

# Recurrent and Metastatic Breast Cancer Data Collection Project

Pilot report  
March 2012

**ABS**  
ASSOCIATION OF  
BREAST SURGERY

breast  
cancer  
care 



West Midlands  
Cancer Intelligence Unit

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## Acknowledgements

Fifteen breast units and associated regional cancer registries provided data for this project, which was supported by Breast Cancer Care, National Cancer Intelligence Network, the Association for Breast Surgery and the West Midlands Cancer Intelligence Unit.

Thank you to the Eastern Cancer Registry and Information Centre for developing the online tool that was used in the Pilot.

## **Definitions**

### **Metastatic breast cancer**

Metastatic (also known as secondary or advanced) breast cancer occurs when breast cancer cells spread from the first (primary) tumour in the breast through the lymphatic or blood system to other parts of the body. The most common parts of the body that breast cancer spreads to are the bones, liver, lungs and brain. A diagnosis of metastatic breast cancer means that the cancer cannot be cured, although it can be controlled, sometimes for years.

### **Local recurrence**

When breast cancer returns in the chest/breast area, or in the skin near the original site or scar, this is called a local recurrence. In this case the cancer cells have remained in the local area despite treatment and have grown again.

### **Regional recurrence**

This is breast cancer which has come back following treatment and has spread to lymph nodes (glands) around the breast. The lymph nodes involved may be in the armpit (axilla), around the breastbone (sternum) and between the ribs (called internal mammary nodes), or the nodes above and below the collarbone (clavicle).

## **Foreword by Professor Sir Mike Richards**

Although the outcomes of breast cancer have improved greatly over the past 20 years, dealing with recurrent and metastatic disease remains a significant and challenging medical problem, particularly in view of the high prevalence of the disease.

Having survived the diagnosis and treatment for primary breast cancer, to develop recurrent disease is a devastating, potentially life-threatening experience. It has recently become clear that despite a renewed focus on collecting cancer information in the NHS, we do not have adequate information on which to base our assessment of the outcome of primary breast cancer treatments, or to plan the provision of care for those who develop further disease.

Breast Cancer Care and other charities have undertaken commendable work in highlighting these deficiencies; not least in making us aware of the difference women report in the way in which their primary disease was managed and their less satisfactory experiences when diagnosed with metastases and recurrence.

Although the main aim of this pilot was to identify what information could be collated from routine NHS data and cancer registries, valuable feedback has been gained from multidisciplinary teams on how they are focusing their management of this patient group. They have made a vital contribution to the pilot, and it will be important to disseminate what we have learnt from them as the collection of secondary breast cancer data is rolled out nationally in 2012/13 and units plan how they will deliver better quality care for this group of patients.

A handwritten signature in black ink, appearing to read 'Mike Richards', with a stylized, cursive script.

**Professor Sir Mike Richards**

## Executive summary

This report describes the rationale, findings and recommendations of a pilot project undertaken on collection of data on recurrent and metastatic breast cancer.

It is estimated that around 550,000 people are alive in the UK after a diagnosis of breast cancer (1), but it is unknown how many of them have recurrent or metastatic disease. The lack of information on recurrence and metastasis of breast cancer means that the effectiveness of treatments for primary cancers cannot be adequately assessed and the care of patients with recurrent and metastatic cancer cannot be fully evaluated. This makes it difficult to plan and resource services for this group of patients (2).

Breast Cancer Care highlighted the lack of data on secondary breast cancer in 2006, and with other charities and supporters welcomed the announcement in *Improving Outcomes: a Strategy for Cancer* in January 2011 that during 2011/12 data on recurrence/metastasis in patients with breast cancer would be piloted with the aim of undertaking full collection from April 2012 (3).

The overall aim of the project was to discover the extent of information on recurrent and metastatic breast cancer available through current mandated NHS data sources, and to determine how this may be assimilated with related data flows to regional cancer registries, in order to inform recommendations for future national data collection.

Fifteen breast cancer units across England took part in the pilot for six months from June to November 2011. They identified 598 patients with recurrent and/or metastatic breast cancer, who were then matched with the National Cancer Waiting Times Monitoring Dataset (NCWTMDS) and with data received by cancer registries.

The key findings are listed in Table 1. Overall, 94% of the patients identified by the breast units were found in NCWTDS, cancer registry data, or in both. There were, however, deficits in the depth and accuracy of information available from these sources when compared with that provided in data submitted for the pilot by breast units.

Lack of clinical nurse specialist support for patients with recurrent and metastatic breast cancer was identified as an issue from the information provided by breast units, with only half reported to be referred for such support.

Recommendations are made at the end of the report with the aim of supporting better collection of information and provision of care for these patients.

