

What the data tell us & what do we do next?

NCIN Breast TSSG Clinical Leads Workshop
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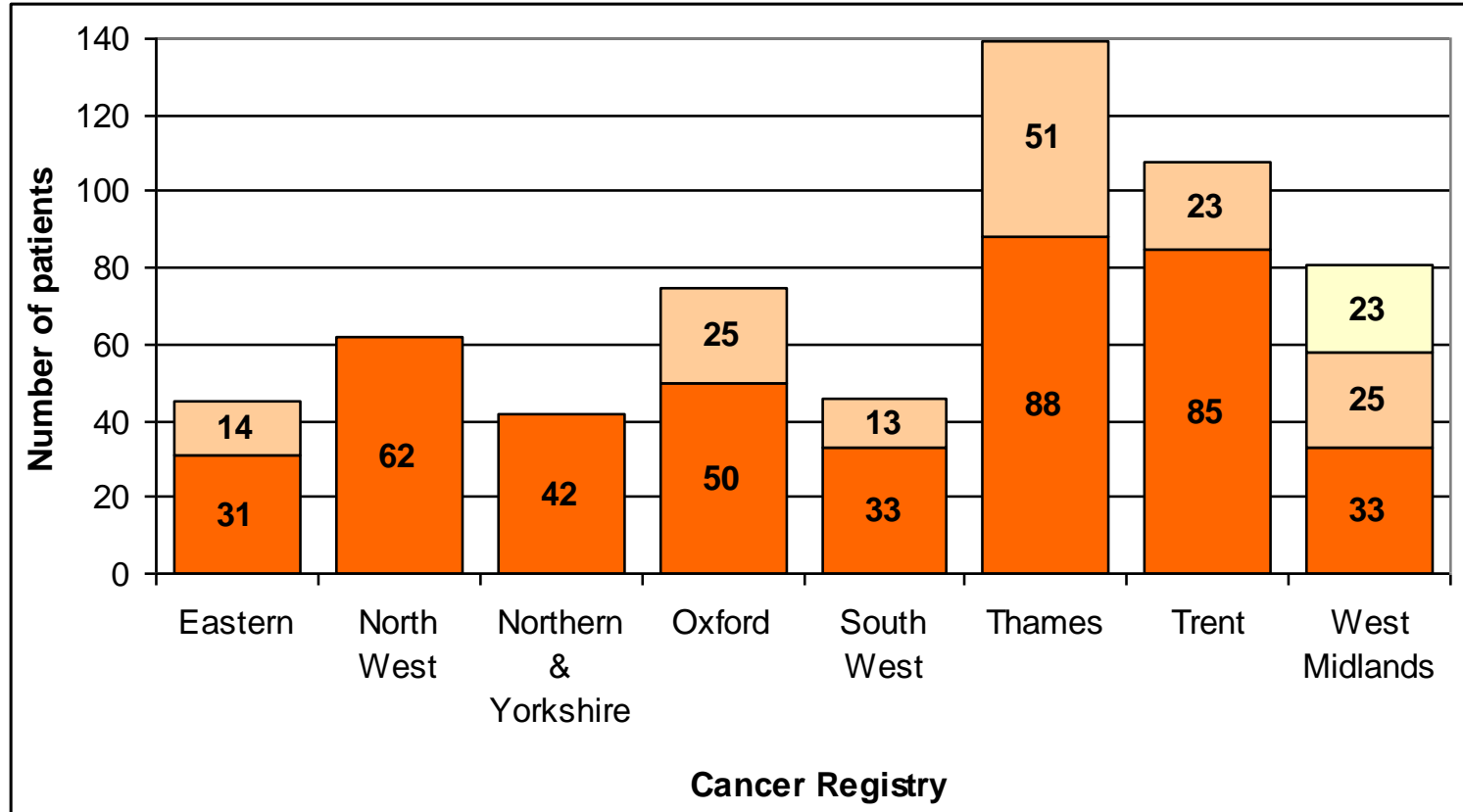
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Summary

