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Using Cancer Registration and MDT Data to Provide Information on Recurrent and Metastatic Breast Cancer

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Counting ALL patients with 2° BC

Information on the incidence of secondary (breast) cancer is incomplete:

- Clinical trials
- Some breast units have good data

2006 - Breast Cancer Care

- Established the Secondary Breast Cancer Taskforce
- Set up the 'Stand up and be Counted Campaign'

June 2008 - at the NCIN launch

- Data on recurrent and metastatic cancers should be collected
- Via the Cancer Waiting Times data

From 1 April 2012, all NHS Trusts should have been recording recurrent and metastatic breast cancer patients

- NCWTMDS
- MDT data

The WM KIT has been tasked with monitoring the implementation of this recommendation



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How can we obtain information on 2^o breast cancers?

Cancer registration data: population based recording of primary breast cancers

Most registries: record information up to 6/12 months after diagnosis

With improved completeness of national dataset

- HES/PAS
- NCWTMDS
- SACT
- RTDS

The National Cancer Registration Service (NCRS) should be able to record data on diagnostic and treatment events along the **whole cancer pathway**, including those for secondary breast cancers

West Midlands NCRS: already records this information with no time limit on follow up

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West Midlands Recurrence Algorithm

4 Recurrence algorithm



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West Midlands recurrence algorithm

The primary treatment pathway for breast cancer may have a long duration

- ❑ Hard to distinguish between recurrence and progression of disease

The first step in automatically calculating recurrence status

- ❑ Does the case have a clearly defined primary treatment pathway?

Once the primary treatment pathway length has been calculated

- ❑ Examine the timing of other diagnosis/treatment events

Cases without a clearly defined primary treatment pathway

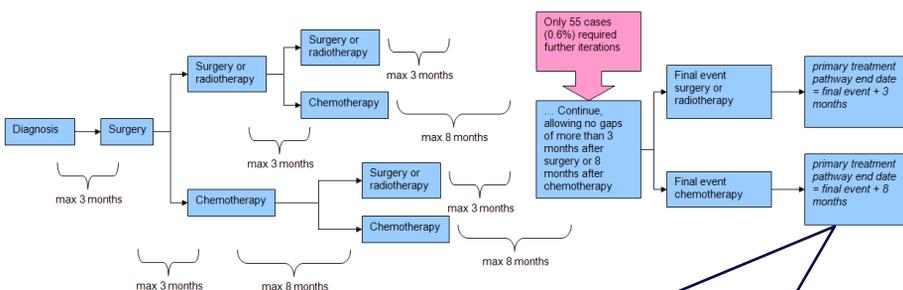
- ❑ Currently sent for manual checking
- ❑ Testing is ongoing to see if more cases can be included in the algorithm

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Primary treatment pathway



Recent development work has amended the algorithm slightly. Rather than adding a 3 or 8 month “buffer” at the end of the primary treatment pathway in every case, only extend the primary treatment pathway end date if there were further diagnosis/treatment events recorded in this period

6 Recurrence algorithm



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Recurrence algorithm results

8,633 surgically treated invasive breast cancers diagnosed in 2003-05 had a clearly defined primary treatment pathway

- Less than 3 months from diagnosis to first surgery
- No neo-adjuvant treatment
- No partial dates recorded for primary surgery, radiotherapy & chemotherapy (which would make the primary treatment pathway unclear)
- The primary diagnosis phase had a clear end point (a gap of a year before any potential recurrence events)

827 of the 8,633 invasive breast cancers had further diagnosis/treatment events after a gap of a year or more after the primary treatment phase

- Potential recurrence rate 10% [827/8,633]
- Maximum follow up period = 9.5 years (1 Jan 2003)
- Minimum follow up period = 6.5 years (31 Dec 2005)

The recurrences recorded on the West Midlands cancer registration database, their timing and nature, will be validated using external clinical input and external clinical databases

