

Recent, ongoing and planned analyses of childhood cancer data

Cancer Network CTYA Clinical Leads Workshop

28 November 2011

Kroll ME *et al.* Childhood cancer registration in Britain: capture-recapture estimates of completeness of ascertainment.

***Br J Cancer* 2011,104, 1227-1233**

NRCT registrations of children with cancer in England, Wales and Scotland diagnosed 2003-2004.

Stratified capture-recapture applied to notifications from general cancer registries and CCLG registrations.

Results verified by cross-checking with HES for leukaemia patients from England born in 1998 and diagnosed before 2005.

Childhood cancer registration in Britain: capture-recapture estimates of completeness of ascertainment

General cancer registries notified 92-96% of cases, depending on assumptions about how many received after February 2007 resulted from feedback by NRCT to general registries of cases previously only registered via CCLG.

CCLG notified 93% of cases.

Overall completeness estimate for NRCT was 99-100%.

Childhood cancer registration in Britain: capture-recapture estimates of completeness of ascertainment

HES file contained 432 different IDs.

390 (90%) automatically matched to 297 NRCT cases on NHS number or birthdate + sex + postcode.

Distinct IDs don't necessarily represent distinct patients.

297 NRCT cases:

- 269 leukaemia patients, born 1998, diagnosed before 2005 while resident in England
- 2 born 1997
- 3 not resident in England at diagnosis
- 16 non-leukaemia cancer
- 7 non-cancer

4 relevant NRCT cases not matched with HES: apparently not NHS in-patients while resident in England

Childhood cancer registration in Britain: capture-recapture estimates of completeness of ascertainment

The 42 unmatched IDs were grouped by NHS number, birthdate, sex, postcode as available.

26 probably distinct patients:

- 9 possible matches to NRCT cases linked to other HES IDs
- 4 definite matches to cases already known to be ineligible for NRCT
- 2 further patients found to be non-UK resident at diagnosis by enquiry to treatment centres
- 4 likely haematological, non-leukaemic diagnosis from check with full HES database
- 7 perhaps unidentified treatment fragments or errors (11 leukaemia episodes in total)

Shah A *et al.* Place of death and hospital care for children who died of cancer in England, 1999-2006.

***Eur J Cancer* 2011, 47, 2175-2181**

NRCT registrations of children who were diagnosed with cancer and died were linked to HES and death certificates.

96% of children with cancer registrations were linked to HES.

