

National Recurrent and Metastatic Breast Cancer: Monitoring data collection

NCIIN Breast SSCRG workshop
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Background

- 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.
- 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
- 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 6 months **Pilot Project**

Results from Pilot Project



- 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
- Results presented at NCIN conference in **June 2012** and published as a Data Briefing in **August 2012**

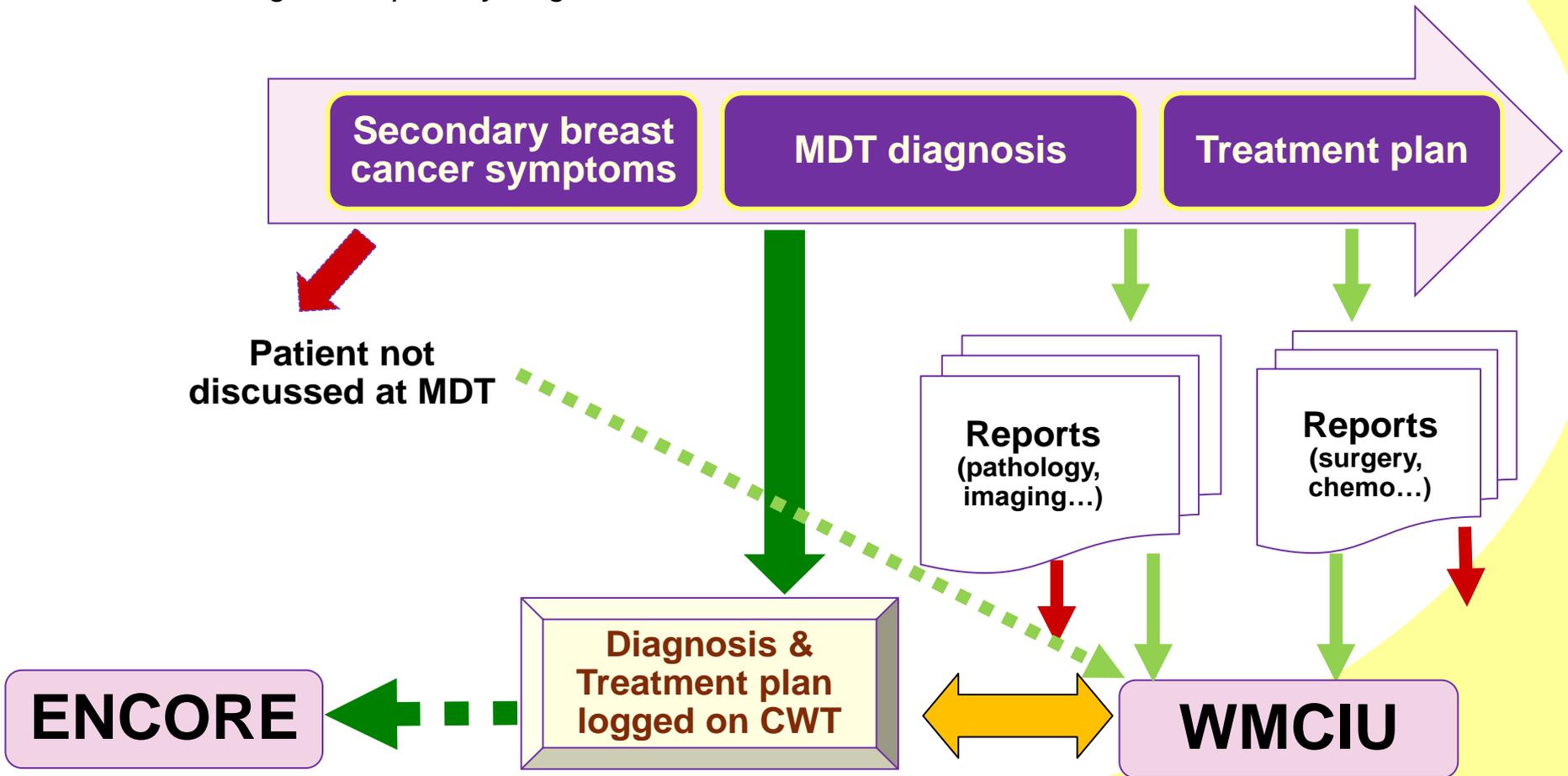
Recommendation

- From **1 April 2012**, all NHS trusts should have been recording recurrent and metastatic breast cancer patients in CWT and MDT data
- Following the 'Recurrent and metastatic breast cancer pilot', a **recommendation** was made to breast MDTs asking them to ensure they
 - *"submit data on all patients with recurrent and metastatic breast cancer (**whether or not they have active treatment**) through monthly NCWTMDS submissions (a mandatory requirement since 2009)".*
- The WMCIU has been tasked with **monitoring** the implementation of this recommendation.

Monitoring

The West Midlands Cancer Intelligence Unit routinely records information on recurrence and metastasis long after a primary diagnosis of cancer

- WMCIU receives data
- WMCIU does not receive data
- WMCIU receives some data
- Monitor – WM – THIS PRESENTATION



Methodology



- Identify patients with secondary breast cancer on WMCIU's cancer registration database
 - Treated or diagnosed in **April - Jun 2012**
- Match cohort against CWT
 - Does CWT contain records for these patients?
 - ❖ **October 2011 – July 2012**
 - If yes, is a diagnosis of secondary breast cancer recorded on CWT for the period?
 - Any variation between NHS Trusts?
 - Were patients discussed at MDT?
- Repeat matching for Jul-Sept 2012 (**ongoing**)
- Reverse matching: secondary disease found on CWT but not on WMCIU database

Cancer registration records



Disease Type (Apr-Jun 2012, West Midlands)	Number of cases	%
Mets at diagnosis	6	2%
Regional/ Distant Mets	271	68%
Local recurrence/ Disease progression	119	30%
Total	396	100%

Note:

Records from 41 patients with recurrences or disease progression recorded at the WMCIU who had further surgery post adjuvant treatment within the period of interest were used as 'control' for this study.

- ✓ 2 had no match in CWT
- ✓ 39 had a match in CWT
- ✓ For the 39 with a match, no indication of secondary disease was found on CWT