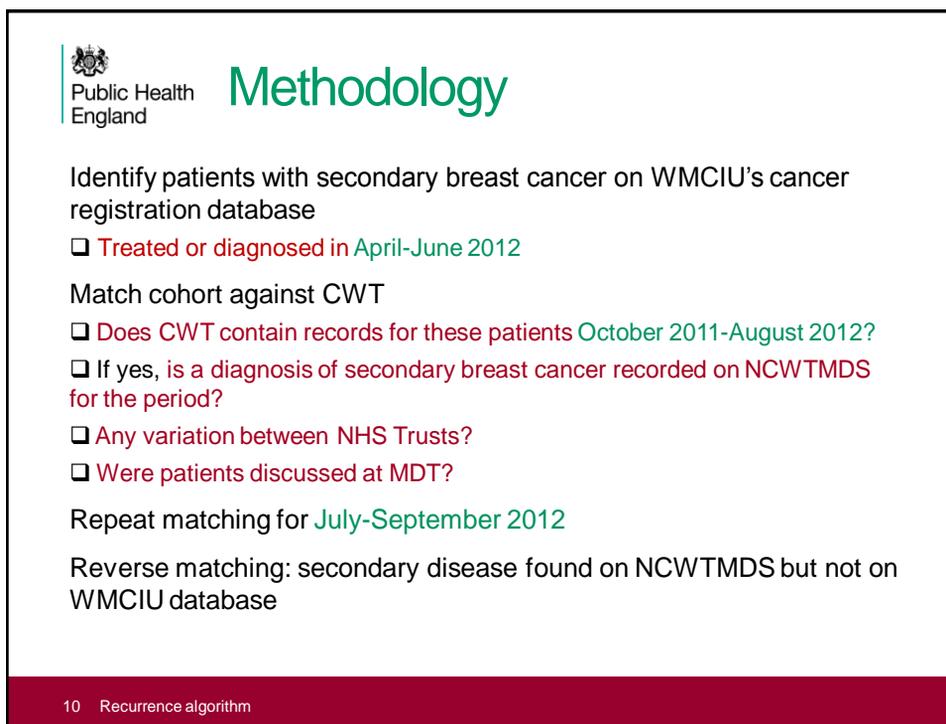
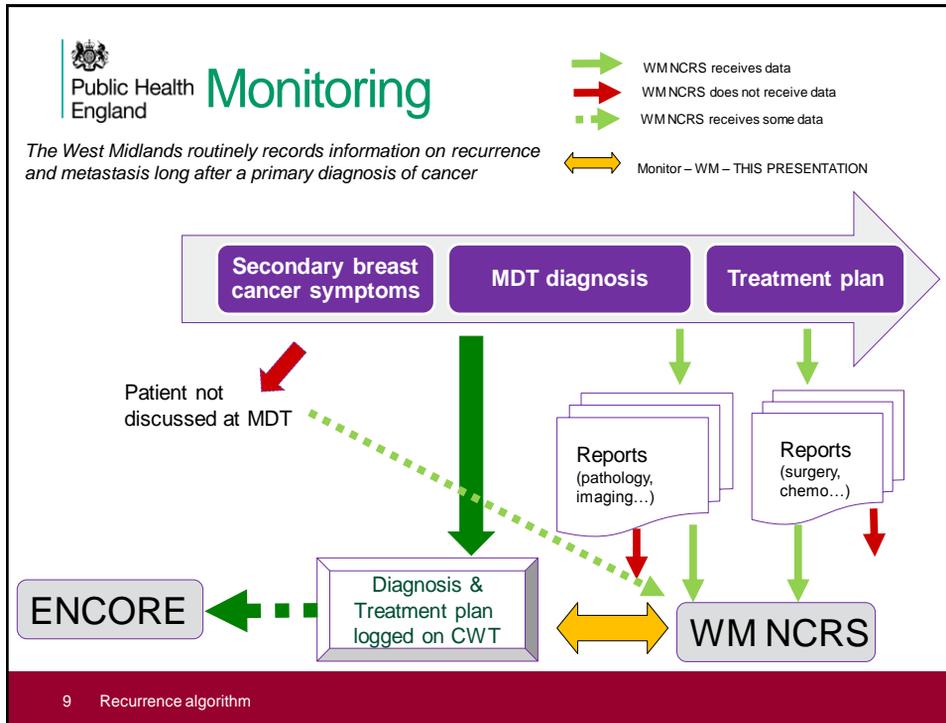
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Monitoring Recurrent and Metastatic Breast Cancer Data Collection