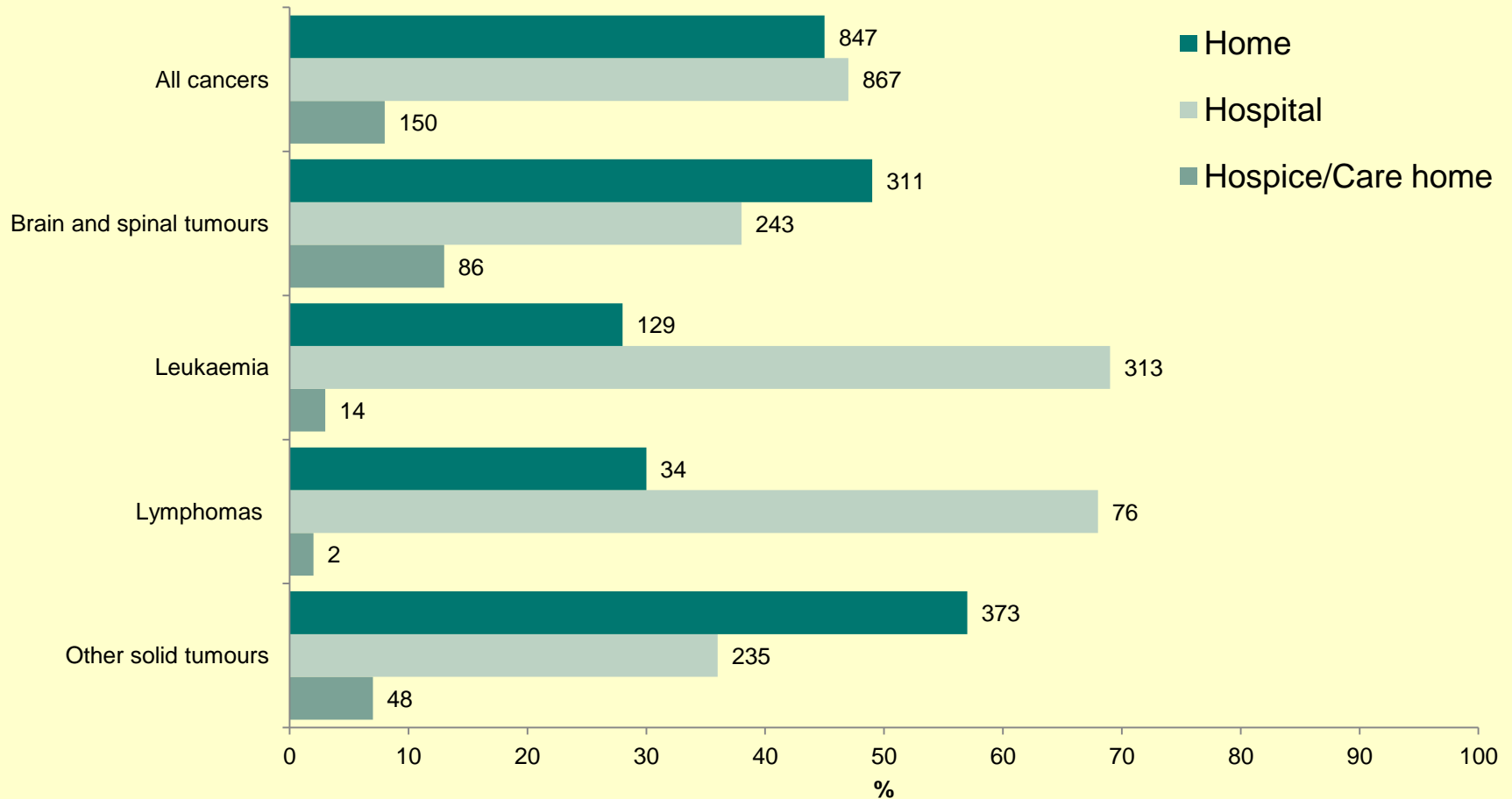
14% of children who died in hospital did not have their death recorded in a HES episode; of these, about half died in intensive care units.

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

- Place of death was home for 45% of children, hospital for 47%, hospice /care home for 8%.
- 74% of those who died in hospital were admitted as emergencies or transferred from another hospital.