**Table 1: Pilot project key findings**

**Key findings**

- 15 participating units collected data for 6 months between June and November 2011
- 598 patients were reported with recurrent or metastatic breast cancer
- 347 (58%) were recorded to have distant metastasis, including 116 (19%) with both distant and local/regional disease
- For 486 (81%) of the 598 there were matched reports on the National Cancer Waiting Times Monitoring Dataset (NCWTMDS)
- For 510 (85%) of the 598 some information was received by the local cancer registry
- Cancer registry data included pathology reports for 69%, MDT (multidisciplinary team) reports for 44%, radiotherapy reports for 17%, and death certification for 11%
- 53% of patients were recorded to be referred to a clinical nurse specialist, palliative care nurse specialist or other key worker at the time of recurrence/metastasis

# **1. Background**

## **1.1 Breast Cancer Care's campaign**

Breast Cancer Care identified the need for accurate monitoring of the numbers of people living with metastatic breast cancer in 2006 when it established the Secondary Breast Cancer Taskforce. The Taskforce was the first national coalition of healthcare professionals, charities, policy makers and people with metastatic breast cancer in the UK. It was set up to identify gaps in the treatment, support and care of people living with metastatic breast cancer through surveys, research and expert consensus.

In considering how to improve the care of this patient group a logical starting point for the Taskforce was to understand the number of people living with metastatic breast cancer. This information is needed to be able to plan treatment and support services accurately and to investigate improvements in prognosis following recent treatment advances. The Taskforce was surprised to discover these data were not collected nationally.

In light of this the Taskforce set up the 'Stand up and be Counted Campaign' calling for the Department of Health, Scottish Executive and the Welsh Assembly to make the collection of data on incidence and survival of metastatic breast cancer part of the required minimal data set. The campaign involved:

- surveying all the cancer registries in the UK about the issue
- meeting with key policy makers
- a postcard campaign collecting statements of support from people affected by metastatic breast cancer
- working with the West Midlands Cancer Intelligence Unit who are specialists in breast cancer data and analysis.

This information was collated and developed into a policy briefing, which was launched at an event for people with metastatic breast cancer and policy makers in Westminster in October 2007.

The Cancer Reform Strategy (DH) was published in December 2007 and announced the formation of the National Cancer Intelligence Network (NCIN) whose role would be to establish, build and maintain a new national repository of cancer data. At the NCIN's launch in June 2008 it was announced that data on recurrence and metastatic cancers should be collected through the National Cancer Waiting Times Monitoring Dataset from January 2009.

Breast Cancer Care kept in contact with the NCIN during 2009 to see if the requirement was being met. In 2010, the Chair of the All-Party Parliamentary Group for Breast Cancer Annette Brook MP asked the Prime Minister a question on the issue of data collection for metastatic breast cancer, and also asked him if he would meet with the group to discuss it.



*Representatives from breast cancer charities and the All-Party Parliamentary Group on Breast Cancer with the Prime Minister, David Cameron*

This led to a successful meeting with the Prime Minister in December 2010, and a commitment followed in *Improving Outcomes: a Strategy for Cancer* (3), to ensure that these data would be collected, initially via a pilot project: *‘During 2011/12 we will pilot the collection of data on recurrence/metastasis on patients with breast cancer with the aim of undertaking full collection from April 2012. The learning from this exercise will, in time, be applied to the collection of information on other forms of metastatic cancer’.*



## **2. Aims and methods**

### **2.1 Pilot aims**

The specific pilot aims were:

- to identify, by direct submission of data from breast multidisciplinary teams, a clinically defined group of patients diagnosed with recurrent and metastatic breast cancer
- to compare the data that are available on this same group of patients from mandated NHS data collections and from regional cancer registries
- to identify through this analysis any deficits in the information and the need for any additional items or any changes to the data collection process
- to ascertain, from the data gathered and feedback from the pilot sites, what local processes are in place for managing these patients and their access to a clinical nurse specialist (CNS).

### **2.2 Pilot methods**

Fifteen pilot sites collected data on recurrent and metastatic cancer (appendix 1), including local disease (ipsilateral and contralateral recurrences) as well as regional and distant metastasis for the six month period 1 June to 30 November 2011, detailing:

- 1) date of MDM discussion
- 2) hospital and consultant
- 3) route of presentation
- 4) tumour site
- 5) diagnostic confirmation
- 6) treatment plan.

The majority of the data items on the MDM pilot pro forma were those that should already be routinely collected through a mandated NHS dataset.

Feedback was obtained from participating units during this period by teleconference and questionnaire.

Most units affirmed that they already considered patients with metastatic disease at their multidisciplinary team meeting (MDM). Data collection was overseen by MDT co-ordinators and data managers, with clinicians closely involved in the process.

All pilot sites were asked to upload the data captured on the pilot pro forma to a secure web-based database. Some difficulties were reported in collecting all necessary data from the MDM for a complete data submission, as there was no facility for amending or updating

electronic submissions. However, this process was specific for the pilot and will not have any bearing on any future recommendations made.

Most (13/15) of the participating breast units were already aware that patients with recurrent and metastatic disease identified in the MDM should, since January 2009, also be reported by routine submission to the NCWTMDS whenever a new treatment was initiated. This covers any treatment modality, including the option of 'no treatment' as an agreed part of the treatment plan.