Coding of breast recurrence/ metastatic disease on CWT



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

**Rule used to identify secondary breast disease on CWT:
at least one of the above must be true**

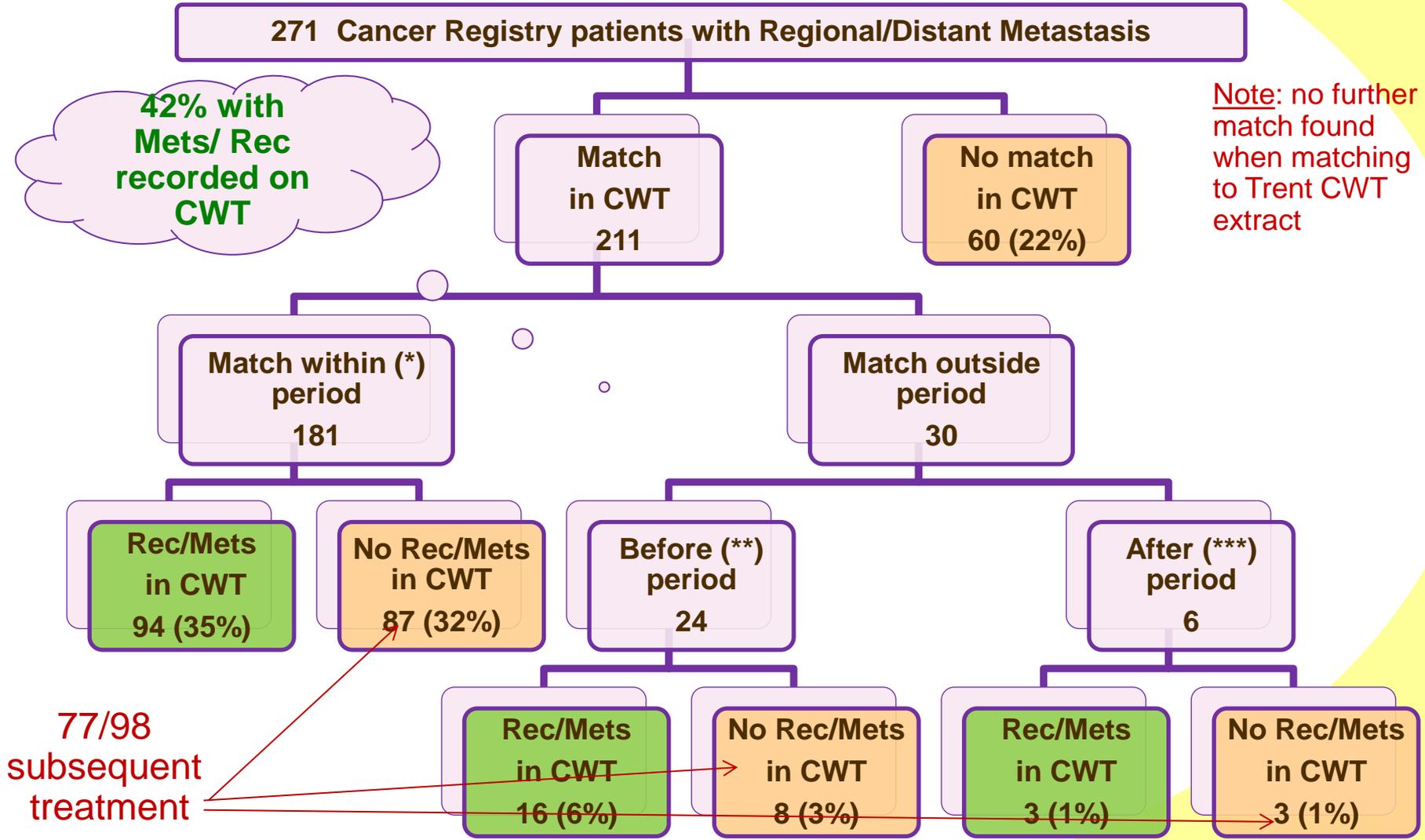
Match against CWT

(regional and distant metastasis)

271 Cancer Registry patients with Regional/Distant Metastasis

42% with
Mets/ Rec
recorded on
CWT

Note: no further
match found
when matching
to Trent CWT
extract



Match against CWT

(Metastasis at first diagnosis)



- 6 patients were first diagnosed with metastatic breast cancer in April – June 2012
 - 1 recorded on CWT with Mets at diagnosis; discussed at MDT
 - 4 recorded on CWT for Primary breast cancer (no indication of Mets) – All were discussed at MDT
 - 1 not found on CWT

Variation between NHS Trusts



WM NHS Trust	Average N° of 1° BCs diagnosed at Trust in Apr-Jun (2010/11/12)	N° patients with Regional/ Distant Mets on Registry records (Apr-Jun 2012)	% Recorded on CWT with 2° BC (Oct 2011 - Aug 2012)	Ratio 1°/2° (Registry data)
A	151	20	50%	0.13
B	129	32	34%	0.25
C	124	29	34%	0.23
D	120	24	63%	0.20
E	110	17	24%	0.16
F	108	34	0%	0.31
G	82	33	55%	0.40
H	79	13	46%	0.17
I	63	6	50%	0.10
J	62	20	70%	0.32
K	60	6	83%	0.10
L	58	9	56%	0.15
M	56	7	86%	0.13
N	51	2	50%	0.04
O	34	5	40%	0.15

