

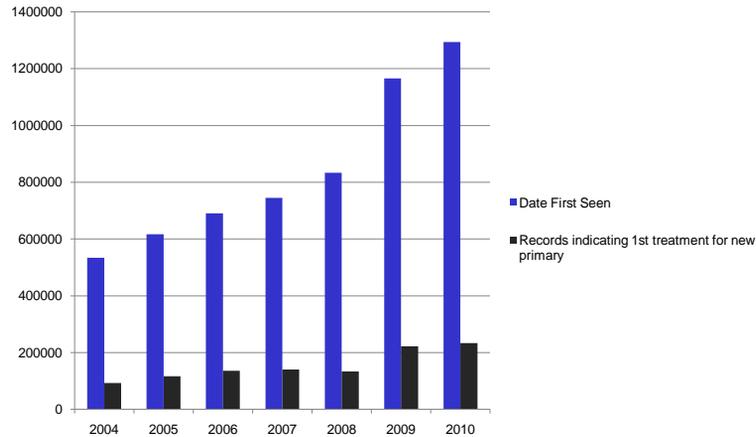
## Using CWT data to improve cancer registration

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Trent Cancer Registry

### CWT records indicating cancer diagnosis

- Three fields in the CWT record that indicate a positive diagnosis of cancer
  - Decision To Treat Date
  - First Treatment Date
  - Cancer Status showing diagnosis of new cancer confirmed or first treatment commenced.
- Small numbers with
  - 1<sup>st</sup> treat date and no decision to treat date
  - Inconsistency with Cancer Status and 1<sup>st</sup> treat date

## Cancer Waiting Times data 2004 – 08 GFoCWT data 2009-10



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## Existing data feeds to the registry

- PAS – electronic since late 80s. Enhancement to PAS systems. Coding inpatient consultant episode with a certain diagnosis code prompts clinical coder to create/amend a cancer registration.
- Pathology – Electronic path sent to registry. Extracted by SNOMED code
- ONS – cancer deaths and non cancer deaths
- Extra Regionals

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## Existing data feeds to the registry

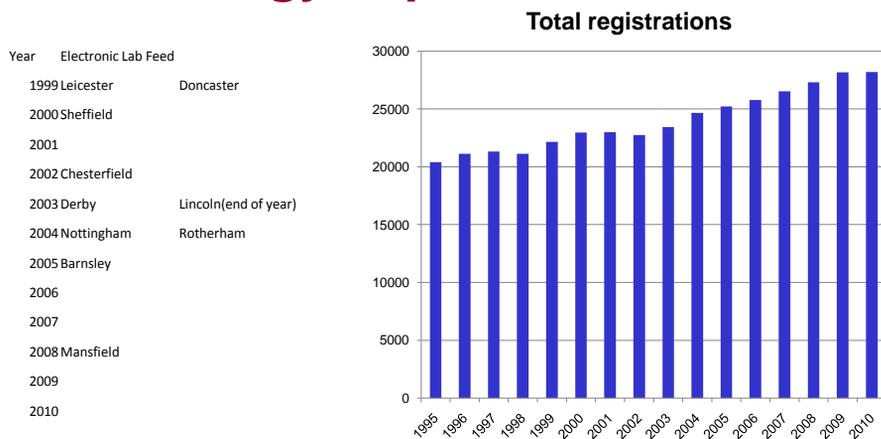
- Trent cancer registry seen significant increase in the amount of electronic data supplied to the registry, particularly pathology since diagnosis year 2004.
- Contributed to rise in ascertainment and quality.
- Significant backlog to clear.

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## Pathology impact on incidence

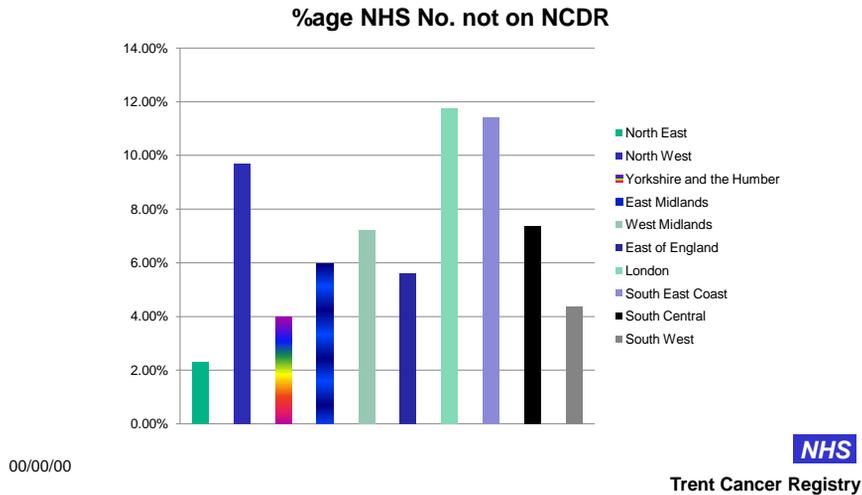


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- Compare 2007 CWT against complete 2007 NCDR using DTD or 1<sup>st</sup> Treat Date as indicator of cancer.



