

**Secondary.
Not second rate.**

**breast
cancer
care**



**Secondary breast cancer
Part three: support and impact
January 2017**

ONLY 27%

were told about a palliative and
supportive care organisation

With thanks to Quality Health for their support with the survey design and methodology, drawing the patient sample and data analysis.

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

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

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	
Reviewing the picture today	
Current policy in the nations	
Section 3: Methodology	8
Questionnaire design and development	
Identifying the sample	
The Secondary Breast Cancer Advisory Committee	
Timescales and fieldwork	
Response rate	
Limitations of research	
Section 4: Findings and recommendations	10
Care, Treatment and Support	
Coordinated care	
Impact	
Section 5: Conclusion	17
References and notes	18

Section 1: Introduction

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

Because of a lack of evidence about patient experience, and as part of our ongoing focus on secondary breast cancer, we recently revisited the landscape for people living with a secondary breast cancer diagnosis across England, Scotland and Wales.

This is the first study in these nations specifically using patient experience to try to identify potential ways of improving the care of people living with secondary breast cancer, which is often inadequate.

Not only is this information invaluable for Breast Cancer Care's campaigning, influencing and service provision in this area, but we also hope

breast care teams, commissioners and providers 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 across England, Scotland and Wales** and **Secondary breast cancer – Part two: who's counting** (about data collection in England's hospital trusts).

It highlights the ongoing difficulties faced by people with secondary breast cancer throughout their treatment and as their cancer changes.

Future reports will focus on specialist nursing provision in England, Scotland and Wales and on recommendations for addressing the problems highlighted by our evidence.



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, lungs, liver or 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 people die from the disease¹.

Breast Cancer Care offers 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, in 2015–16 35 women aged 45 and under attended a residential event 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 people in similar situations. Our telephone Helpline and Ask Our Nurses email service 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, policy-makers 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.

The Taskforce identified the following gaps in meeting the needs of secondary breast cancer patients:

- 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.
- Multidisciplinary teams (MDTs) were not discussing secondary breast cancer patients routinely or consistently.

- The information needs of people with secondary breast cancer were not being met.
- Psychosocial needs were not being assessed at diagnosis of secondary breast cancer or at key points thereafter.
- A lack of timely access to a specialist palliative and supportive care team.

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.

- Access to a clinical nurse specialist is variable.
- People are unaware of the range of services palliative and supportive care teams offer, often associating palliative care only with the end of life and not with the management of pain and other symptoms.
- Information is often not provided at key times: at diagnosis; as treatment changes; or as the disease progresses.

This means that patients are often not getting support to live with the pain and side effects of their diagnosis and treatment, nor are they, their families and friends, getting the emotional support they need.

The National Cancer Patient Experience Surveys (CPES) across England, Scotland and Wales, as a measurement tool, are helping to drive improvements in cancer care⁵. While these surveys are effective in gaining a national understanding of patient experience and need on a wide range of different cancers, to date they have not allowed us to draw conclusions about the specific needs and experiences of people with secondary breast cancer⁶.

In England and Scotland, the wording on 'type of diagnosis' precludes easy identification of these patients. Consequently, making national improvements in secondary breast cancer care based on this limited intelligence is difficult and non-specific.

However, more recently in Wales, questions that identify patients with secondary cancer have been included in the Wales Cancer Patient Experience Survey and we look forward to considering the learning from the data when available.

In addition, 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 data⁷.

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.

Without knowing how many people go on to develop secondary breast cancer, we do not have a full picture of the effectiveness of treatments for primary breast cancer. At a time when NHS budgets are increasingly under pressure, this information would help inform decisions about which treatments should be funded.

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 being treated for primary breast cancer.

Reviewing the picture today

It is timely and important that Breast Cancer Care has reviewed the picture for people with secondary breast cancer across England, Scotland and Wales. Our survey of patient experience and need is one of the largest of its kind focused on this patient group.

