

# Place of death and hospital care for children who died of cancer in England, 1999-2006

Anjali Shah, Nicole Diggins, Charles Stiller, Dermot Murphy, Jane Passmore, Mike Murphy  
Childhood Cancer Research Group, University of Oxford



## 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

To describe patterns of hospital care and to evaluate factors influencing place of death for children who died after a diagnosis of cancer in England during 1999-2006.

## 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

Death Certificate	HES	Cases	%
Hospital death	Hospital death	796	85%
Hospital death	No record of death	131	14%
Non-hospital death	Hospital death	14	1%
<b>Total</b>		<b>941</b>	<b>100%</b>

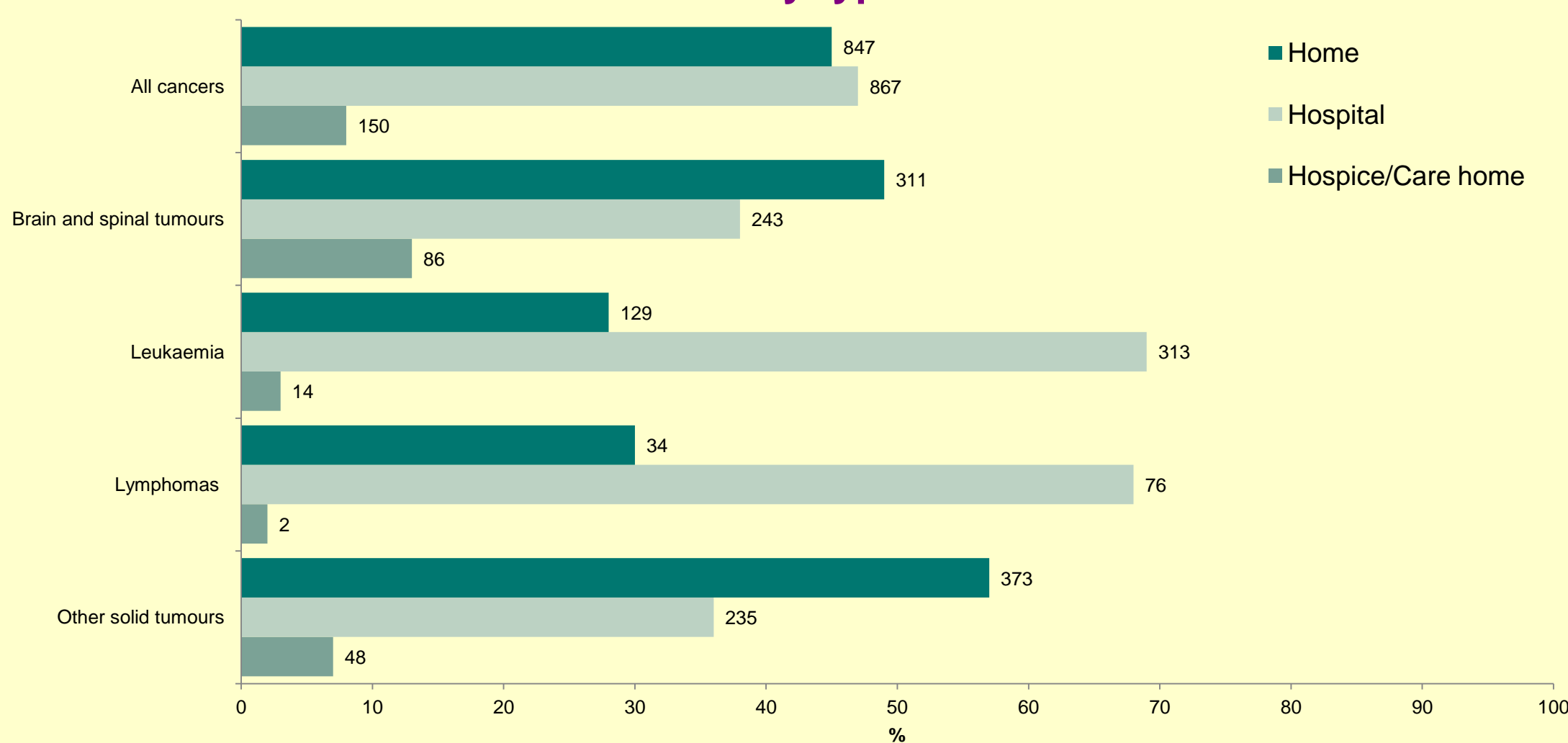
Where HES had no record of death, records from two specialist centres show that about half of these patients died in an intensive care unit.