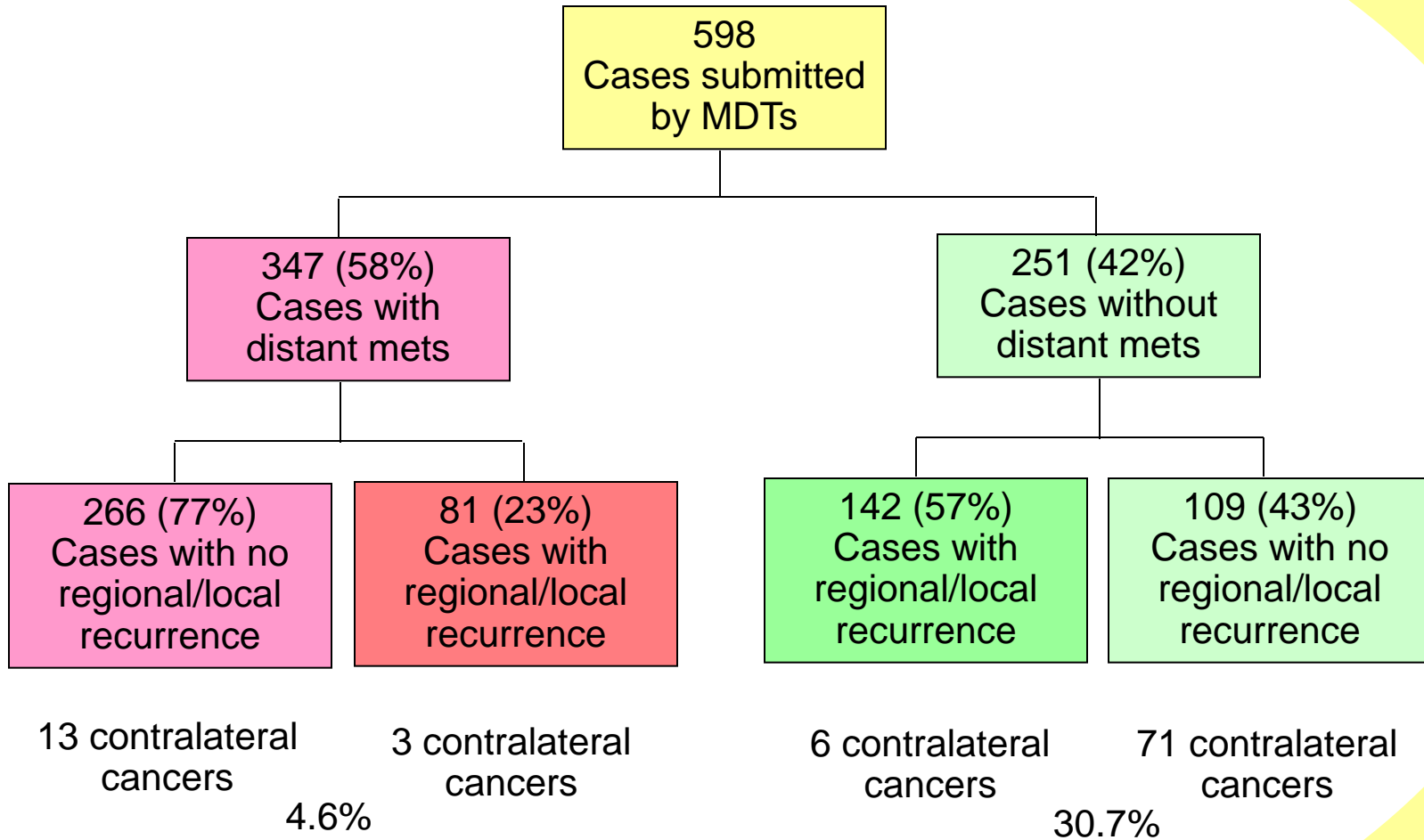
- Cases submitted
- Diagnosis types
- Time from 1st primary diagnosis
- Presentation routes
- Access to key personnel
- Routine data feeds
- Conclusions