The key aims for the survey were to:

- ascertain the current experiences and needs of people living with secondary breast cancer in accessing care and treatment from statutory and non-statutory providers
- assess change since the 2008 Taskforce findings

- identify gaps in care, treatment, support and information
- explore ways Breast Cancer Care might increase access to its services for people with secondary breast cancer.

The results are startling. From the stark findings in our first report on diagnosis, to the lack of data collection, to the difficulty in accessing existing information and support services, it is clear little has changed and there is still much to be done.

Current policy in the nations

England

In July 2015, the Independent Cancer Taskforce published its final report **Achieving world-class cancer outcomes: A strategy for England 2015–2020**, setting out a bold and ambitious strategy for the NHS in England to deliver significant improvements to cancer care. It followed NHS England's **Five Year Forward View**, published in October 2014, and aimed to meet the challenge of improving cancer outcomes to match the best in Europe against a backdrop of increasing rates of diagnosis in future years.

An implementation plan was published by NHS England in May 2016, providing information about how some of the strategy's 96 recommendations would be delivered.

The bulk of the cancer strategy focuses on the prevention, treatment, support and experience of people living with and beyond early stage cancer. However, there are some recommendations that would have a direct impact on the care for people living with secondary breast cancer. These include:

- recommendation 90, which mandates the collection of data on all secondary cancers
- recommendation 61, which states that all cancer patients should have a clinical nurse specialist
- recommendation 38, which recommends streamlined MDT processes so that specialist time is focused on cancer cases that don't follow well-established clinical pathways, with other patients being discussed more briefly.

Further, the National Institute for Health and Care Excellence (NICE) has two guidelines specifically relating to secondary breast cancer: **CG80 - Early and Locally Advanced Breast Cancer** and **CG81 - Advanced Breast Cancer: Diagnosis and Treatment**.

Breast Cancer Care feels there is a gap between these two guidelines, as well as a lack of guidance in the **Suspected Cancer Guideline** on recognising and referring potential secondary cancers. Breast Cancer Care believes that this is a missed opportunity, given our findings in Part one of our recent report series⁹.

Scotland

The main cancer strategy in Scotland, **Beating Cancer: Ambition and Action Plan** 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 Scotland⁹, this is a missed opportunity to improve care and support for this patient group.

Breast Cancer Care would like to understand more from the Scottish Government about how support and care will be offered to this group of patients 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)**. The strategy 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 a 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.

We also encourage the Wales Cancer Network to ensure that healthcare professionals formally refer patients to existing support services as per our recommendations in this report.

Section 3: Methodology

Questionnaire design and development

The questionnaire was designed and developed towards the end of 2015 and in early 2016. It involved a detailed process of drafting, reviewing, testing and revising the questions. Breast Cancer Care worked closely with Quality Health on designing and agreeing the final question set.

As part of the process, cognitive testing was carried out with volunteers with secondary breast cancer. The volunteers completed the draft questionnaire and were then invited to share their answers to the questions and comment on the wording of the questions, the response options, any omissions, and the layout and length of the survey. In total, 14 people were interviewed and we are immensely grateful for their time and input.

Identifying the sample

The respondents for this survey came from two sources.

First, data that had been gathered as part of the CPES 2015 in England was used. Unfortunately, we were unable to use patient data from the Scottish CPES (2015–16) or the forthcoming Wales CPES (2016)¹⁰.

Every respondent to CPES has the option of agreeing to receive further questionnaires about their health. It was only these people we approached with our survey.

On other occasions when follow-on surveys have been sent to CPES respondents, a unique identifier (ICD10 code) is used to identify the cohort of patients required. However, people with secondary breast cancer are not easily identified using this code. Therefore, we first extracted a sample that included all women with breast cancer (primary and secondary) and then applied rules to that data¹¹ depending on how the respondents had answered specific questions in the survey. This way, we were able to identify respondents who either had a recurrence of their primary breast cancer or who had secondary breast cancer.

The total sample size was 1,000. It was expected that around half the people in the sample would not be eligible to complete the survey because of having a recurrence rather than a diagnosis of

secondary breast cancer. There is more about this in the section 'Limitations of research'.