The project was supported by a Steering Group; see Appendix 5 for a list of members.

### 3. Findings and discussion from the pilot

#### 3.1 Data from multidisciplinary teams (MDTs)

Altogether 598 patients with recurrent and/or metastatic breast cancer were identified by the 15 participating breast units during the six months of the study (Table 2). Three hundred and forty seven (58%) of these patients were reported to have distant metastases; one third (116) of these were reported also to have local or regional disease.

In 251 (42%) patients with no recorded distant metastases, a mixture of local and regional recurrence was identified, including 209 with local disease, 29 with regional disease and 10 with local and regional disease. Thirty three new primary cancers were reported in this group.

Contralateral (on the opposite side to the original primary breast cancer) local or regional disease was reported in 93 (16%) of the total group of 598 patients.

**Table 2: Number of patients by breast unit, by region**

Breast cancer unit	Cancer registry	Number of patients	% of patients
A	Eastern	14	2%
B	Eastern	31	5%
C	North West	62	10%
D	Northern & Yorkshire	42	7%
E	Oxford	25	4%
F	Oxford	50	8%
G	South West	13	2%
H	South West	33	6%
I	Thames	51	9%
J	Thames	88	15%
K	Trent	85	14%
L	Trent	23	4%
M	West Midlands	25	4%
N	West Midlands	33	6%
O	West Midlands	23	4%
<b>TOTAL PATIENTS</b>		<b>598</b>	<b>100%</b>

The time from original primary breast cancer diagnosis was available in 489 patients (Table 3) and showed lengthy variation in time to recurrence; the original primary had been diagnosed in 1979-99 in 19%, in 2000-9 in 47%, and in 2010-11 in 16%.

**Table 3: Time from original primary breast cancer diagnosis**

Diagnosis date of primary breast cancer	Patients entered in pilot	
	Number	%
1970-1979	4	1%
1980-1989	20	3%
1990-1999	88	15%
2000-2009	281	47%
2010	46	8%
2011 Jan-Apr	8	1%
2011 May onward	42	7%
unknown	109	18%
<b>ALL YEARS</b>	<b>598</b>	<b>100%</b>

Feedback from MDTs indicates that the pilot has stimulated interest in how these patients are managed. The NICE Quality standard for breast cancer (National Institute for Health and Clinical Excellence: August 2011) states that *'People who develop local recurrence, regional recurrence and/or distant metastatic disease have their treatment and care discussed by the multidisciplinary team'* (4). The majority of units responded that this was already part of their routine practice. Sites where this was not usual practice felt participation had raised awareness, one for example reporting, *'It has focused our team's attention on these patients and we are discussing whether we should have a dedicated metastatic MDM'*. Some units already had a section of their MDM dedicated to patients with metastatic disease, and as a result of taking part in the pilot one hospital has set up a separate MDM for metastatic breast cancer patients (See Appendix 2).

For breast MDTs and their patients, accurate collection of data on recurrent and metastatic breast cancer should enable a better understanding of disease-free survival, metastatic disease-free survival and survival after diagnosis with recurrent or metastatic disease. It should also provide valuable information to inform and improve the clinical pathway and management of metastatic breast cancer outside a clinical trial setting.

As it is unlikely that every patient with recurrent or metastatic breast cancer seen in the participating units was reported, the data from this pilot are not a suitable basis for estimating the full extent and nature of recurrent and metastatic breast cancer nationally. Variation observed in the number of patients identified by units suggests reporting may not have been complete, and there were some gaps in the data recorded by MDTs which may have been due to unavailable information at the time of submission.

### 3.2 Routes of referral

Helping people to navigate the many different routes observed in ‘finding their way’ back to the breast team poses a challenge for primary care and hospitals. In many instances (44%; Table 4) recurrent or metastatic disease was discovered in ways other than by routine clinical or radiological follow-up.

Detailed descriptions of patients’ clinical presentations provided by participating units reveal a wide range of symptoms and much variation in the route back to the multidisciplinary breast team. The role of general practitioners (GPs) in referring symptomatic patients for urgent investigation is important: 25% of referrals were made for symptoms through two-week cancer wait appointments, and a further 4% through other GP referrals. The fact that 13% came via emergency admissions suggests that there may sometimes be a delay in recognising and acting earlier on symptoms of metastatic disease. Referrals in or between hospitals identified 9%, and only 12 patients (2%) were categorised as self-referred.

**Table 4: Presentation routes**

Route of presentation	Number of patients	% of patients
Symptomatic ‘cancer waiting time’ referral	151	25%
Routine clinical follow-up	116	19%
Emergency admission	78	13%
Routine imaging follow-up	72	12%
NHSBSP screening	38	6%
Internal referral from within hospital	38	6%
Other GP referral	21	4%
Other follow-up	16	3%
Referral from other hospital	19	3%
Unknown	16	3%
Other	14	2%
Patient self-referral	12	2%
At diagnosis/treatment of primary tumours	7	1%
<b>TOTAL PATIENTS</b>	<b>598</b>	<b>100%</b>

### 3.3 Supportive care

Part of the dataset the pilot sites were asked to collect was whether each patient was signposted to supportive care in the form of a CNS, palliative care professional or other key worker. These data are not currently part of any standard NHS data flow; however it is intended that this information will be required through the new cancer outcomes and services dataset (COSD) which it is planned will come into effect from January 2013 subject to becoming an NHS Information Standard.

