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Estimated completeness of ascertainment for childhood cancer in the UK, 2005-2010

CTYA SSCRG
September 2013

Estimated completeness of ascertainment for childhood cancer in the UK, 2005-2010

Programme Management

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Introduction

This report presents estimated completeness of ascertainment for childhood cancer in the UK, 2005-2010, the most recent period for which registration by the National Registry of Childhood Tumours (NRCT) has been declared complete. The most recent published estimates of completeness of ascertainment of childhood cancer in Britain by the NRCT cover years 2003-2004 [1].

The purpose of this report is to assess whether NCRT is under reporting ascertainment of childhood cancers or not.

Method

NRCT

The Childhood Cancer Research Group (CCRG) based in the University of Oxford houses the NRCT, a population based register of malignancies and benign brain tumours diagnosed in children aged under 15 years who live in England, Wales or Scotland (and Northern Ireland, since 1993) at the time of diagnosis. The NCRT is one of the largest and most important specialist childhood cancer registries in the world. It is the NCIN lead tumour registry for the delivery of national childhood cancer intelligence for England. Its work plan is annually agreed with its oversight group, the NCIN Childhood and Teenage Young Adult Site Specific Clinical Reference Group (CTYA SSCRG).

Analyses of NRCT data and its linked datasets allow description and analyses of trends and distributions of cancer incidence, mortality, survival and hospitalization.

Ascertainment completeness

This report is based on NRCT records for all children diagnosed at age <15 years and resident in the UK at the time of diagnosis. It includes diagnoses during 2005-2010 of malignant neoplasm or non-malignant CNS tumour included in the International Classification of Childhood Cancer, Third Edition (ICCC-3) [2].

Sources of ascertainment by the NRCT during this period were direct notification from paediatric oncology principal treatment centres (PTC) affiliated to the Children's Cancer and Leukaemia Group (CCLG), data exchange with general (all ages) regional and national cancer registries throughout the UK, and death certificates with a neoplasm as underlying cause (not Northern Ireland)..

The total number of eligible cases was 9,619. Of these, 8,683 had been notified from a CCLG PTC and 9,375 from regional and national cancer registries or death certificates. Of the latter, 11 had been notified to the NRCT by death certificate only (DCO) and there were a further 19 cases that were not notified from a PTC and were DCO registrations received from a cancer registry.

Capture-recapture estimates of completeness of ascertainment were calculated by a two-source method similar to that used for the 2003-2004 analysis. The estimated total number of cases in the population was defined as

$$a+b+c + (bc/(a+1)^{1}$$

The estimated completeness was defined as the total number of cases registered divided by the estimated total number in the population, expressed as a percentage. In addition to a crude overall estimate, stratified estimates were produced by region of residence (English SHA, Scotland, Wales or Northern Ireland), year of diagnosis, age at diagnosis (0, 1-4, 5-9, 10-14) and diagnostic group (ICCC-3).

[1]

a = number of cases notified direct from a PTC and from a cancer registry and/or death certificates
b = number of cases notified from a cancer registry and/ death certificate but not direct from a PTC
c = number of cases notified direct from a PTC only

Results

Table 1 shows numbers of cases and estimated completeness overall and stratified by region, year of diagnosis, age at diagnosis and diagnostic group as described above.

The overall estimate of completeness was 99.7%. All regions had estimated completeness of at least 99.5%. Estimated completeness was between 99.7% and 99.9% for each year during 2005-2009 but was slightly lower, 99.4% for 2010. Estimated completeness was higher for children diagnosed at ages 1-4 and 5-9 years, 99.8% - 99.9%, than for those diagnosed in the first year of life or at age 10-14 years, 99.5%. The overall estimate of completeness remained at 99.7% when stratified by region, year or age.

Estimated completeness was over 99% for nearly all diagnostic groups. The exceptions were ICCC-3 group XI, carcinoma and melanoma, 97.9% and group XII, other and unspecified malignancies, 80.1%. This last group contained only 61 registrations in total, mostly of completely unspecified morphology. The overall estimate of completeness stratified by ICCC-3 group was 99.5%.