Second, Breast Cancer Care invited people with secondary breast cancer to take part in the survey online using a range of social media and other networks, including Facebook and Twitter, targeted email communications to people using our secondary breast cancer services, and via our campaigns community. This was particularly useful for inviting people from Scotland and Wales to take part.

Timescales and fieldwork

The fieldwork was undertaken between 7 March and 31 May 2016.

Online, we ran two bursts of activity: one to launch the survey and another, through Facebook location targeting, to further promote the survey in geographical areas with low engagement.

Additionally, six qualitative telephone interviews were undertaken. We identified the interviewees from people who indicated that they would be happy to take part in further research after completing the survey. The questions for the qualitative interviews were based on key themes from the findings, enabling us to delve deeper into some of the issues and trends the quantitative evidence had highlighted.

The Secondary Breast Cancer Advisory Committee

In November 2016, using a co-production approach, Breast Cancer Care established a Secondary Breast Cancer Advisory Committee made up of patients, healthcare professionals, cancer charities, representatives from government departments from England, Scotland and Wales and other bodies, and others with expertise and interest in the area of secondary breast cancer. This was modelled on Breast Cancer Care's original Secondary Breast Cancer Taskforce.

In recent years co-production has become an important part of public service and policy development in the UK. It promotes the creation of relevant and person-centred policy.

Our advisory committee was given the task of discussing and interpreting the key themes of the research and agreeing practical solutions to some of the problems highlighted by the data.

Response rate

A total of 430 people with secondary breast cancer responded to the postal survey, representing a 45% response rate¹². In addition, 411 people completed the online survey via Breast Cancer Care's online channels. A total of 841 responses were received.

Limitations of research

It is possible that people with particularly negative or positive experiences may have been more motivated to take part in order to share their experiences.

However, the main limitation of our research was in the sampling of the data. As explained, drawing the sample from data taken from CPES in England made it difficult to target respondents in Scotland and Wales. To resolve this, we also replicated the survey online so that those with a diagnosis of secondary breast cancer who had not received a copy of the postal survey and/or who lived in Scotland and Wales could participate.

Using the data gathered from CPES in England also made it difficult to separate people with a diagnosis of recurrence from people with secondary breast cancer. Some people with a recurrence may have received the survey. To mitigate the risk of inappropriate responses, an explanation of secondary breast cancer and recurrence was given in the covering letter that went out with the postal questionnaire. Another shorter explanation was given on the front page of the questionnaire itself.

Anyone who had not had a confirmed diagnosis of secondary breast cancer was asked to disregard the questionnaire.

We also asked people to call Breast Cancer Care's or Quality Health's helplines in case of any concern or if they were unsure whether they were eligible for the survey.



Section 4: Findings and recommendations

Our research focused on four key areas relating to the care pathway for people with secondary breast cancer:

- before diagnosis of secondary breast cancer and finding out what was wrong
- treatment and care provided and received
- support for people with secondary breast cancer
- the impact of living with the disease.

This report focuses principally on the sections covering 'support' and 'impact' and also includes some of the data on treatment and care.

Demographics

There was one male respondent to the survey, with all others (840) identifying themselves as female.

14% of respondents were aged between 25 and 44; 56% of respondents were aged between 45 and 64; 30% were aged over 65¹³. There were no respondents under the age of 25.

95% of respondents identified themselves as being white British; 2% white other, 1% as black/black British and 1% Asian.

72% of respondents had a previous diagnosis of primary breast cancer; for 28% their diagnosis of secondary breast cancer was their first diagnosis (meaning that the breast cancer had already spread at the point of diagnosis).

Just under half (44%) had started treatment for secondary breast cancer between one and three years ago; 28% had started treatment within the past year, 16% between three and five years ago, and 12% had started treatment more than five years ago.