A little over half (53%) of patients in the pilot were recorded as being offered any form of supportive care from a CNS, palliative care professional or other key worker. Although it is possible that some patients already had ongoing supportive care or were referred without it being recorded, this finding is consistent with research showing that patients with a diagnosis of metastatic breast cancer receive less supportive care compared to when they had their primary breast cancer diagnosis (5). Such support may not be available from their previous breast nurse; a survey of 276 breast cancer nurses reported that 57% felt unable to adequately care for patients with metastatic breast cancer due to not having the time or the necessary skills (6). The NICE Quality standard for breast cancer includes a statement that *'People with recurrent or advanced breast cancer have access to a "key worker", who is a clinical nurse specialist and whose role is to provide continuity of care and support, offer referral to psychological services if required and liaise with other healthcare professionals, including the GP and specialist palliative care services'* (4).

### **3.4 Data matching with the National Cancer Waiting Times Monitoring Dataset (NCWTMDS) and registries**

One of the primary aims of the pilot was to discover if routine NHS data sources could be relied upon to capture information on this group of patients identified by MDTs, which is adequate for future purposes both in terms of completeness and accuracy. Information on the 598 patients identified by the pilot breast units was matched against the NCWTMDS in the Cancer Waiting Times database (CWT-db). A record was deemed 'matched' if information on the patient could be found in the NCWTMDS within the period March-November 2011.

Overall 486 (81%) of the 598 patients were found in the CWT-db. The figure varied from 70% to 91% between regions (Table 5) and was highest (91%) when surgery was part of the treatment plan (Table 6). However there was a wide inter-unit variation in cancer waiting time data for patients for whom neither surgery nor radiotherapy was planned. For 73 patients overall in the MDM pilot data for who no planned treatment was recorded, 59% were matched through the NCWTMDS data, with a unit range from 61-96%.

The pilot uncovered some uncertainty around the requirements for the NCWTMDS data, and it is likely that if this were to be systematically addressed the overall figure of 81% found in NCWTMDS alone would increase. In particular there appears to be a need to ensure that the NCWTMDS data are submitted for patients with recurrent and metastatic disease who are not undergoing a surgical procedure.

The regional cancer registries had received some information on recurrence or metastasis for 510 patients (85%). This included a pathology report for 69%, an MDT report for 44%, a radiotherapy report for 17%, and death certification for 11%.

Taking both sources overall, 94% of patients had some information in either the NCWTMDS data or cancer registry records, leaving 38 (6%) of the 598 patients for whom no information was available.

Though it is encouraging that the majority of patients identified by MDTs were found through a combination of NCWTMDS and registry data, there were deficits and disparities. For example, in 265 patients reported by MDTs to have distant metastases and also found on the CWT-db, only 43% had metastatic disease recorded on the CWT-db; and 4% of patients reported by MDT data as not having distant metastases were recorded as having metastases on the CWT-db.

The differences between MDT pilot data and available matched data from the CWT-db and registries suggests a need for future work to improve the correlation between patient clinical data, cancer waits submissions and registry data. Notwithstanding the variation currently seen there is potential to achieve a high level of completeness of identification of these patients by improving data comprehensiveness and combining both sources.

**Table 5: Matching with the National Cancer Waiting Times Monitoring Dataset (NCWTMDS)**

Cancer registry	Did the CWT-db contain a record of patient for the period studied?		Total	% in CWT
	No	Yes		
Eastern	4	41	45	<b>91%</b>
North West	9	53	62	<b>85%</b>
Northern & Yorkshire	5	37	42	<b>88%</b>
Oxford	14	61	75	<b>81%</b>
South West	14	32	46	<b>70%</b>
Thames	32	107	139	<b>77%</b>
Trent	22	86	108	<b>80%</b>
West Midlands	12	69	81	<b>85%</b>
<b>TOTAL</b>	<b>112</b>	<b>486</b>	<b>598</b>	<b>81%</b>

**Table 6: Matching with NCWTMDS by treatment planned as given by pilot units**

Was surgical treatment planned?	Did the CWT-db contain record of patient for the period studied?		Total	% in CWT
	No	Yes		
<b>No</b>	92	288	380	76%
<b>Yes</b>	20	198	218	91%
<b>TOTAL</b>	<b>112</b>	<b>486</b>	<b>598</b>	<b>81%</b>

Additional unit and registry data tables that provide the background to these findings are included in Appendix 6.



## **4. Monitoring of future data collection**

The WMCIU and the NCIN will review the provider based returns made via the NCWTMDS with other data returns received by the regional registries against an estimate of caseload for each provider.