Table 2 shows results of equivalent analyses for Great Britain. These are presented for continuity with the published results for 2003-2004 and because the NRCT has not received death certificates from Northern Ireland. The results are essentially the same as those for the UK as a whole.

Discussion

The results of the analysis indicate that the NRCT achieved a very high level of completeness of ascertainment for childhood cancer throughout the UK for the period 2005-2010.

The main difference compared with the 2003-2004 analysis is that the proportion of cases in Great Britain that were notified by another cancer registry was 97%, higher than the 92-96% in the earlier study (depending on assumptions). While this may reflect increased ascertainment levels by the regional and national all-ages cancer registries generally, it probably also results from the more regular data exchange between the NRCT and the other registries during 2005-2010.

The slightly lower completeness estimate for 2010 compared with 2005-2009 suggests that there may still be a few very late registrations to come for 2010. However, it has not yet been possible to investigate cases not notified direct from a PTC for 2010 as thoroughly as for earlier years and some of these registrations may be found to be ineligible because the children were overseas residents at diagnosis or did not in fact have a malignancy.

The analysis by age at diagnosis indicates that one half of unregistered cases were diagnosed at age 10-14 years, presumably a consequence of the slightly lower rate of referral to CCLG PTCs for this age group.

The only ICCC-3 groups with estimated completeness below 99% were XI (carcinoma and melanoma), 98%, and XII (other and unspecified malignant neoplasms), 80%. The slightly lower estimate for group XI is consistent with the high average age at diagnosis for those tumours.

Registrations in Group XII were predominantly of totally unspecified morphology, nearly all without any diagnostic report. If more information could be collected on this rather small number of patients, a high proportion would probably be redistributed among other diagnostic groups, mainly the non-CNS solid tumours in groups IV – XI.

The estimates presented here should be interpreted with some caution because the sources of ascertainment are not strictly independent, a limitation which also applied to the 2003-2004 analysis. However, this limitation could not be avoided without an independent survey of all hospitals in the UK, for which resources are not available.

Nevertheless, the extremely high estimated level of completeness throughout the study period supports the belief that the NRCT has almost complete ascertainment of all types of childhood cancer for the whole of the UK throughout the period 2005-2010.

Table 1 Childhood cancer in the UK, 2005-2010. Numbers of cases in NRCT by source, capture-recapture estimate of numbers in population (C-R est) and estimated completeness

	Number of cases					
	Total	**CR or DC only**	**PTC only**	**Both**	**C-R est**	**Completeness (%)**
Overall	9619	936	244	8439	9646.1	99.7
Region of residence						
North East	409	12	6	391	409.2	100
North West	1061	66	41	954	1063.8	99.7
Yorks & Humber	803	63	16	724	804.4	99.8
E Midlands	701	58	21	622	703.0	99.7
W Midlands	809	39	24	746	810.3	99.8
East of England	894	68	6	820	894.5	99.9
London	1276	197	35	1044	1282.6	99.5
SE Coast	703	96	9	598	704.4	99.8
South Central	653	67	22	564	655.6	99.6
South West	792	82	25	685	795.0	99.6
Unknown (England)	11	10	0	1	11	100
England	8112	758	205	7149	8133.7	99.7
Wales	478	40	1	437	478.1	100
England & Wales	8590	798	206	7586	8611.7	99.7
Scotland	707	42	37	628	709.5	99.7
Great Britain	9297	840	243	8214	9321.8	99.7
Northern Ireland	322	96	1	225	322.4	99.9

Table 1 Childhood cancer in the UK, 2005-2010. Numbers of cases in NRCT by source, capture-recapture estimate of numbers in population (C-R est) and estimated completeness

