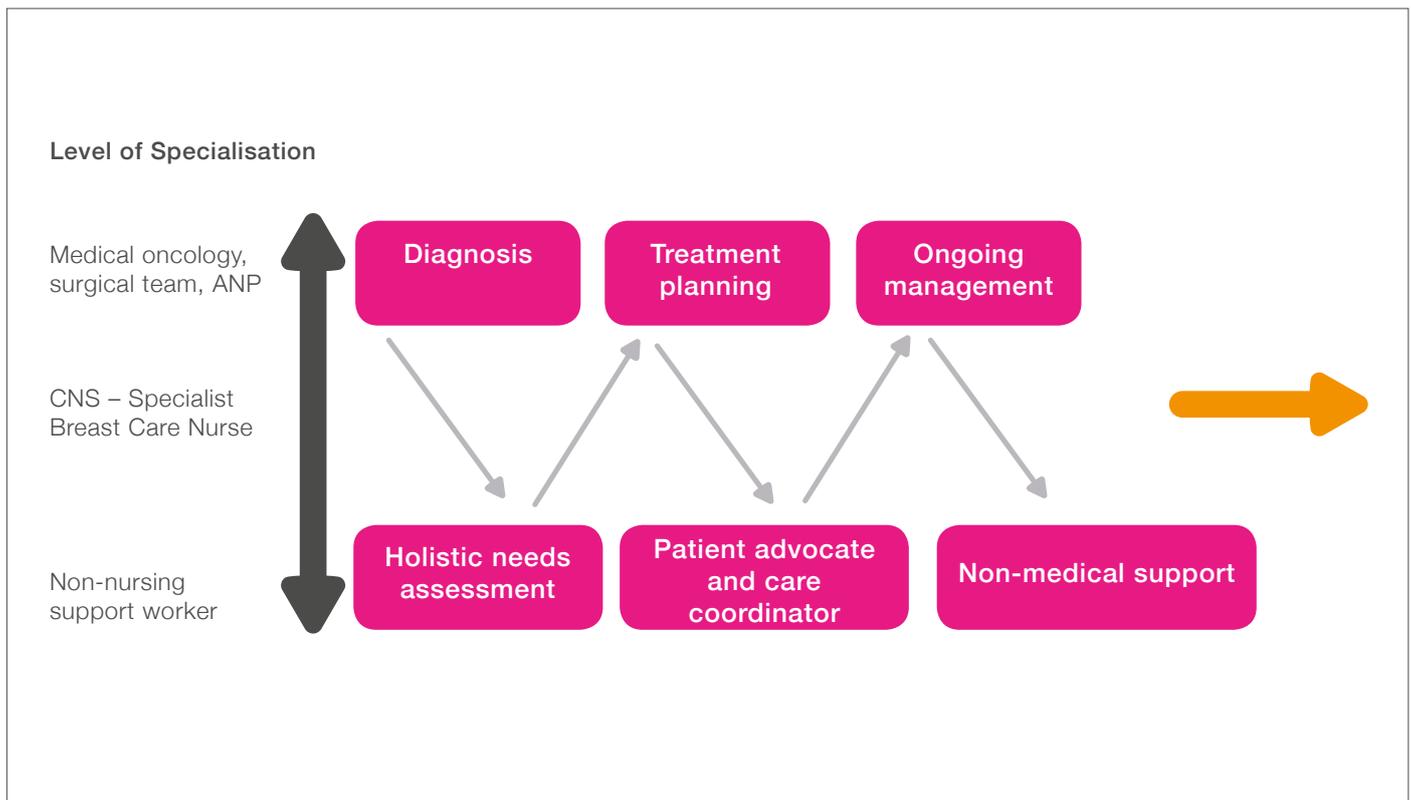


Figure 6: Care for secondary breast cancer patients - role of non-nurse support worker

