# National Registry of Childhood Tumours Progress Report, 2010

The material which follows constitutes the first of a series of reports produced by the National Registry of Childhood Tumours (NRCT) for the National Cancer Intelligence Network (NCIN). The report is loosely modelled on the Registry Reports that have been produced in previous years for the Children's Cancer and Leukaemia Group (CCLG, formerly United Kingdom Children's Cancer Study Group, UKCCSG). There is some new, predominantly population-based content. Some other material which was available in previous Registry Reports, notably on patterns of supraregional referral for selected childhood cancers and on patterns of occurrence of multiple neoplasms, has been held back for separate reports to be issued later in the year. The contents of this report follow a scheme that was approved by the NCIN Children, Teenagers and Young Adults Clinical Reference Group (CTYA CRG) in 2010.

The report was written by Charles Stiller, many of the analyses and tabulations were done by Mary Kroll and Nicole Diggens, and data collection was managed by Anita Bayne, all at the Childhood Cancer Research Group (CCRG). We are, as always, very grateful to all those organisations and individuals that have provided information on which the report is based.

# 1. Registration and Follow-up

The NRCT is population-based for cases of cancer diagnosed among children aged under 15 years in Great Britain (England, Scotland and Wales) from 1962 onwards. Since 1993 ascertainment of cases in Northern Ireland has also been virtually complete, hence the NRCT is population-based for the whole of the UK from 1993 onwards. Cases are ascertained from national and regional cancer registries throughout the UK, from specialist children's tumour registries in certain regions of England, from death certificates throughout Great Britain, from entries to clinical trials, and from the paediatric oncology principal treatment centres affiliated to

the CCLG throughout the UK. Registration data are also collected from the CCLG centre in Dublin, thus providing complete coverage of CCLG patients throughout the British Isles. Until the end of 2008, CCLG registrations were sent to the CCLG Data Centre and forwarded to the CCRG. Since the beginning of 2009, they have been sent direct to CCRG.

Table 1.1 shows numbers of registered cases of cancer in the NRCT for children resident in Great Britain at diagnosis from 1962 to 2007, the latest year for which registration is virtually complete. Table 1.2 shows the numbers for the whole of the UK for 1993-2007. The diagnostic categories in Tables 1.1 and 1.2 are the 12 main groups of the International Classification of Childhood Cancer, Third Edition (ICCC-3). The NRCT now contains 63,700 registrations for children with cancer in Great Britain over the 46-year period 1962-2007, and 23,443 registrations for the UK over the 15-year period 1993-2007.

At the time of writing, registration data for over 44,000 CCLG patients aged under 15 at diagnosis and diagnosed during 1977 onwards have been entered into the NRCT database. Throughout this report, numbers of CCLG registrations include registrations for non-malignant neoplasms and allied conditions in addition to those for cancers contained in ICCC-3, except where otherwise stated. Registration of CCLG patients up to 2009 is almost complete, and data for 414 patients diagnosed during 2010 have been added to the database. Table 1.3 shows all registered children under 15 years of age at diagnosis on the database, classified by CCLG centre and year of diagnosis. The centres at Nottingham and Leicester have recently amalgamated to form a single East Midlands centre, and there is close co-operation between GOS and UCLH. Throughout this report, data are shown separately for each of these centres. Table 1.4 shows the same patients classified by detailed diagnostic category and year of diagnosis. Table 1.5(i) shows the numbers of registrations for 2001-2005 by centre and broad diagnostic group. Overall, the two most frequent diagnostic groups were leukaemia (30%) and CNS tumours (22%). A similar pattern was found at most individual centres, but there were several exceptions. At Bart's/Royal London, the equal largest groups were leukaemia and retinoblastoma (36%). CNS tumours outnumbered leukaemia by a considerable margin at Nottingham and less markedly at Newcastle, but were hardly ever registered from Leicester, Bart's/Royal London and Middlesex/UCLH. Bone tumours were the largest group at

Middlesex/UCLH, accounting for 31% of registrations. Table 1.5(ii) shows similar data for 2006-2010. Registration from Bart's/Royal London ceased in 2005. GOS, like Nottingham, had more registrations for CNS tumours than for leukaemia. Otherwise, there was little change from the patterns observed in 2001-2005.

Follow-up information is obtained from matching with population-based death notifications for children dying of neoplasms in Great Britain, from flagging in the NHS Central Registers and (especially for recently diagnosed patients and for those registered in Ireland) from direct enquiry to CCLG centres.

Table 1.1 Numbers of registrations by ICCC-3 main diagnostic group. National Registry of Childhood Tumours, Great Britain, 1962-2007

	1962-2007	1991-2000	2001-2007
Leukaemias, myeloproliferative & myelodysplastic diseases	20806	4723	3359
Lymphomas & reticuloendothelial neoplasms	6566	1423	1108
CNS & miscellaneous intracranial & intraspinal neoplasms	15134	3619	2736
Neuroblastoma & other peripheral nervous cell tumours	4158	896	642
Retinoblastoma	1840	429	292
Renal tumours	3708	805	560
Hepatic tumours	563	138	129
Malignant bone tumours	2743	563	432
Soft tissue & other extarosseous sarcomas	4025	1027	695
Germ cell tumours, trophoblastic tumours & neoplasms of gonads	1929	490	354
Other malignant epithelial neoplasms & malignant melanomas	1870	479	367
Other & unspecified malignant neoplasms	358	98	61
Total	63700	14690	10735

 $Table 1.2\ \ Numbers \ of \ registrations \ by \ ICCC-3\ main\ diagnostic\ group.\ \ National\ Registry\ of\ Childhood\ Tumours,\ United\ Kingdom,\ 1993-2007$ 

	1993-2007	1993-2000	2001-2007
Leukaemias, myeloproliferative & myelodysplastic diseases	7430	3972	3458
Lymphomas & reticuloendothelial neoplasms	2328	1185	1143
CNS & miscellaneous intracranial & intraspinal neoplasms	5901	3081	2820
Neuroblastoma & other peripheral nervous cell tumours	1400	742	658
Retinoblastoma	648	345	303
Renal tumours	1297	669	618
Hepatic tumours	251	116	135
Malignant bone tumours	917	474	443
Soft tissue & other extarosseous sarcomas	1565	854	711
Germ cell tumours, trophoblastic tumours & neoplasms of gonads	764	401	363
Other malignant epithelial neoplasms & malignant melanomas	792	417	375
Other & unspecified malignant neoplasms	150	83	67
Total	23443	12339	11094

## TABLE 1.3 CCLG REGISTRATIONS FOR CHILDREN AGED UNDER 15, BY CENTRE, 1977-2010

# Diag Year

Centre	1977- 1978	1979- 1980	1981- 1982	1983- 1984	1985- 1986	1987- 1988	1989- 1990	1991- 1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Aberdeen	1	3	17	25	21	22	36	24	14	14	15	8	18	21	14	9	11	16	17	15	12	8	10	14	9	1	375
Barts/RLH	56	65	73	78	126	130	146	166	86	75	76	79	79	59	74	67	69	55	51	36	6						1652
Belfast		41	45	55	53	65	78	70	34	35	29	37	37	35	30	33	29	33	49	31	35	35	35	30	40	7	1001
Birmingham	95	160	182	188	221	253	279	301	129	164	170	151	152	161	144	141	140	170	165	191	156	150	175	166	169	28	4401
Bristol	81	101	124	111	123	151	175	146	94	100	123	114	105	99	110	79	86	103	92	89	85	100	97	112	110	11	2721
Cambridge		33	29	39	58	78	96	111	40	49	60	51	66	73	83	65	71	85	82	99	74	112	100	96	122	37	1809
Cardiff	45	57	67	72	59	76	82	81	46	35	53	45	44	56	71	48	57	56	47	33	62	66	54	74	51	18	1455
Dublin		12	81	100	132	139	132	126	92	71	82	69	79	98	91	100	119	115	120	129	99	113	122	128	142		2491
Edinburgh	20	25	24	44	63	64	49	54	37	33	42	36	53	42	44	47	51	68	49	58	47	44	39	53	44	8	1138
Glasgow	69	76	75	118	111	111	130	125	68	72	63	53	64	63	60	46	62	61	61	68	63	56	64	86	72	17	1914
GOS	203	235	309	306	275	281	257	296	180	201	193	188	210	155	187	157	146	213	176	183	180	196	201	219	176	47	5370
Leeds	84	109	109	108	129	150	169	183	85	102	98	90	91	107	90	97	108	108	92	88	81	96	88	88	88	15	2653
Leicester			18	39	51	31	49	36	20	21	23	19	15	21	15	28	23	26	20	30	23	32	27	23	21	13	624
Liverpool	70	94	76	88	101	99	116	124	70	71	76	89	70	77	85	77	84	100	84	108	90	80	83	82	78	29	2201
Manchester	131	183	177	185	158	183	173	182	129	100	124	120	122	97	122	111	134	117	136	104	120	112	102	120	103	27	3372
Middlesex/UCLH						1	4	23	25	25	25	24	32	46	36	40	30	36	40	44	43	28	39	42	42	14	639
Newcastle	55	104	109	110	119	124	120	134	68	60	69	78	78	71	73	80	91	90	71	85	85	92	65	82	70	15	2198
Nottingham	28	23	60	47	65	77	90	94	48	43	61	47	49	72	65	76	62	52	59	60	45	73	50	67	75	22	1510
Oxford				1	2	1	4	32	39	51	45	52	49	56	57	57	56	55	68	70	72	67	73	70	54	24	1055
Royal Marsden	71	99	83	90	80	113	113	129	57	58	70	83	83	111	90	116	109	125	84	88	128	109	111	151	148	38	2537
Sheffield	65	76	77	61	80	80	85	83	41	45	45	50	50	51	58	59	63	69	58	48	55	62	67	49	56	17	1550
Southampton	13	52	59	56	61	77	92	125	77	52	53	74	70	70	62	59	68	68	73	67	76	62	68	74	69	26	1703
Total	1087	1548	1794	1921	2088	2306	2475	2645	1479	1477	1595	1557	1616	1641	1661	1592	1669	1821	1694	1724	1637	1693	1670	1826	1739	414	44369

