

National Recurrent and Metastatic Breast Cancer Pilot

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Summary

- Why was the pilot started?
- Cases submitted
- Diagnosis types
- Time from 1st primary diagnosis
- Presentation routes
- Access to key personnel
- Notification to cancer registries
- Conclusions

Why was the pilot started?



- 2006 - **Breast Cancer Care** established the **Secondary Breast Cancer Taskforce** which set up the 'Stand up and be Counted Campaign'
 - Called for the Department of Health, Scottish Executive and the Welsh Assembly to make the collection of data on metastatic breast cancer incidence and survival a requirement.
 - 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 WMCIU as the NCIN breast cancer lead registry
- December 2007 - the **Cancer Reform Strategy** announced the formation of the NCIN
- June 2008 - at the **NCIN launch** it was announced that data on recurrence and metastatic cancers should be collected via the **Cancer Waiting Times** data

Why was the pilot started?

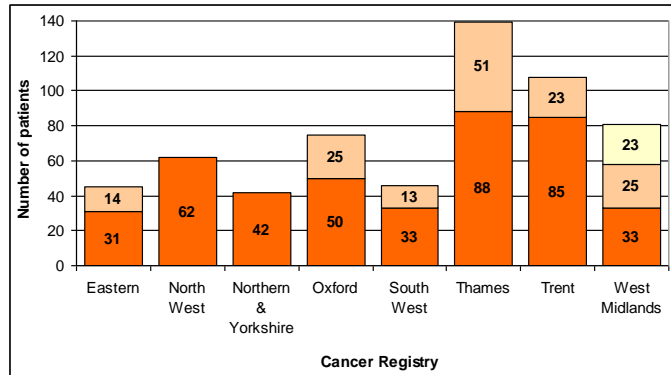


- 2010 - the Chair of the **All Party Parliamentary Group for Breast Cancer** Annette Brook, MP asked a question on the issue of data collection for metastatic breast cancer leading to a meeting with David Cameron



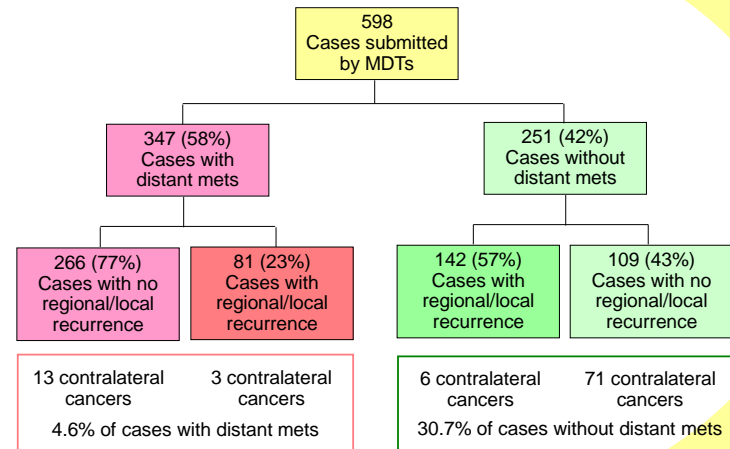
- January 2011 - **Improving Outcomes: A Strategy for Cancer** commitment made to ensure that data on recurrent and metastatic breast cancer will be collected initially via a **Pilot Project**

Cases submitted to the pilot



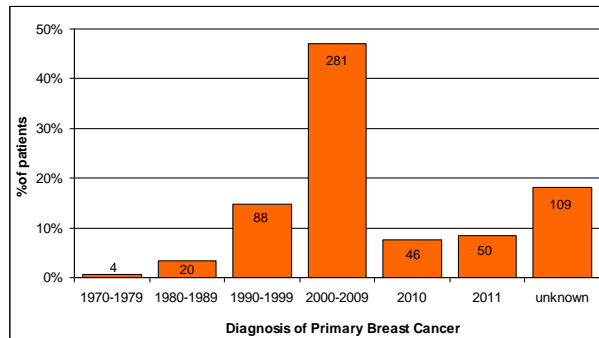
598 cases submitted by 15 NHS Trust breast MDTs in the 8 English cancer registry catchment areas