Figure 6, above, shows the possible ways in which a support worker role might be integrated into existing breast care units. The vertical axis shows the degree of specialisation required for different parts of treatment, while the horizontal axis shows the elements of treatments along the patient journey. This diagram shows that a support worker might be responsible for conducting less clinical type tasks, such as the HNA at diagnosis and throughout key points of treatment, acting as the patient advocate and organiser, and linking in with other non-medical support perhaps outside of the hospital, while the CNS would be freed to focus on more clinical parts of the patient journey, such as treatment planning, treatment options and treatment management, while overseeing the role of the support worker. Breast Cancer Care would encourage breast care units to use this diagram as a model or point of discussion for plans of how best to utilise available resources and staff to improve the patient experience, as per our Standards of Care (p24).

In saying this, we acknowledge that there is limited practical application of the support worker role for people with secondary breast cancer, and we further recommend that more work be undertaken to understand how such a role can add the most value for patients in line with our Standards of Care, and the wider breast care team.

There is also insufficient evidence from this research to recommend that the support worker role is necessary in every breast care team. However, we strongly encourage further research specifically for secondary breast cancer patients. This should include looking at whether the role should sit within the hospital or as part of a service within the community, and how it might work alongside specialist nurses and other professionals as part of the multidisciplinary team. We also recommend that it is considered within local planning discussions – especially given the current financial constraints on the NHS – as a lower-cost option for improving patient experience and allowing the CNS to focus on those patients with the most complex needs.

Enhancing the community support offer across the whole care pathway

We have looked at specialist nursing provision for secondary breast cancer within the wider system of care across both hospital and community services. Within this, we identified the functions performed by different staff including oncologists, CNSs, community nurses, and staff within voluntary and community sector organisations.

As expected, we found that people living with secondary breast cancer have complex and wide-ranging needs, which change as they live longer with the disease. Successfully meeting these needs requires a holistic and multi-agency response across the health and care system.

During our site visits, we identified a number of different ways in which breast care teams link patients with support services in the community. These included:

- the development of a successful partnership with a local hospice with staff from the day therapy service having close links with the hospital's multidisciplinary team meeting (at NHS Highland)
- systematic identification of non-medical needs through a formalised HNA process, with active referrals towards local support agencies from inside the hospital at the point of assessment (at The Christie NHS Foundation Trust, Nottingham University Hospitals NHS Trust and Northumbria Healthcare NHS Foundation Trust)
- the use of Cancer Information Centre managers as a point of referral and follow-up for patients with specific support needs (at United Lincolnshire Hospitals NHS Trust and Homerton University Hospital NHS Foundation Trust).

Around two thirds of the organisations that responded to our mapping survey also said that they had formal or informal links with local services that provide care and support for people with secondary breast cancer. Within those organisations:

- 47% mentioned links with a local hospice
- 42% mentioned links with a peer support group
- 32% mentioned links with a local cancer centre run by a cancer charity.

However, many patients also told us that they felt as though they had to 'fend for themselves' in terms of accessing support on a range of issues such as financial advice, emotional support, communicating with children and other family members, and accessing respite and palliative care services. People often found out about support in these areas through word of mouth, or through other places in their local community. This supports our previous report **Secondary Breast Cancer – part three: Support and impact**, which outlines the difficulty people living with secondary breast cancer have in accessing existing support services. For example, in Breast Cancer Care's own cancer patient experience survey that underpinned the Support and Impact report, we found that:

- only 28% were made aware of palliative care services
- only 36% were made aware of counselling or psychotherapy
- only 44% were made aware of local breast cancer support groups or opportunities to speak with other people with secondary breast cancer.

Given the range of services provided, not just by Breast Cancer Care but by other charities too, it is disappointing to see so few were made aware of the support available to people with secondary breast cancer.