Care, treatment and support

This section of the survey asked respondents about the care, treatment and support they received as a person living with secondary breast cancer. We asked what support (defined as access to and quality of information and services) they received and when, whether the support they received helped, and how they rated it. We also asked about the treatment and care received since diagnosis from a range of healthcare professionals, such as GPs, hospital doctors, hospital nurses, specialist nurses, community nurses, palliative and supportive care nurses and so on.

Our findings show:

- 16% of respondents across England, Scotland and Wales were not provided with any information about any of the services provided by leading support charities, such as Breast Cancer Care, Macmillan, Marie Curie or others
- only 27% were told about a palliative and supportive care organisation such as Marie Curie or a local hospice
- only 46% were told about Breast Cancer Care
- 64% were told about Macmillan.

We would want these figures to be much closer to 100% given that the third sector is able to reduce the burden on government-funded services significantly by complementing the care that patients receive with free services.

'The only specific support I have had outside of my oncologist for secondary breast cancer has come from Breast Cancer Care. Specifically, information leaflets, Helpline and the Younger Women Together with Secondaries course, which helped to point me in the direction of useful sources of further information and support and helped me to connect with others in the same position who live a bit closer to me.'

We also asked respondents more broadly about additional support services provided. Less than a third (28%) were made aware of general palliative care services, and only 36% were made aware of counselling.

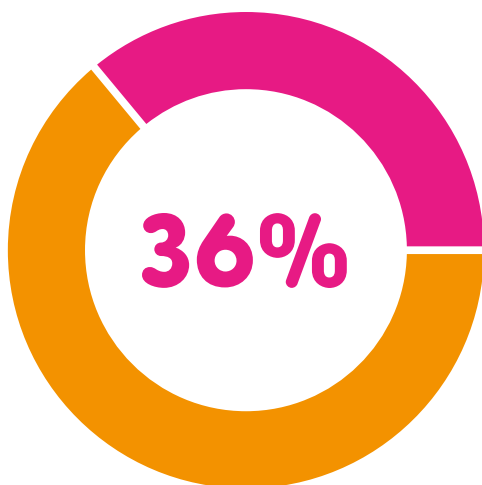
Less than half (44%) were made aware of local breast cancer support groups or opportunities to speak with other people with secondary breast cancer, such as Breast Cancer Care's Living with Secondary Breast Cancer sessions and online tools.

This contrasts with the 2015 CPES data in England, the 2015–16 CPES data in Scotland and the 2013 CPES data in Wales, which covers breast cancer patients of all stages. This data shows that 74.9% of people with breast cancer in England said that hospital staff gave them information about support or self-help groups for people with cancer, 83% in Scotland and 77% in Wales.

'Feels like I've been more proactively seeking information and support rather than it being freely offered.'

Among respondents who were signposted to and accessed additional support services, such as those provided by Breast Cancer Care, 61% found it beneficial to speak to other people with secondary breast cancer. Very few respondents stated that none of the services they accessed had helped.

Given the range of services provided, not just by Breast Cancer Care but by other charities too, and the results from our survey showing the clear benefits of these services to the experience of patients with secondary breast cancer, it is disappointing to see that so few were made aware of the support available to people living with secondary breast cancer.



Only **36%** were made aware of counselling or psychotherapy

We also asked patients about the level of support they received not just at diagnosis, but also as their condition and treatment progressed. The results show that the level of support provided over the course of the disease drastically waned:

- 55% of respondents were given information about secondary breast cancer at diagnosis
- 41% during their treatment
- 16% as their cancer changed
- 20% as their treatment changed
- 16% stated they were not given information at any point during their treatment.

These figures show that as a patient lives longer with secondary breast cancer, the support provided to help them deal with the ongoing impact wanes.

As treatments improve, people with secondary breast cancer will live longer. So it is vital that the right support is available both for the benefit of the patient and to mitigate additional strain on the NHS to care for people with secondary breast cancer for longer.



We also asked respondents who accessed services, whether they were signposted to them or not, and to rate the quality of information provided. The results showed that very few respondents had used all the services available to them. A particularly low number of respondents had used a pain clinic, palliative care or counselling/psychiatry services.