### Validation of ethnicity

Information Source	Cases	%
Validated between CCLG and HES	1,624	87%
CCLG only	166	9%
Unknown / missing	74	4%
<b>Total</b>	<b>1,864</b>	<b>100%</b>

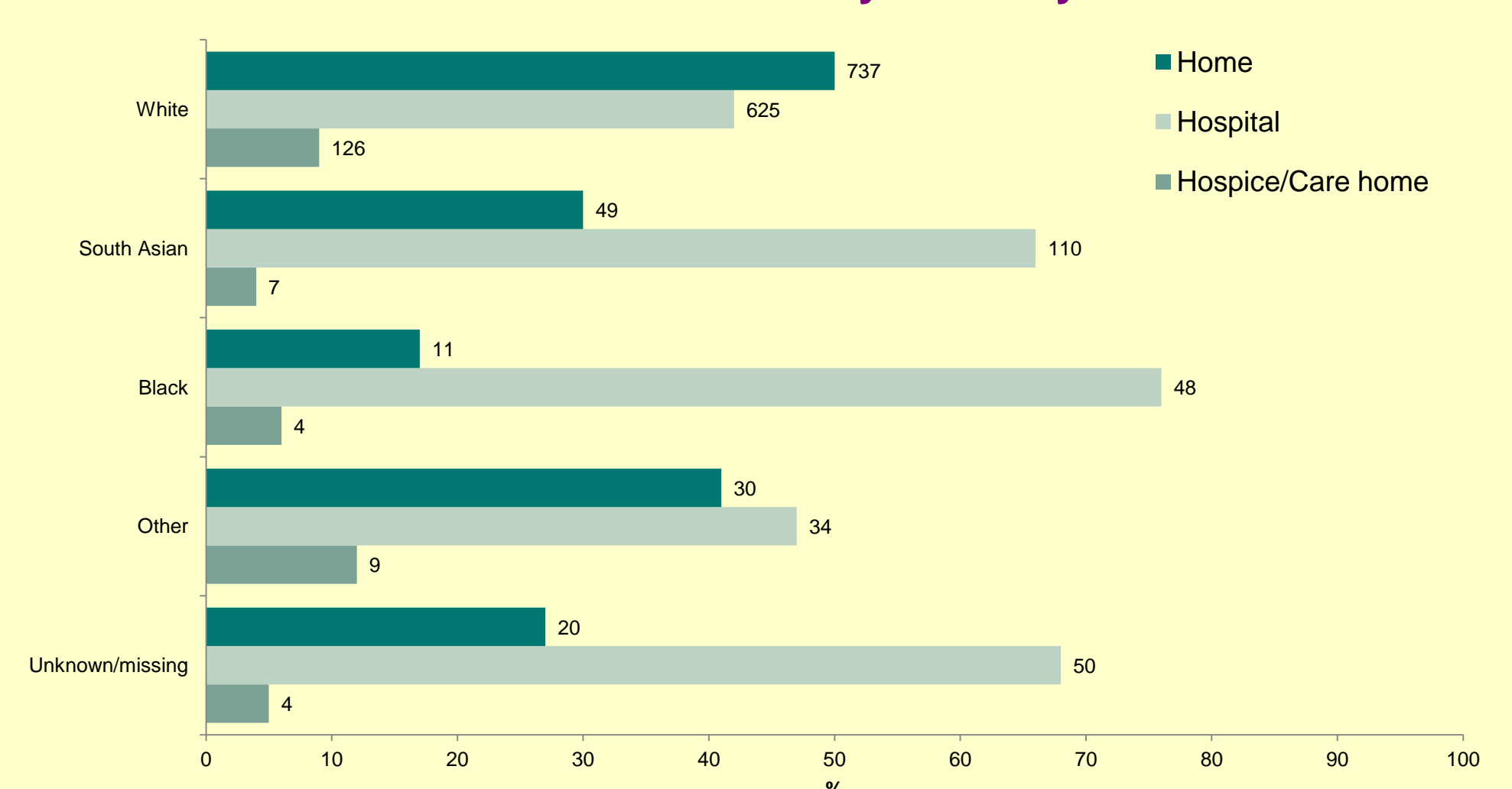
A good concurrence was found when validating ethnicity between HES providers and CCLG centres. CCLG was 99% accurate when compared with HES.