Adopting a multidisciplinary approach to the assessment and review of non-medical needs to facilitate early signposting and referral to support services

Organisation: Northumbria Healthcare NHS Foundation Trust, Northumberland, England

Type: General Acute and Community Trust

Northumbria Healthcare NHS Foundation Trust is responsible for the wellbeing of around half a million people across Northumberland and North Tyneside. It covers one of the largest geographical areas of any NHS trust in England. The trust provides hospital and community services, including health and adult social care, across a demography ranging from dense urban populations to sparsely inhabited rural areas, and has recently opened the UK's only dedicated emergency hospital. This has given some of its other sites more space and flexibility in terms of the way services are delivered. The trust's charitable fund also raises funds to support service improvement.

A rigorous multidisciplinary approach means that primary breast cancer services, and the oncology team responsible for people with secondary breast cancer, work together as one team. Combined CNSs for primary and secondary breast cancer are available for every patient when they attend oncology outpatient appointments. Care is reviewed regularly by the specialist nursing team to ensure that patients are appropriately tracked through the system and any follow-up actions are taken. This helps to ensure that changes to a patient's care and support requirements are identified early. Referrals to other services, such as lymphoedema, auricular acupuncture and Macmillan community services, are facilitated as needed by a breast CNS.

The trust's chemotherapy nurses take an active role in the initial assessment of the care and support needs of patients with secondary breast cancer who are receiving chemotherapy treatment. A comprehensive HNA is carried out at the point when chemotherapy starts, which facilitates early signposting and referral to support services elsewhere in the trust, or provided by external partners (for example, advice on benefits or family support services).

All nursing staff receive level 2 psychological support training, and the trust's psychology team provides supervision for nursing staff, in addition to direct patient contact where needed. The trust has a comprehensive inclusion policy, ensuring that the specific needs of secondary breast cancer patients can be met through contact with a range of different hospital and community services. This is supported by partnerships with local charities to help fill gaps in service provision locally, and includes, for example, arrangements to help with transport across the Hexham General Hospital catchment area, and referrals towards the benefits advice surgeries at a local Maggie's Centre for patients at Wansbeck General Hospital (as well as to their local Citizens Advice Bureau or Macmillan benefits officer within their local area). The nursing team is also working with local partners to develop additional in-house services such as complementary therapies.

Staff feel that this approach leads to greater autonomy and empowerment across the whole team, supports a strong nurse-led approach, and gives patients several different points of access to specialist advice and support.

Among the sites we visited we found that specialist staff, and in many cases the hospital-based CNS, often act as a patient's primary point of contact, providing signposting to other services, advocacy and linking people into non-medical support services in the community (such as financial advice, help and support at home, and support with employment or returning to work). However, based on our discussions with

staff and patients, we believe there are more opportunities to consider how some of these functions, including responsibility for assessing a person's non-medical support needs, could be the responsibility of local voluntary and community sector organisations that currently provide support for people with secondary breast cancer. In many cases this could be a local hospice or other cancer support service.

We received feedback from staff and patients about this already happening, typically combined with a very positive patient experience, although more often coming about by chance rather than through a formal referral system or agreed patient pathway. There is also often a misconception among patients that community nurses and other support services (including hospice day services) are there just for the very end of life, meaning that some patients don't access available support early in their treatment.



Partnership working with community services to provide earlier support for patients with non-medical needs across a remote population

Organisation: NHS Highland, Inverness, Scotland

Type: Scottish Health Board

NHS Highland is one of 14 regional health boards in Scotland. The board provides services to a population of 320,000 spread over 32,500 square kilometres, covering some of the most rural and remote areas in the UK. The organisation is responsible for health and social care services across the region, provided from the main district general hospital in Inverness, community hospitals, rural general hospitals, GP surgeries, health centres and care homes.

The breast care team based at Raigmore Hospital in Inverness has no dedicated specialist nursing provision for secondary breast cancer. However, they have two whole-time equivalent breast care nurses who historically have worked only with primary breast cancer patients, but who now provide support for secondary breast cancer patients. This is often around the time of diagnosis, at which point they provide emotional support, counselling, information and advice on benefits and financial assistance, often linking in with nurses and other support services in the community. The CNSs use the cancer concerns checklist as part of their initial assessment, to identify non-medical issues that might require additional support.