Only 6% of respondents used a pain clinic, while only 21% had input from palliative and supportive care services. This is despite 90% of people living with secondary breast cancer reporting that they experience physical pain, potentially affecting an estimated 32,400 people¹⁴.

Further, only 25% used counselling or psychiatric services, despite the obvious emotional strain of living with an incurable life-limiting disease.

When broken down by age, older people were even less likely to use counselling or psychiatry services, with this figure dropping to 14% in the group aged 65–74, and 8% in the age group 75–84.

Of the respondents who received information on support services, 83% rated the information as good, very good or excellent. This shows that the problem lies not in the quality of information or support itself, but access to it. Healthcare professionals must ensure that each patient is appropriately signposted and has access to existing services.

Recommendations

We know that the effects of secondary breast cancer can have a dramatic impact on people's quality of life and ability to live well.

It is clear from the findings that patients are not being consistently signposted to available support services, which means they are not benefiting from (often free) services that could improve quality of life.

More needs to be done to ensure that access to NHS pain clinics, palliative and supportive care/hospices, counselling/clinical psychology/psychiatry, dieticians, physiotherapists, complementary therapies, occupational therapies and charity sector service providers is improved.

The **Cancer Strategy for England** addresses the issue of access to services for primary cancer patients through the Recovery Package¹⁵. This package is made up of a number of different interventions, including a holistic needs assessment (HNA), information on side effects of treatment and how to manage them, information on the potential markers of recurrence, a key contact for rapid re-entry into the system, a treatment summary, access to patient education and a support event that signposts to rehabilitation, work and financial support services. The Recovery Package, developed and tested through the National Cancer Survivorship Initiative (NCSI), can greatly improve the outcomes of care for primary cancer patients. **The Cancer Delivery Plan for Wales (2016-2020)** also states that the Wales Cancer Network is to 'lead on the consistent application across Wales of elements of the "recovery package" as appropriate to identified needs (eg key worker, electronic holistic needs assessment, care planning...)'.

Breast Cancer Care recommends there should be a similar package available for people with secondary cancers, including secondary breast cancer. This could be a Support Package that includes an HNA, referral to support services, information on treatments and side effects, and direction to further information through a patient education and support event. The Support Package would address the issues of access to information and support as highlighted by our data above.

The Cancer Alliances in England, the Wales Cancer Network, the West of Scotland Cancer Network, the South East Scotland Cancer Network and the North of Scotland Cancer Network would be responsible for ensuring the Support Package

is applied. Additionally, we would suggest there is clear guidance on responsibility for ensuring that patients are made aware of the Support Package.

We also recommend that, as with the Recovery Package, the Support Package is made up of three central components: assessment and care planning; access to a health and wellbeing event; and a treatment summary and cancer care review. These components would be tailored to suit the complexities and different support needs of secondary cancers, including secondary breast cancer.

The HNA would be an integral part of the Support Package as the main part of ‘assessment and care planning’. As a framework for a conversation between a patient and healthcare professional, the HNA allows the patient to highlight their individual needs in relation to secondary breast cancer and the healthcare professional an opportunity to signpost that patient to existing services.

This idea supports NHS England’s **Commissioning Intentions for 2017/18–2018/19** published in September 2016, which require that all parts of the Recovery Package should be available to all patients, including an HNA and care plan at the point of diagnosis. While we support NHS England’s intentions, we suggest that the HNA and other support services for people with secondary breast cancer could be better targeted through the suggested secondary cancers Support Package.

We welcome NICE guidelines that state ‘assessment and discussion of patients’ needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching).¹⁷ Through the Support Package, people living with secondary breast cancer would benefit from an HNA throughout their treatment and towards end of life, not just at diagnosis.