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

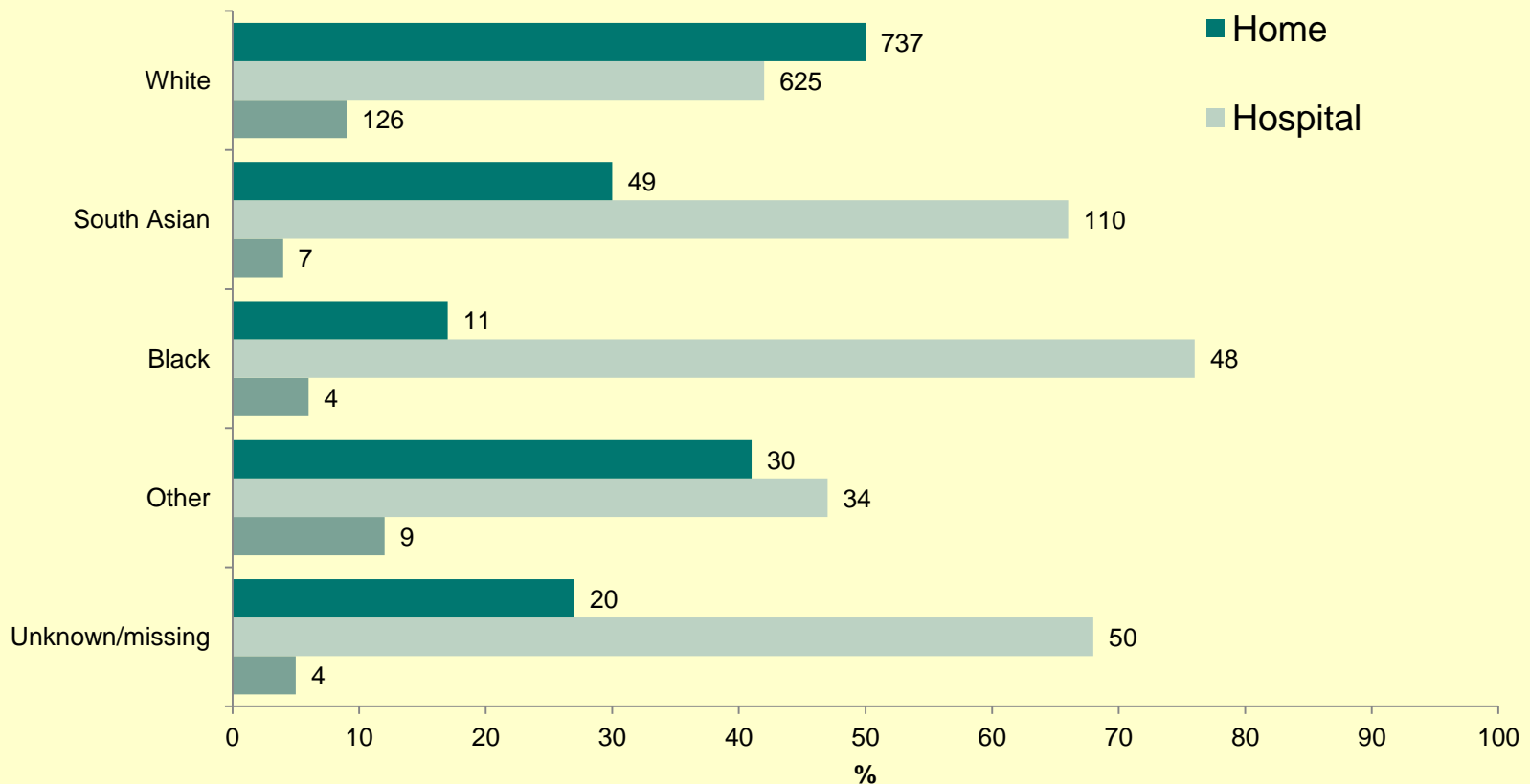
Place of death by type of cancer



Children were more likely to die in hospital if diagnosed with leukaemia or lymphoma

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

Place of death by ethnicity



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

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

Children were also more likely to die in hospital if they:

- died within 6 months of diagnosis
- were from a deprived background

Supra-regional referral patterns of childhood cancer patients

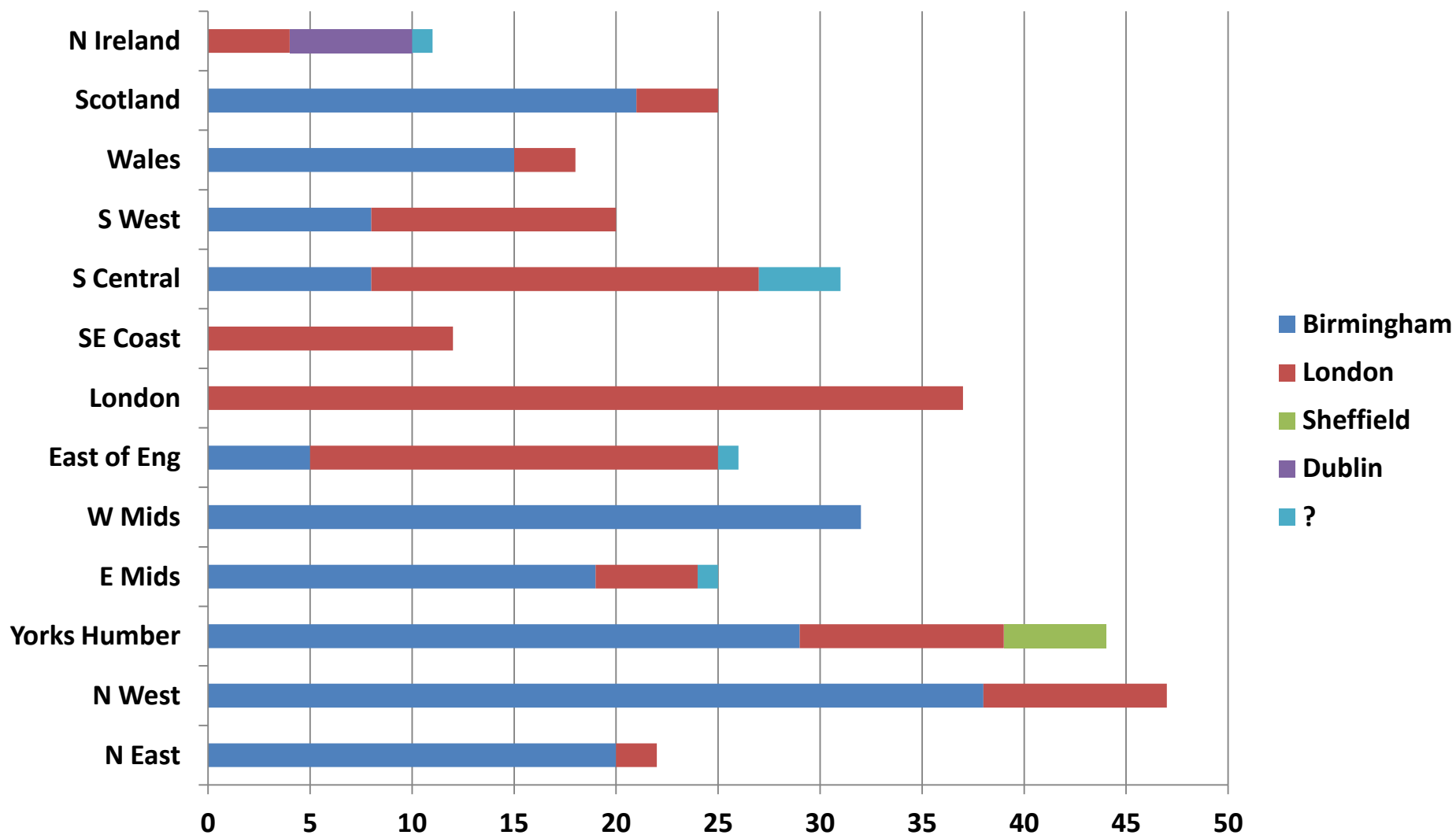
Retinoblastoma, UK, 2002-2009

Liver cancer, UK, 1998-2007