There is a weekly multidisciplinary team meeting for breast cancer, where patients with either primary breast cancer or secondary breast cancer are discussed. The meeting is supported by video-conferencing technology to allow professionals not based in Inverness to take part in the meeting. This includes the neighbouring NHS Western Isles.

Given the remoteness of the population across NHS Highland, patients rely on strong links between the hospital and community

services. Staff from the day service at the local hospice have established close working arrangements with the breast care nurses and the wider oncology team. The hospice offers a range of group activities and one-to-one support, supporting anyone living with advancing illness, not just people who need palliative care. The hospice is also building a 'virtual hospice' service, enabling it to reach out to many more people across the region living with a life-limiting illness, to provide support and to help link up professionals involved in a person's care.

There are clear pathways for referral to a local cancer centre, community nurses (particularly in the more rural areas), GPs and the Cancer Information Centre. Coordination of care for people with complex needs is typically provided by the community Macmillan nurse.

While the breast care nurses have an open-door policy for patients at NHS Highland, they are a limited resource, which means that they are not as proactive as they would like to be in terms of patient follow-up after the initial assessment has taken place. Much of this needs to be driven by the patients themselves. This is why it's important for the nursing team to link people in with local support groups and other cancer support services so that there is a mechanism for ongoing review. This includes various patient-led support groups, including a very popular group in the North Highlands, which can be attended by anyone with a cancer diagnosis.

The availability of support services in remote communities will always present a challenge for NHS Highland. However, by working closely with community partners to build formal and informal support networks, and to activate resources within those communities, more people with secondary breast cancer are likely to get the right support as and when they need it.

Recommendations

In light of the learning from the sites that we visited for this research, and the feedback we received in the mapping survey, we believe that there are opportunities to make better use of resources within the community to support people with secondary breast cancer. This would appropriately address the issue our research has highlighted: that despite some trusts providing links to local services, patients still indicated that they feel as though they are fending for themselves, often because staff do not have time to see every patient with support needs and then signpost or refer accordingly. The current agenda between health and social care is one of integration, and we believe that shifting some functions of the in-hospital team out to the wider care and support system would free up CNS time, while at the same time offering a highly responsive and patient-centred model of care that ensures people with secondary breast cancer receive the right support when they most need it.

As shown in the findings, some community support and coordination is already happening, which has helped improve patient experience in some instances. However, as mentioned earlier, it was more by chance than through a formal referral system and agreed patient pathway. We suggest again that further research be undertaken around the benefit of a structured care pathway as a way to improve both the patient experience and the efficiency of breast care teams.

Further, as per the previous two reports in this series, we recommend the introduction of a dedicated multidisciplinary team for secondary breast cancer, or at the very least, a specific section in an existing multidisciplinary team meeting for secondary breast cancer patients to be routinely discussed. We would add to this recommendation here by suggesting that a wider team, including representatives from community-based services, be present in these meetings to ensure a holistic discussion of treatment. This could include representatives from local community organisations such as a hospice or cancer centre.

The **Cancer Strategy for England** addresses the role and structure of multidisciplinary team meetings in recommendation 38, stating 'NHS England should encourage providers to streamline MDT processes such that specialist time is focused on those cancer cases that don't follow well-established clinical pathways, with other patients being discussed more briefly'.

Beating Cancer: Ambition and Action in

Scotland states that MDT meetings should engage with people with cancer, their carers and families to ensure their treatment package is tailored to the person's individual circumstances. The **Wales Cancer Delivery Plan** states in relation to multidisciplinary team meetings that the Wales Cancer Network will evaluate multidisciplinary team person-centred skills – specifically communication and palliative care – and develop and implement an action plan.