## Trent's 'missing' cases

- About 1500 cases on CWT indicating a positive cancer diagnosis where we don't have the patient at all.
- Not an outlier but different to our neighbouring registry NYCRIS
- We knew South West were using them routinely and their 'missing' %age is lower than ours

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## Acknowledgement

- Decided to load into the registry database all patients on CWT with
  - A 1<sup>st</sup> Treatment Date in 2008
  - Or a Decision to Treat Date in 2008
  - Or a Date First Seen in 2008 with a cancer status indicating a new cancer
- Create a basis of diagnosis of CWTO where all we have is CWT data and follow all these cases up with trusts

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## Upsetting the registration team

- Loaded into PRAXIS 21,071 CWT records.
- After electronic and manual matching we had
  - 19,005 matches with existing tumours
  - 1,487 new patients
  - 573 new tumours on existing patients
  - 6 abandoned records (non registerable missing demographics)
- About 180 of the matches were outstanding DCOs where follow up was not yet complete.

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## Implement new follow up procedure

- Created standard report showing all information for a CWT only tumour.
- Includes supporting HES and CWT information.
- Checked internally before sending to trusts and other registries.
- Can also provide as a csv or spreadsheet.

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Registrations with only a Cancer Waiting Times source.

TCR ID	0000001 2	Basis of Diagnosis	C	Date of Diagnosis	00/00/2008
Patient name	Blank	Blank		Date of Birth	00/00/1900
NHS Number	0000000000	Hospital	THE ACUTE TRUST, ANYTOWN		
ICR Diagnosis	C64 KIDNEY, EXCEPT RENAL PELVIS (C64)			Date of Death	
Cause IA					
Cause IB					
Cause IC					
Cause II					

Other Tumours On registry database

Diagnosis Date	Cancer Site
00/00/2007	C187 SIGMOID COLON (C18.7)

CWT Records for patient

Site	Treated at	Treated date	Decision at	Decision date	First Seen at	First Seen date
C18	RZZZZ	05-apr-2007	RZZZZ	05-apr-2007		
C64	RZZZZ	12-aug-2008	RZZZZ	12-aug-2008		

See records with a cancer diagnosis

Admit date	Hospital	Diagnoses	Procedures
05/04/2007	RZZZZ	C187_N288.J10X.G20X	H103.H152.U081.U081.Y982.U081.U09
05/04/2007	RZZZZ	C187_N288.J189.A419.J10X.G20X	-
05/04/2007	RZZZZ	C187_N288.J189.A419.J10X.G20X	-

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## Information registry needs

- **Short questionnaire included with each tumour**
  - Is the tumour on CWT a secondary?
  - Will the trust be making a new primary registration?
  - Is the diagnosis date accurate? If not can you provide an accurate date?
  - If not diagnosed at your trust can you provide any further information e.g. diagnosing hospital

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## Upset the trusts

- **Agree deadline with trusts for return of report.**
- **Usual outcomes are**
  - Trust informs registry they will complete a cancer registration. Go into normal follow up procedure
  - Trust sends registry to another hospital
  - Trust informs registry tumour is a secondary. May require full registration for a new primary if cannot link to the primary on registry database.

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## Cancellations

- After follow up we do cancel some of the CWT Only cases.
  - Further follow up confirms the patient did not have cancer
  - Information returned from the Trust confirms that the patient had a non register able condition
  - A full registration for the patient is held by another registry
  - Diagnosed abroad
  - Recurrences
  - Wrong site code provided by CWT so we can subsequently link the CWTO record to an existing tumour on our database.

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## CWT only cases and ONS

- Until we get information back from the trust CWT Only cases stay on the registry system and if no further information received will be sent to ONS.
- CWT Only cases are more likely to be new primary tumours based on experience of follow up so far.

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## Cancellations...