## TABLE 1.4 CCLG REGISTRATIONS FOR CHILDREN AGED UNDER 15, BY DIAGNOSTIC GROUP, 1977-2010

## Diag Year

DiagGpText	1977- 1978	1979- 1980	1981- 1982	1983- 1984	1985- 1986	1987- 1988	1989- 1990	1991- 1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Precursor-cell ALL	332	485	531	570	576	631	695	711	389	374	378	379	377	427	389	377	369	454	393	427	397	403	370	412	430	128	11404
Mature B-cell leukaemia		7	6	11	14	6	5	16	5	6	5	5	5	5	5	5	8	7	3	2	1	2	2	2	1	1	135
AML	76	86	107	101	127	125	135	120	76	79	68	81	75	66	85	69	74	81	88	81	70	76	71	75	86	17	2195
CML	4	7	5	10	15	7	15	5	3	5	5	6	13	4	6	7	4	8	13	6	3	10	13	5	5		184
MDS	1		3	1	3	6	9	21	7	4	10	12	8	15	11	5	9	11	3	4	6	3	8	5	5		170
JMML/CMML	2	4	8	6	10	7	8	10	5	2	2	6	9	4	12	6	7	5	9	10	15	4	5	6	4	1	167
Other and unspecified leukaemia	5	5	6	3	6	5	8	4	2	3	6	2	7	5	3		3	5	3	5	4	4	2	5	3	1	105
Hodgkin lymphoma	58	78	90	84	110	72	74	105	47	48	65	57	61	59	64	69	82	100	55	84	81	79	70	80	77	12	1861
NHL	84	115	111	118	132	152	154	162	78	75	93	74	92	103	93	91	79	100	73	83	82	89	82	99	83	16	2513
Other lymphoreticular	5	10	6	3	2	2	3	2			1				1			2		1	1	1					40
Ependymoma	15	19	20	27	23	32	38	35	26	23	31	22	29	32	27	31	27	31	30	32	22	27	36	36	30	5	706
Choroid plexus tumours	2		3	7	2	6	8	10	7	13	7	10	12	6	10	10	10	8	10	12	13	12	9	12	10	4	213
Low-grade astrocytoma	33	58	32	60	86	86	115	133	104	102	127	109	129	128	132	130	166	126	129	127	140	140	144	140	132	35	2843
High-grade astrocytoma	6	11	8	20	17	27	38	48	19	29	34	28	25	26	25	19	22	28	30	23	33	18	22	25	16	9	606
Unspecified astrocytoma	11	2	13	8	9	9	7	18	16	11	6	2	3	4		3	5	6	1	2	1	2	3	4	17	3	166
Medulloblastoma	42	58	65	71	59	66	73	98	43	57	48	52	51	54	56	49	51	64	60	62	54	62	50	46	52	14	1457
Other embryonal CNS		1	4	7	14	25	33	35	16	15	18	18	18	22	25	18	22	20	15	15	22	30	12	20	30	8	463
Other glioma	23	25	24	37	38	40	56	53	17	29	36	30	35	39	37	40	45	35	40	42	26	49	48	43	44	10	941
Pituitary adenoma and carcinoma		1	1				2	2		1	4		1		2	2	2	2	4	3	3	6	3	5	1	1	46
Craniopharyngioma	10	6	5	4	9	10	13	22	8	20	20	21	14	18	18	20	13	19	17	21	19	20	17	27	17	2	390
Pineal parenchymal tumours	6	3	6	5	4	6	3	3	3	6	2	2	5	6	5	4	4	4	4	7	6	6	5	2	3	1	111
Neuronal and neuronal-glial tumours	1	1	2	1	1	3	3	8	6	15	12	14	23	16	15	20	11	19	9	20	31	28	16	27	13	4	319
Meningioma	1	2	2		1	2	4	7	4	5	3	3	4	8		1	2	1	4	3	3	6	1	8	4		79
Unspecified CNS tumours	8	4	8	3	7	3	5	5	4	3	13	2	5	7	6	3	4	8	8	10	9	6	14	13	13		171
Neuroblastoma	71	106	162	151	149	210	211	195	89	87	92	101	97	103	110	78	106	106	122	88	104	81	100	94	102	15	2930
Other malignant peripheral nerve cell		2	2	2	1	3	1	2			2		1	2		3	1	1	1	2		2	2			1	31
Retinoblastoma	5	13	14	42	66	74	75	92	63	46	39	36	43	31	35	42	35	52	42	43	33	41	46	38	42	8	1096
Wilms Tumour	77	97	111	132	130	158	164	148	79	91	66	85	89	82	67	81	91	97	86	87	83	77	81	83	76	28	2446
Rhabdoid renal tumour		2	6	4	3	4	3	5	1	2	1	4	4	2	3	1	3	4	5	5	3	5	4	1	2	2	79
Renal sarcomas	1	3	3	6	6	9	3	4	2	3	2	2	4	2	3	5	4	5	4	2	3	4	2	5	6		93
Renal pPNET							1	1		2	2		2			1	2	3	1	1			1				17
Renal carcinoma	1	3	1	3		3	1	3		5	1	4			1	2	1	1		4	3	2	1	5	4		49
Unspecified malignant renal							1				1																2
Hepatoblastoma	11	8	15	13	15	19	14	21	17	10	8	16	13	9	9	15	20	16	19	16	15	22	19	11	14	4	369
Hepatic carcinoma	2	2	3	6	2	7	4	3	2	2	2	2	2	2	5	2	1	2	2	7	2		4	3			69
Unspecified malignant hepatic																		1									1
Osteosarcoma	12	36	42	33	38	42	35	39	36	30	47	36	30	28	34	32	34	44	35	28	33	36	29	54	32	8	883
Chondrosarcoma	1	1	1	1	3		1	1			1	1		1	1	2	1	1	1								18
ESFT of bone	17	49	43	50	43	45	48	45	21	19	27	24	20	21	27	25	37	31	42	27	19	29	22	27	20	4	782
Other malignant bone	4	3	3	4	4	1	2	1	2	1	3		3	2	3	1	3	1	3	1	3		1	2			51
Rhabdomyosarcoma	46	82	100	111	117	124	118	129	78	56	62	65	55	51	58	55	44	52	71	65	60	38	54	54	62	14	1821
Fibrosarcoma, etc.	4	2	15	4	9	7	8	8		4	3	1	5	1	3	4	4	1	1	5	3	4	1	8	6	3	114

#### TABLE 1.4 CCLG REGISTRATIONS FOR CHILDREN AGED UNDER 15, BY DIAGNOSTIC GROUP, 1977-2010

#### Diag Year

DiagGpText	1977- 1978	1979- 1980	1981- 1982	1983- 1984	1985- 1986	1987- 1988	1989- 1990	1991- 1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
MPNST	1	1	2	3	1	3	5	5	1	2	6	3	4	3	6	2	3	1	5	4	2	2	3	3	2	1	74
Kaposi sarcoma	1												1										3				5
Extraosseous ESFT	2	7	4	8	10	15	20	29	15	15	16	14	22	17	13	15	21	19	18	19	10	15	11	16	16	2	369
Extrarenal rhabdoid tumour					2	2	3	3	1	5	3	4	2		3		2		2	1	3	3	6	8	10	3	66
Fibrohistiocytic sarcomas	1	1	5		1	3	3	2	2	2	1			2	2	1	2	3		1				3	3	1	39
Synovial sarcoma		3	2	2	3	6	5	6	7	5	9	1	5	6	9	5	5	7	4	8	4	8	7	7	7	1	132
Other specified soft-tissue sarcomas	5	9	4	6	6	9	6	10	4	9	11	3	7	1	4	8	11	7	4	7	4	10	5	7	2		159
Unspecified soft-tissue sarcoma	8	8	2	11	6	11	11	6	3	3	9	6	10	3	5	4	9	6	6	7	5	3	8	8	4	1	163
Intracranial & intraspinal germ cell tumours	6	10	9	9	16	9	12	35	12	17	9	20	9	11	18	16	17	14	19	17	12	16	22	13	16	5	369
Other malignant extragonadal germ cell tumours	11	8	18	10	11	26	24	14	15	7	9	13	7	12	12	12	14	15	11	15	17	17	13	16	15	5	347
Gonadal germ cell tumours	18	23	27	30	46	37	26	26	17	18	26	21	22	14	21	22	20	14	12	14	16	18	24	24	18	4	558
Other malignant gonadal tumours			2	1	3	5	2			1		1			1	1	1		1			2	2	2	1		26
Adrenocortical carcinoma	4	3	4	3	3	1	1	6	1	1	2	2	2	4	2	5	7	1	3	2	1	3	1		1		63
Thyroid carcinoma	1	4	1	3	4	4	4	3	2	1	2	7	2	7	5	7	13	6	6	9	11	8	11	10	10		141
Nasopharyngeal carcinoma	4	6	7	5	5	5	1	7	2	1	3	4	2	3	3	3	1		5	4	1	5	4	2	3		86
Malignant melanoma	2	6	2	4	3	4	1	7	7	3	7	4	3	3	7	4	3	9	3	6	3	4	5	5	3		108
Skin carcinoma	1	1	1		1					2			1	2		1			1		2	1	1				15
Other carcinomas	5	2	7	9	4	10	8	4	6	5	6	9	6	7	5	6	4	8	1	8	5	5	6	7	4	2	149
Pancreatoblastoma				2	1						1	1	2					1				1					9
Pleuropulmonary blastoma								1		1		2		1	3	1		4		3		3	1	3	3		26
Other specified malignant				1				2	1				1	1	1		1				1						9
Unspecified malignant	2	1	5	3	2	4	4		1					1	1	1		1	1		1				1		29
Lymphoproliferative disease									1		4	3	3	3	4	4	3	3	4	3	4		1	3	1		44
LCH single system	10	15	20	22	27	26	30	33	19	28	23	30	38	27	28	32	25	37	30	24	33	30	34	39	4		664
LCH multi system	10	13	26	20	17	21	19	18	13	4	5	6	11	10	9	8	7	8	3	9	3	3	2	12	8		265
LCH unspecified	2		2			4	1				4	2			1			2		4	4	1	3	4	31	4	69
HLH	3	2		2	3	2	6	6	8	4	9	5	10	5	14	4	5	6	13	6	11	18	10	14	14	1	181
Ganglioneuroma	1	1	3	7	7	6	13	10	7	1	7	3	6	10	7	12	10	5	11	5	9	5	4	10	11	1	172
Other non-malignant peripheral nervous cell			3	1	1	3	5	2	2	1	3	4	6	5	2		2	2	4	3	1	2	3	1	4	1	61
Non-malignant embryonal renal	2	6	7	11	6	5	5	6	5	7	6	4	3	7	6	4	3	6	7	4	5	9	11	5	7	3	150
Non-malignant bone		1	1	1	5	3	3	3	2	2	2	2	1	1	5	1	3	1	5	2	4	1	2	4	6	1	62
Fibromatosis			1	4	3	4	6	7	8	2	3	6	10	4	5	7	5	6	10	5	4	4	3	10	5	3	125
NF & neurofibromatosis		3	4	3	4	13	8	9	2	9	11	6	5	11	12	7	8	7	11	7	1	9	10	12	5	1	178
Other non-malignant soft-tissue	3	3	8	4	12	9	8	13	10	12	8	6	11	22	14	19	11	14	11	17	17	19	29	34	23	8	345
Non-CNS non-gonadal non-malignant germ cell	5	10	17	8	13	10	13	17	17	10	16	16	7	13	15	18	13	18	13	18	10	13	25	18	22	1	356
Gonadal non-malignant germ-cell	1	1	6	4	7	6	17	12	3	10	12	15	14	13	15	16	18	11	20	14	12	17	12	21	14	1	292
Other non-malignant gonadal	1		2	2		2	3	5	4	3	4	8	4	4	8	5	6	4	7	5	4	6	8	7	6	4	112
Adrenocortical adenoma		2	2	2			1	2	1	1	2	3	3	1	3	1		3	2	2	3	2	2	2	2	1	43
Other non-malignant		1	3	1	4	4	7	6	5	2	3	11	7	16	6	12	10	10	5	8	8	6	8	14	14		171
Total	1087	1548	1794	1921	2088	2306	2475	2645	1479	1477	1595	1557	1616	1641	1661	1592	1669	1821	1694	1724	1637	1693	1670	1826	1738	414	44368