From January 2013 other data items that are currently not collected as part of the NCWTMDS, e.g. those relating to supportive care, will be required through COSD and will likewise be reviewed by the WMCIU and the NCIN on a regular basis. These will include:

- route of presentation
- date of diagnostic confirmation
- supportive care – CNS
- supportive care – palliative care
- supportive care – other key worker.

Breast Cancer Care will maintain contact with WMCIU and NCIN to ensure data are flowing and will use the information available as appropriate to support its secondary breast cancer campaigning work.

The NCIN and WMCIU should work with DH to promote routine collection of data on recurrent and metastatic breast cancer by all breast cancer units through the CWT-db and make these NCWTMDS data, and more, routinely available.

## **5. Recommendations from the pilot**

The following recommendations aim to support better data collection and improved care for patients with recurrent and metastatic breast cancer:

- 1) All breast cancer units in England to submit data on patients with recurrent and metastatic breast cancer. These data should be captured through the NCWTMDS which has been a mandatory requirement since 2009. See Appendices 2 and 3 for advice on this.
- 2) Breast Unit MDT co-ordinators and data managers should ensure, in collaboration with clinical colleagues, that data are collected for each breast team. This will be a locally determined process for each breast unit to agree. Data should be collected at the time of patient contact and be included in the monthly NCWTMDS data returns made by each provider.
- 3) Additional information on supportive care is to be collected as required from January 2013 in the COSD (see Appendix 4).
- 4) GPs to ensure that patients with a previous history of breast cancer and symptoms that could indicate recurrent or metastatic disease are referred urgently for assessment through the existing cancer wait process.
- 5) Providers should ensure that local arrangements are in place for urgent clinical review of patients with suspected recurrence or metastasis.
- 6) Patients with recurrent or metastatic breast cancer should receive multidisciplinary care and the support of a CNS, as outlined in the NICE breast quality standard. This may be achieved within the existing MDT or through a separate process.

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## Glossary

The **Association of Breast Surgery** represents healthcare professionals treating malignant and benign breast disease in the UK, Ireland and worldwide. It focuses on education, audit and guidelines to enhance the treatment of patients with breast disease.

[www.associationofbreastsurgery.org.uk](http://www.associationofbreastsurgery.org.uk)

**Breast Cancer Care** is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do. Improving the care of people affected by secondary breast cancer is a key area of impact for the organisation. Visit [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) or call our free helpline on 0808 800 6000.

**Cancer Outcomes and Services Dataset (COSD)** The COSD will be the new national standard for reporting cancer in the NHS in England. It will replace the current national cancer dataset and will include the cancer registration dataset and additional site specific data items relevant to the different tumour types. It will be aligned with existing national cancer datasets. The COSD is being developed by the NCIN in collaboration with its Site Specific Clinical Reference Groups. For more information [http://www.ncin.org.uk/collecting\\_and\\_using\\_data/data\\_collection/cancer\\_outcomes\\_and\\_services\\_dataset.aspx](http://www.ncin.org.uk/collecting_and_using_data/data_collection/cancer_outcomes_and_services_dataset.aspx)

**Cancer Waiting Times Database (CWT-db)** This database holds the National Cancer Waiting Times Monitoring Dataset (NCWTMDS) and is managed by Open Exeter.

**Contralateral** On the other side of the body

**Ipsilateral** On the same side of the body

**Local recurrence** When breast cancer returns in the chest/breast area or in the skin near the original site or scar, this is called a local recurrence. Cancer cells have remained in the local area despite treatment and have grown again.

**MDM** Multidisciplinary team meeting

**MDT** Multidisciplinary team

**Metastatic breast cancer** Also known as secondary or advanced breast cancer, metastatic breast cancer occurs when breast cancer cells spread from the first (primary) tumour in the breast through the lymphatic or blood system to other parts of the body. The most common parts of the body that breast cancer spreads to are the bones, liver, lungs and brain. A diagnosis of metastatic breast cancer means that the cancer cannot be cured, although it can be controlled, sometimes for years.

**National Cancer Intelligence Network (NCIN)** A UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.

**National Cancer Waiting Times Monitoring Dataset (NCWTMDS)** This is used by the NHS and Department of Health to: monitor timed pathways of care for cancer patients; manage pathways of care for cancer patients; performance manage elective services for cancer patients; report against the requirements of the NHS Operating Framework for cancer waiting times; support the right to access cancer services within the NHS Constitution (the two-week wait); produce national, official and local statistics for cancer patients; and support investment planning for cancer services. Applies to system suppliers of IT to the NHS, cancer registries and providers of acute cancer treatment services.

**National Institute for Health and Clinical Excellence (NICE)** develops evidence-based guidelines on the most effective ways to diagnose, treat and prevent disease and ill health.

**Regional recurrence** Breast cancer which has come back following treatment and has spread to lymph nodes (glands) around the breast. The lymph nodes involved may be in the armpit (axilla), around the breastbone (sternum) and between the ribs (called internal mammary nodes), or the nodes above and below the collarbone (clavicle).

