

November 2012  
Gateway Reference Number 18327

Dear Colleague

**Re: Collection of Data on Recurrent and Metastatic Breast Cancer – Next Steps**

The following letter has been sent to all Trust Chief Executives and is being sent to you for information.

There are more than half a million people alive in the UK after a diagnosis of breast cancer, but we do not know how many of them have recurrent or metastatic disease. This gap in routinely collected data means that we lack knowledge on the effectiveness of primary breast cancer treatments, and also on the care of those who develop recurrent and metastatic disease.

**Pilot Study**

In response to this concern, and to inform recommendations for future national data collection (*Improving Outcomes: a Strategy for Cancer* DH January 2011), a six month pilot project was performed to identify the extent to which information on recurrent and metastatic breast cancer is available through existing mandated NHS data sources and regional cancer registries. A recent National Cancer Intelligence Network (NCIN) data briefing on the findings of the pilot is attached, and the full report is available at [www.ncin.org.uk](http://www.ncin.org.uk).

Overall the pilot found data on 94% of patients in the National Cancer Waiting Times Monitoring Data Set (NCWTMDS) or cancer registry data, but the information from these sources was not complete. The amount of information submitted by multidisciplinary teams (MDTs) varied, and around half of patients had no documented clinical nurse specialist (CNS) support.

Feedback from pilot sites highlighted the important clinical role MDTs have in managing this group of patients, specifically the need to record the date of recurrence or metastasis, and to agree a management plan that includes diagnostic assessment, treatment and support.

### NICE Quality Standards

The NICE Quality Standards for Breast Cancer <http://guidance.nice.org.uk/QS12> published in August 2011 support the need for action:

Standard 11 states that "*People who develop local recurrence, regional recurrence and/or distant metastatic disease have their treatment and care discussed by the multidisciplinary team*";

Standard 12 states that "*People with recurrent or advanced breast cancer have access to a 'key worker', who is a clinical nurse specialist 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*".

### Data

Review of current data submissions through the NCWTMDS and to registries is now underway, and a monitoring specification is being developed. Collection of the Cancer Outcomes and Services Dataset (COSD) by NHS Trusts and the transfer of these data items to English cancer registries is mandated from January 1<sup>st</sup> 2013 (ROCR/OR/2142/FT6/001MAND). This will apply to all new diagnoses of cancer and all diagnoses of recurrent and/or metastatic breast cancer from that date, and will include submission of information on supportive care; see

[http://www.ncin.org.uk/collecting\\_and\\_using\\_data/data\\_collection/cosd.aspx](http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd.aspx).

### National Cancer Peer Review

From 2013, National Cancer Peer Review (NCPR) will incorporate measures to support improvements in data collection (through COSD) and in the clinical care provided for patients with recurrent and metastatic breast cancer. The requirement for discussion at the MDT meeting will address MDT treatment planning for patients with recurrent or metastatic breast cancer, and access to a Clinical Nurse Specialist or other key worker(s). The NCIN breast cancer service profile, which incorporates the NCPR Clinical Lines of Enquiry, will ultimately include Trust and MDT based information on patients with recurrent and/or metastatic breast cancer.

### Actions

There are three important steps that Breast Unit MDTs in England should be taking now to support better data collection and improved clinical care for patients with recurrent and metastatic breast cancer:

1. ensure that data are collected on breast cancer recurrences and metastases at the time of patient contact, by a locally agreed process
2. submit data on all patients with recurrent and/or metastatic breast cancer (whether or not they have active treatment) through monthly NCWTMDS submissions, a mandatory requirement since 2009 (ROCR/OR/0018/FT6/002MAND), see ([http://www.ncin.org.uk/publications/data\\_briefings/recurrent\\_and\\_metastatic\\_breast\\_cancer.aspx](http://www.ncin.org.uk/publications/data_briefings/recurrent_and_metastatic_breast_cancer.aspx))
3. ensure that all patients with recurrent and/or metastatic breast cancer receive multidisciplinary care including the support of a CNS, as outlined in the NICE breast quality standards.

Providers should ensure that local arrangements are in place for urgent clinical review of patients with suspected recurrence or metastasis.

General practitioners are asked 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.

A toolkit aimed at nurses caring for patients with metastatic breast cancer, focusing on practical ways of developing and improving specialist nursing services for these patients can be found at <http://www.breastcancercare.org.uk/healthcare-professionals/resources-publications/reports-briefings-toolkits/secondary-breast-cancer-nursing-toolkit>

In summary, our aim must be both to obtain better measurement of outcomes from primary breast cancer treatment, and to secure improvements in the multidisciplinary care and outcomes of those with recurrence or metastasis. Better information on the size of this problem across England will also facilitate planning of the use of existing resources. We strongly encourage you to take the steps outlined above to improve breast cancer clinical care, outcomes and experience for patients diagnosed with recurrent or metastatic breast cancer.

Yours sincerely



Martin Lee  
Chair, NCIN Breast Clinical Reference Group



Professor Sir Mike Richards  
National Cancer Director



Adrian Harnett  
Consultant Clinical Oncologist  
Chair, Breast Cancer Quality Standard Topic Expert Group

***The Recurrent and Metastatic Breast Cancer pilot project was carried out in co-operation with:***