# TABLE 1.5(i) CCLG REGISTRATIONS FOR CHILDREN AGED UNDER 15, BY CENTRE AND DIAGNOSTIC GROUP, 2001-2005

Centre	Leukaemia	Lymphomas	CNS	SNS	Retino- blastoma	Renal	Hepatic	Bone	Soft tissue sarcoma	Germ-cell etc	Epithelial	Other malignant	Other non- malignant	Total
Aberdeen	25	5	11	7		4		3	6	2	1		7	71
Barts/RLH	79	18	3	9	79	11	2	2	3	3	4		4	217
Belfast	56	21	36	9	2	20	3	7	12	3	1	1	6	177
Birmingham	242	64	163	40	79	41	11	25	45	25	17		70	822
Bristol	122	43	108	29	2	33	5	15	24	15	11	2	46	455
Cambridge	128	39	108	23	4	23	3	11	30	12	4	1	25	411
Cardiff	80	22	57	13	2	12	1	8	19	9	2	2	28	255
Dublin	184	65	87	50	7	39	11	32	46	11	4	2	44	582
Edinburgh	77	27	64	18	3	15		10	24	9	1		25	273
GOS	271	42	233	83		60	16	6	44	23	8	1	111	898
Glasgow	112	39	56	18	2	12	4	16	34	4	2	1	15	315
Leeds	144	61	100	25	4	19	5	20	23	15	8		53	477
Leicester	50	12	1	16	1	12		6	8	4		1	11	122
Liverpool	153	41	126	20	1	22	6	13	22	8	3		51	466
Manchester	182	52	135	32	3	40	6	30	37	16	13	1	64	611
Middlesex/UCLH	55	40	4	4		5	1	59	13	3	4		5	193
Newcastle	115	42	120	25	5	17	6	15	29	13	9		26	422
Nottingham	67	34	100	13		7	1	9	13	5	3	1	25	278
Oxford	100	25	88	24		22	1	11	20	6	6		18	321
Royal Marsden	152	73	141	36		40	9	16	26	18	10		13	534
Sheffield	81	26	68	15	11	18	4	14	12	12	7		25	293
Southampton	113	32	68	22		26	6	16	26	13	5		25	352
Total	2588	823	1877	531	205	498	101	344	516	229	123	13	697	8545

# TABLE 1.5(ii) CCLG REGISTRATIONS FOR CHILDREN AGED UNDER 15, BY CENTRE AND DIAGNOSTIC GROUP, 2006-2010

Centre	Leukaemia	Lymphomas	CNS	SNS	Retino- blastoma	Renal	Hepatic	Bone	Soft tissue sarcoma	Germ-cell etc	Epithelial	Other malignant	Other non- malignant	Total
Aberdeen	11	4	8	6		4	1	1	2	1		1	3	42
Belfast	44	23	30	8	7	7	2	6	11	5	2		2	147
Birmingham	194	49	140	24	84	33	6	21	38	20	10	1	68	688
Bristol	117	34	99	29	4	20	5	20	37	18	9		38	430
Cambridge	135	40	96	25	5	24	1	9	27	24	8	1	72	467
Cardiff	88	16	72	12	1	11	2	7	22	3	6		23	263
Dublin	159	42	114	37	13	33	7	11	34	15	3	2	35	505
Edinburgh	61	10	53	8	1	11	1	5	7	3	2		26	188
GOS	221	60	229	59	9	59	11	2	40	27	3	1	118	839
Glasgow	96	22	58	18	5	13	4	13	22	8	2		34	295
Leeds	108	40	75	28	2	15	6	19	22	15	4		41	375
Leicester	56	11	6	7	3	5		5	9		1		13	116
Liverpool	93	33	90	20	10	13	3	14	20	14	3	1	38	352
Manchester	136	48	93	26	5	21	6	20	31	14	7		57	464
Middlesex/UCLH	29	32	14					46	16	9	9		10	165
Newcastle	89	30	89	20	2	15	2	13	19	10	7		28	324
Nottingham	70	37	92	8	3	23	5	7	14	10	3	1	14	287
Oxford	88	30	77	13	7	12	1	7	8	11	4		30	288
Royal Marsden	190	67	136	28		36	6	14	29	13	10	3	24	556
Sheffield	77	32	55	10	3	15	2	8	11	4	4		30	251
Southampton	103	28	52	11	11	19	6	16	14	9	4	1	25	299
Total	2165	688	1678	397	175	389	77	264	433	233	101	12	729	7341

### 2. Patterns of Referral to CCLG Centres

The National Registry of Childhood Tumours receives copies of all notifications to cancer registries in the UK for children aged under 15 at diagnosis. By linking these records with the CCLG (formerly UKCCSG) Register the proportion of children initially referred to CCLG centres can be estimated as the proportion notified by cancer registration who have also been registered at diagnosis with the CCLG. Children who are in the CCLG Register but have not yet been notified through the cancer registration scheme cannot be included in these calculations as the number of non-CCLG patients who have also not been notified by cancer registration is unknown. Ascertainment by the Northern Ireland Cancer Registry is considered to be virtually complete only for 1993 onwards. Therefore, for continuity between calendar periods, the analyses of national data in Tables 2.1 and 2.2 refer to Great Britain only.

#### Analysis by diagnostic group and age at diagnosis in Great Britain

Table 2.1 shows the estimated proportions of children aged under 15 in the principal diagnostic groups who were registered with UKCCSG/CCLG during successive calendar periods. By 2003-2007, 90% of children with cancer were initially referred to a CCLG centre. Between the 1980s and 1990s there was a marked increase in percentage referred for CNS tumours and bone sarcomas. The only main diagnostic groups with a referral rate below 75% were epithelial tumours (two thirds of which were melanomas and carcinomas of the thyroid and skin) and the small and heterogeneous group of other and unspecified tumours.

Table 2.2 shows the estimated proportions referred by age group during successive calendar periods. The referral rate has always been relatively low for children aged 10 years and above, and especially for those aged 13-14, but the gap has diminished.

#### Analysis by country and region of residence in the UK

Table 2.3 shows the estimated proportions of children referred by region of domicile. In England, the classification is by Strategic Health Authorities — In the most recent years, at least 80% of children in every English region, Wales, Scotland and Northern Ireland were referred to UKCCSG/CCLG centres. The referral rate in Northern Ireland was considerably lower until recently, largely because referral of children with CNS tumours was only 11% in 1993-97 and 23% in 1998-2002, but this proportion increased dramatically to 64% in 2003-07.

#### Langerhans cell histiocytosis

LCH is not routinely registered by cancer registries. A recent study from the BPSU, CCLG and Newcastle University estimated incidence per million child years in the UK and Ireland as 9.9 at age 0, 4.8 at age 1-4, 4.5 at age 5-9 and 1.8 at age 10-14 [Salotti et al., 2009]. Table 2.4 shows numbers of cases of LCH initially referred to a UKCCSG/CCLG centre in successive calendar periods with estimates of the referral rate based on expected numbers derived by applying the rates from this study to the child population of Great Britain. The estimated percentage of children with LCH who were referred to a UKCCSG/CCLG centre rose from 38% in 1978-82 to around 80% in 1998 onwards.

#### Referral by centre and region of residence

Table 2.5 shows the regions of residence for children registered at each centre during 1978-92, 1993-97, 1998-2002, 2003-2007 and 2008-2010. The great majority of children were treated at centres within their region of residence or an adjoining region. Referral patterns within South East England (London and South East Coast) have been complex but children have usually been referred to one of the London centres. In recent years, a higher proportion of patients at GOS have been London residents and there has been a shift from GOS to Royal Marsden as the main referral centre for the South East Coast. Referral patterns in the current decade for the much smaller geographical areas covered by Cancer Networks in England and Wales and by

Health Boards in Scotland are discussed below. The main exception to the broadly regional pattern of referral relates to retinoblastoma, for which supra-regional referral has applied to a large proportion of patients for many years. Recent patterns for retinoblastoma will be discussed in a forthcoming special report.