- When adding in CWT records created the following
  - 1,487 new patients
  - 573 new tumours on existing patients
- Out of these 2,060 new tumours 458 were subsequently cancelled.
- 6 main reasons for cancellations were

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## More specific site or morphology already on Praxis

- 188 records (42%) were cancelled for this reason, this category included
  - Lymphomas and leukaemia's where CWT provided the site of origin not the site linked to the morphology
  - Mesotheliomas (as above)
  - Melanomas (as above)
  - Colon unspecified
  - Overlapping sites

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## Mets, benign conditions

- **Metastases on CWT from a primary already identified in Praxis 48 records (10%) were cancelled for this reason**
- **Benign conditions and therefore non registerable 35 records (8%) were cancelled for this reason**

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## Not confirmed as cancer

- **98 records (22%) were cancelled for this reason, this category included**
  - Further investigations ruled out cancer
  - Cancer never confirmed by tests but still suspicious
  - Patient died before confirmation of cancer (without a Cancer Death Certificate to support diagnosis)
  - Raised PSA's only for patients with suspected prostate cancer
  - Watch and wait for patients with suspected prostate cancer
  - Not enough information in notes to support diagnosis of cancer

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## Subsequent skins

- **Subsequent skin registrations for non melanoma skins 35 records (8%) were cancelled for this reason**

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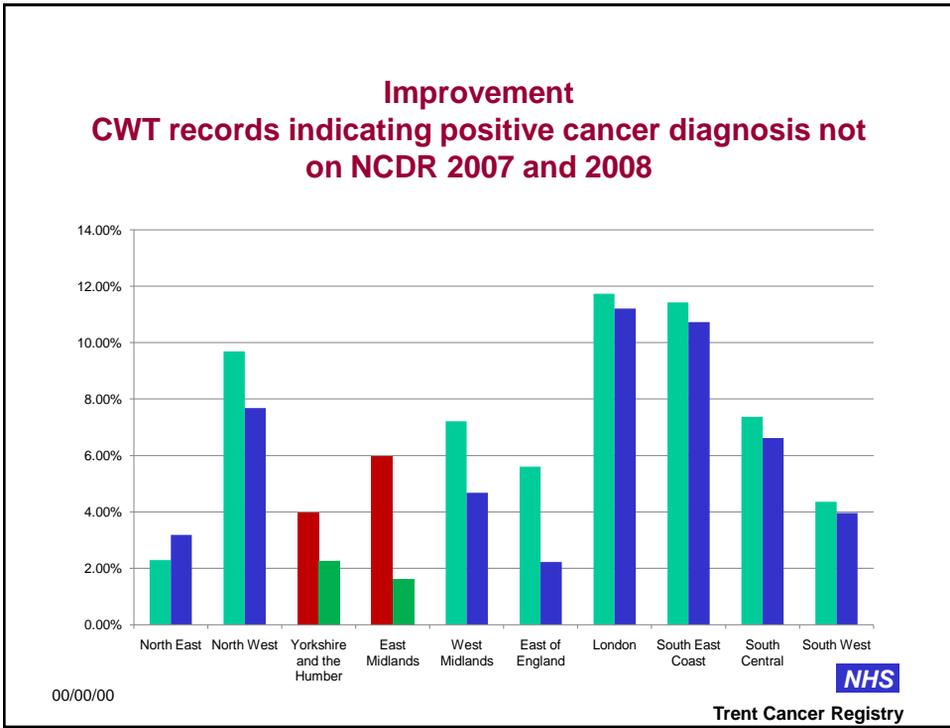
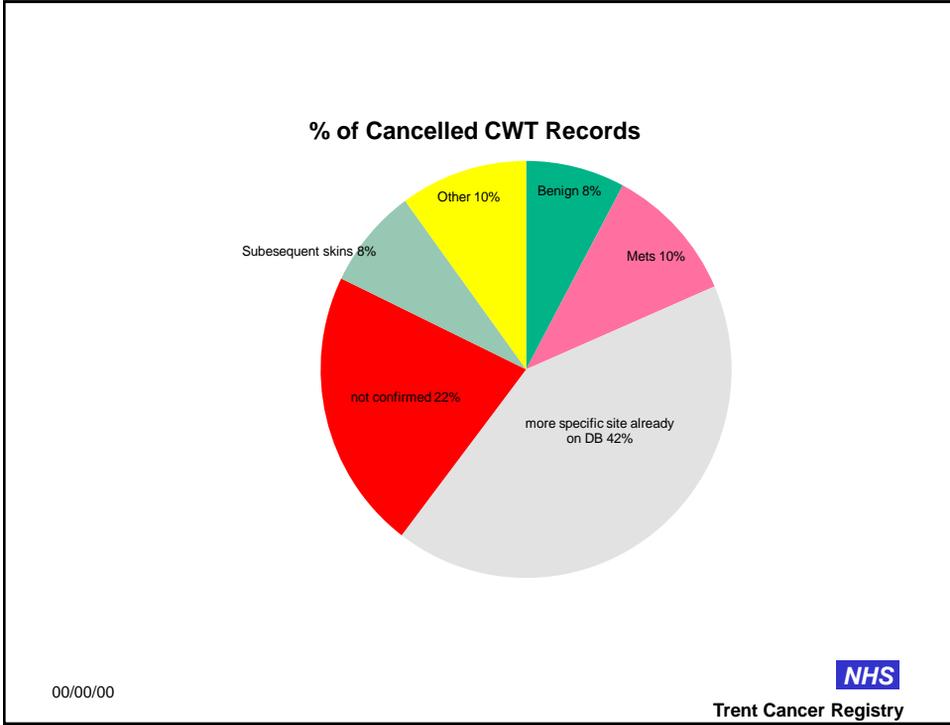
## Other cancellation reason