	Number of cases					
	Total	**CR or DC only**	**PTC only**	**Both**	**C-R est**	**Completeness (%)**
Overall	9619	936	244	8439	9646.1	99.7
UK (stratified)	9619				9643.7	99.7
Year of diagnosis						
2005	1574	147	32	1395	1577.4	99.8
2006	1610	169	38	1403	1614.6	99.7
2007	1520	135	20	1365	1522.0	99.9
2008	1669	159	39	1471	1673.2	99.7
2009	1601	140	46	1415	1605.5	99.7
2010	1645	186	69	1390	1654.2	99.4
2005-2010 (stratified)	9619				9646.9	99.7
Age at diagnosis						
0	918	104	33	781	922.4	99.5
1-4	3456	193	76	3187	3460.6	99.9
5-9	2345	214	54	2077	2350.6	99.8
10-14	2900	425	81	2394	2914.4	99.5
0-14 (stratified)	9619				9647.9	99.7
ICCC-3 group						
I Leukaemia	2907	103	46	2758	2908.7	99.9
II Lymphoma	1008	82	32	894	1010.9	99.7
III CNS	2530	300	88	2142	2542.3	99.5
IV Neuroblastoma etc	554	12	17	525	554.4	99.9
V Retinoblastoma	262	51	5	206	263.2	99.5
VI Renal	500	7	4	489	500.1	100
VII Hepatic	110	12	0	98	110.0	100
VIII Bone	382	35	7	340	382.7	99.8
IX Soft-tissue sarcoma	621	65	10	546	622.2	99.8
X Gonadal/germ cell	347	35	26	286	350.2	99.1
XI Carcinoma/melanoma	329	177	6	146	336.2	97.9
XII Other & unspecified	69	57	3	9	86.1	80.1
I-XII Total (stratified)	9619				9667.0.	99.5

Table 2. Childhood cancer in Great Britain, 2005-2010. Numbers of cases in NRCT by source, capture-recapture estimate of numbers in population (C-R est) and estimated completeness

	Number of cases					
	Total	**CR or DC only**	**PTC only**	**Both**	**C-R est**	**Completeness (%)**
Overall	9297	840	243	8214	9321.8	99.7
Region of residence						
North East	409	12	6	391	409.2	100
North West	1061	66	41	954	1063.8	99.7
Yorks & Humber	803	63	16	724	804.4	99.8
E Midlands	701	58	21	622	703.0	99.7
W Midlands	809	39	24	746	810.3	99.8
East of England	894	68	6	820	894.5	99.9
London	1276	197	35	1044	1282.6	99.5
SE Coast	703	96	9	598	704.4	99.8
South Central	653	67	22	564	655.6	99.6
South West	792	82	25	685	795.0	99.6
Unknown (England)	11	10	0	1	11	100
England	8112	758	205	7149	8133.7	99.7
Wales	478	40	1	437	478.1	100
England & Wales	8590	798	206	7586	8611.7	99.7
Scotland	707	42	37	628	709.5	99.7
Great Britain (stratified)	9297				9321.3	99.7
Year of diagnosis						
2005	1529	137	32	1360	1532.2	99.8
2006	1554	147	38	1369	1558.1	99.7
2007	1462	115	20	1327	1463.7	99.9
2008	1618	140	39	1439	1621.8	99.8
2009	1552	130	45	1377	1556.2	99.7
2010	1582	171	69	1342	1590.8	99.4
2005-2010 (stratified)	9297				9322.9	99.7
Age at diagnosis						
0	881	94	33	754	885.1	99.5
1-4	3347	171	76	3100	3351.2	99.9
5-9	2261	184	54	2023	2265.9	99.8
10-14	2808	391	80	2337	2821.4	99.5
0-14 (stratified)	9297				9323.6	99.7
ICCC-3 group						
I Leukaemia	2825	93	46	2686	2826.6	99.9
II Lymphoma	971	76	32	863	973.8	99.7
III CNS	2435	254	87	2094	2445.5	99.6
IV Neuroblastoma etc	540	10	17	513	540.3	99.9
V Retinoblastoma	254	51	5	198	255.3	99.5
VI Renal	490	6	4	480	490.0	100
VII Hepatic	103	10	0	93	103.0	100

Table 2. Childhood cancer in Great Britain, 2005-2010. Numbers of cases in NRCT by source, capture-recapture estimate of numbers in population (C-R est) and estimated completeness

		Number of cases					
		Total	**CR or DC only**	**PTC only**	**Both**	**C-R est**	**Completeness (%)**
Overall		9297	840	243	8214	9321.8	99.7
	VIII Bone	371	34	7	330	371.7	99.8
	IX Soft-tissue sarcoma	597	59	10	528	598.1	99.8
	X Gonadal/germ cell	334	30	26	278	336.8	99.2
	XI Carcinoma/melanoma	316	168	6	142	323.0	97.8
	XII Other & unspecified	61	49	3	9	75.7	80.6
	I-XII Total (stratified)	9297				9340.0	99.5

