What the NCIN is doing for Less Common cancers...

Chris Carrigan

To be covered today.....

• What is “Less Common”
• What do we already know
• What are we planning
  • Inputs
  • Process
  • Outputs
• Questions
What is “Less Common”? 

- “Common” (just under half)  
  - Breast, Colorectal, Lung & Prostate  
  - 30,000 – 40,000 each  
- “Less Common” (just over half)  
  - All other cancers  
  - 10,000 or fewer
What do we already know?

Published sources which have statistics

Published sources and tools which have statistics on less common cancers

Cancer Commissioning Toolkit

Key information for commissioners, but Charities can have access too.
14 cancer types

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>No. of Patients</th>
<th>Age-standardised proportion**</th>
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<th>Age-standardised proportion**</th>
</tr>
</thead>
<tbody>
<tr>
<td>C00-C14 &amp; C30-C32: Head and neck</td>
<td>13,552</td>
<td>48.9</td>
<td>48.0</td>
<td>49.7</td>
<td>5,985</td>
<td>18.7</td>
</tr>
<tr>
<td>C15: Oesophagus</td>
<td>4,652</td>
<td>16.0</td>
<td>15.5</td>
<td>16.5</td>
<td>2,307</td>
<td>6.3</td>
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<tr>
<td>C16: Stomach</td>
<td>5,092</td>
<td>16.8</td>
<td>16.3</td>
<td>17.3</td>
<td>2,622</td>
<td>6.8</td>
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<tr>
<td>C18-C20: Colorectum</td>
<td>42,086</td>
<td>138.6</td>
<td>137.2</td>
<td>139.9</td>
<td>33,214</td>
<td>87.6</td>
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<tr>
<td>C22: Liver</td>
<td>1,099</td>
<td>3.9</td>
<td>3.7</td>
<td>4.1</td>
<td>579</td>
<td>1.8</td>
</tr>
<tr>
<td>C25: Pancreas</td>
<td>1,565</td>
<td>5.4</td>
<td>5.2</td>
<td>5.7</td>
<td>1,540</td>
<td>4.5</td>
</tr>
<tr>
<td>C33-C34: Trachea, bronchus and lung</td>
<td>13,656</td>
<td>45.5</td>
<td>44.7</td>
<td>46.2</td>
<td>10,669</td>
<td>31.0</td>
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<tr>
<td>C43: Malignant melanoma</td>
<td>13,497</td>
<td>48.3</td>
<td>47.5</td>
<td>49.1</td>
<td>17,561</td>
<td>58.4</td>
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<tr>
<td>C45: Mesothelioma</td>
<td>1,330</td>
<td>4.5</td>
<td>4.2</td>
<td>4.7</td>
<td>320</td>
<td>0.9</td>
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<tr>
<td>C50: Breast</td>
<td>937</td>
<td>3.1</td>
<td>2.9</td>
<td>3.3</td>
<td>147,807</td>
<td>480.1</td>
</tr>
<tr>
<td>C53: Cervix uteri</td>
<td>8,223</td>
<td>30.0</td>
<td>29.4</td>
<td>30.7</td>
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<td></td>
</tr>
<tr>
<td>C54-C55: Uterus</td>
<td>19,569</td>
<td>60.9</td>
<td>60.1</td>
<td>61.8</td>
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<td></td>
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<tr>
<td>C56: Ovary</td>
<td>13,005</td>
<td>43.6</td>
<td>42.8</td>
<td>44.3</td>
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<td>C61: Prostate</td>
<td>108,243</td>
<td>347.8</td>
<td>345.8</td>
<td>349.9</td>
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<tr>
<td>C62: Testis</td>
<td>7,751</td>
<td>30.6</td>
<td>29.9</td>
<td>31.3</td>
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<td></td>
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<tr>
<td>C64-C66 &amp; C68: Kidney</td>
<td>8,867</td>
<td>31.0</td>
<td>30.3</td>
<td>31.6</td>
<td>5,253</td>
<td>16.2</td>
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<tr>
<td>C67: Bladder</td>
<td>16,248</td>
<td>51.7</td>
<td>50.9</td>
<td>52.6</td>
<td>5,106</td>
<td>12.7</td>
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<tr>
<td>C70-C72: Brain and other parts of cns</td>
<td>3,007</td>
<td>11.9</td>
<td>11.5</td>
<td>12.4</td>
<td>2,172</td>
<td>8.5</td>
</tr>
<tr>
<td>C81: Hodgkin disease</td>
<td>2,939</td>
<td>11.5</td>
<td>11.1</td>
<td>12.0</td>
<td>2,236</td>
<td>8.5</td>
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<tr>
<td>C82-C85 &amp; C96: Non-Hodgkin lymphoma</td>
<td>12,898</td>
<td>45.6</td>
<td>44.8</td>
<td>46.4</td>
<td>11,309</td>
<td>34.4</td>
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<tr>
<td>C88 &amp; C90: Myeloma</td>
<td>4,277</td>
<td>14.5</td>
<td>14.1</td>
<td>15.0</td>
<td>3,404</td>
<td>9.6</td>
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<tr>
<td>C91-C95: Leukaemia</td>
<td>8,225</td>
<td>29.8</td>
<td>29.2</td>
<td>30.5</td>
<td>5,792</td>
<td>18.7</td>
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<tr>
<td>Other Malignant Neoplasms</td>
<td>12,595</td>
<td>45.5</td>
<td>44.7</td>
<td>46.3</td>
<td>17,901</td>
<td>57.9</td>
</tr>
</tbody>
</table>