Patients would also be referred to a health and wellbeing event for secondary cancers as part of the Support Package. This event would focus on living as well as possible for as long as possible, rather than the primary cancer discourse of ‘living with and beyond’. Breast Cancer Care runs such an event for people with secondary breast cancer through our Living with Secondary Breast Cancer service. These events are run every month in 24 locations across the UK, providing information on topics such as pain management, treatments

and side effects. They also offer attendees a space to talk openly to other people in a similar situation. Facilitated by a counsellor and with regular professional guests such as clinical nurse specialists, benefits advisers and others, the sessions provide information and support in a relaxed environment. In a recent evaluation, 93% of women said they were satisfied or very satisfied with the service.

The final component of the Support Package would be the treatment summary. This is used as a final summary document for patients with primary breast cancer, but could be used as an ongoing document by a person with secondary breast cancer when using any services they have been referred to, and in ongoing discussions with the range of healthcare professionals providing their treatment.

As per recommendation 55 in the **Cancer Strategy for England**, we would also suggest that the Support Package is included in the proposed set of metrics to encourage providers and commissioners to focus more consistently on improving people’s experience of their care, treatment and support¹⁸.

Coordinated care

We know that care can sometimes become disjointed or difficult to manage because of the large number of healthcare professionals involved in the care and treatment of a patient, and the range of needs of a person with secondary breast cancer. So we asked respondents about their experience of the care pathway.

Some indicated that they felt their care could be better managed or coordinated:

- 19% said that they did not feel that all the healthcare professionals they came into contact with had a good understanding of them and their condition
- only about half (58%) felt that their care was completely well-managed and coordinated, dropping to 50% in the 25–44 age group.

This is in direct contrast to the experience of breast cancer patients overall (all stages). In the 2015 CPES in England, 61% of respondents said that the different people treating and caring for them always worked well together to give them the best possible care. The 2015–16 CPES data in Scotland shows that 63% of respondents agreed the different people treating and caring for them

always worked well together to give them the best possible care, while 65% of respondents agreed with this statement in the 2013 Welsh CPES.

‘Sometimes I feel as if I’m falling through the medical cracks as no one seems to be prepared to just take responsibility for coordinating appointments/treatments.’

In our survey, only 31% said they felt that all the different people caring for them always worked well together to give them the best possible treatment. Again, when broken down by age, this figure drops to 23% in the 25–34 age group, and 27% in the 35–44 group.

This shows that the perception of care coordination between age groups is different, perhaps because care and treatment is geared towards an older demographic and/or because older people can be less critical of the healthcare they receive. These figures show that there are still a very large number of people affected by secondary breast cancer who are not receiving well coordinated care.

‘You need to tell your story so many times to so many different doctors. You have to become an expert in your own condition to ensure you are getting the treatment you need.’

Recommendations

An MDT is considered the ‘gold standard’ in planning treatment and care for a patient living with secondary breast cancer. However, we know that many MDT meetings do not specifically discuss secondary cancers and often don’t discuss people with secondary breast cancer at all.

Breast Cancer Care believes this omission leads to ineffective treatment planning for people living with secondary breast cancer and for healthcare professionals.

It may be that secondary breast cancer patients are not discussed because of a large number of primary cases taking precedence and other discussions unrelated to secondary breast cancer taking up a large portion of the meeting.

It’s also likely that the right people aren’t in the room for a discussion about secondary breast cancer patients.

The **Cancer Strategy for England** addresses the role and structure of MDT 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.’¹⁹

The Scottish **Beating Cancer** strategy, as noted, does not appropriately address the concerns of people with secondary cancers. With reference to MDTs, it states, ‘It is essential that when considering what treatments to recommend, healthcare professionals involved in people’s care – commonly called MDTs – engage also with people with cancer, carers and their families to ensure that the treatment “package” agreed is tailored to the person’s individual circumstances so that people can get on with their everyday life as far as possible.’

Further, in Wales the **Cancer Delivery Plan** states in Key Action 36 that the Wales Cancer Network will evaluate MDT person-centred skills – specifically communication and palliative care – and develop and implement an action plan.

While we agree with the above direction in England, Scotland and Wales, we would build on these actions to encourage the separation of people with secondary breast cancer from patients with primary breast cancer.