While we agree with the above policy direction from England, Scotland and Wales, Breast Cancer Care would build on these actions to encourage not only the separation of people with secondary breast cancer from primary breast cancer multidisciplinary team meetings, to ensure they are given appropriate time and space to be discussed at length, but also that the full range of relevant professionals actively participate in secondary breast cancer multidisciplinary teams. For example, a full holistic treatment should be discussed with not only traditionally clinical healthcare professionals, but also with palliative care representatives, counsellors and other professionals from the community.

Breast Cancer Care also recommends that breast care units in England, Scotland and Wales consider how best to implement immediately processes that include the wider community resource in the current cancer patient journey to alleviate the pressure on existing in-hospital resources. Through the information gathered at our site visits, we have attempted to itemise the individual parts of holistic treatment for secondary breast cancer in Figure 7, opposite, and categorise them against the level of specialisation required to carry out those tasks. We hope that Figure 7 is used as a springboard for individual breast care units to consider tasks that may be provided by existing services in the community in order to make better use of specialist medical in-hospital resources, such as the CNS role.

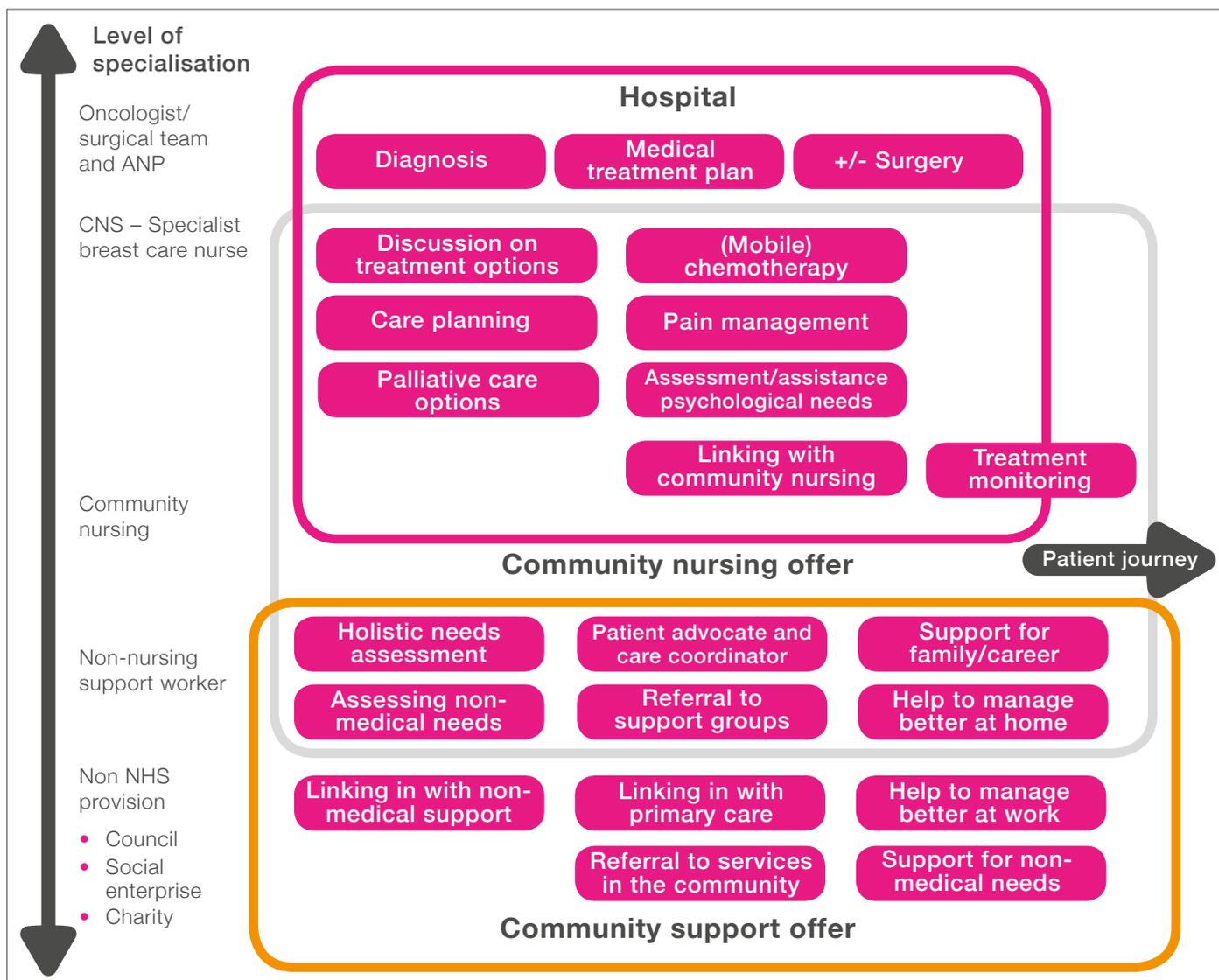


Figure 7: Framework for developing an enhanced community support offer

The degree of specialisation is shown vertically on the left. This ranges from medical oncology and surgical teams at the top, down through the roles of a CNS, community nurse and a non-nurse support worker at the bottom. The patient journey is represented from left to right, starting with diagnosis and treatment planning through to monitoring and provision of ongoing support. The rest of the diagram shows the elements of treatment along the patient journey that might be performed by different care professionals at different points in time. The elements have been grouped by the different parts of the system that could be responsible for delivery – acute hospital, community nursing, and other support in the community.