Bone cancer, England & Wales, 1998-2007

Referral of children with retinoblastoma to ophthalmological centres

UK, 2002-2009



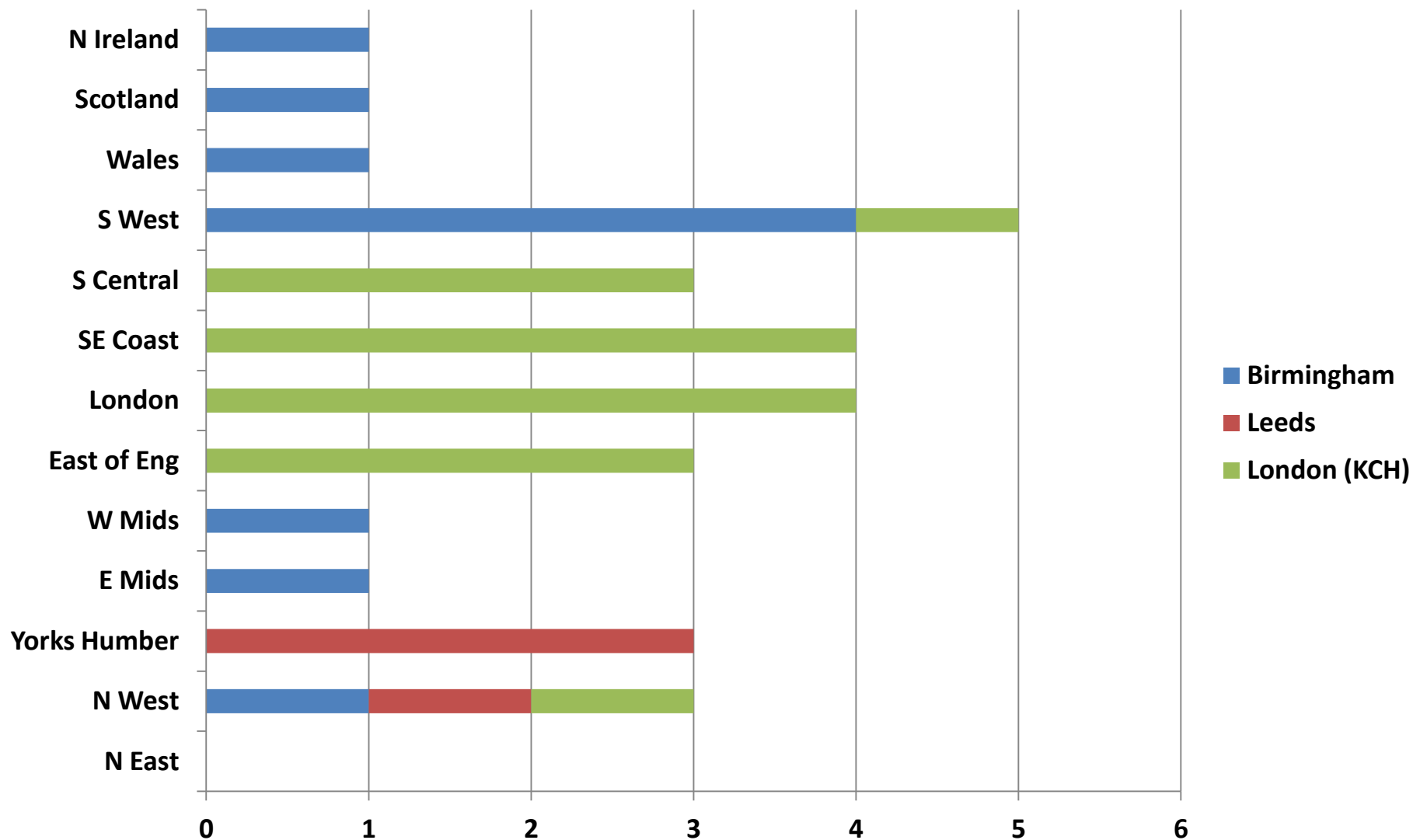
Children with liver cancer

UK, 1998-2007

	Transplant	No transplant	Total
Total	30 (14%)	183	213