Breast Cancer Care recommends that, as per recommendation 19 of our **Secondary breast cancer – Part two: who’s counting** report on data, hospitals should establish or maintain a dedicated MDT for secondary breast cancer patients, or at the very least, a specific section in an existing MDT meeting for secondary breast cancer patients to be routinely discussed.

This will provide not only a prime opportunity to collect data but also to improve the care pathway and support provided to people living with secondary breast cancer.

Further, we recommend that a key worker should be identified for the patient at the MDT meeting who will be responsible for the coordination of care, and that this person should attend all MDT meetings that discuss the care, treatment and implementation of a Support Package for their patient.

Whatever approach is taken, it is clear that more work should be conducted in this area to examine the best and most functional structure for MDTs in the UK. We are aware of the work of charity Cancer Research UK on this issue and look forward to reviewing the research they publish.

Impact

We know that a diagnosis of secondary breast cancer is life-changing. This section of the survey asked respondents about the impact that secondary breast cancer has on their lives with regard to managing side effects, finance, employment, and relationships with friends and family.

We also received a great deal of feedback from patient representatives in our Secondary Breast Cancer Advisory Committee meeting that highlighted the huge impact of a secondary breast cancer diagnosis on identity, early retirement, relationships, sex and intimacy, and children.

The data shows that people affected by secondary breast cancer are having particular difficulty accessing financial support and support for carers.

Our results show:

- nearly three quarters (72%) of respondents indicated that secondary breast cancer has had a financial impact on them
- a fifth (21%) of respondents indicated they lost income due to taking time off work
- a third (31%) lost income by retiring earlier than planned.

This financial impact is compounded by a further 42% of respondents stating that they are paying more for utility bills as a result of being at home more. Patient representatives of the Secondary Breast Cancer Advisory Committee also indicated that accessing financial support is often complicated, emotional and confusing.

'We lost quite a lot of money through me not working, and the extra costs involved. In transporting me, feeding me, clothing me, keeping the heating on because it was over winter, keeping the heating on because I was at home and cold.'

We also asked patients about the impact of their secondary breast cancer diagnosis on their support networks:

- 72% of respondents indicated that their friend or family member had not been offered support
- only 23% indicated that their friend or family member had definitely been given enough information to assist them to manage their side effects and know when to seek medical help
- 36% explicitly indicated that their friend or family member needed more support to do this.

'I don't think a lot is told about how it affects people's personal relationships. Cancer can break or make a marriage and this issue never gets discussed.'

It is also important to note, however, that nearly a fifth of respondents (18%) indicated that they did not have a friend or family member to provide care or support. This is supported by feedback from patient representatives at the Secondary Breast Cancer Advisory Committee, who indicated that it is important to remember that not everyone has a partner or close friend to rely on, and that support networks vary for patients from different cultural backgrounds.

Recommendations

Breast Cancer Care recommends that a Support Package including an HNA be considered a crucial part of care and treatment for people with secondary breast cancer. This would address difficulties in access to financial support.

We recommend that the healthcare professional conducting the HNA is able to have a clear and helpful discussion with the patient about holistic needs, such as financial impact and assistance that may be available.

We also support the development of a non-nurse key worker role that takes on the responsibility of non-clinical work, such as providing assistance to accessing financial support for secondary breast cancer patients. This would remove some of the administrative burden on other healthcare professionals, such as clinical nurse specialists.

As noted, Breast Cancer Care runs Living with Secondary Breast Cancer sessions across the UK. We regularly invite benefits advisers to speak about accessing financial support.

'He's [husband] in denial at the moment.
He's taken it worse than me, actually.'

Our data also shows that carers for people affected by secondary breast cancer are not getting the support they need. We acknowledge the consistent mention of carers in the **Cancer Strategy for England** when referring to improved outcomes for 'patients, carers, friends and family' throughout the document but we note that there are no specific recommendations in relation to support for carers.

We also note that there is no reference to the needs of carers in the key Scottish or Welsh policy documents. We feel this is a missed opportunity in Scotland and Wales, but welcome the **Carers (Scotland) Act 2016**, designed to support carers' health and wellbeing.