This diagram shows that there are several elements of the care pathway that may be conducted by existing services in the community throughout the patient journey, such as assessing non-medical needs, referral to support groups,

or acting as an advocate for patients and care coordinator. Breast Cancer Care recommends that breast care units consider whether there may opportunities to make better use of existing resources in the community using this diagram as a possible model.

It is important to emphasise that our research does not suggest that assessment and care planning should be the role of a non-specialist worker in the community. Instead this role can act on the patient's behalf, provide a named single point of contact, ensure that care and support planning happens when it is needed, and the outcomes are shared with those individuals involved in the care and support of that person, preferably through a multidisciplinary team meeting. We also acknowledge the difficulty of using different staff for support needs as this may create additional appointments that in turn give patients with secondary breast cancer less time at home or at work. However, with further research, this role could reduce the burden on the CNS role.

Section 5: Conclusion

It is clear that people living with secondary breast cancer are greatly affected by the disease but are often not getting the care and support they need, even in the hospital setting. This is particularly worrying given that we know that access to a specialist nurse can significantly improve quality of life and emotional wellbeing from the point of diagnosis.

This study, the first of its kind to map the current nursing provision for people living with secondary breast cancer, proposes practical suggestions for improvement. Breast Cancer Care will continue to

work in partnership with governments and the NHS to address and improve the situation and support available through the NHS and the third sector, locally, nationally and online.

It is imperative that rapid improvements are made in the areas we have highlighted if we are to improve the lives of people living with secondary breast cancer and achieve world-class cancer outcomes.



