**Background**

- Despite improvements in survival, cancer remains an important cause of death among children.
- Palliative medicine has developed over the last 20 years, and an increasing number of hospices for children have been opened in England.
- Palliative care services are acknowledged to vary in availability and quality across England.
- The Department of Health aims to improve services and provide a total approach to palliative care.

**Objective**


**Methods**

- The National Registry of Childhood Tumours (NRCT) is a population-based register of malignancies and benign brain tumours.
- The NRCT has been linked to Hospital Episode Statistics (HES) and death certificate data for children who were diagnosed and died of cancer during 1999-2006.
- Over 90% of NRCT cases are first notified from Children’s Cancer and Leukaemia Group (CCLG) clinicians.
- HES contain records of overnight and day case admissions to NHS hospitals and treatment centres in England.
- Multivariable logistic modeling was used to assess factors that influence dying at home or in hospital.

**Results**

- Cancer registrations for 1,864 (96%) children who were diagnosed and died of cancer during 1999-2006 in England were linked to HES records.
- Similar proportions of children died at home (45%) and in hospital (47%).
- Of the children who died in hospital, 74% were admitted as an emergency or transferred from another hospital.
- The percentage of children dying in a hospice or care home increased from 2% to 10%.
- Place of death varied by type of cancer, short survival (<6 months), ethnicity, socio-economic status, and treatment at a specialist centre.
- Between diagnosis and death, children with leukaemia spent 28% of their time in hospital, compared with 17% for children with brain or spinal tumours.
- Radiotherapy was not included, as this data is not collected in HES.

**Validation of hospital as place of death**

<table>
<thead>
<tr>
<th>Death Certificate</th>
<th>HES</th>
<th>Cases</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital death</td>
<td></td>
<td>796</td>
<td>85%</td>
</tr>
<tr>
<td>Hospital death</td>
<td>No record of death</td>
<td>131</td>
<td>14%</td>
</tr>
<tr>
<td>Non-hospital death</td>
<td></td>
<td>14</td>
<td>1%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>941</td>
<td>100%</td>
</tr>
</tbody>
</table>

Where HES had no record of death, records from two specialist centres show that about half of these patients died in an intensive care unit.

**Validation of ethnicity**

<table>
<thead>
<tr>
<th>Information Source</th>
<th>Cases</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Validated between CCLG and HES</td>
<td>1,624</td>
<td>87%</td>
</tr>
<tr>
<td>CCLG only</td>
<td>166</td>
<td>9%</td>
</tr>
<tr>
<td>Unknown / missing</td>
<td>74</td>
<td>4%</td>
</tr>
<tr>
<td>Total</td>
<td>1,864</td>
<td>100%</td>
</tr>
</tbody>
</table>

A good concurrence was found when validating ethnicity between HES providers and CCLG centres. CCLG was 99% accurate when compared with HES.

**Place of death by type of cancer**

- More children with leukaemias and lymphomas died in hospital than children with other tumours.

**Average time from diagnosis to death (days)**

- Average time between diagnosis and death was longer for children who died at home than in hospital.

**Place of death by ethnicity**

- More white children died at home compared with children from ethnic minorities.

**Average hospital stay from diagnosis to death (bed days)**

- For all cancers, a child spent about a fifth of their time between diagnosis and death in hospital.

**Conclusion**

- The linkage between NRCT and HES records was excellent at 96%.
- Although anomalies exist within HES data, validation of dying in hospital and ethnicity showed a good concurrence between HES and other sources.
- Similar proportions of children are dying at home (45%) or in hospital (47%). Dying in a hospice is rare although the proportion is increasing.
- Greater proportions of children diagnosed with a leukaemia or lymphoma, those dying within six months of diagnosis, Asian and Black children, those from a deprived background, and those not treated in a CCLG centre died in a hospital.
- Further research is required to find explanations for these patterns and to evaluate methods to increase the proportion of children dying at home who wish to do so.