The Department of Health in England has recently closed a four-month consultation on a new carers' strategy to improve support for carers.

The Department of Health says this document will consider health, financial concerns and other support carers need to live well while caring for a family member or friend. We welcome this strategy and look forward to reviewing this document when it is published.

The services offered by Breast Cancer Care are also available to carers.

Anyone in need of support can call our free telephone Helpline. However, Breast Cancer Care still has a large role to play in raising awareness of the needs of carers for people affected by breast cancer, a group of people who are often overlooked.

More consideration will be given to opportunities to support the work of other organisations focused on this area, such as Carers Trust and Carers UK.

We also acknowledge the potential for further research to gather evidence from carers themselves, rather than people affected by secondary breast cancer, about the difficulties they face and how support could be targeted to greatest effect.



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 to live well. This is particularly worrying when we know good-quality information and support is available, but people are not being signposted to it.

A lack of support in dealing with the wide-ranging impact of secondary breast cancer has a deep impact on the lived experience of people with the disease, on people's trust in their healthcare system and their healthcare professionals, and on their emotional health and wellbeing.

Breast Cancer Care will continue to work in partnership with governments and the NHS to address and improve the situation and increase the understanding of information and support available to people 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, 2011.
- 2 Breast Cancer Care's **Secondary Breast Cancer Resource Pack** won the Patient Information Award for Long-Term Conditions from the British Medical Association in 2016.
- 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/publications then the Secondary breast cancer section to see and order all our free 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 The Cancer Patient Experience Surveys commenced in England in 2010, in Scotland in 2015, and in Wales in 2013.
- 6 The 2016 Cancer Patient Experience Survey for Wales has included a specific question that indicates splitting out those with a diagnosis of recurrence from those with secondary disease may be possible (Q.77: When your cancer came back did it: Come back only in the same place as before; Spread to somewhere else in the body?).
- 7 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.
- 8 Breast Cancer Care released our **Diagnosis** report on the 15 July 2016. You can access a copy of this report online under the Campaigns section of our website.
- 9 Breast Cancer Care Scotland, Prevalence of Secondary Breast Cancer in Scotland: Number of cancer survivors (prevalence) in 2013.
- 10 Results of the Wales CPES (2016) are due to be released by March 2017.
- 11 The rules involved identifying women who ticked 'yes' to the following question: 'Had your cancer spread to other organs or parts of your body at the time you were first told about your cancer?' If they ticked 'no' to that question, but 'yes' to the next question: 'My cancer was taken out/treated without any sign of further problem, but has since come back/spread to other parts of my body', they were also included in the sample.
- 12 While a 45% response rate is still significant, it is lower than the 65.7% response rate for the 2015 Cancer Patient Experience Survey in England from where the data was drawn. This can be attributed to the fact that not all of those drawn from the sample were expected to have secondary breast cancer; the others were expected to have had a breast cancer recurrence and therefore were ineligible to participate.
- 13 For the purposes of this report, and to ensure that numbers were sufficient to draw meaningful conclusions, age bands were merged in some places as follows: 25–34 and 35–44; 45–54 and 55–64; 65 and above.

- 14 Breast Cancer Care conducted an online survey, Share your Experiences, with 204 secondary breast cancer patients between 19 August 2014 to 22 September 2014.
- 15 The Independent Cancer Taskforce (2015), Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020, Recommendation 65.
- 16 NHS Operational Planning and Contract Guidance 2017–2019.
- 17 National Institute for Health and Care Excellence (2015) Advanced Breast Cancer: Diagnosis and Treatment, CG81.
- 18 The Independent Cancer Taskforce (2015), Achieving World-Class Cancer Outcomes: A Strategy for England 2015–2020, Recommendation 55.
- 19 The Independent Cancer Taskforce (2015), Achieving World-Class Cancer Outcomes: A Strategy for England 2015–2020, Recommendation 38.



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**

Central Office

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