Cases submitted to the pilot



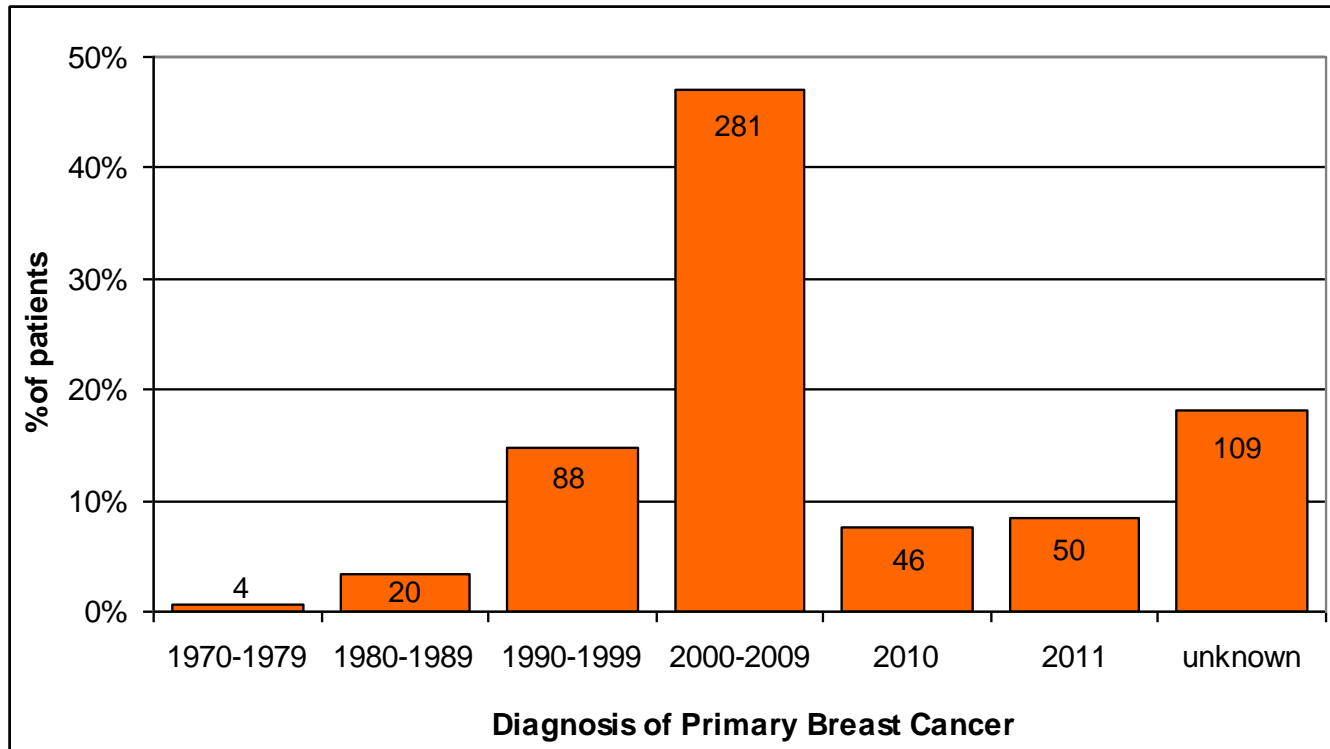
598 cases submitted by 15 NHS Trust breast MDTs in the 8 English cancer registry catchment areas

