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
  – 1st treat date and no decision to treat date
  – Inconsistency with Cancer Status and 1st treat date
Cancer Waiting Times data 2004 – 08
GFOCWT data 2009-10

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
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.

Pathology impact on incidence

<table>
<thead>
<tr>
<th>Year</th>
<th>Electronic Lab Feed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>Leicester</td>
</tr>
<tr>
<td>2000</td>
<td>Sheffield</td>
</tr>
<tr>
<td>2001</td>
<td>Doncaster</td>
</tr>
<tr>
<td>2002</td>
<td>Chesterfield</td>
</tr>
<tr>
<td>2003</td>
<td>Derby</td>
</tr>
<tr>
<td>2004</td>
<td>Nottingham</td>
</tr>
<tr>
<td>2005</td>
<td>Rotherham</td>
</tr>
<tr>
<td>2006</td>
<td>Mansfield</td>
</tr>
<tr>
<td>2007</td>
<td></td>
</tr>
<tr>
<td>2008</td>
<td></td>
</tr>
<tr>
<td>2009</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td></td>
</tr>
</tbody>
</table>

Total registrations

NHS
Trent Cancer Registry
• Compare 2007 CWT against complete 2007 NCDR using DTD or 1st 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
Acknowledgement

• Decided to load into the registry database all patients on CWT with
  – A 1st 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

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.
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.
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

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.
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.

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.
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

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
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

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
Subsequent skins

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

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)
% of Cancelled CWT Records

- Benign 8%
- Mets 10%
- more specific site already on DB 42%
- not confirmed 22%
- Subsequent skins 8%
- Other 10%

Improvement
CWT records indicating positive cancer diagnosis not on NCDR 2007 and 2008
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

Characteristics of CWT cases not on merged registry dataset for 2008

<table>
<thead>
<tr>
<th>Site</th>
<th>Total with DTD or 1st treat date</th>
<th>Not on NCDR at all</th>
<th>% not on NCDR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leukaemia(C91-C95)</td>
<td>4150</td>
<td>764</td>
<td>18.41%</td>
</tr>
<tr>
<td>Melanoma(C43)</td>
<td>8924</td>
<td>913</td>
<td>10.23%</td>
</tr>
<tr>
<td>Prostate (C61)</td>
<td>24972</td>
<td>1994</td>
<td>7.98%</td>
</tr>
<tr>
<td>Male genital excl prostate (C60, C62,C630)</td>
<td>1946</td>
<td>125</td>
<td>6.42%</td>
</tr>
<tr>
<td>Lymphoma (C81-C85)</td>
<td>7658</td>
<td>477</td>
<td>6.23%</td>
</tr>
<tr>
<td>Gynae(C51 - C58)</td>
<td>11969</td>
<td>522</td>
<td>4.36%</td>
</tr>
<tr>
<td>Lung(C33, C34)</td>
<td>23554</td>
<td>915</td>
<td>3.88%</td>
</tr>
<tr>
<td>Colorectal (C18 - C21)</td>
<td>25965</td>
<td>859</td>
<td>3.31%</td>
</tr>
<tr>
<td>Upper Gi(C15 - C17)</td>
<td>10361</td>
<td>228</td>
<td>2.20%</td>
</tr>
<tr>
<td>Breast (C50)</td>
<td>33963</td>
<td>734</td>
<td>2.16%</td>
</tr>
</tbody>
</table>
Profile of CWT cases not on merged registry dataset 2008

% not on NCDR

Trent Leukaemia Incidence

Total
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

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.
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.

The End