#### Referral by Cancer Network (England and Wales)

Since 2001, England has been covered by Cancer Networks, numbering 32 at the end of 2009, whose areas are each comprised of those of several Primary Care Trusts. A further three Cancer Networks cover Wales. Table 7 shows the CCLG centres from which children resident in each Cancer Network area were registered during 2001-2009. Retinoblastoma is excluded from this table because many children are registered from the two supraregional referral centres for this tumour. Results are presented separately for the periods 2001-2004 and 2005-2009 since 2004 was the final year in which any non-retinoblastoma patients were registered from Barts/RLH. Fifteen of the 32 English Networks and all three Welsh Networks had at least 85% of their registrations from a single centre in both periods. More complicated referral patterns were seen in the remaining English Networks, predominantly in a large area of southern England including much of East Anglia, but also in the Severn valley and Humber and Yorkshire coast areas.

In 2005-2009 there were a number of changes in referral from 2001-2004, many of which were direct, or presumed indirect, consequences of the cessation of paediatric oncology at Barts/RLH. In 2001-2004, Barts/RLH accounted for 44% of referrals in North East London and 6-13% of those in West London, North London, Mid Anglia and South Essex. In 2005-2009, those components of referral seem largely to have moved to GOS in North East and North London, to UCLH in South Essex and to Cambridge in Mid Anglia. For West London, GOS and UCLH both saw increases in registrations while registration of children from this Network ceased not only at Barts/RLH but also at Royal Marsden. The increase in referrals to GOS from the Networks mentioned above was offset by reductions in referrals from Norfolk & Waveney and West Anglia (with corresponding increase to Cambridge) and from Kent & Medway and Sussex (with increases mainly at Royal Marsden). In Sussex, a

reduction in referral to Southampton was also balanced by an increase at Royal Marsden.

In the Three Counties (Herefordshire, Worcestershire, Gloucestershire) Network there was a sizeable increase in the proportion of children referred to Bristol and a corresponding decrease in the proportion referred to Birmingham. This was entirely due to changes in the relative frequencies of children who were resident in the five Primary Care Trusts (PCTs) of this network, and there was no evidence of change in referral pattern by PCT. Smaller changes in other Networks could also be explained by variation in the relative frequencies of children diagnosed from individual PCTs.

#### Referral by Health Board (Scotland)

Table 2.7 shows CCLG centre of non-retinoblastoma registrations by Health Board for 2001-2009. As in the analysis of referral by Cancer Network, centres with fewer than 5% of the registrations for a Health Board are not shown. Most Health Boards had at least 85% of their registrations at a single centre. The exceptions were Central (Forth Valley), Dumfries and Galloway, and three Health Boards in the north of the country, Highland, Orkney and Shetland.

#### **Irish Republic**

Individual cancer registration records are not received from the Irish Republic. Table 2.8 shows estimated referral rates for 1994-2000 based on published data from the National Cancer Registry of Ireland (Stack *et al*, 2007). Referral rates were lower than in the UK overall and for several diagnostic groups, notably leukaemia, CNS tumours and retinoblastoma.

Table 2.9 shows CCLG registrations for 2001-2007. The annual number of registrations was 107 compared with 77 in 1994-2000. The size of the population at risk was similar during the two periods. The annual numbers of CCLG patients in 2001-2007 and cancer registrations in 1994-2000 were very similar for leukaemias, lymphomas and bone tumours. There were more CCLG registrations than cancer registrations for several diagnostic groups, notably SNS tumours (nearly all of which

are neuroblastoma), renal tumours, hepatic tumours and soft tissue sarcomas, indicating increased incidence for these groups. For CNS tumours, retinoblastoma, germ-cell and gonadal tumours, epithelial tumours and other and unspecified tumours, the annual number of CCLG patients in 2001-2007 was lower than the annual number of cancer registrations in 1994-2000, suggesting that incidence has decreased or referral to CCLG was incomplete.

Table 2.1 Percentages of children aged under 15 with cancer or non-malignant CNS tumour initially referred to UKCCSG/CCLG, classified by diagnostic group. Great Britain 1978-2007

**Diagnostic Group** 

Year of diagnosis

		1978-82	1983-87	1988-92	1993-97	1998-2002	2003-2007
I	Leukaemia	70	81	86	92	93	95
	Lymphoid	71	83	88	92	95	97
	AML	72	81	87	97	96	95
	CML	43	66	68	69	77	92
	JMML/CMML	65	100	100	100	97	97
	Myelodysplasia	-	-	78	68	66	52
	Other & unspecified	43	31	39	61	76	72
II	Lymphomas	70	79	84	90	91	91
	Hodgkin lymphoma	63	72	77	89	92	96
	NHL & other lymphoma	75	84	89	92	91	87
III	CNS etc	31	40	54	76	86	88
	Choroid plexus tumours	15	46	61	89	89	95
	Ependymoma	28	44	57	82	92	92
	Astrocytoma	26	40	53	79	88	90
	Embryonal	49	54	70	87	97	96
	Other gliomas	31	38	54	76	92	92
	Craniopharyngioma	22	15	40	67	84	90
	Other CNS	26	20	24	49	54	67
IV	SNS etc	80	93	95	98	98	97
	Neuroblastoma	81	93	95	99	98	98
V	Retinoblastoma	11	68	83	94	92	91
VI	Renal tumours	76	91	92	96	98	98
	Wilms' tumour etc	76	91	93	97	99	99
	Renal carcinoma	-	-	-	77	-	73
VII	Hepatic tumours	67	75	82	96	93	97
	Hepatoblastoma	73	83	91	98	97	100
	Hepatic carcinoma	45	56	63	-	75	88
VIII	Bone tumours	48	65	65	90	93	94
	Osteosarcoma	42	57	56	91	94	95
	Ewing sarcoma of bone	59	79	84	94	97	98
	All other malignant bone	33	37	23	53	63	47

<sup>-</sup> Fewer than 10 children with cancer registrations in this category

Table 2.1 (continued)

# Diagnostic group

# Year of diagnosis

		1978-82	1983-87	1988-92	1993-97	1998-2002	2003-2007
IX	Soft tissue sarcomas	67	82	84	88	88	87
	Rhabdomyosarcoma	77	91	94	98	97	98
	Fibrosarcoma etc	51	51	62	60	73	69
	Extraosseous ESFT	85	89	90	96	99	97
	Synovial sarcoma	33	60	75	78	82	76
	All other specified	48	53	55	66	59	61
	Unspecified	42	74	71	78	75	78
X	Germ-cell and gonadal	50	63	71	84	87	84
	CNS germ-cell	39	35	63	88	84	96
	Other non-gonadal germ cell	70	94	82	84	92	81
	Malignant gonadal germ-cell	50	76	75	82	86	78
	All other malignant gonadal	-	21	50	-	-	-
XI	Epithelial	27	19	23	27	40	42
	Adrenocortical Carcinoma	77	42	-	-	100	-
	Thyroid carcinoma	21	19	36	37	55	65
	Nasopharyngeal Carcinoma	58	86	58	92	-	95
	Malignant melanoma	10	6	10	13	33	27
	Skin carcinoma	9	2	0	5	4	6
	Other carcinoma	29	24	28	33	38	41
XII	Other & unspecified	37	41	16	14	36	15
	Total	57	69	76	86	90	90

<sup>-</sup> Fewer than 10 children with cancer registrations in this category.

Table 2.2 Percentages of children with cancer or non-malignant CNS tumour initially referred to UKCCSG/CCLG, classified by age at diagnosis, Great Britain 1978-2007

# Year of diagnosis

Age at diagnosis	1978-82	1983-87	1988-92	1993-97	1998-2002	2003-2007
0-9	62	74	81	89	92	92
10-12	55	63	67	79	87	85
13-14	35	46	50	68	77	83
Total	57	69	76	86	90	90

Table 2.3 Percentages of children in the UK with cancer or non-malignant CNS tumour initially referred to UKCCSG/CCLG, classified by country of domicile, and Strategic Health Authority (SHA) within England, 1978-2007

Region	1978-82	1983-87	1988-92	1993-97	1998-2002	2003-2007
North East	72	81	87	92	95	96
North West	78	79	82	91	95	93
Yorks & Humber	70	74	88	91	95	92
East Midlands	47	75	82	88	92	92
West Midlands	55	75	83	92	95	95
East of England	57	65	74	89	92	91
London	50	59	62	81	85	88
South East Coast	53	64	68	81	88	86
South Central	39	46	57	79	88	88
South West	51	64	77	85	87	86
England	58	68	76	87	91	90
Wales	60	59	76	76	83	84
England & Wales	58	68	76	86	90	90
Scotland	42	74	75	83	87	91
Great Britain	57	69	76	86	90	90
N Ireland				60	61	77
UK				85	89	90

Table 2.4 Expected numbers of incident cases of children with LCH and estimated percentage initially referred to UKCCSG/CCLG, Great Britain 1978-2007

Expected numbers are based on the incidence rates given by Salotti JA, Nanduri V, Pearce MS, Parker L, Lynn R, Windebank KP. Incidence and clinical features of Langerhans cell histiocytosis in the UK and Ireland. Arch Dis Child. 2009;94:376-80

			Year	of diagnosis		
	1978-82	1983-87	1988-92	1993-97	1998-2002	2003-2007
Expected	220	210	217	221	215	208
UKCCSG/CCLG (%)	84 (38)	95 (45)	109 (50)	166 (75)	175 (81)	166 (80)