Types of diagnosis



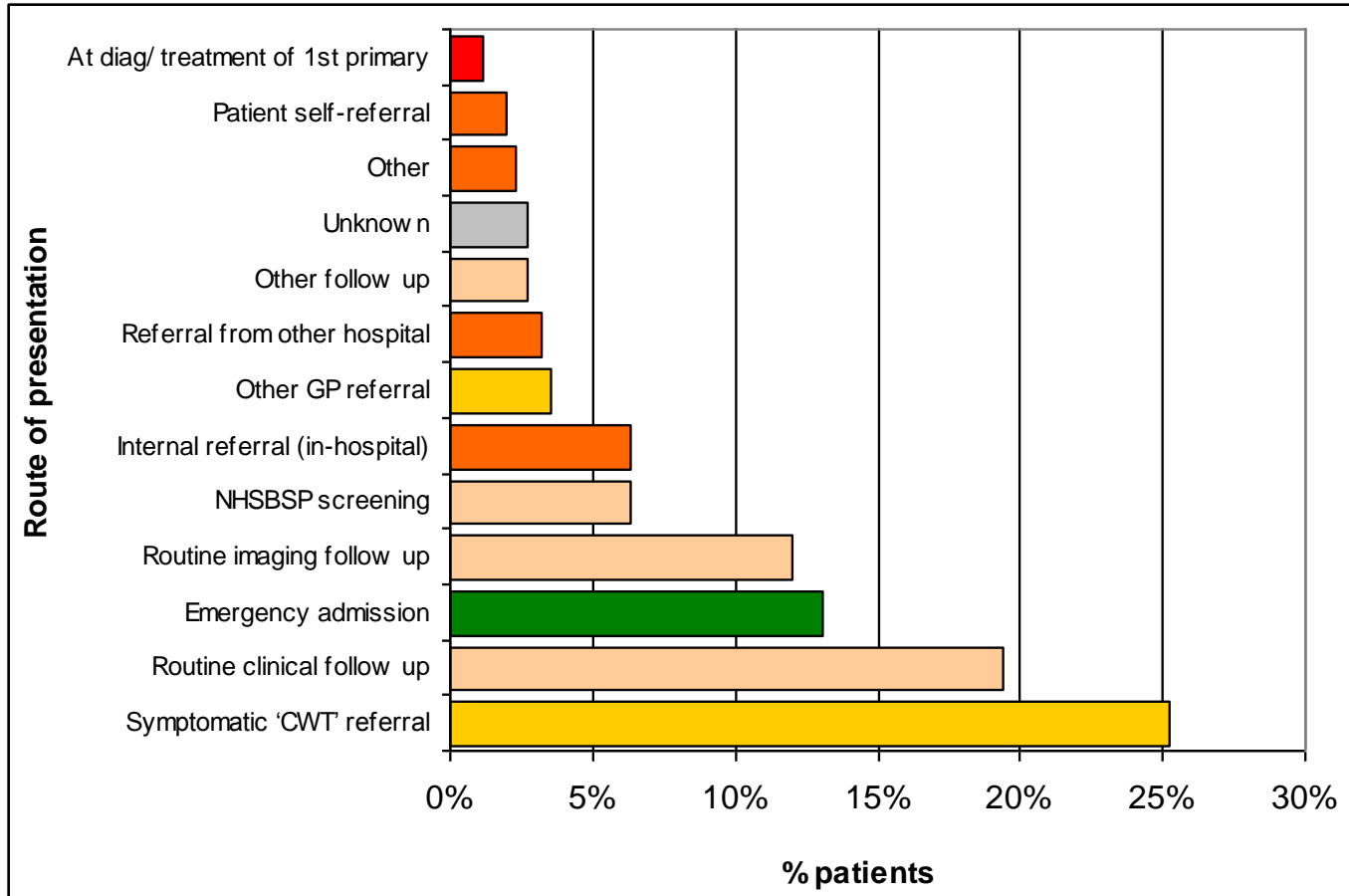
Some anomalies in database
Very useful to send cases back to MDTs for verification