References

1. Kroll ME, Murphy MFG, Carpenter LM, Stiller CA: Childhood cancer registration in Britain: capture-recapture estimates of completeness of ascertainment. *British Journal of Cancer* 2011*;* 104 (7): 1227-1233

2. Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P: International Classification of Childhood Cancer, third edition. *Cancer* 2005; 103 (7): 1457-1467

Appendix 1: Childhood classification

This list consists of all malignant ICD-10 codes plus a detailed list of combinations of ICD-10 with ICD-O-3 M-code for the non-malignant[2].

ICD-10 codes included in International Classification of Childhood Cancer, 3rd edition

ICD-10	ICD-O-3 morphology	ICD-O-3 behaviour
C00-C97, D46	Any	Any
D32, D33, D35.2, D35.3, D35.4, D42, D43, D44.3, D44.4, D44.5	8000-8005, 8270-8281, 8291, 8300, 9060-9101, 9350-9352, 9360-9362, 9380-9480, 9492, 9493, 9501-9509, 9530-9539, 9582	0-2

[2] Table 1 illustrated in Appendix 1 is reproduced from the reference "Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P (2005) International Classification of Childhood Cancer, third edition. *Cancer* **103** (7): 1457-1467".

Table 1 International Classification of Childhood Cancer, Third Edition: Main Classification Table				
		ICD-0-3 code(s) [10]		
	Diagnostic Group	**Morphology**		**Topography**
I.	**Leukemias, myeloproliferative diseases, and myelodysplastic diseases**			
	a. Lymphoid leukemias	9820, 9823, 9826, 9827, 9831–9837, 9940, 9948		
	b. Acute myeloid leukemias	9840, 9861, 9866, 9867, 9870–9874, 9891, 9895–9897, 9910, 9920,9931		
	c. Chronic myeloproliferative diseases	9863, 9875, 9876, 9950, 9960–9964		
	d. Myelodysplastic syndrome and other myeloproliferative diseases	9945, 9946, 9975, 9980, 9982–9987, 9989		
	e. Unspecified and other specified leukemias	9800, 9801, 9805, 9860, 9930		
II.	**Lymphomas and reticuloendothelial neoplasms**			
	a. Hodgkin lymphomas	9650–9655, 9659, 9661–9665, 9667		
	b. Non-Hodgkin lymphomas (except Burkitt lymphoma)	9591, 9670, 9671, 9673, 9675, 9678–9680, 9684, 9689–9691, 9695, 9698–9702, 9705, 9708, 9709, 9714, 9716–9719, 9727–9729, 9731–9734, 9760–9762, 9764–9769, 9970		
	c. Burkitt lymphoma 9687	9687		
	d. Miscellaneous lymphoreticular neoplasms	9740–9742, 9750, 9754–9758		
	e. Unspecified lymphomas	9590, 9596		
III.	**CNS and miscellaneous intracranial and intraspinal neoplasms**			
	a. Ependymomas and choroid plexus tumor	9383, 9390–9394[a]		
	b. Astrocytomas	9380[a]		C72.3
	c. Intracranial and intraspinal embryonal tumors	9470–9474, 9480, 9508a 9501–9504[a]		C70.0–C72.9
	d. Other gliomas	9380[a] 9381, 9382, 9430, 9444, 9450, 9451, 9460[a]		C70.0–C72.2, C72.4–C72.9, C75.1, C75.3
	e. Other specified intracranial and intraspinal neoplasms	8270–8281, 8300, 9350–9352, 9360–9362, 9412, 9413, 9492, 9493, 9505–9507, 9530–9539, 9582[a]		
	f. Unspecified intracranial and intraspinal neoplasms	8000–8005[a]		C70.0–C72.9, C75.1–C75.3
IV.	**Neuroblastoma and other**			