# Table 2.5(i) Region of residence by centre for children in CCLG Register 1978-1992

				т													г г	
Centre	North East	North West	Yorks/ Humber	East Midlands	West Midlands	East Anglia	London	South East Coast	South Central	South West	Wales	Scotland	Northern Ireland	Channel Islands	Isle of Man	Ireland	BFPO	Total
Aberdeen		! !!		<u> </u>					! !	! !	<u> </u>	148	,					148
Barts/RLH	8	38	24	1 29	14	201	241	106	79	27	19	8	12	2	<u> </u>	7	5	820
Belfast		1							  1	 			405	,				407
Birmingham	1	6	,	68	1536	3	2	1	5	5	18	, 1	1		<u> </u>	1		1648
Bristol		 		1	3		1	<u> </u>	7	960	4	,	<u> </u>	2		1	3	982
Cambridge				16	,	417			4								1	438
Cardiff		1							 	1	526	,						528
Dublin		! 	<u> </u>	<u> </u>			<u> </u>		I	! !						722		722
Edinburgh	2			<u> </u>				<u> </u>	! !	' '	'	335	,		<u> </u>	<u> </u>	2	340
Glasgow		ļ!	1	<u>.                                     </u>	1	<u> </u>	1		<u> </u>	<u> </u>	<u> </u>	788	,			2	1	794
GOS		2	2	2 40	) 2	575	770	460	155	33	<u> </u>	1	!	10		1	31	2082
Leeds	8	6	987	7 4	1	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>				1	1006
Leicester		ļ!	<u> </u>	221	1	1	<u> </u>		<u> </u>	<u> </u>	<u> </u>	1	<u> </u>					224
Liverpool		565	5 1	<u>.                                     </u>	3	<u> </u>	<u> </u>		<u> </u>	<u> </u>	145		<u> </u>		22		2	738
Manchester		1279	6	5 27	2	'	2	<u> </u>	_   <u> </u>	'	4		<u> </u>					1321
Middlesex/UCLH		<u> </u>		1	<u> </u>	7	15	5	<u> </u>	<u>                                     </u>	<u> </u>	<u> </u>	<u> </u>					28
Newcastle	755	104	12	<u> </u> 1	<u> </u>	<u> </u>		<u> </u>	<u> </u>	<u> </u>	<u> </u>	3	,					875
Nottingham		ļ!	6	469	1	1		1	<u> </u>	<u> </u>	<u> </u>							478
Oxford		ļ!	<u> </u>	3	3 1	<u> </u>	<u> </u>		35	1	<u> </u>	<u> </u>	<u> </u>					40
Royal Marsden		1	1	1 6	5 5	23	296	312	88	13	2	. 1		1		11	1	761
Sheffield		ļ!	446	5 141	<u> </u>	<u> </u>		<u> </u>	<u> </u>	<u> </u>	<u> </u>	1					2	590
Southampton		ļ!	<u> </u>	<u> </u> '	1	1	1	16	364	131	<u> </u>	<u> </u>	<u> </u>	17			4	535
Total	774	2004	1486	1027	1570	1229	1329	901	739	1171	718	1287	418	32	22	745	53	15505

Table 2.5(ii) Region of residence by centre for children in CCLG Register 1993-1997

Centre	North	North	Yorks/	East	West	East	London	South East	South	South	Wales	Scotland	Northern	Channel	Isle of	Ireland	BFPO	Total
Contro	East	West	Humber	Midlands	Midlands	Anglia	London	Coast	Central	West	vvaico	Occiland	Ireland	Islands	Man	ITOIGITG	ВПО	Total
Aberdeen												68	1					69
Barts/RLH	4	27	11	16	6	78	151	51	17	14	10	3	5	1		1		395
Belfast													172					172
Birmingham		5	1	50	692		1			4	12		1					766
Bristol					5				3	522	3	1					2	536
Cambridge			1	9		250	1		2									263
Cardiff									1		221						1	223
Dublin																393		393
Edinburgh												200					1	201
Glasgow												320						320
GOS	1	1	5	5		263	471	181	25	7	2	1	2	4			4	972
Leeds	1	1	462														2	466
Leicester				98														98
Liverpool		297			4				1	1	68				5			376
Manchester		573	4	11	5						2							595
Middlesex/UCLH				1		35	69	21	2	2							1	131
Newcastle	324	25	2									2						353
Nottingham			1	238	6	2											1	248
Oxford				15	6	10			190	15								236
Royal Marsden						4	137	179	27	2	1					1		351
Sheffield			189	42														231
Southampton						1	1	18	211	84				7			4	326
Total	330	929	676	485	724	643	831	450	479	651	319	595	181	12	5	395	16	7721

# Table 2.5(iii) Region of residence by centre for children in CCLG Register 1998-2002

				ı	1		1			1	r	1	1				1	
Centre	North East	North West	Yorks/ Humber	East Midlands	West Midlands	East Anglia	London	South East Coast	South Central	South West	Wales	Scotland	Northern Ireland	Channel Islands	Isle of Man	Ireland	BFPO	Total
Aberdeen							1					70						71
Barts/RLH	4	9	8	8	3	52	176	23	14	13	4	7	3					324
Belfast													160					160
Birmingham	3	9	5	43	666	1	2	1	3	7	12	3	1					756
Bristol					3					471	1	1						476
Cambridge				11		364												375
Cardiff	1				1			1			285							288
Dublin																523		523
Edinburgh												252						252
Glasgow												292						292
GOS		1	3	1	3	221	450	141	14	7	3	2		9		1	1	857
Leeds	1	7	501														1	510
Leicester				106	5	2												113
Liverpool		328		1	4				1		82				7			423
Manchester		554	4	17	2	1	1	1		1								581
Middlesex/UCLH				5		48	104	21	8	1				1				188
Newcastle	352	44	8														1	405
Nottingham			3	306	16	2												327
Oxford				25	7	3	1		224	21								281
Royal Marsden				2		5	220	302	21	1								551
Sheffield		1	240	59														300
Southampton								49	191	83				4				327
Total	361	953	772	584	710	699	955	539	476	605	387	627	164	14	7	524	3	8380

# Table 2.5(iv) Region of residence by centre for children in CCLG Register 2003-2007

						T						_		<del> </del>			_	1
Centre	North East	North West	Yorks/ Humber	East Midlands	West Midlands	East Anglia	London	South East Coast	South Central	South West	Wales	Scotland	Northern Ireland	Channel Islands	Isle of Man	Ireland	BFPO	Total
Aberdeen		'	<u> </u>			<u> </u>	'	<u> </u>	'	'		62			<u> </u>	<u> </u>	<u> </u>	62
Barts/RLH		4	1 2	2 1	<u>,                                    </u>	14	54	8	4	3	. 1	1	1		<u> </u>	'		93
Belfast		<u></u>	<u> </u>	<u> </u>		<u> </u>	1	<u></u> '		<u> </u>	<u> </u>	<u> </u> '	184					185
Birmingham	11	17	7	62	2 693	3 4	1 1	<u> </u>	4	8	17	12			<u> </u>	1		837
Bristol		<u></u>	<u> </u>	<u> </u>	6	1	<u> </u>	1		455	!	<u> </u>		<u> </u>	<u> </u>			463
Cambridge		I	<u> </u>	14	<u> </u>	445	5 2	2 2			<u> </u>	<u> </u>		<u> </u>		<u> </u>	<u> </u>	464
Cardiff	1	<u></u>	<u> </u>	<u> </u>		<u> </u>	'	<u></u> '		2	259			<u> </u>	<u> </u>			262
Dublin		I	<u> </u>				<u> </u>	<u> </u>				<u> </u>				582		583
Edinburgh	1	I	<u> </u>			<u> </u>	'	<u> </u>	'		<u> </u>	236	,	<u> </u>		<u> </u>	<u> </u>	237
Glasgow		<u> </u>	<u> </u>	<u> </u>		<u> </u>	<u> </u>	<u> </u>	l	<u> </u>		311						312
GOS		2	2 2	2 3	<u>3</u> 1	207	579	122	11	<u> </u>	1	2	2 2	. 1	<u> </u>	3	<u> </u>	936
Leeds	1	2	2 437	7 2	<u>,</u>	1	<u> </u>	<u> </u>	<u> </u>	<u> </u>		<u> </u>	]		<u> </u>	<u> </u>	1	444
Leicester		<sup> </sup>	<u> </u>	121	1 7	3	<u>                                     </u>	1	'	<u> </u> '	!	<u>                                     </u>		<u> </u>	<u> </u>	<u> </u>		132
Liverpool		339	4	<u> </u>	6	<u> </u>	<u> </u> '	<u> </u>	<u> </u>	<u> </u>	86	<u> </u>		<u> </u>	13	<u> </u>	1	445
Manchester		560	4	9	9 3	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	2	<u> </u>		<u> </u>	<u> </u>	<u> </u>	<u> </u>	574
Middlesex/UCLH		<u></u> -	<u> </u>	<u> </u>	<u> </u>	42	126	3 21	4	1	<u> </u>	<u> </u> '	<u> </u>	<u> </u> '	<u> </u>	<u>                                     </u>	<u>                                     </u>	194
Newcastle	348	40	<u> </u> 7	<u> </u>	1	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>		1		<u> </u>	<u> </u>	<u> </u>	1	398
Nottingham		<u></u> '	<u> </u>	270	0 17	<u> </u>	<u>                                     </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u> '	<u> </u>	<u> </u> '	<u> </u>	<u>                                     </u>	<u>                                     </u>	287
Oxford		<u> </u>	<u> </u>	19	9 3	5	5 5	<u> </u>	282	35		<u> </u>	]		<u> </u>	<u> </u>	1	350
Royal Marsden		<u> </u>	<u> </u>	<u> </u>		2	184	304	30	<u> </u> '	<u> </u>	<u> </u>		<u> </u>	<u> </u>	<u> </u>	<u> </u>	520
Sheffield	1	<u> </u>	223	63	3 1	1	<u> </u>	<u> </u>	1	<u> </u>	<u> </u>	<u> </u>	<u> </u>		<u> </u>			290
Southampton		<u> </u>	<u> </u>	<u> </u>		<u> </u>	1	23	208	103		<u> </u>	<u> </u>	11	<u> </u>			346
Total	363	964	678	564	4 738	726	953	482	546	607	366	625	187	12	13	586	, 4	8414