Types of diagnosis



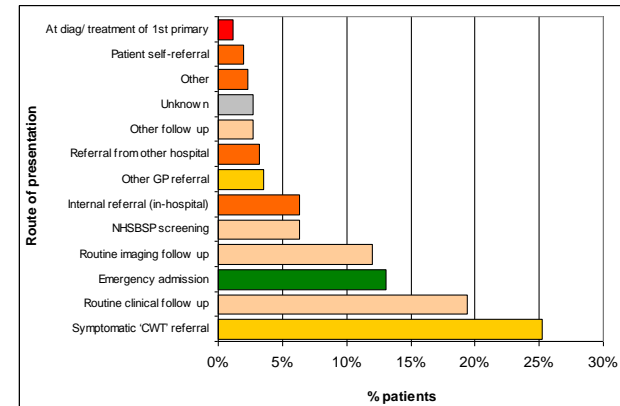
Some anomalies in database
Cases are being sent back to MDTs for verification

Time from 1st primary diagnosis



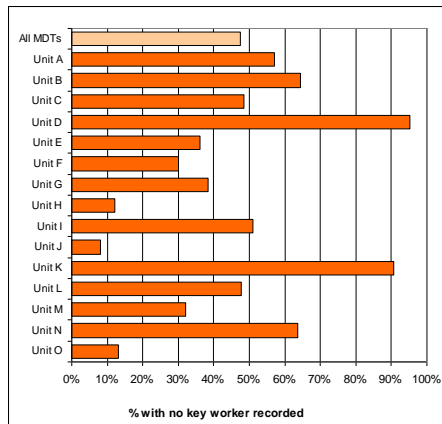
47% of 1st primary tumours were diagnosed 2-10 years before a recurrence or secondary breast cancer

Routes of presentation



■ Routine follow up/screening = 40%
■ GP referral = 29%
■ Hospital referral = 23%
■ Emergency admission = 13%

Access to key personnel



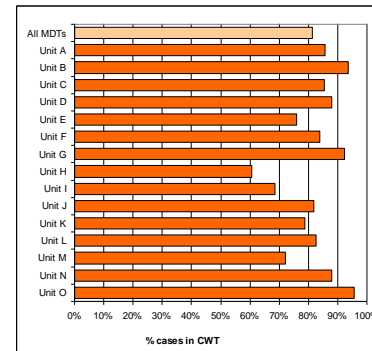
Range 8% - 95%

Overall 47% of patients had no referral to a CNS or palliative care worker recorded

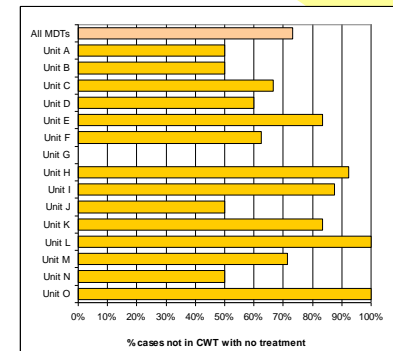
It could be that patients were referred back to their original CNS and this was not recorded

Secondary breast cancer patients may need different key worker skills and support

Cancer waiting times reports

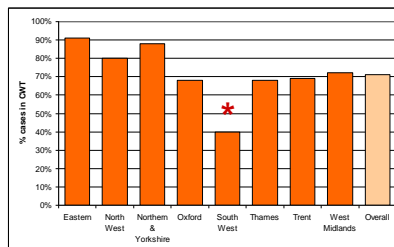


81% of cases were recorded in CWT data
Range 60% (23 cases) - 96% (33 cases)



93% of cases not recorded in CWT data were cases with no treatment
Range 0% (13 cases) - 100% (23 cases)

Notification to cancer registries



* One MDT only 29%

Wide variation between registries in the % cases in CWT data
Range 40% (20 cases) - 91% (23 cases)

Data source	No. cases	%
CWT data	486	81%
Any source at registry	510	85%
Pathology report	414	69%
Radiotherapy data	262	44%
MDT dataset	101	17%
Death certificate	63	11%
CWT data only	50	8%
Registry and CWT	560	94%

94% of cases were recorded either by registries or in the CWT dataset

85% of cases were recorded in routine datasets received by registries

Registries were notified about 47 of the 84 cases (56%) not sent to them in CWT or MDT data

36 pathology, 10 RT, 10 death certs

Conclusions

- 598 cases were submitted by 15 NHS Trust breast MDTs in the 8 English cancer registry catchment areas
 - 58% of cases presented with distant metastases
 - 40% of cases were diagnosed as a result of routine clinical or imaging follow-up or screening
- 47% of patients had no referral to a CNS or palliative care worker recorded
- 81% of cases were recorded in CWT
 - 93% of cases not recorded in CWT had no treatment
- 94% of cases were recorded either by registries or in the CWT dataset
- **From 1 April 2012**, all NHS trusts should be recording recurrent and metastatic breast cancer patients in CWT and MDT data

Thankyou

Thankyou

MDTs participating in the pilot
English cancer registries
Catherine Lagord, Sarah Parr