MDT discussion

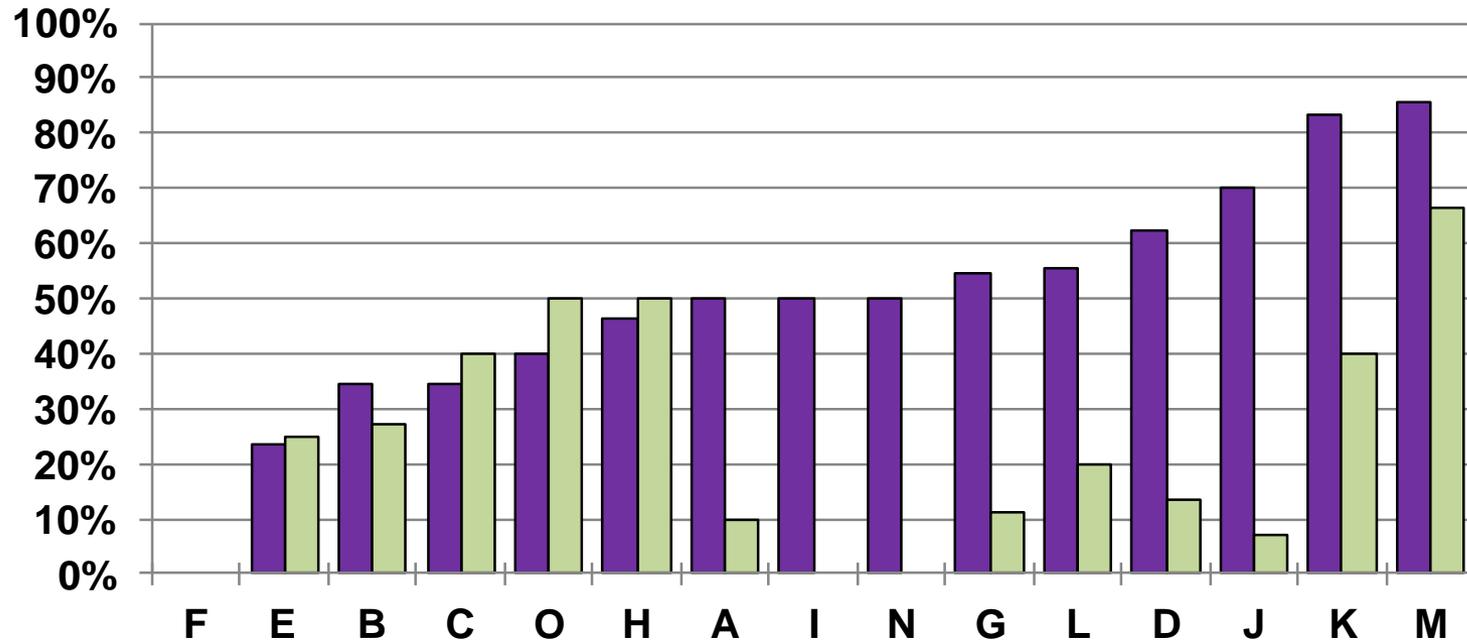


WM NHS Trust	N° patients with Regional/ Distant Mets on Registry records (Apr-Jun 2012)	% Recorded on CWT with 2° BC (Oct 2011 - Aug 2012)	% of CWT cases discussed at MDT
A	20	50%	10%
B	32	34%	27%
C	29	34%	40%
D	24	63%	13%
E	17	24%	25%
F	34	0%	0%
G	33	55%	11%
H	13	46%	50%
I	6	50%	0%
J	20	70%	7%
K	6	83%	40%
L	9	56%	20%
M	7	86%	67%
N	2	50%	0%
O	5	40%	50%