Hepatoblastoma	27 (18%)	120	147
Carcinoma	2 (6%)	30	32
Other tumour types	1 (3%)	33	34
1998-2002	14 (14%)	85	99
2003-2007	16 (14%)	98	114

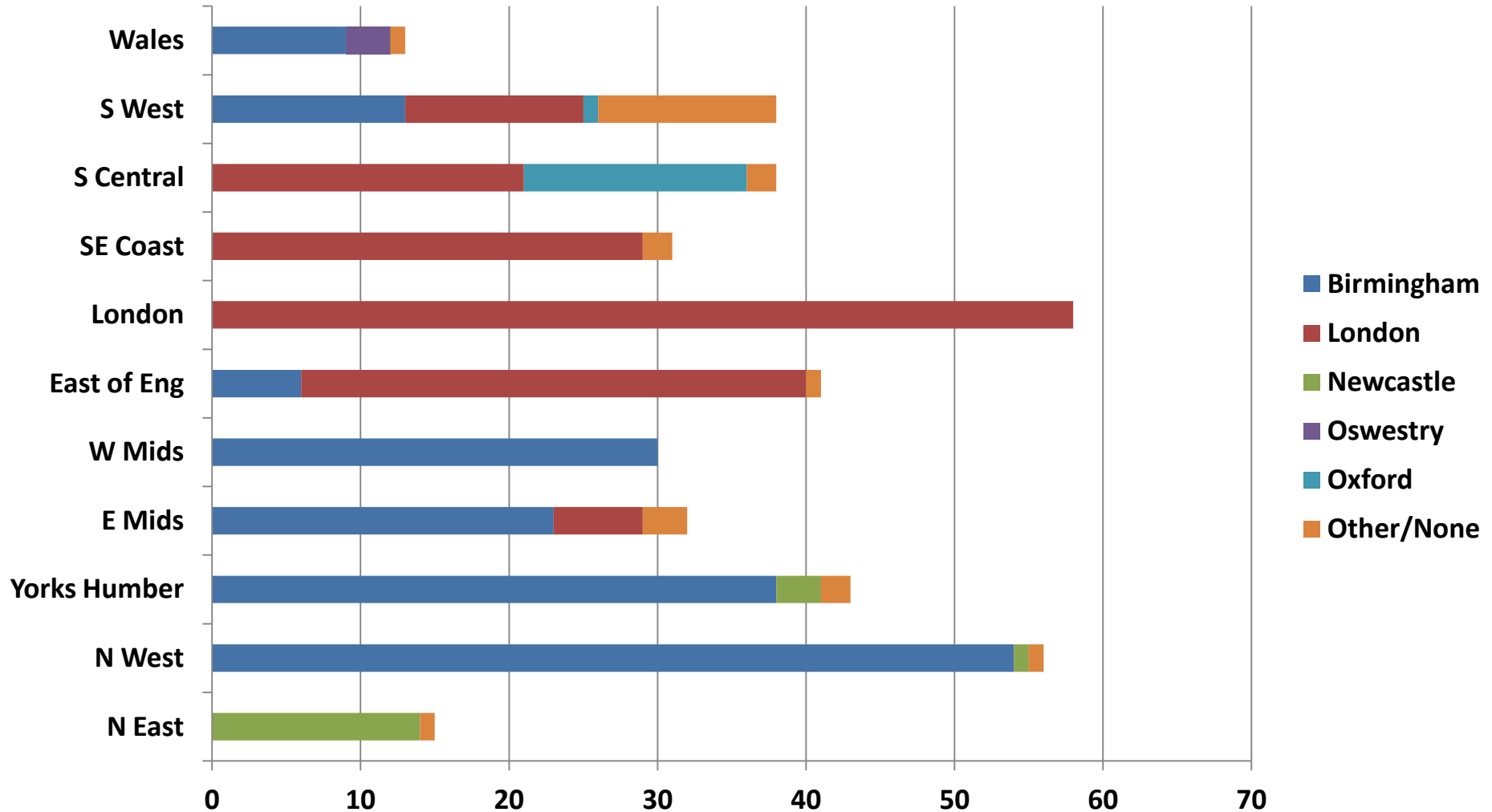
Children with liver cancer who had a liver transplant