# Table 2.5(v) Region of residence by centre for children in CCLG Register 2008-2010

					т——		·	,			ı.			1		i .		
Centre	North East	North West	Yorks/ Humber	East Midlands	West Midlands	East Anglia	London	South East Coast	South Central	South West	Wales	Scotland	Northern Ireland	Channel Islands	Isle of Man	Ireland	BFPO	Total
Aberdeen			'			'						24						24
Barts/RLH		<u> </u>	<u>      </u> '	<u> </u>		<u>      </u> '												
Belfast		ļ	<u>                                     </u>	<u> </u>		<u>                                     </u>							76					76
Birmingham	2	9	12	2 27	295	<u> </u>			4	1	9	3					1	363
Bristol		ļ	<u> </u>	<u> </u>		<u> </u>				232	1							233
Cambridge		ļ	<u> </u>	3	1	245	2											251
Cardiff		ļ	<u> </u>	<u> </u>		<u> </u>					143							143
Dublin		ļ	<u> </u>	<u> </u>		<u> </u>										270		270
Edinburgh		ļ	<u> </u>	<u> </u>		<u> </u>				1		104						105
Glasgow		ļ	<u> </u>	<u> </u>		<u> </u>						175						175
GOS		1		3	1	112	272	39	7	2	1	1	1	1				442
Leeds		1	189	,		<u> </u>	1											191
Leicester		<u> </u>	<u> </u>	50	5	1	1											57
Liverpool		123	<u> </u>	1	7	<u> </u>					52				4	2		189
Manchester		241	3	3 4	1	<u> </u>			1									250
Middlesex/UCLH		<u> </u>	<u>                                     </u>	<u> </u>		32	50	15	1									98
Newcastle	148	15	3	<u>,                                      </u>		<u> </u>						1						167
Nottingham		ļ	1	155	8	<u>                                     </u>												164
Oxford		<u> </u>	<u> </u>	3	,	5	5		116	19								148
Royal Marsden		<u> </u>	<u> </u>	<u> </u>		5	124	199	9									337
Sheffield		]	96	25	1	<u>                                     </u>												122
Southampton		<u> </u>	<u> </u>			<u> </u>		9	98	47				15				169
Total	150	390	305	271	319	400	455	262	236	302	206	308	77	16	4	272	1	3974

Table 2.6 CCLG registrations for all diagnoses except retinoblastoma by Cancer Network and CCLG centre, 2001-2004 and 2005-2009. For each combination of Network and period, the percentage of referrals is shown for all centres with at least 5% of that Network's registrations during the period.

Cancer Network	Centre	% of regi	
		2001-2004	2005-2009
Lancashire & South Cumbria	Manchester	86	91
	Liverpool	10	7
Greater Manchester & Cheshire	Manchester	91	91
	Liverpool	8	8
Merseyside & Cheshire	Liverpool	98	99
North of England	Newcastle	98	97
Yorkshire	Leeds	98	97
Humber & Yorkshire Coast	Leeds	70	75
	Sheffield	28	24
North Trent	Sheffield	93	95
Greater Midlands	Birmingham	93	90
	Nottingham		5
Pan Birmingham	Birmingham	98	98
Arden (Warwickshire)	Birmingham	91	93
	Leicester	6	
East Midlands	Nottingham	84	86
	Sheffield	5	6
	Cambridge		5
Derby & Burton	Nottingham	80	83
	Birmingham	16	16
Leics, Northants & Rutland	Leicester	48	58
	Birmingham	22	23
	Nottingham	16	13
	Oxford	10	5
Norfolk & Waveney	Cambridge	90	97
	GOS	7	
West Anglia	Cambridge	75	84
	GOS	18	11
Mid Anglia	Cambridge	55	66
	GOS	28	25
	Barts/RLH	11	
	UCLH		6
Essex	GOS	74	69
	Barts/RLH	13	
	UCLH	12	23
Mount Vernon (Beds, Herts)	GOS	52	49
	Cambridge	36	38
	UCLH	11	10

Cancer Network	Centre	% of regi	strations
		2001-2004	2005-2008
West London	GOS	72	81
	UCLH	11	14
	R Marsden	10	
	Barts/RLH	6	
North London	GOS	70	83
	UCLH	23	14
	Barts/RLH	7	
NE London	Barts/RLH	44	
	GOS	41	84
	UCLH	14	14
SE London	GOS	48	40
	R Marsden	34	51
	UCLH	14	8
SW London	R Marsden	64	72
	GOS	30	24
Peninsula (Devon, Cornwall)	Bristol	99	99
Dorset	Southampton	95	96
Avon, Somerset & Wilts	Bristol	88	86
	Oxford	9	12
Three Counties (Herefs, Worcs, Gloucs)	Birmingham	51	40
	Bristol	45	54
Thames Valley	Oxford	91	91
Central South Coast	Southampton	94	95
Surrey, W Sussex & Hants	R Marsden	71	78
	GOS	19	17
	Southampton	6	
Sussex	R Marsden	62	81
	GOS	24	15
	Southampton	9	
Kent & Medway	R Marsden	49	62
	GOS	43	25
	UCLH		11
North Wales	Liverpool	99	98
Mid & West Wales	Cardiff	90	90
	Birmingham	10	8
SE Wales	Cardiff	98	98

Table 2.7 CCLG registrations for all diagnoses except retinoblastoma by Scottish Health Board and CCLG centre, 2001-2009. For each Health Board, the percentage of referrals is shown for all centres with at least 5% of that Board's registrations.

Health Board	Centres	% of registrations
Highland	Glasgow	72
	Edinburgh	15
	Aberdeen	13
Grampian	Aberdeen	89
	Edinburgh	6
Tayside	Edinburgh	99
Fife	Edinburgh	100
Lothian	Edinburgh	99
Borders	Edinburgh	95
Central (Forth Valley)	Glasgow	71
	Edinburgh	28
Argyll & Clyde	Glasgow	99
Greater Glasgow	Glasgow	100
Lanark	Glasgow	95
Ayrshire & Arran	Glasgow	100
Dumfries & Galloway	Glasgow	82
	Edinburgh	14
Orkney	Aberdeen	50
	Glasgow	25
	Edinburgh	25
Shetland	Aberdeen	80
	Edinburgh	20
Western Isles	Glasgow	100

Table 2.8 Childhood cancer in the Irish Republic 1994-2000

Total registrations are derived from Stack M, Walsh PM, Comber H, Ryan CA, O'Lorcain P. Childhood cancer in Ireland: a population-based study. Arch Dis Child 2007; 92:890-897

Diagnostic group	Total registrations	UKCCSG registrations	Estimated referral rate (%)
Leukaemia	237	156	66
Lymphoma	90	77	86
CNS tumours	215	119	55
SNS tumours	37	31	84
Retinoblastoma	16	6	38
Renal tumours	36	36	100
Hepatic tumours	4	3	75
Bone tumours	37	32	86
Soft-tissue sarcomas	50	45	90
Germ-cell & gonadal	27	20	74
Epithelial	27	11	41
Other & unspecified	11	2	18
Total	787	538	68

Table 2.9 Childhood cancer in the Irish Republic 2001-2007

Total numbers of children initially referred to a UKCCSG/CCLG centre 2001-2007, with 1994-2000 annual average UKCCSG referrals and total cancer registrations for comparison

Diagnostic group	UKCCS	SG/CCLG	UKCCSG	Cancer
	2001 Total	1-2007 Annual	1994-2000 Annual	registrations 1994-2000 Annual
Leukaemia	247	35.3	22.3	33.9
Lymphoma	82	11.7	11.0	12.9
CNS tumours	139	19.9	17.0	30.7
SNS tumours	66	9.4	4.4	5.3
Retinoblastoma	11	1.6	0.9	2.3
Renal tumours	53	7.6	5.1	5.1
Hepatic tumours	15	2.1	0.4	0.6
Bone tumours	39	5.6	4.6	5.3
Soft-tissue sarcomas	66	9.4	6.4	7.1
Germ-cell & gonadal	22	3.1	2.9	3.9
Epithelial	5	0.7	1.6	3.9
Other & unspecified	3	0.4	0.3	1.6
Total	745	106.9	76.9	112.4

## 3. Survival

#### Population-based survival 1973-2007

Table 3.1 and Figures 3.1-3.11 present population-based survival rates for all childhood cancers and for each of Groups I-X in ICCC-3. The results are for children diagnosed during 1973-2007 and included in the National Registry of Childhood Tumours. Most survivors have been followed up until the end of August 2010. Cases ascertained by death certificate only have been excluded.

Overall and for all diagnostic groups, the trend in survival by year of diagnosis was highly significant (p<0.0001). The largest percentage-point increase in five-year survival compared with the previous period for all cancers combined was in 1978-82. The largest such increase for lymphomas, neuroblastoma etc, retinoblastoma, renal tumours and soft tissue sarcoma were also in 1978-82. The largest increases were in 1983-87 for leukaemias and bone tumours, in 1988-92 for germ-cell and gonadal tumours and in 1993-97 for CNS tumours and hepatic tumours. The predominance of earlier calendar periods in those comparisons is quite largely accounted by the fact that as survival rates increased over time there was much less room for further large increases.

An alternative way of comparing changes in survival between successive periods is to calculate the reduction in the risk of death within 5 years from diagnosis as a percentage of the risk for the previous period. For all cancers combined the largest reduction in the risk of death was in 1983-87 compared with 1978-82; the probability of death within five years for children diagnosed in 1983-87 was 0.365, a reduction of 21% from the probability of 0.463 in 1978-82. Among individual broad diagnostic groups, the largest percentage reductions in mortality were in 1978-82 for lymphoma (34%), neuroblastoma etc (20%) and soft-tissue sarcomas (21%), in 1983-87 for bone tumours (27%), in 1988-92 for germ-cell and gonadal tumours (41%), in 1993-97 for CNS tumours (28%), retinoblastoma (43%) and hepatic tumours (47%) and in 2003-07 for leukaemia (27%). The largest reduction for renal tumours was in 1998-2002 (37%), but this was followed by a rise of 34% in 2003-07, and the overall percentage decrease in the risk of death within 5 years from diagnosis between 1993-97 and

2003-07 was 15%. These fluctuations, however, are based on rather small numbers of deaths and the five-year survival rate remained well above 80%.

#### Survival of CCLG Patients 1978-2008

Tables 3.2-3.4 and Figures 3.12-3.126 present survival data for all CCLG patients registered at diagnosis throughout the UK and Ireland.