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</tr>
</thead>
<tbody>
<tr>
<td>C00-C97 excl. C44: All malignant neoplasms (excl. non-melanoma skin cancer)</td>
<td>282,516</td>
<td>951.0</td>
</tr>
<tr>
<td></td>
<td>316,574</td>
<td>997.0</td>
</tr>
<tr>
<td></td>
<td>599,090</td>
<td>961.5</td>
</tr>
</tbody>
</table>

*Age-standardised proportion to the European Standard Population. Crude and age-standardised proportions are shown per 100,000 population.

[^1]: All other malignant neoplasms includes the following ICD-10 codes: C17, C21, C23-C24, C26, C37-C41, C46-C49, C51-C52, C57-C58, C60, C63, C69, C73-C80, C97.


Published sources and tools which have statistics on less common cancers

NCIN Statistical reports

Examples:
- UK incidence & mortality
- Cancer survival
- Incidence by Deprivation
- Prevalence
- Cancer by Ethnicity
Published sources and tools which have statistics on less common cancers

NCIN specialised Analysis/Tools

- Routes to diagnosis
- Major resections
- Cancer in Men
- Cancer equalities portal
- Profiles e.g. for GP practices

NCIN data briefing and the Site Specific Clinical Reference Groups (SSCRGs)

Example briefsheets:
- Bone Sarcomas: incidence and survival rates
- Malignant Pleural Mesothelioma
- Route to Diagnosis
- Oral Cavity Cancer
- Geographic Variation in cancer of the lower oesophagus
  - Geographic Variation in primary liver and gall bladder cancer
Pooling knowledge

- 40% of patients with less common cancers waited for over 3 months before seeking medical advice
  - Rarer Cancers Foundation
- Patients with rarer cancers visit their GP on three or more occasions prior to onward referral
  - Patient Experience Survey (2010)
- Patients diagnosed at Emergency have far poorer survival
  - Routes to Diagnosis (2010)
What are we planning?

Inputs, Process, Outputs

Inputs

• Cancer Outcomes and Services Dataset
  • Site-specific data items
  • Trust requirement to submit
• Systemic Anti-Cancer Therapy dataset
  • Chemotherapy
• Piloting augmented Brain data collection
• Piloting secondary Breast cancer
Process

• Shift in Timeliness
  • 2008 completed in 18 months
  • 2009 completed in 15 months
  • 2010 due to be 12 months

• Single National System (ENCORE)
  • Already underway, complete by end 12/13

• Improved and Consistent Staging
  • National Staging Panel

National Work Programme

• National (central) analyses
• Site-specific analyses (13)
  • Children
  • Teenage and Young Adults
  • Plus 7 (less common) cancer-types
Outputs

- Rules and regulations - small numbers
- Statistics for rarer cancers
  - NCIN and Cancer 52 website
  - Trends in Incidence, Mortality and Survival for less common cancers
  - Compare with common cancers
- Information about CUPs

Outputs

- Earlier diagnosis
  - Extend Routes to Diagnosis (2006-2008)
  - Less common vs. Top-4?
- Experience of Care
  - Detailed analysis of PES (w. Macmillan)
- Profiles by cancer type?
  - Myeloma example at the C52 workshop **
And finally, the Future .......

- Completely different scenario
- Complexity and Depth
- Patient as the denominator
- Disease, time, characteristic
- Speciality-extensible
- Information Governance

So what is “Less Common”?

- Breast cancer in a young woman?
- Lung Cancer in a patient with a particular genetic type?
- Particular set of co-morbid conditions?
Some final thoughts for you and me....

- Targeted Investment
  - £1,000 from each Cancer52 member buys a full time analyst
- Prioritisation
  - Making sure that the less common cancers get fair coverage
- Can’t do everything yet...!

What the NCIN is doing for less common cancers...

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