**West Midlands Cancer Intelligence Unit (WMCIU)** is the regional cancer registry for the West Midlands and the National Cancer Intelligence Network lead registry for breast cancer. [www.wmpho.org.uk/wmciu](http://www.wmpho.org.uk/wmciu)

## Appendix 1

### Pilot sites

Cancer Registry	Trust
Eastern	Cambridge University Hospitals NHS Foundation Trust
Eastern	Southend University Hospital NHS Foundation Trust
North West	Royal Liverpool & Broadgreen University Hospitals NHS Trust
North & Yorkshire	The Leeds Teaching Hospitals NHS Trust
Oxford	Buckinghamshire Healthcare NHS Trust
Oxford	Royal Berkshire NHS Foundation Trust
South West	Great Western Hospitals NHS Foundation Trust
South West	Winchester & Eastleigh Healthcare NHS Trust
Thames	East Sussex Healthcare NHS Trust
Thames	The Royal Marsden NHS Foundation Trust
Trent	Royal Derby Hospitals NHS Foundation Trust
Trent	Sheffield Teaching Hospitals NHS Foundation Trust
West Midlands	University Hospitals Coventry & Warwickshire NHS Trust
West Midlands	Worcestershire Acute Hospitals NHS Trust
West Midlands	Wye Valley NHS Trust

## Appendix 2

### Advice for breast units on NCWTMDS data collection and new MDT models

#### NCWTMDS data collection

All patients receiving NHS care for the management of their secondary breast cancer should be reported through the NCWTMDS on a monthly basis whenever a different treatment is commenced.

*NB: within the NCWTMDS there is also an option to report the waiting times for those patients who do not receive any treatment, whether for personal or medical reasons.*

In addition to the data items relating to the date on which treatment was both agreed with the patient and commenced, data relating to the reason for the cancer treatment, e.g. treatment for a distant recurrence of cancer (metastatic disease), plus those sites where metastatic disease is present are also required.

#### MDT models

As a result of taking part in the pilot, Addenbrooke's Hospital in Cambridge has set up a specific MDT for metastatic breast cancer patients. The Cambridge Breast Cancer Unit recognises the importance of ensuring MDT input to the care of patients with metastatic disease, a key issue highlighted by Breast Cancer Care. To this end, a dedicated metastatic MDT was established at the end of 2011. This provides a weekly forum to discuss the cases of new patients and those with complex management problems. Each patient's case is discussed together with relevant scan and pathology results. The input provided by radiology, pathology, oncology, surgery, nursing and palliative care enables us to decide on the optimal treatment plan. The MDT is also proving an excellent point at which to identify clinical research opportunities for our patients. These studies include new ways to more closely monitor patients on treatment, as well as clinical trials of new drugs. Furthermore the data collected at these meetings will be invaluable to facilitate audit and new research projects for the future.

Another model, which has been developed in some trusts, is to have a dedicated section in the multidisciplinary meeting. It follows the post-operative cases when the oncologists are present. Though it requires extra time it doesn't necessitate a separate time in the week when many clinicians' job plans will require adjustment and may prove to be problematic. It has the additional advantage that all other team members are present, and the patient's care is enhanced by a full multidisciplinary discussion of the diagnosis and management of recurrent or metastatic disease.

## Appendix 3

### Key NCWTMDS data items for collection from April 2012

The following data items will act as a 'flag' to the regional cancer registries of the presence of recurrence or metastatic disease.

#### Cancer treatment event type

This identifies the phase treatment has reached during a cancer patient pathway for primary, recurrent or metastatic cancer. The codes that can be used are:

01	First definitive treatment for a new primary cancer
02	Second or subsequent treatment for a new primary cancer
03	Treatment for a local recurrence of a primary cancer
04	Treatment for a regional recurrence of cancer
05	Treatment for a distant recurrence of cancer (metastatic disease)
06	Treatment for multiple recurrences of cancer (local and/or regional and/or distant)
07	First treatment for metastatic disease following an unknown primary
08	Second or subsequent treatment for metastatic disease following an unknown primary
09	Treatment for relapse of primary cancer (second or subsequent)
10	Treatment for progression of primary cancer (second or subsequent)

A value of 3, 4, 5, 6, 7 or 8 in the field [Cancer treatment event type] will indicate recurrence or metastatic disease.