Table 3.2 gives five-year survival rates with the results of a test for trend for diagnostic groups with at least 50 registrations. For most of those with at least 150 registrations, survival rates are shown for five periods of diagnosis (1978-87, 1988-92, 1993-97, 1998-2002, 2003-2008) while for the remainder they are shown for two periods (1978-97, 1998-2008). Table 3.3 gives overall five-year survival rates for selected smaller diagnostic groups and also for dysembryoplastic neuroepithelial tumour, for which there were more than 50 registrations but nearly all since 1996. Survival graphs are shown for all patients with a malignant neoplasm or non-malignant CNS tumour (Figure 3.12) and for each of the diagnostic groups in Tables 3.2 and 3.3 (Figures 3.13-3.39, 3.46-3.93). There were significant increases in survival rates for a wide range of diagnostic groups. In many instances, the greatest improvements took place in the 1980s but more recently there have been substantial improvements in survival for children with acute leukaemia, ependymoma, neuroblastoma and hepatoblastoma.

Survival has also been analysed in relation to primary site for selected groups of CNS tumours (Table 3.4). Survival curves for children with astrocytoma, glioma or unspecified tumour in the brain stem are shown in figures 3.40-3.43. The survival rate for low-grade astrocytoma increased significantly over the study period but there was little evidence of improvement for high grade astrocytoma and other tumours in the same site. Figures 3.44 and 3.45 show survival curves for the two main types of spinal cord tumour, ependymoma and astrocytoma. Survival from spinal cord ependymoma increased significantly over time.

For selected diagnostic groups, survival rates have also been calculated for children diagnosed during calendar periods roughly corresponding to the periods of entry to

successive trials. The results relate to all children diagnosed during a given period, not just those who were actually entered. The survival graphs for these are shown in Figures 3.94-3.126.

Results for ALL are presented separately according to Down syndrome status and age at diagnosis. Infants aged under one year, who have a markedly worse prognosis than older children, were excluded from some UKALL trials and since 1992 have had their own study protocols. Down syndrome is an adverse prognostic factor in ALL, and Down's children have sometimes been less likely to be entered in national trials.

Among non-Down's children with precursor-cell ALL, survival of infants remained fairly constant throughout 1978-88. Survival increased successively thereafter and in 1999-2005, the era of the INTERFANT 99 trial, five-year survival exceeded 50% for the first time.

Survival of older non-Down's children with ALL increased with each successive trial period. The increase in survival was rather small between 1991-96 and 1997-99 (eras of UKALL XI and ALL 97), but this was followed by a larger increase in 2000-02 (era of ALL 97/99). One-year survival reached 96% in the era of UKALL XI and has remained at that level; the more recent increases in overall survival since then are the result of continuing decreases in subsequent mortality among one-year survivors. In 2003 onwards, the era of ALL2003, five-year survival was over 90%.

Children with Down syndrome and ALL have also experienced a substantial increase in survival rates. There was an especially large improvement in 1991-96 (era of UKALL XI) compared with previous years, when the gap between Down's and non-Down's children was greatly narrowed. In 1997-2002 (era of ALL97 and ALL 97/99), the survival rate decreased again. This was entirely due to a substantial fall in one-year survival from 92% in 1991-96 to 68% in 1997-2002. The increase in subsequent survival among patients who had survived one year that was achieved in the era of UKALL XI was maintained. In 2003-08 (era of ALL 2003) one-year survival increased to 85% and five-year survival was 69%.

At the start of the study period, the outlook for children with mature B-cell leukaemia was very poor, with fewer than a quarter surviving five years. Between the periods of the second and third series of NHL studies, five-year survival increased dramatically from 40% to 69%. Five-year survival during 1996-2008 was 76%.

For AML, survival has also been analysed separately for children with and without Down syndrome. Among non-Down's children, survival increased with each successive study period during 1983-2008. Survival of Down's children has also increased, but for this group there was no change before 1988. During 1988-94 (era of AML 10), survival was still lower than for non-Down's patients, but during 1995-2002 (AML 12), Down's children had the better prognosis, with five-year survival of 74% compared with 61% for non-Down's children. This improvement was maintained during 2003-08, with five-year survival reaching 81%. From the mid 1990s onwards, Down syndrome children with AML have had a markedly better outcome than those with ALL.

Five-year survival for Hodgkin lymphoma was already over 90% at the start of the first UKCCSG study; there have only been small increases since then. Separate protocols for T-cell and B-cell NHL were used throughout the study period. Survival for T-NHL rose between the eras of the first and second series of NHL studies but then showed no consistent pattern until 2004-2008 (era of the 2004/08 trial), when three-year survival was 91% compared with 72-79% for children diagnosed throughout the previous 19 years. Survival from B-NHL increased with each successive trial period. Survival from anaplastic large cell lymphoma has been significantly higher since 1998, when specific trials for this subtype of NHL began.

Young age at diagnosis is an adverse factor for ependymoma. From 1992, children under 3 years of age were eligible for the infant brain tumour study, and survival since then was higher than previously. Survival of older children with ependymoma has also increased, but less markedly.

Survival from low-grade astrocytoma was higher during the era of LGG-1 (1997-2003) than previously. There has so far been no further increase since the start of LGG-2 in 2004.

Young age at diagnosis is also an adverse factor for medulloblastoma and other PNET, and in the 1990s special protocols were available for the treatment of children aged under 3 years. Before then, some younger children – though no infants aged under a year – were included in trials where most patients were older. There has been no straightforward trend in survival for the 0-2 year age group. For older children, survival was lower in the mid to late 1980s than it was in the era of the first UKCCSG Brain Tumour Study. Survival increased in the 1990s with PNET-3, but has so far remained similar since the start of PNET-4. Survival was higher during the three years between the end of PNET-3 and the start of PNET-4 but the difference was non-significant.

Age is also an important prognostic factor in neuroblastoma, with infants aged under a year having a much higher survival rate than children aged 1 year and over, and entry to most trials has been limited to one or the other of these age groups. Survival of infants in the era of ENSG8 was hardly different from earlier years, but has increased since the start of the 1999 03 study; five-year survival rose from 80% to 90% between the two trial periods. For children aged 1-14 years survival in the period of ENSG1 and 3 (1982-1989) was higher than previously. Survival increased further since then and five-year survival has reached 53% in the era of the current high-risk neuroblastoma trial.

Survival from Wilms' tumour showed a steady increase between successive trial eras. In the era of the current SIOP trial (2002 onwards) the risk of death within one year from diagnosis was 3.4%, a one-third reduction from the one-year mortality rate of 5.2% in the preceding era (UKW-3 trial, 1992-2001). There is no evidence of any increase in survival from rhabdoid renal tumour or renal clear cell sarcoma during the entire study period.

Survival rates for hepatoblastoma during SIOPEL-1 were substantially higher than before but there was no further increase in the period of SIOPEL-2. Survival has increased again since the opening of SIOPEL-3, with five year survival reaching 82%. There was no sign of a trend in survival rates for hepatic carcinoma.

For osteosarcoma, five-year survival during the MRC trial era ending in 1982 was 39%. Throughout the period 1983-2004, five-year survival fluctuated between 54% and 60%. There was a further increase to 71% in the era of the EURAMOS trial from 2005 onwards. Survival rates for Ewing sarcoma were markedly higher during the era of the second UKCCSG study but have shown no change since then. For rhabdomyosarcoma there was little sign of a trend during 1978-88, with five-year survival of 53-58%. Survival during the eras of MMT-89, MMT-95 and RMS 2005 has been higher (64-68% at five years), but with only small increases between successive periods.

There was a major change in the chemotherapy protocol for germ-cell tumours part way through the period of entry to the first UKCCSG study. Survival rates for gonadal and other extracranial tumours increased sharply at the time of this change. Since the start of the second study there has been a further improvement in survival for ovarian and extragonadal tumours. Survival from intracranial germinoma and other types of CNS germ-cell tumours increased substantially since the opening of the SIOP study in 1997.

Five-year survival from single-system Langerhans cell histiocytosis (LCH) was already 95% during 1978-90, before the first LCH trial opened, but has increased still further since then. There was little change in survival from multi-system LCH between 1978-90 and the era of the second trial, ending in 2001. So far, no deaths have been recorded among children diagnosed during 2002-2008, the era of the third trial. For haemophagocytic lymphohistiocytosis (HLH) five-year survival increased from 14% during 1978-94, before the start of HLH-94, to 34% during the era of HLH-94. Survival increased further since then, to 55% in the most recent period.

Table 3.1 Population-based survival of children with cancer in Great Britain diagnosed 1973-2007 by period of diagnosis

Five-year actuarial survival (%)

Diagnostic group	1973-1977	1978-1982	1983-1987	1988-1992	1993-1997	1998-2002	2003-2007	$X^{2}$ (1df) for trend
Leukaemias	40	51	63	72	76	80	86	1923***
Lymphomas	50	67	77	84	85	87	89	475.0***
CNS tumours	43	49	57	58	70	72	71	606.5***
Neuroblastoma etc	20	37	40	44	55	63	64	359.1***
Retinoblastoma	85	90	92	95	97	98	98	47.9***
Renal tumours	68	75	81	81	81	88	84	64.8***
Hepatic tumours	20	24	30	43	70	68	70	81.8***
Bone tumours	31	32	50	60	64	59	67	171.3***
Soft tissue sarcomas	41	53	60	60	67	66	67	107.5***
Germ cell & gonadal tumours	56	65	74	85	85	89	92	137.8***
All cancers	44	54	63	68	75	77	80	3544***

<sup>\*\*\*</sup>p<0.001

Table 3.2 Survival of CCLG patients diagnosed 1978-2008 by period of diagnosis. In the test for trend, brackets around the X<sup>2</sup> value indicate a negative trend. Results for certain diagnostic subgroups, mainly 'other and unspecified', whose composition may have changed over the years are printed in italics.