References and notes

- 1 Maher, J and McConnell, H (2011) New pathways of care for cancer survivors: adding the numbers, British Journal of Cancer
- 2 The **Secondary Breast Cancer Resource Pack** won the Patient Information Award for Long-Term Conditions from the British Medical Association in 2015
- 3 If you are interested in obtaining a **Secondary Breast Cancer Resource Pack** for yourself or for your hospital or practice, visit www.breastcancercare.org.uk and click on the Secondary Breast Cancer part of the Information and Support section of the website to see all our publications relating to secondary breast cancer
- 4 Breast Cancer Care (2008), Secondary Breast Cancer Taskforce: Improving the care of people with metastatic breast cancer
- 5 Breast Cancer Care released our 'Who's Counting?' report on data on the 22 September 2016. You can access a copy of this report online under the Campaigns section of our website
- 6 Reed E, Scanlon K, Fenlon D (2010) European Journal of Cancer Care 19, 575–58
- 7 'Specialist nurses: Changing lives, saving money', Royal College of Nursing, February 2010
- 8 'Specialist Nurses Make a Difference', Royal College of Nursing Policy Unit, Policy Briefing 14/2009, October 2009
- 9 'Clinical nurse specialists: adding value to care', Royal College of Nursing, April 2010
- 10 National Cancer Patient Experience Survey 2015, available at: www.ncpes.co.uk/index.php
- 11 Wales Cancer Patient Experience Survey National Report, January 2014, p9 Available at: <http://gov.wales/docs/dhss/publications/140117canceren.pdf>
- 12 'Advanced nurse practitioners: An RCN guide to advanced nursing practice, advanced nurse practitioners and programme accreditation', revised May 2012
- 13 Indicative role specification for a Macmillan Cancer Support Worker – Care Co-ordination, Macmillan Cancer Support, August 2011, available at: www.macmillan.org.uk/documents/aboutus/health_professionals/onetoonesupport/rolespecificationformacmillancancersupportworker.pdf
- 14 Available at: www.nice.org.uk/guidance/cg81
- 15 'Achieving world-class cancer outcomes: A strategy for England 2015-2020', available at: www.england.nhs.uk/wp-content/uploads/2016/10/cancer-one-year-on.pdf
- 16 'What's important to me. A Review of Choice in End of Life Care', The Choice in End of Life Care Programme Board, February 2015. Available at: www.gov.uk/government/publications/choice-in-end-of-life-care
- 17 Beating Cancer: Ambition and Action, Scottish Government, April 2016. Available at: www.gov.scot/Publications/2016/03/9784/downloads
- 18 Breast Cancer Care Scotland, Prevalence of Secondary Breast Cancer in Scotland: Number of cancer survivors (prevalence) in 2013
- 19 Available at: <http://gov.wales/topics/health/nhswales/plans/cancer-plan/?lang=en>
- 20 'Career and Education Framework for Cancer Nursing', UK Oncology Nursing Society and Royal College of Nursing, February 2017
- 21 Available at: www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/onetoonesupportpilotreportfinal.pdf
- 22 National Cancer Patient Experience Survey 2015, available at: www.ncpes.co.uk/index.php
- 23 National Cancer Policy Board of the Institute of Medicine (2004), Meeting Psychosocial Needs of Women with Breast Cancer, The National Academies Press, p32

- 24 Due to the lack of accurate data on the number of patients with secondary breast cancer, and the absence of systems to track nursing encounters, this estimate is based on professional judgement. However, it was quoted without prompting by nursing staff consistently across a number of the sites we visited
- 25 See for example: Impact Briefs: Clinical Nurse Specialists (2014), Macmillan Cancer Support, available at: www.macmillan.org.uk/documents/aboutus/research/impactbriefs/impactbriefs-clinicalnursespecialists2014.pdf
- 26 A care pathway is a tool used in healthcare settings to standardise processes, reduce variation and improve quality. There is some evidence that a care pathway can improve outcomes. See: Middleton S, Barnett J, Reeves D (2001) What is an Integrated Care Pathway? What is ...?, 3 (3): Feb 1–8
- 27 Achieving world-class cancer outcomes: A strategy for England 2015-2020, p. 5. Available at: www.england.nhs.uk/wp-content/uploads/2016/10/cancer-one-year-on.pdf
- 28 Ibid, p53
- 29 Cancer Delivery Plan for Wales 2016-2020, Welsh Government, p13
- 30 Ibid, p13
- 31 Evaluation of phase 1 of the one-to-one support implementation project, Final Report, 2015. Available at: www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/onetoonesupportpilotreportfinal.pdf



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.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **[breastcancercare.org.uk](https://www.breastcancercare.org.uk)**

Central Office

Breast Cancer Care
Chester House
1-3 Brixton Road
London SW9 6DE
Phone: 0345 092 0800
Email: info@breastcancercare.org.uk