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Coding on NCWTMDS

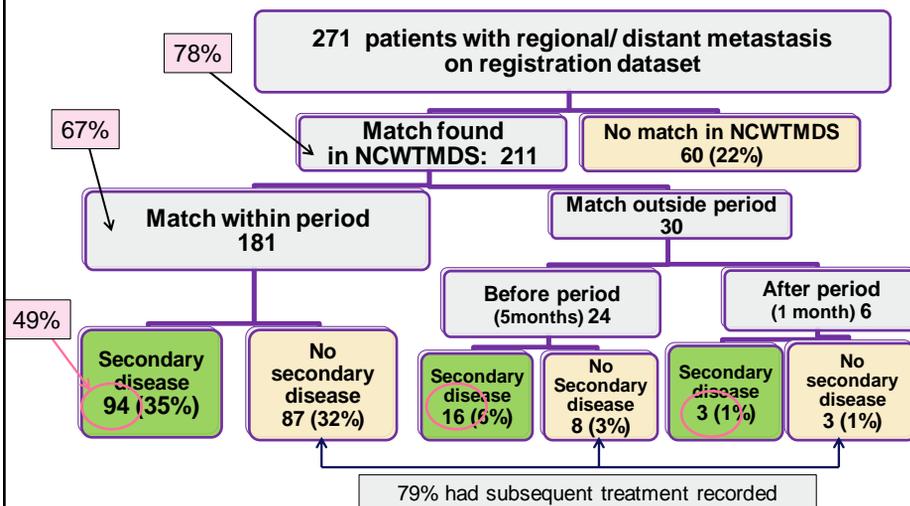
CWT data item	Values	Meaning
Cancer treatment event type	3	Treatment for a local recurrence of a primary cancer
	4	Treatment for a regional recurrence of cancer
	5	Treatment for a distant recurrence of cancer (metastatic disease)
	6	Treatment for multiple recurrences of cancer (local and/or regional and/or distant)
	7	First treatment for metastatic disease following an unknown primary
	8	Second or subsequent treatment for metastatic disease following an unknown primary
Metastatic site	1	Bone
	2	Brain
	3	Liver
	4	Lung
	5	Other metastatic site
	6	Multiple metastatic sites
	7	Unknown metastatic site
Cancer or Symptomatic Breast Referral Patient Status	15	Suspected recurrent cancer
	16	Diagnosis of recurrent cancer confirmed - first treatment not yet planned
	17	Diagnosis of recurrent cancer confirmed - English NHS first treatment planned
	18	Diagnosis of recurrent cancer confirmed - no English NHS treatment planned
	19	Diagnosis of recurrent cancer confirmed - subsequent treatment not yet planned
	20	Diagnosis of recurrent cancer confirmed - subsequent English NHS treatment planned

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Matching results - regional/distant metastases Q1



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Matching results

Ascertainment x Timeliness

67% (181/271) of cases registered in April-June 2012 with regional or distant metastases, had an event recorded in the NCWTMDS within the period of interest (March-July 2012)

Q2 = 68% (183/271)

Ascertainment x Timeliness x Accuracy

52% (94/181) of these cases, NCWTMDS also recorded the presence of secondary disease

Q2 = 50% (92/183)

35% (94/271) of cases registered in April-June 2012 with regional or distant metastases, also had a secondary event recorded on NCWTMDS within period of interest (March-July 2012)

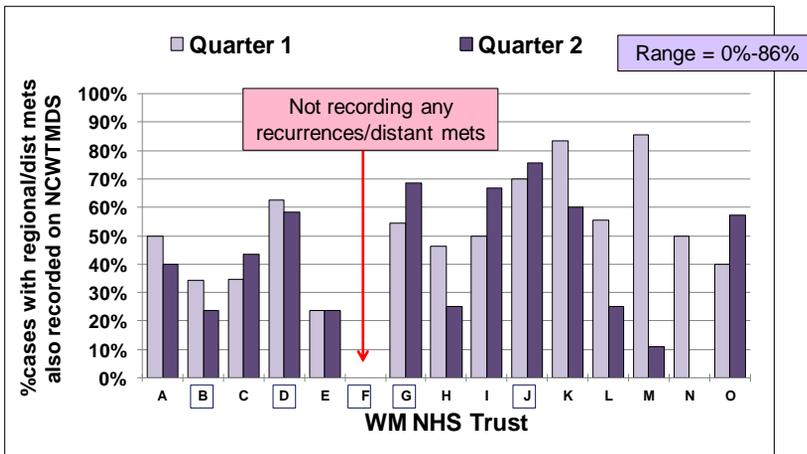
Q2 = 35% (92/271)



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Results for Individual NHS Trusts

Are regional recs/distant mets identified by cancer registry also on NCWTMDS?



Cancer centres providing RT

CWT events included if in Jan – Nov 2012

Are regional recs/distant mets identified by cancer registry also on NCWTMDS?