Time from 1st primary diagnosis



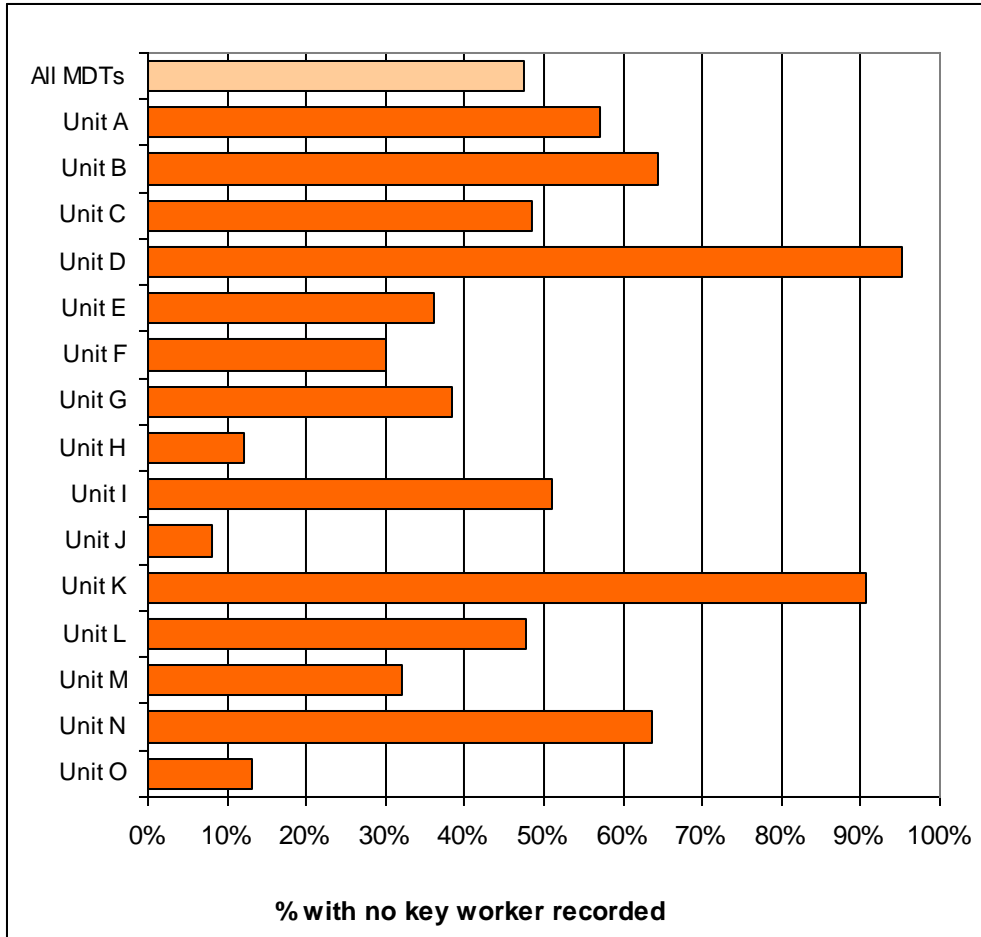
47% of 1st primary tumours were recorded as having been diagnosed 2-10 years before a recurrence or secondary breast cancer