Referral to liver disease centres, UK, 1998-2007



Referral of children with bone sarcoma of limbs to bone tumour services

England & Wales, 1998-2007

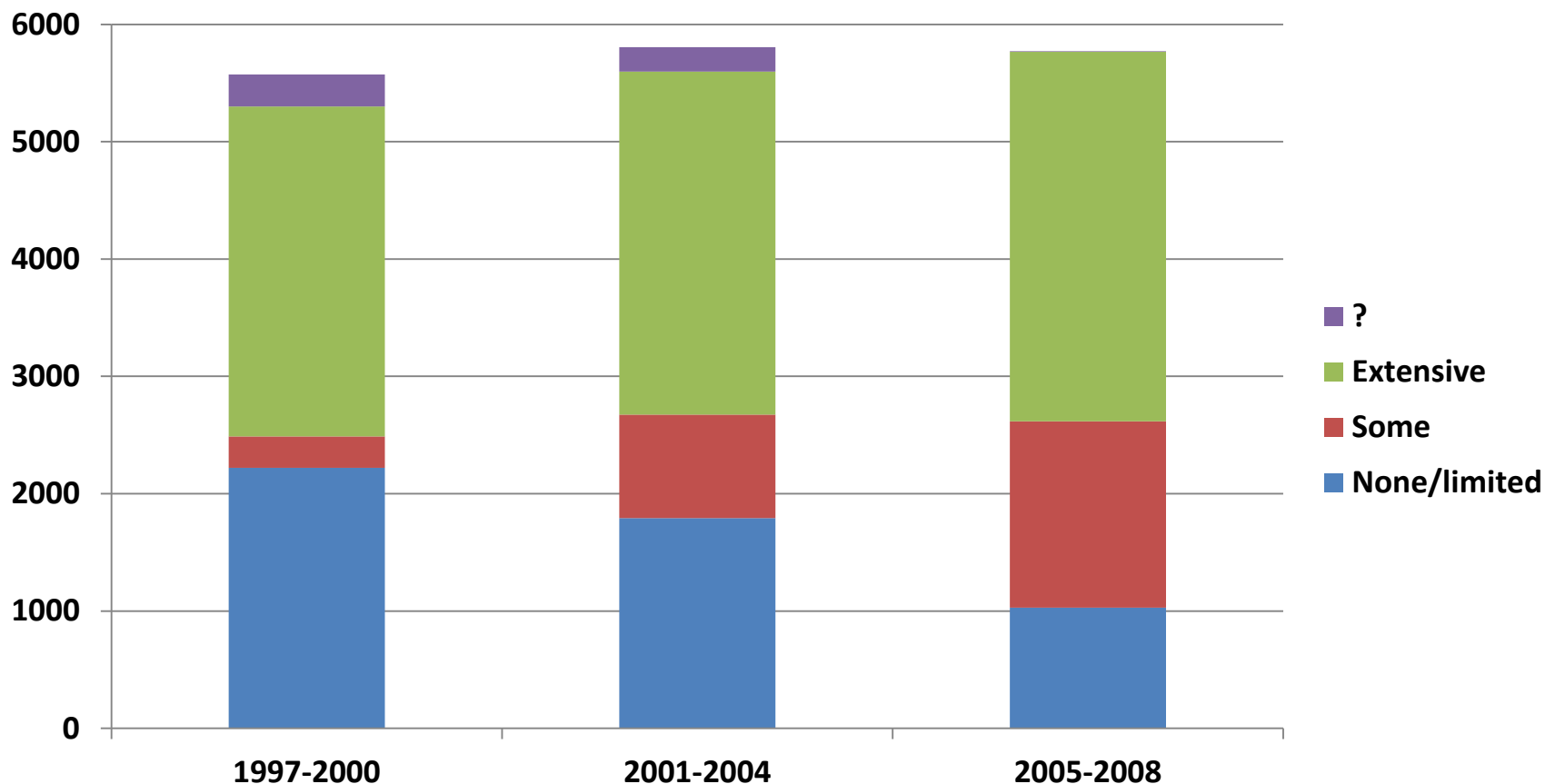


**Survey of extent of shared care
at UK PTCs for childhood cancer,
1997 onwards**

Centres classified by extent of shared care

	1997-2000	2001-2004	2005-2008
None/limited	10	8	5
Some	2	4	7
Extensive	8	8	8
?	1	1	1
Total	21	21	21

Children with cancer registered from PTCs by extent of shared care at PTC UK, 1997-2008



Shared care at UK PTCs for childhood cancer

Next step:

- Survival by extent of shared care at PTC

Early mortality (30 day) rate in paediatric CNS tumour surgery in the UK

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1 Leeds General Infirmary

2 NRCT/CCRG

3 National Specialist Commissioning Team (England)

4 University of Leeds

5 NHS London

Early mortality (30 day) rate in paediatric CNS tumour surgery in the UK

Eligible cases from NRCT:

- histologically verified CNS tumour
- UK resident at diagnosis
- diagnosed 2004-2007
- age <15 years

Exclusions:

- optic nerve glioma
- PM diagnosis

30-day post-operative mortality by tumour type

	N (patients)	30 day mortality (%)
Ependymoma	111	4 (3.6)
Choroid plexus carcinoma	16	3 (18.8)
Choroid plexus papilloma	29	0
Low grade astrocytoma	399	0
High grade astrocytoma	93	9 (9.7)
Other glioma	68	3 (4.4)
Medulloblastoma	212	5 (2.4)
Other embryonal	77	10 (13.0)
Germ cell	59	1 (1.7)
Pineal parenchymal	24	1 (4.2)
Craniopharyngioma	75	0
All other	119	0
Total	1282	36 (2.8)

30-day post-operative mortality by age

	N (patients)	30 day mortality (%)
Age <2 years	185	13 (7.0)
Age 2-14 years	1097	23 (2.1)
Total	1282	36 (2.8)

30-day post-operative mortality by case load

Patients per year	N (centres)	N (patients)	30 day mortality (%)	Expected deaths adjusted for tumour type	Expected deaths adjusted for age
28-46	2	297	11 (3.7)	7.97	8.41
20-22	4	329	7 (2.1)	9.02	9.46
15-19	5	353	12 (3.4)	9.24	9.59
0-13	9	303	6 (2.0)	9.77	8.54
Total	20	1282	36 (2.8)	36	36

Forthcoming Data Briefings

- Patterns of occurrence of second and subsequent primary cancers in CTYA (jointly with NWCIS)
- Use of hospital resources by CTYA with cancer, by age, gender and diagnostic group (jointly with NWCIS)
- Survival of children with cancer by socioeconomic status, ethnicity, region of residence, urban/rural status of residence