Table 1 International Classification of Childhood Cancer, Third Edition: Main Classification Table				
		ICD-0-3 code(s) [10]		
	Diagnostic Group	**Morphology**		**Topography**
	peripheral nervous cell tumors			
	a. Neuroblastoma and ganglioneuroblastoma	9490, 9500		
	b. Other peripheral nervous cell tumors	8680–8683, 8690–8693, 8700, 9520–9523 9501–9504		C00.0–C69.9, C73.9–C76.8, C80.9
V.	**Retinoblastoma**	9510–9514		
VI	**Renal tumors**			
	a. Nephroblastoma and other nonepithelial renal tumors	8959, 8960, 8964–8967 8963, 9364		C64.9
	b. Renal carcinomas	8010–8041, 8050–8075, 8082, 8120–8122, 8130–8141, 8143, 8155, 8190–8201, 8210, 8211, 8221–8231, 8240, 8241, 8244–8246, 8260–8263, 8290, 8310, 8320, 8323, 8401, 8430, 8440, 8480– 8490, 8504, 8510, 8550, 8560–8576 8311, 8312, 8316–8319, 8361		C64.9
	c. Unspecified malignant renal tumors	8000–8005		C64.9
VII.	**Hepatic tumors**			
	a. Hepatoblastoma	8970		
	b. Hepatic carcinomas	8010–8041, 8050–8075, 8082, 8120–8122, 8140, 8141, 8143, 8155, 8190–8201, 8210, 8211, 8230, 8231, 8240, 8241, 8244–8246, 8260–8264, 8310, 8320, 8323, 8401, 8430, 8440, 8480–8490, 8504, 8510, 8550, 8560–8576 8160–8180		C22.0, C22.1
	c. Unspecified malignant hepatic tumors	8000–8005		C22.0, C22.1
VIII.	**Malignant bone tumors**			
	a. Osteosarcomas	9180–9187, 9191–9195, 9200		C40.0–C41.9, C76.0– C76.8,C80.9
	b. Chondrosarcomas	9210, 9220, 9240 9221, 9230, 9241–9243		C40.0–C41.9, C76.0– C76.8,C80
	c. Ewing tumor and related sarcomas of bone	9260 9363–9365		C40.0–C41.9, C76.0–C76.8, C80.9 C40.0–C41.9

Table 1 International Classification of Childhood Cancer, Third Edition: Main Classification Table				
		ICD-0-3 code(s) [10]		
	Diagnostic Group	**Morphology**		**Topography**
	d. Other specified malignant bone tumors	8810, 8811, 8823, 8830 8812, 9250, 9261, 9262, 9270–9275, 9280–9282, 9290, 9300–9302, 9310–9312, 9320–9322, 9330, 9340–9342, 9370–9372		C40.0–C41.9
	e. Unspecified malignant bone tumors	8000–8005, 8800, 8801, 8803–8805		C40.0–C41.9
XI.	**Soft tissue and other extraosseous sarcomas**			
	a. Rhabdomyosarcomas	8900–8905, 8910, 8912, 8920, 8991		
	b. Fibrosarcomas, peripheral nerve sheath tumors, and other fibrous neoplasms	8810, 8811, 8813–8815, 8821, 8823, 8834–8835 8820, 8822, 8824–8827, 9150, 9160, 9491, 9540–9571, 9580		C00.0–C39.9, C44.0–C76.8, C80.9
	c. Kaposi sarcoma	9140		
	d. Other specified soft tissue sarcomas	8587, 8710–8713, 8806, 8831–8833, 8836, 8840–8842, 8850–8858, 8860–8862, 8870, 8880, 8881, 8890–8898, 8921, 8982, 8990, 9040–9044, 9120–9125, 9130–9133, 9135, 9136, 9141, 9142, 9161, 9170–9175, 9231, 9251, 9252, 9373, 9581 8830 8963 9180, 9210, 9220, 9240 9260 9364 9365		 C00.0–C39.9, C44.0–C76.8, C80.9 C00.0–C63.9, C65.9–C69.9, C73.9–C76.8, C80.9 C49.0–C49.9 C00.0–C39.9, C47.0–C75.9 C00.0–C39.9, C47.0–C63.9, C65.9–C69.9, C73.9–C76.8, C80.9 C00.0–C39.9, C47.0–C63.9, C65.9–C76.8, C80.9
	e. Unspecified soft tissue sarcomas	8800–8805		C00.0–C39.9,