#### Metastatic site

This item is used where the primary cancer has spread elsewhere in the body to identify the site of the metastatic disease, i.e. where primary cancer has spread. National codes to choose from are:

01	Bone
02	Brain
03	Liver
04	Lung
05	Other metastatic site
06	Multiple metastatic sites
07	Unknown metastatic site

The value list for this data item has been reviewed and the Information Standards Board has approved an extension for July 2012. Further information can be found at

<http://www.isb.nhs.uk/documents/isb-0147/amd-23-2011/index.html>

For details of the full NCWTMDS dataset go to:

[http://www.datadictionary.nhs.uk/data\\_dictionary/messages/clinical\\_data\\_sets/data\\_sets/national\\_cancer\\_waiting\\_times\\_monitoring\\_data\\_set\\_fr.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/messages/clinical_data_sets/data_sets/national_cancer_waiting_times_monitoring_data_set_fr.asp?shownav=1)



## **Appendix 4**

### **Key COSD data items for collection from January 2013**

From January 2013 other data items that are currently not collected as part of the NCWTMDS, e.g. those relating to supportive care, will be required through COSD and will likewise be reviewed by the WMCIU and the NCIN on a regular basis. These will include:

- Route of presentation
- Date of diagnostic confirmation
- Supportive care – CNS
- Supportive care – palliative care
- Supportive care – other key worker

(See COSD dataset for full definition and codes, [www.NCIN.org.uk](http://www.NCIN.org.uk) )

## **Appendix 5**

### **Steering Group members**

Martin Lee (Chair), Breast Surgeon, NCIN Breast Clinical Reference Group, Medical Director, NHS Coventry and NHS Warwickshire

Di Riley, Associate Director, Clinical Outcomes Programme, NCIN

Jane Allberry, Deputy Director, Cancer, Cardiovascular, End of Life Care and Dermatology, Department of Health

Gill Lawrence, Director, West Midlands Cancer Intelligence Unit

Catherine Lagord, Breast Cancer Audit Project Manager, West Midlands Cancer Intelligence Unit

Emma Pennery, Clinical Director, Breast Cancer Care

Dora Wheeler (Project Manager), Policy and Campaigns Officer, Breast Cancer Care

Jem Rashbass, National Director for Cancer Registration Modernisation, c/o Eastern Cancer Registration and Information Centre

Murray Brunt, Clinical Oncologist, University Hospital of North Staffordshire (NCIN Breast Clinical Reference Group)

Teresa Smith, MDT Co-ordinator, Cambridge Breast Unit

Lesley Raynor, Breast Care Nurse, Southend University Hospital

Alison Thorpe, Breast Care Nurse, Southend University Hospital

## Appendix 6

### Additional unit and registry data tables

**Table A: Number of patients recorded by breast unit, by month of diagnosis**

Unit	Month of diagnosis (2011)								TOTAL
	Before Jun	Jun	Jul	Aug	Sept	Oct	Nov	Unknown	
Unit A	3	1	3	2	2		3		14
Unit B	1	11	3	5	5	6			31
Unit C	1	10	15	5	16	9	6		62
Unit D	1	16	9	10	4	2			42
Unit E		5	3	9	4	2	2		25
Unit F		12	8	9	6	4	10	1	50
Unit G	2	8	1	2					13
Unit H		7	3	6	3	9	4	1	33
Unit I	1	11	16	12	4	3	4		51
Unit J	1	24	21	17	17	7	1		88
Unit K		10	13	20	13	12	14	3	85
Unit L	1	7	6	8				1	23
Unit M		4	6	3	7	3	1	1	25
Unit N	1	6	4	9	4	6	2	1	33
Unit O	3	2	5	4	5	3	1		23
<b>TOTAL</b>	<b>15</b>	<b>134</b>	<b>116</b>	<b>121</b>	<b>90</b>	<b>66</b>	<b>48</b>	<b>8</b>	<b>598</b>

**Table B: Proportion of patients with distant metastasis who also had breast disease at presentation**

Breast disease at presentation?	Number of patients	% of patients
Yes, type unknown	16	5%
Yes, breast cancer recurrence	47	14%
Yes, new primary breast tumour	30	9%
No	254	73%
<b>TOTAL</b>	<b>347</b>	<b>100%</b>

**Table C: Diagnosis of breast disease and/or axillary/regional recurrence among patients with distant metastasis at presentation**

Breast disease at presentation?	Presence of axillary or other regional recurrence?	
	No	Yes
Yes, type unknown	13	3
Yes, new primary breast tumour	22	8
Yes, breast cancer recurrence	31	16
No	231	23
<b>TOTAL</b>	<b>297</b>	<b>50</b>

**Table D: Proportion of patients with no distant metastasis who had breast disease at presentation**

Breast disease at presentation?	Number of patients	% of patients
Yes, type unknown	68	27%
Yes, breast cancer recurrence	105	42%
Yes, new primary breast tumour	33	13%
Yes, recurrence and new primary	3	1%
No	40	16%
<b>TOTAL</b>	<b>249</b>	<b>100%</b>

**Table E: Diagnosis of breast disease and/or axillary/regional recurrence among patients without distant metastasis at presentation**

Breast disease at presentation?	Presence of axillary or other regional recurrence?	
	No	Yes
Yes, type unknown	67	1
Yes, breast cancer recurrence	99	6
Yes, new primary breast tumour	31	2
Yes, recurrence and new primary	2	1
No	11	29
<b>TOTAL</b>	<b>210</b>	<b>39</b>

**Table F: Matching with the National Cancer waiting Times Monitoring Dataset (NCWTMDS) patients with no surgery and no radiotherapy planned**