### Place of death by type of cancer



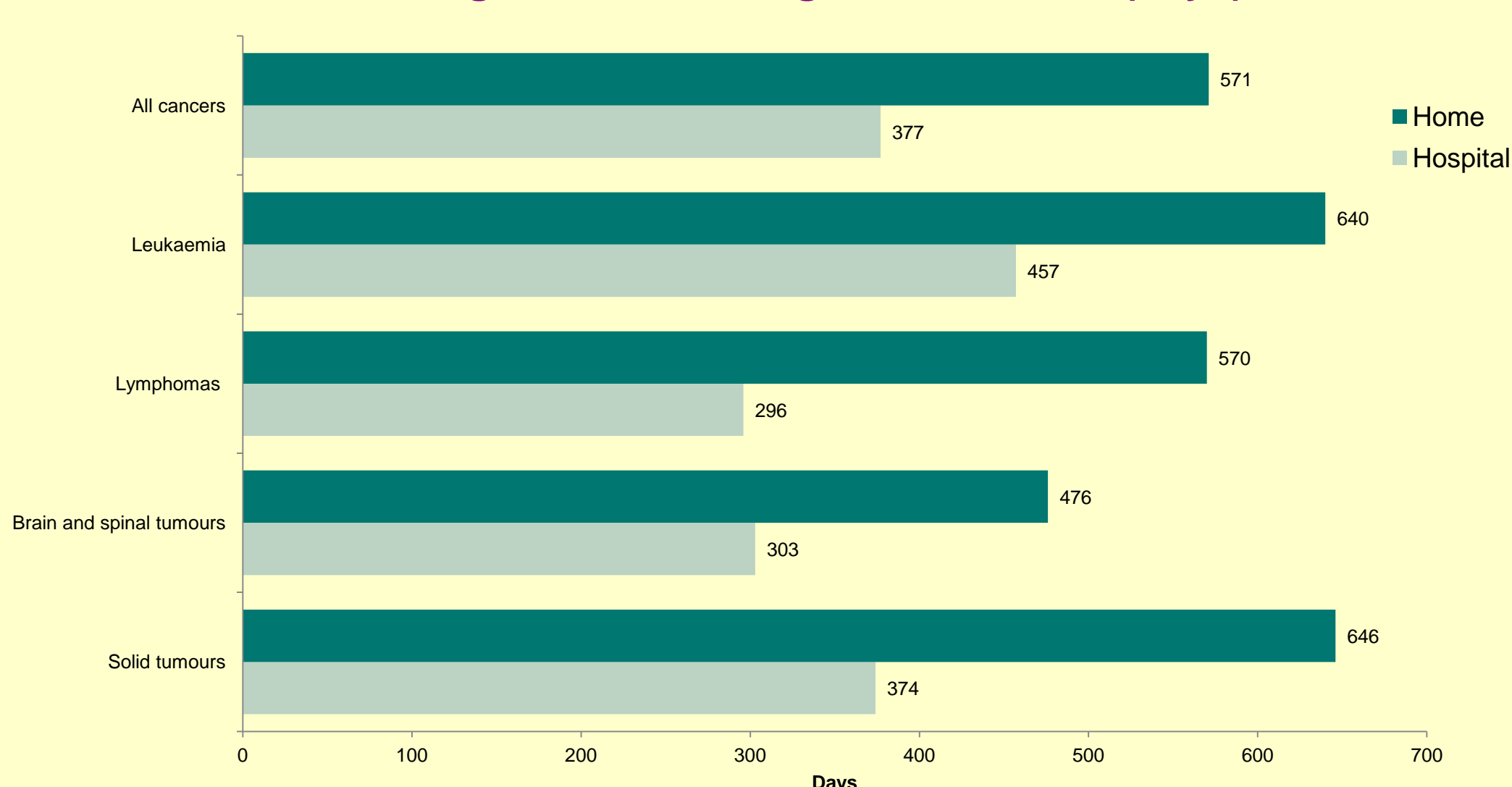
More children with leukaemias and lymphomas died in hospital than children with other tumours.