WM NHS Trust	Average No. 1° BC at Trust in Apr-Jun (2010/11/12)	No. cases regional/dist mets at registry (Apr-Jun 2012)	% on CWT with 2° BC Mar-Jul 2012 Q1	Ratio 2°/1° registry data Q1	No. cases regional/dist mets at registry (Jul-Sep 2012)	% on CWT with 2° BC Jun-Oct 2012 Q2	Ratio 2°/1° registry data Q2
A	151	20	50%	0.13	15	40%	0.10
B	129	32	34%	0.25	34	24%	0.26
C	124	29	34%	0.23	23	43%	0.19
D	120	24	63%	0.20	24	58%	0.28
E	110	17	24%	0.16	21	24%	0.19
F	108	34	0%	0.31	33	0%	0.30
G	82	33	55%	0.40	32	69%	0.39
H	79	13	46%	0.17	4	25%	0.05
I	63	6	50%	0.10	3	67%	0.05
J	62	20	70%	0.32	33	76%	0.53
K	60	6	83%	0.10	5	60%	0.08
L	58	9	56%	0.15	8	25%	0.14
M	56	7	86%	0.13	9	11%	0.16
N	51	2	50%	0.04	1	0%	0.02
O	34	5	40%	0.15	7	57%	0.21
Total	1287	257	43%	0.20	252	41%	0.20

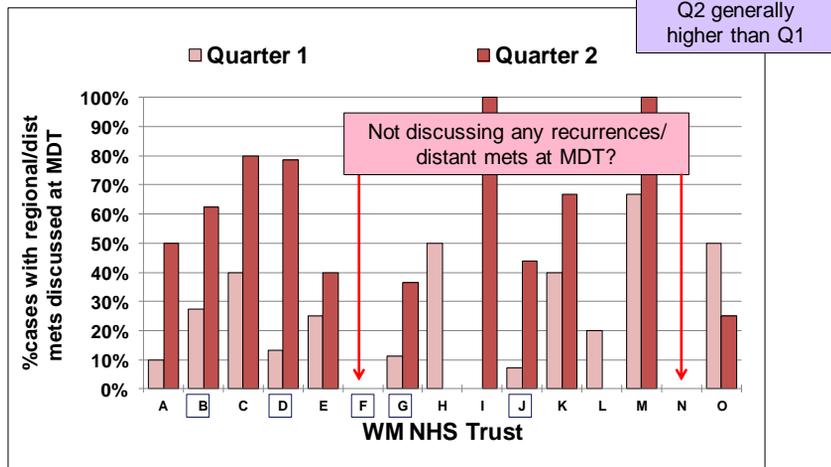
Who will chase this Trust?

Higher because of RT to recs?

Cancer centres providing RT

CWT events included if in Jan – Nov 2012

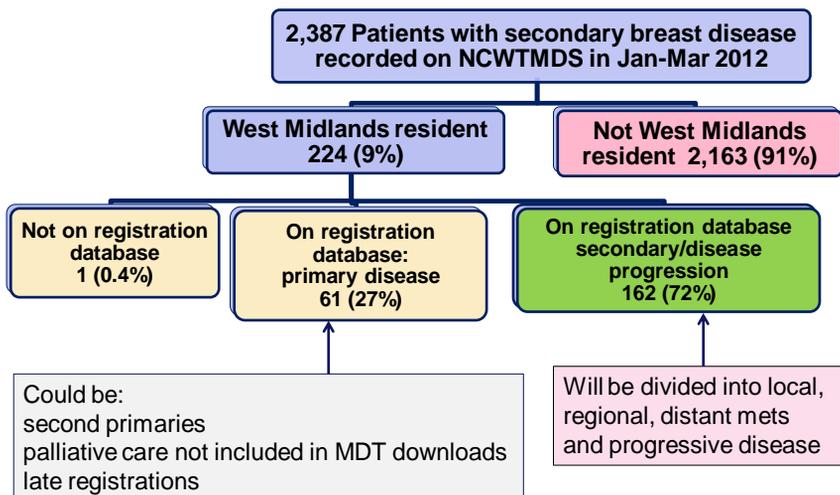
Are cases with regional/distant mets identified by cancer registry discussed by MDT?



☐ Cancer centres providing RT

CWT events included if in Jan – Nov 2012

Reverse matching Q1





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Next steps.....

Breast MDTs to ensure information on secondary breast cancer is captured on NCWTMDS

Who will follow up Trusts with missing data in the West Midlands?

How will we know how much information is missing in Trusts in other regions?

The NCRS will collect follow up cancer-related data for all cancer patients, without time limit:

❑ HES/PAS, NCWTMDS, pathology reports etc...

The NCRS will identify potential recurrences/secondary breast cancer

❑ Either (*direct method*) because treatment/diagnosis event is flagged as 'secondary' by clinicians and/or NHS Trusts

❖ Path report, NCWTMDS etc...

❑ Or (*indirect method*) by applying recurrence algorithm to ENCORE

❖ Identify where timing of the treatment/ diagnosis event suggests this is not related to a primary

❖ Triggers alert for coder to suspect secondary breast cancer



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Acknowledgments

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