Table 1 International Classification of Childhood Cancer, Third Edition: Main Classification Table				
		ICD-0-3 code(s) [10]		
	Diagnostic Group	**Morphology**		**Topography**
				C44.0–C76.8
X.	**Germ cell tumors, trophoblastic tumors, and neoplasms of gonads**			
	a. Intracranial and intraspinal germ cell tumors	9060–9065, 9070–9072, 9080–9085, 9100, 9101[a]		C70.0–C72.9, C75.1–C75.3
	b. Malignant extracranial and extragonadal germ cell tumors	9060–9065, 9070–9072, 9080–9085, 9100–9105		C00.0–C55.9, C57.0–C61.9, C63.0–C69.9, C73.9–C75.0, C75.4–C76.8, C80.9
	c. Malignant gonadal germ cell tumors	9060–9065, 9070–9073, 9080–9085, 9090, 9091, 9100, 9101		C56.9, C62.0–C62.9
	d. Gonadal carcinomas	8010–8041, 8050–8075, 8082, 8120–8122, 8130–8141, 8143, 8190– 8201, 8210, 8211, 8221–8241, 8244–8246, 8260–8263, 8290, 8310, 8313, 8320, 8323, 8380–8384, 8430, 8440, 8480–8490, 8504, 8510, 8550, 8560–8573, 9000, 9014, 9015 8441–8444, 8450, 8451, 8460–8473		C56.9, C62.0–C62.9
	e. Other and unspecified malignant gonadal tumors	8590–8671 8000–8005		C56.9, C62.0–C62.9
XI.	**Other malignant epithelial neoplasms and malignant melanomas**			
	a. Adrenocortical carcinomas	8370–8375		
	b. Thyroid carcinomas	8010–8041, 8050–8075, 8082, 8120–8122, 8130–8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244–8246, 8260–8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8510, 8560–8573 8330–8337, 8340–8347, 8350		C73.9
	c. Nasopharyngeal carcinomas	8010–8041, 8050–8075, 8082, 8083, 8120–8122, 8130–8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244–8246, 8260–8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8500–8576		C11.0–C11.9
	d. Malignant melanomas	8720–8780, 8790		

Table 1 International Classification of Childhood Cancer, Third Edition: Main Classification Table				
		ICD-0-3 code(s) [10]		
	Diagnostic Group	**Morphology**		**Topography**
	e. Skin carcinomas	8010–8041, 8050–8075, 8078, 8082, 8090–8110, 8140, 8143, 8147, 8190, 8200, 8240, 8246, 8247, 8260, 8310, 8320, 8323, 8390–8420, 8430, 8480, 8542, 8560, 8570–8573, 8940, 8941		C44.0-C44.9
	f. Other and unspecified carcinomas	8010–8084, 8120–8157, 8190–8264, 8290, 8310, 8313–8315, 8320–8325, 8360, 8380–8384, 8430–8440, 8452–8454, 8480–8586, 8588–8589, 8940, 8941, 8983, 9000, 9010–9016, 9020, 9030		C00.0–C10.9, C12.9–C21.8, C23.9–C39.9, C48.0–C48.8, C50.0–C55.9, C57.0–C61.9, C63.0–C63.9, C65.9–C72.9, C75.0–C76.8, C80.9
XII.	**Other and unspecified malignant neoplasms**			
	a. Other specified malignant tumors	8930–8936, 8950, 8951, 8971–8981, 9050–9055, 9110 9363		C00.0–C39.9, C47.0–C75.9
	b. Other unspecified malignant tumors	8000–8005		C00.0–C21.8, C23.9–C39.9, C42.0–C55.9, C57.0–C61.9, C63.0–C63.9, C65.9–C69.9, C73.9–C75.0, C75.4–C80.9

Appendix 2: About NCIN

The National Cancer Intelligence Network (NCIN) is a UK-wide partnership operated by Public Health England. The NCIN coordinates and develops analysis and intelligence to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients.

Contact us

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