- **45 records (10%) were cancelled for this reason, Included in the figure for other are:**
  - Diagnosed abroad (4)
  - Duplicate (both patient and tumour)(18)
  - Earlier date of diagnosis on Praxis (5)
  - Extra Regionals (7)
  - Incorrect patient merge (2)
  - Recurrence (7)
  - Wrong site code provided by CWT (2)

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## Outstanding CWT Only cases

- For 2008 we still have 244 CWT Only cases on the database that have gone to ONS
  - 99 are Extra Regional
  - 109 are for two trusts that couldn't follow up the lists we sent them.
- For 2009 we still have 608 CWT Only cases on the database that have gone to ONS
  - 259 are extra regional
  - 200 are for 2 large acute trusts that have not followed up the lists

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## Characteristics of CWT cases not on merged registry dataset for 2008

Site	Total with DTD or 1st treat date	Not on NCDR at all	% not on NCDR
Leukaemia(C91-C95)	4150	764	18.41%
Melanoma(C43)	8924	913	10.23%
Prostate (C61)	24972	1994	7.98%
Male genital excl prostate (C60, C62,C630)	1946	125	6.42%
Lymphoma (C81-C85)	7658	477	6.23%
Gynae(C51 - C58)	11969	522	4.36%
Lung(C33, C34)	23554	915	3.88%
Colorectal (C18 - C21)	25965	859	3.31%
Upper GI(C15 - C17)	10361	228	2.20%
Breast (C50)	33963	734	2.16%

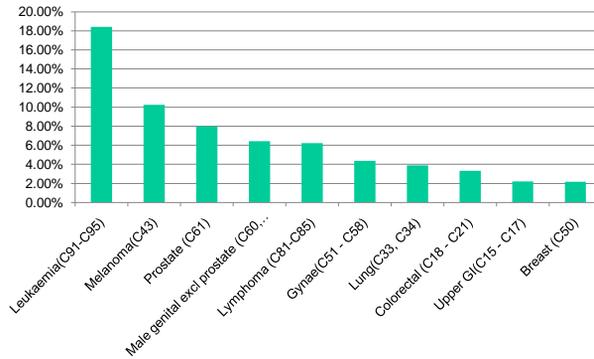
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## Profile of CWT cases not on merged registry dataset 2008

% not on NCDR



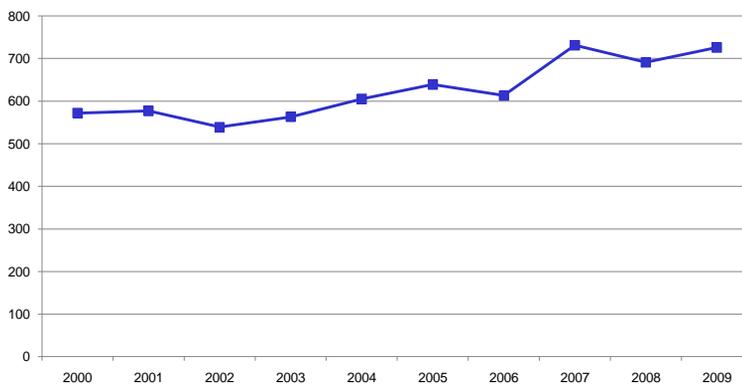
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## Trent Leukaemia Incidence

Total



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## Leukaemia ascertainment

- In 2006 15.3% of CWT Leukaemia cases indicating cancer from East Midlands not on Merged registry dataset
- By 2008 this was 5%
- Not all due to CWT but closer correlation indicates completeness of case ascertainment

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## Conclusions

- CWT useful for registration but cannot create full registration.
- Significant geographical variations
- Small but significant percentage of non-registerable cases.
- For Trent highlighted problems with traditional data flows that are only now being addressed with MDT data.
- Useful as a check that ascertainment is complete.

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## Conclusions

- Develop ongoing QA checks for new national Cancer registration system.
- Agree methods and protocols for chasing up cross boundary CWT only cases.
- National agreement needed on criteria for CWT Only cases to ONS.
- Feedback mechanisms to CWT data providers.

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The End



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