Recurrent and Metastatic Breast Cancer
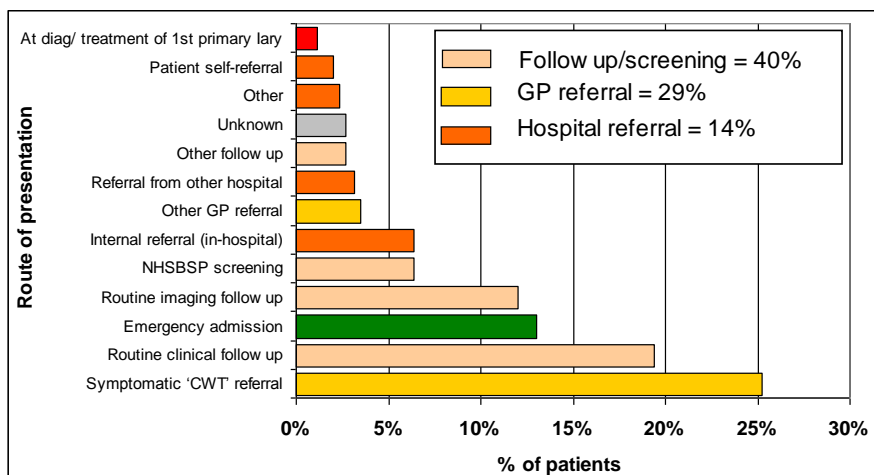
NCIN Data Briefing

Introduction

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 have recurrent or metastatic disease. This information is needed to assess the outcome of primary cancer treatments, and to plan the provision of care for those who develop further disease. In January 2011, *Improving Outcomes: a Strategy for Cancer* announced that during 2011/12 the collection of data on recurrences and/or metastasis in breast cancer patients would be piloted with the aim of undertaking full collection from April 2012 *(2)*. This data briefing summarises the finding of the pilot.

Pilot set up

The aim of the pilot was to discover how much information on recurrent and metastatic breast cancer is available through current mandated NHS data sources and 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.

KEY MESSAGES FROM PILOT:

- *In 598 recurrent breast cancer patients from an MDT data pilot, 58% had distant metastases, and 40% presented through routine follow-up or screening*

- *85% were identified in routine datasets by cancer registries, 81% in cancer waiting time data (NCWTMDS), and 94% by at least one of these routes*

- *Most (93%) of those not recorded in the NCWTMDS had not received any treatment*

- *Referral to a CNS or palliative care worker was documented for only 53% of patients.*
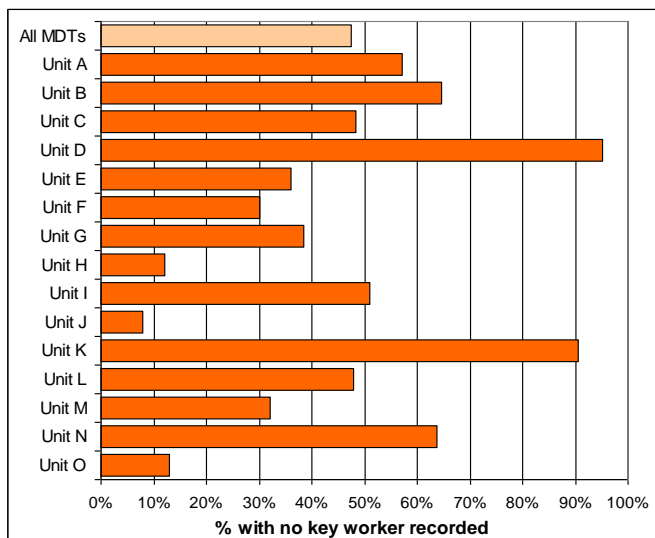
Pilot findings

Presentation Routes: Detailed descriptions of patients' clinical presentations provided by participating units revealed a wide range of symptoms, and much variation in the route back to the multidisciplinary breast team (**Figure 1**). 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. 9% of patients came from referrals in or between hospitals, and only 12 patients (2%) were categorised as self-referred.

Figure 1

Using information to improve quality and choice

June 2012

% with no key worker recorded

(Chart categories: All MDTs, Unit A, Unit B, Unit C, Unit D, Unit E, Unit F, Unit G, Unit H, Unit I, Unit J, Unit K, Unit L, Unit M, Unit N, Unit O; x-axis 0%–100%)

Access to Key Personnel: Pilot sites also indicated whether patients were signposted to supportive care (a cancer nurse specialist [CNS], palliative care professional or other key worker) (**Figure 2**). Although these data are not currently part of standard NHS data flows they will be required in the new Cancer Outcomes and Services Dataset (COSD) (effective from January 2013, subject to becoming an NHS Information Standard). Overall, 47% of patients had no referral to a CNS or palliative care worker recorded. (It is possible that referral was not recorded in those seen by their original CNS or requiring different support.)

Routine Data Feeds: Overall, 486 patients (81%) were recorded in NCWTMDS. This varied from 70% to 91% between regions and was highest (91%) when the treatment plan included surgery. 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 for whom no planned treatment was recorded, 59% were matched through the NCWTMDS data, with a unit range from 61-96%. The pilot uncovered a need to ensure that NCWTMDS data are submitted for patients with recurrent and metastatic disease who are not undergoing a surgical procedure. The regional cancer registries had received information on recurrence or metastasis for 510 patients (85%). 69% had a pathology report, 44% an MDT report, 17% a radiotherapy report and 11% a death certificate. Overall, 94% of patients had information in either the NCWTMDS data or cancer registry records, leaving 38 patients (6%) for whom no information was recorded.

Recommendations

All breast cancer units in England should capture, through the NCWTMDS, information on patients with recurrent and metastatic breast cancer (mandatory requirement since 2009).

GPs should ensure that patients with a previous history of breast cancer and symptoms that could indicate recurrent or metastatic disease are referred urgently through the existing cancer wait process.

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

Further Information

This data briefing is based on "Recurrent and Metastatic Breast Cancer Data Collection Project" (Pilot report, March 2012 http://www.ncin.org.uk/view.aspx?rid=1043)

(1) Cancer prevalence in the United Kingdom: estimates for 2008. Maddams, J. et al. (2009). *British Journal of Cancer.* 101, 541-547

(2) *Improving Outcomes: a Strategy for Cancer.* Department of Health, January 2011. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalass et/dh_123394.pdf

FIND OUT MORE:

The West Midlands Cancer Intelligence Unit is the lead cancer registry for breast cancer http://www.wmpho.org.uk/wmciu

Other useful resources within the NCIN partnership: www.breastcancercare.org.uk

www.ncin.org.uk/databriefings

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