Patients with no surgery and no radiotherapy planned by breast unit	Did CWT-db contain record of patient for the period studied?		Total	% in CWT
Breast unit	No	Yes		
Unit H	12	5	17	29%
Unit M	5	6	11	55%
Unit E	5	7	12	58%
Unit I	14	20	34	59%
Unit K	15	28	43	65%
Unit F	5	14	19	74%
Unit J	8	27	35	77%
Unit L	4	14	18	78%
Unit C	6	24	30	80%
Unit O	1	4	5	80%
Unit A	1	5	6	83%
Unit N	2	11	13	85%
Unit D	3	21	24	88%
Unit B	1	16	17	94%
Unit G	0	3	3	100%
<b>ALL UNITS</b>	<b>82</b>	<b>205</b>	<b>287</b>	<b>71%</b>

**Table G: Matching against cancer registries pathology report**

Cancer registry	Pathology report received?		Total	% path report
	No	Yes		
ECRIC	21	24	45	53%
NWCIS	15	47	62	76%
NYCRIS	16	26	42	62%
OCIU	22	53	75	71%
SWCIS	11	35	46	76%
Thames	36	103	139	74%
Trent	43	65	108	60%
WMCIU	20	61	81	75%
<b>All cancer registries</b>	<b>184</b>	<b>414</b>	<b>598</b>	<b>69%</b>

**Table H: Matching against cancer registries MDT report**

Cancer registry	MDT report received?		Total	% MDT report
	No	Yes		
ECRIC	25	20	45	44%
NWCIS	18	44	62	71%
NYCRIS	3	39	42	93%
OCIU	35	40	75	53%
SWCIS	34	12	46	26%
Thames	69	70	139	50%
Trent	102	6	108	6%
WMCIU	50	31	81	38%
<b>All cancer registries</b>	<b>336</b>	<b>262</b>	<b>598</b>	<b>44%</b>

**Table I: Matching against cancer registries radiotherapy report**

Cancer registry	Radiotherapy report received?		Total	% Radiotherapy report
	No	Yes		
ECRIC	39	6	45	13%
NWCIS	56	6	62	10%
NYCRIS	26	16	42	38%
OCIU	70	5	75	7%
SWCIS	30	16	46	35%
Thames	118	21	139	15%
Trent	94	14	108	13%
WMCIU	64	17	81	21%
<b>All cancer registries</b>	<b>497</b>	<b>101</b>	<b>598</b>	<b>17%</b>

**Table J: Matching against cancer registries death certificate**

Cancer registry	Death certificate received?		Total	% Death certificate
	No	Yes		
ECRIC	42	3	45	7%
NWCIS	59	3	62	5%
NYCRIS	32	10	42	24%
OCIU	68	7	75	9%
SWCIS	44	2	46	4%
Thames	119	20	139	14%
Trent	103	5	108	5%
WMCIU	68	13	81	16%
<b>All cancer registries</b>	<b>535</b>	<b>63</b>	<b>598</b>	<b>11%</b>

Overall, for 85% of the patients identified by the pilot units, Cancer Registries had received information through one or several of their routine data feeds (Table K).

**Table K: Matching against cancer registries – all data sources**

Cancer registry	Report received from any data source?		Total	% Information (any source) received
	No	Yes		
ECRIC	9	36	45	80%
NWCIS	6	56	62	90%
NYCRIS	1	41	42	98%
OCIU	14	61	75	81%
SWCIS	5	41	46	89%
Thames	14	125	139	90%
Trent	34	74	108	69%
WMCIU	5	76	81	94%
<b>All cancer registries</b>	<b>88</b>	<b>510</b>	<b>598</b>	<b>85%</b>

**Table L: Treatment plan reported by pilot units**

Treatment plan (**)	% of patients
Endocrine therapy	45%
Surgery	36%
Chemotherapy	29%
Radiotherapy	26%
Targeted therapy	5%
Bisphosphonate	14%
No treatment recorded	12%

**\*\*** Plan for a patient may contain more than one treatment modality

This report describes the rationale, findings and recommendations of a pilot project undertaken on collection of data on recurrent and metastatic breast cancer. The 15 breast units and associated regional cancer registries who took part were supported by:

Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do. Improving the care of people affected by secondary breast cancer is a key area of impact for the organisation. Visit [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk) or call our free helpline on 0808 800 6000.

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. [www.ncin.org.uk](http://www.ncin.org.uk)

The Association of Breast Surgery represents healthcare professionals treating malignant and benign breast disease in the UK, Ireland and worldwide. It focuses on education, audit and guidelines to enhance the treatment of patients with breast disease. [www.associationofbreastsurgery.org.uk](http://www.associationofbreastsurgery.org.uk)

The West Midlands Cancer Intelligence Unit is the regional cancer registry for the West Midlands and the NCIN lead registry for breast cancer. [www.wmpho.org.uk/wmciu](http://www.wmpho.org.uk/wmciu)

For an electronic copy of this report, visit [www.ncin.org.uk](http://www.ncin.org.uk)



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