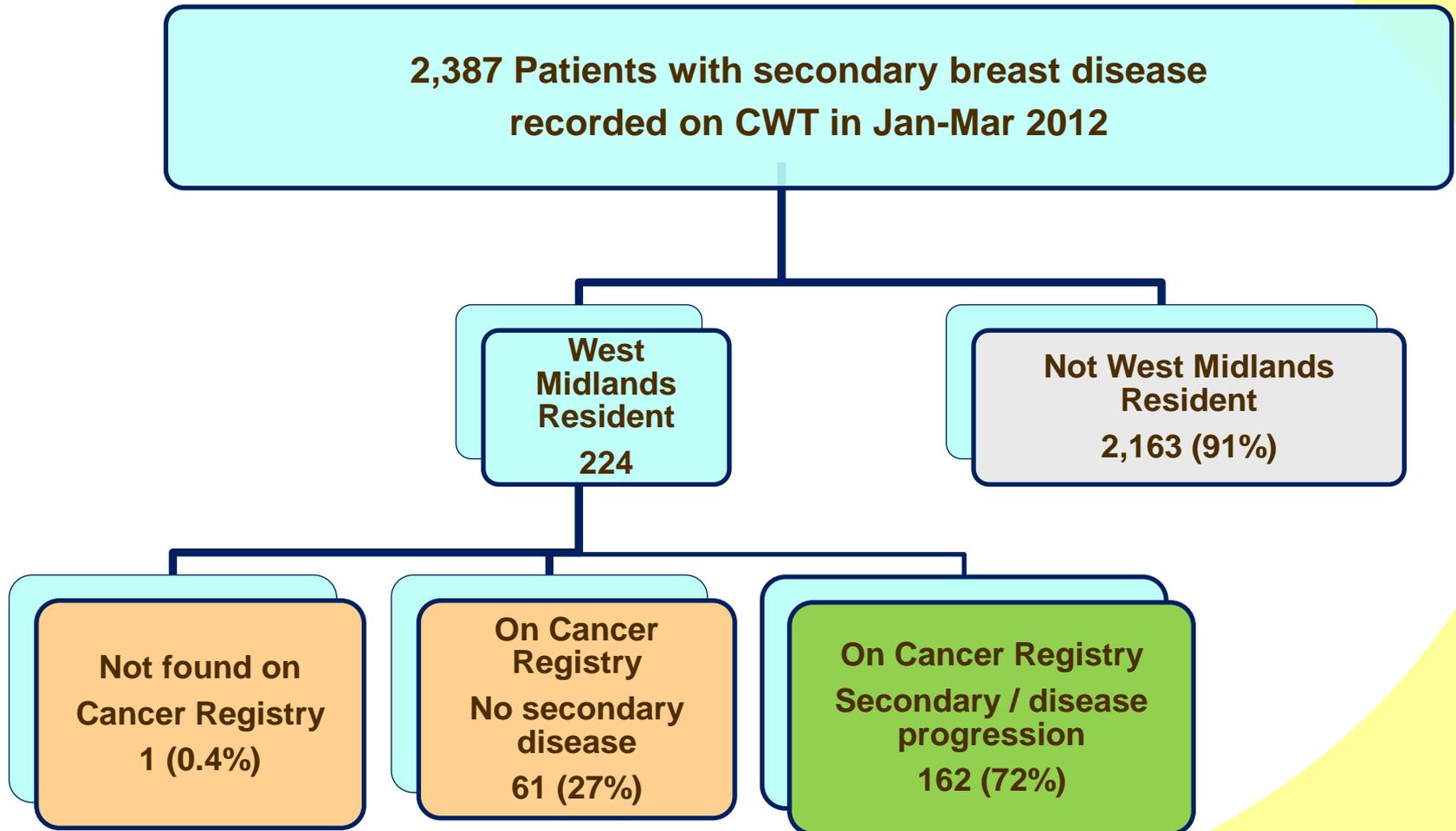
Variation between NHS Trusts

Results by Trust

- % Registry cases also recorded on CWT with Ilary BC
- % Ilary BCs discussed at MDT (CWT data)



Reverse Matching



Thankyou

Thankyou

Catherine Lagord
Jackie Charman