Routes of presentation



Follow up/screening = 40%
 GP referral = 29%
 Hospital referral = 23%

Access to key personnel



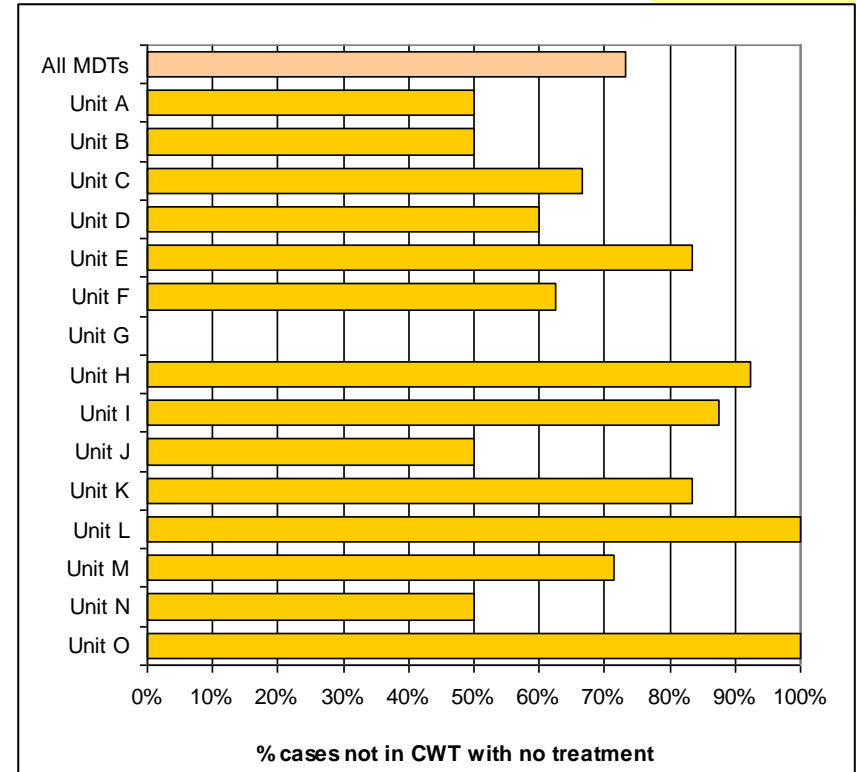
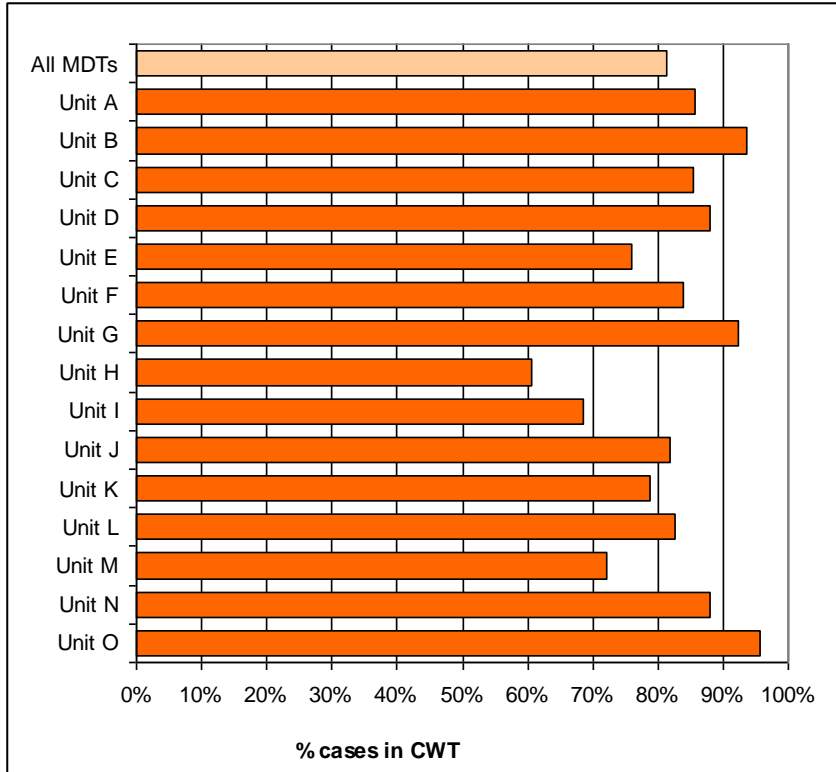
Range 8% - 95%

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

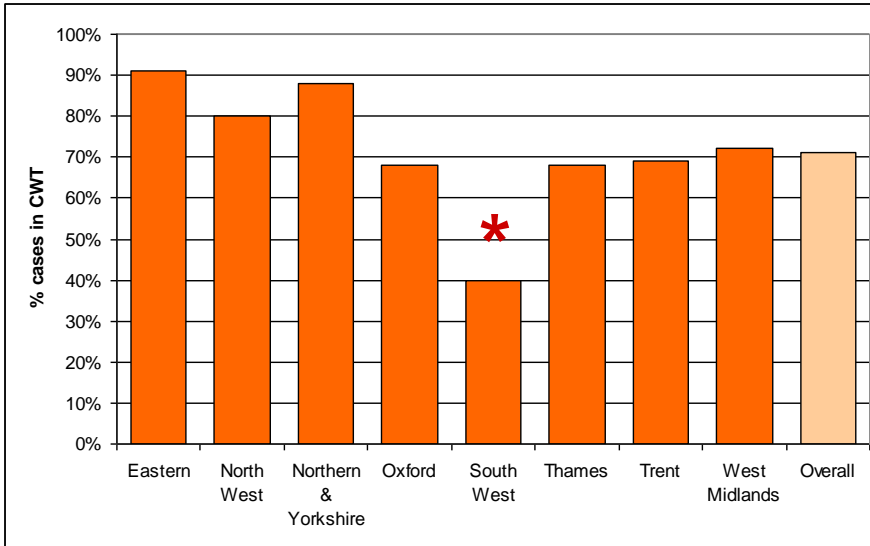
Cancer waiting times reports



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 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
 - 85% of cases were recorded in the routine datasets received by registries
 - Registries were notified about 56% of cases not sent to them in CWT or MDT data

Thankyou

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MDTs participating in the pilot
Cancer registries
Catherine Lagord, Sarah Parr