### Place of death by ethnicity



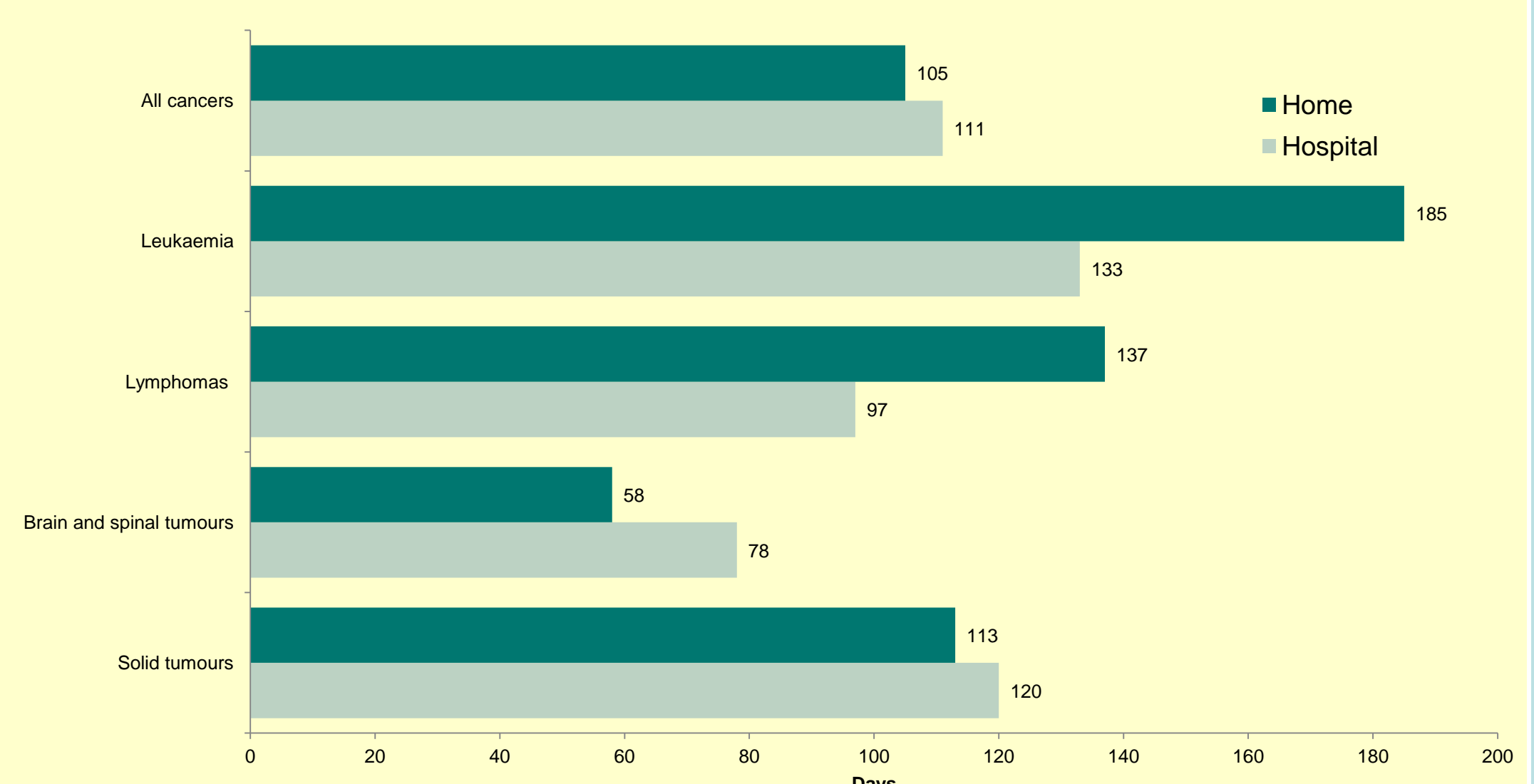
More white children died at home compared with children from ethnic minorities.

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



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

### 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.