

# Lifetime Hospital Contact After Diagnosis of a Childhood Tumour

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## Background

The National Registry of Childhood Tumours (NRCT) is a population-based register of malignancies and benign brain tumours diagnosed in children under the age of 15. It covers England, Scotland, and Wales since 1962 and Northern Ireland since 1993. It contains over 80,000 cases and is complete to 2004. Over 90% of its cases are first notified from Children's Cancer and Leukaemia Group (CCLG) clinicians. Hospital Episode Statistics (HES) contains records of day cases and overnight admissions to NHS hospitals and NHS-funded treatment centres in England and patients living in England admitted to hospitals in Wales.

## Objective

The Children Cancer Research Group (CCRG) linked data from the NRCT to HES records to obtain a picture of variation in patterns of hospital contact for children with tumours and to determine areas for more detailed analysis. The linked dataset does NOT contain outpatient data. To adjust for differences in the way inpatient day cases and outpatient cases are classified between hospitals, some analyses were done for episodes involving overnight stays only.

## Methods

The CCRG sent the National Cancer Services Analysis Team (NatCanSAT) a file containing 5535 NRCT cases that were diagnosed between 1999-2002 in England and Wales. NatCanSat returned a file containing HES inpatient records with NHS numbers that matched the NRCT cases. This HES data spans 9 years from 1 April 1997 to 31 March 2006. The CCRG linked the HES records to the NRCT cases using NHS number and verified matches using additional identifiers.

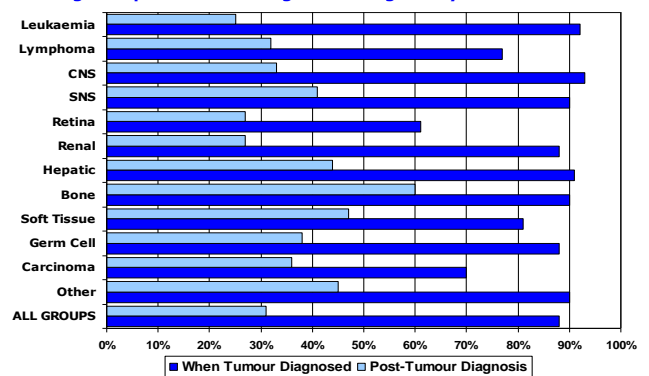
## Results

90.5% of the NRCT cases were linked to at least one HES record, providing 184,791 HES inpatient episodes for 5011 NRCT cases. Linkage rates were higher for cases registered with CCLG clinicians (92% compared with 71% for non-CCLG cases). Patterns of hospital contact vary with tumour type, origin of registration, age at diagnosis, episode date in relation to tumour diagnosis date, and episode outcome. Some examples include:

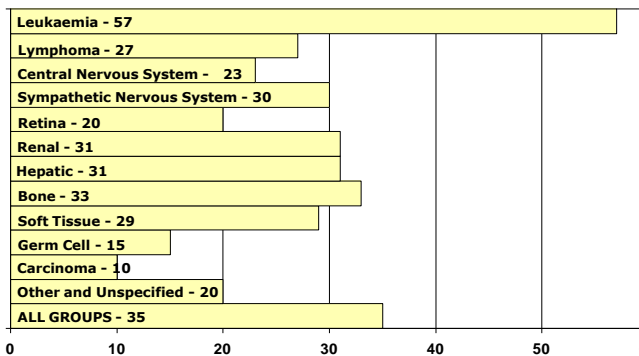
### Mean Length of Stay (in Days) for Different Admission Types

Tumour Group	Pre-Tumour Diagnosis	Tumour Diagnosis Admission	Post-Tumour Diagnosis - Discharged Alive	Post-Tumour Diagnosis - Died in Hospital
Leukaemia	2	13	2	23
Lymphoma	2	8	2	19
Central Nervous System	2	12	2	20
Sympathetic Nervous System	3	13	3	15
Retina	3	2	1	6
Renal	2	9	2	31
Hepatic	5	9	3	15
Bone	2	6	3	12
Soft Tissue	2	9	3	14
Germ Cell	2	10	3	10
Carcinoma	2	5	3	36
Other	3	8	2	7
ALL GROUPS	2	11	2	19

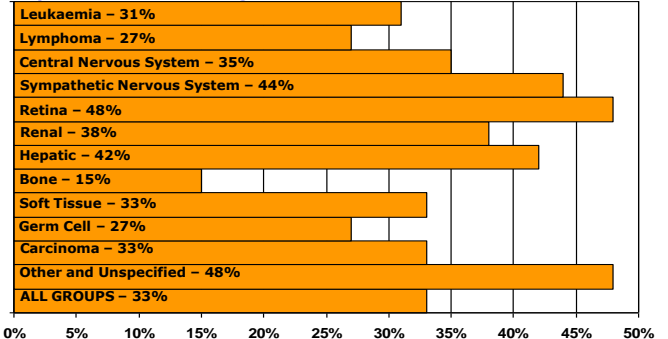
### Percentage of Episodes Involving an Overnight Stay



### Mean Number of Post-Tumour Diagnosis Episodes per Patient



### Percentage of Children with Hospital Admissions More than 30 Days Prior to Tumour Diagnosis



### CCLG Centre Variation - Number of Cases Registered, Number of Episodes per Patient, and Age at Diagnosis

Tumour Group	Number of Cases: Mean (Min-Max)	Mean Diagnosis Age: Mean (Min-Max)	Mean Number of Post-Tumour Diagnosis Episodes per Patient - All Episodes: Mean (Min-Max)	Mean Number of Post-Tumour Diagnosis Episodes per Patient - Overnight Episodes: Mean (Min-Max)
Leukaemia	97 (27 - 167)	5.6 (4 - 11)	56 (40 - 95)	13 (11 - 17)
Lymphoma	31 (8 - 59)	8.9 (6 - 12)	28 (17 - 50)	9 (6 - 14)
Central Nervous System	77 (9 - 170)	5.3 (4 - 8)	23 (13 - 38)	8 (6 - 12)
Sympathetic Nervous System	19 (1 - 83)	2.6 (1 - 11)	28 (19 - 48)	13 (9 - 19)
Retina	12 (1 - 83)	0.8 (0 - 3)	18 (4 - 41)	7 (1 - 12)
Renal	17 (2 - 51)	2.9 (2 - 11)	30 (17 - 60)	9 (6 - 21)
Hepatic	4 (1 - 12)	2.4 (0 - 14)	34 (10 - 126)	13 (7 - 26)
Bone	13 (4 - 58)	10.4 (8 - 12)	36 (21 - 60)	20 (15 - 27)
Soft Tissue	19 (7 - 37)	5.9 (3 - 11)	30 (16 - 46)	15 (10 - 21)
Germ Cell	10 (1 - 18)	7.3 (3 - 13)	15 (6 - 29)	8 (3 - 23)
Carcinoma	6 (3 - 10)	8.1 (3 - 13)	12 (5 - 51)	5 (3 - 10)
Other	1 (1 - 2)	4.9 (1 - 14)	36 (1 - 111)	14 (1 - 31)
ALL GROUPS	290 (78 - 554)	5.9 (3.9 - 10.8)	37 (27 - 59)	12 (10 - 18)

## Conclusion

This study highlighted a number of areas for further research, including in-depth analysis of the month prior to diagnosis, comparison of registration location with subsequent treatment location, and analysis of consultant specialities for single vs. multiple episode spells in which tumour diagnosis occurred. The CCRG is currently analysing in detail the acute lymphoid leukaemia cases (n=1327), a homogeneous group that accounts for 26% of the linked dataset.