#### Five-year actuarial survival (%)

Diagnostic Group	1978-87	1988-92	1993-97	1998-2002	2003-2008	1978-97	1998-2008	X <sup>2</sup> (1df) for trend
Precursor ALL	66	79	81	85	90			563.0***
Mature B-cell leukaemia						51	76	29.2***
AML	28	49	58	64	69			226.8***
CML	36	43	64	86	90			38.6***
Myelodysplasia	29	42	50	61	68			11.8***
JMML & CMML	6	32	38	38	67			40.5***
Other & unspecified leukaemia						41	68	18.9***
Hodgkin lymphoma	91	94	93	95	94			9.35**
NHL	65	77	79	83	88			104.2***
Ependymoma	44	43	68	64	68			16.3***
Choroid plexus papilloma						82	97	17.4***
Choroid plexus carcinoma						28	22	(0.10)
Low grade astrocytoma	83	83	93	93	94			42.7***
High grade astrocytoma	22	23	19	14	12			(3.98)*
Unspec. Astrocytoma						48	60	(0.47)
Medulloblastoma	53	47	61	67	63			22.0***
Other PNET	29	34	29	36	39			3.50
ATRT						20	21	(0.03)
Oligodendroglioma						65	59	(1.04)
Other glioma	25	26	32	41	42			17.1***

Diagnostic Group	1978-87	1988-92	1993-97	1998-2002	2003-2008	1978-97	1998-2008	$X^2$ (1df) for trend
Craniopharyngioma	90	91	95	95	94			1.28
Pineoblastoma						31	35	5.51*
Ganglioglioma						83	90	1.52
Meningioma						74	94	9.48*
Unspecified CNS						48	38	(0.68)
Neuroblastoma	38	45	55	61	65			157.3***
Retinoblastoma bilateral	90	93	96	100	99			14.2***
Retinoblastoma unilateral	90	96	97	97	98			8.73**
Wilms tumour	82	81	85	92	91			32.1***
Rhabdoid renal tumour						26	16	(1.01)
Renal clear cell sarcoma						80	77	(0.49)
Hepatoblastoma	40	56	71	83	81			43.3***
Hepatic carcinoma						26	16	(0.05)
Osteosarcoma	47	57	58	52	67			13.0***
Ewing sarcoma of bone	42	68	66	64	63			22.9***
Rhabdomyosarcoma	57	59	66	70	65			24.1***
MPNST						32	56	3.28
Other fibrosarcoma etc						71	94	16.0***
Extraosseous ESFT	53	45	63	52	70			5.91*
Synovial sarcoma						81	78	0.25
Other specified soft tissue sarcoma	65	<i>79</i>	67	57	55			(1.85)
Unspecified soft-tissue sarcoma						38	46	0.18
Intracranial & intra-spinal germinoma	70	83	85	88	91			7.14*
Other CNS germ-cell						45	75	13.8***
Other malig. extra-gonadal germ-cell	55	89	76	88	90			30.4***
Gonadal malig. germ-cell	91	97	96	97	98			20.4***
Adrenocortical carcinoma						23	69	16.5***
Thyroid carcinoma, non-medullary						100	99	-

Diagnostic Group	1978-87	1988-92	1993-97	1998-2002	2003-2008	1978-97	1998-2008	X <sup>2</sup> (1df) for trend
Nasopharyngeal carcinoma						68	93	6.94**
Malignant melanoma						50	60	2.58
Misc. other carcinoma						51	50	0.47
LCH single system	93	99	98	99	99			8.68**
LCH multi system	67	71	74	79	100			9.26**
HLH						17	50	26.8***
Ganglioneuroma						100	99	-
Mesoblastic nephroma						98	98	-
Fibromatosis						90	98	1.90
Misc non-malig soft tissue	94	100	95	99	95			(0.00)
Other non-gonadal non-malig. germ-cell	96	97	98	99	99			1.29
Gonadal non-malig. germ-cell	100	100	98	100	100			-
Other non-malignant gonadal						97	94	(0.03)

<sup>\*</sup> P<0.05

<sup>\*\*</sup> P<0.01

<sup>\*\*\*</sup> P<0.001

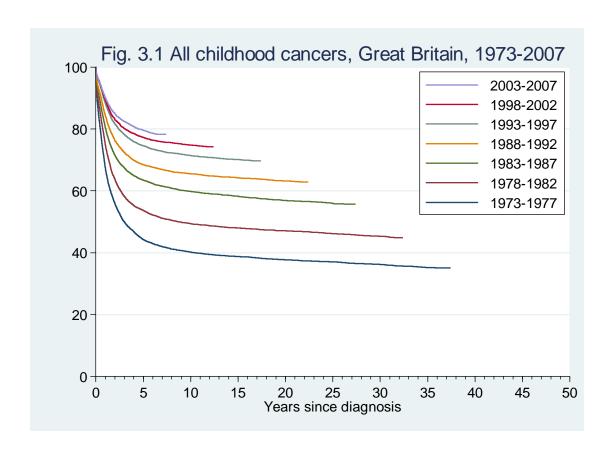
## Table 3.3 Survival of CCLG patients diagnosed 1978-2008

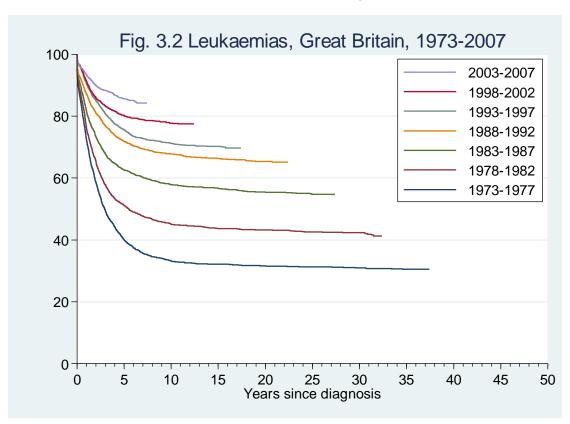
Diagnostic group	Five-year actuarial survival %
Pinealoma & Pineocytoma	78
DNET	99
Renal PNET	27
Renal carcinoma	64
Chondrosarcoma	47
Extrarenal rhabdoid tumour	23
Leiomyosarcoma	84
Other malignant gonadal tumours	52
Thyroid carcinoma, medullary	95
Salivary gland carcinoma	93
Colorectal carcinoma	17
Pleuropulmonary blastoma	78
Lymphoproliferative disease	66
Adrenocortical adenoma	100

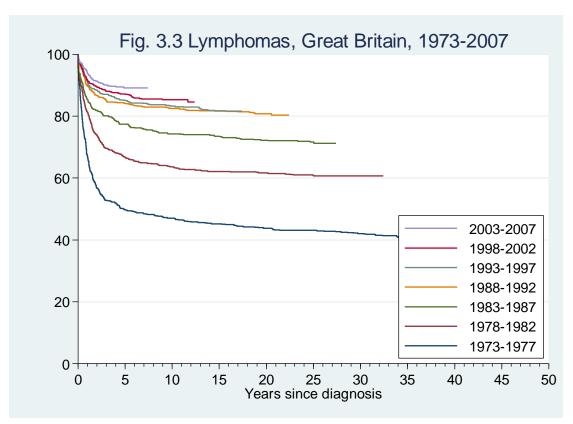
Table 3.4 Survival of CCLG patients diagnosed 1978-2008 with selected CNS tumours. Note that these results relate to patients also included in Table 3.2.

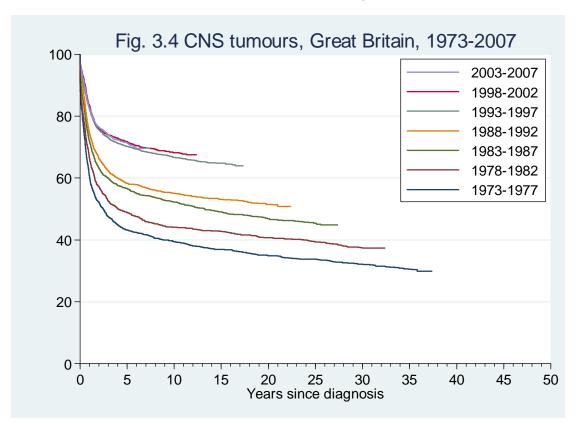
### Five-year actuarial survival (%)

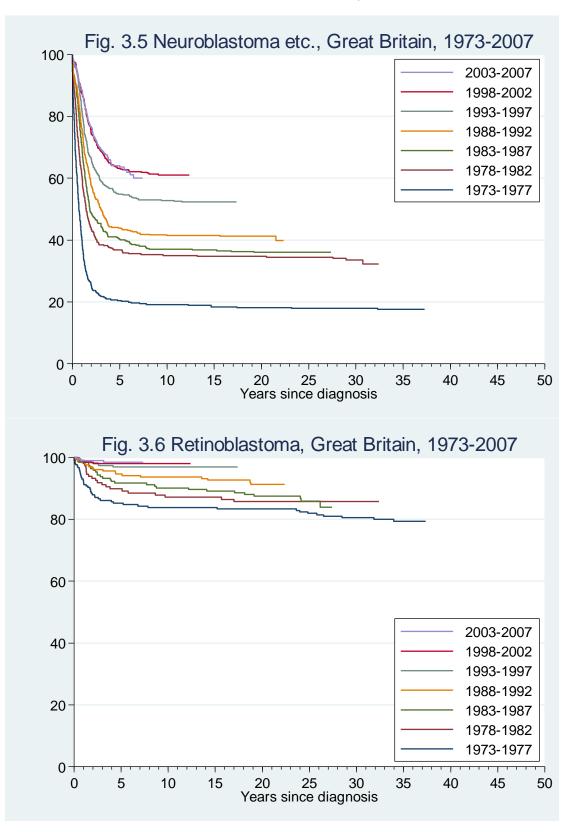
Diagnostic group		1978-87	1988-92	1993-97	1998-2002	2003-2008	1978-97	1998-2008	$X^{2}$ (1df) for trend
(i)	Astrocytoma, glioma or unspecified tumour of brain stem								
	Total	17	16	26	34	27			4.95*
	Low-grade astrocytoma	38	40	64	85	74			15.8***
	High-grade astrocytoma						6	0	(0.13)
	Unspec astrocytoma, other glioma & unspecified	14	14	18	23	18			0.12
(ii)	Spinal cord								
	Ependymoma						91	100	7.09*
	Astrocytoma	60	71	81	81	70			(0.30)

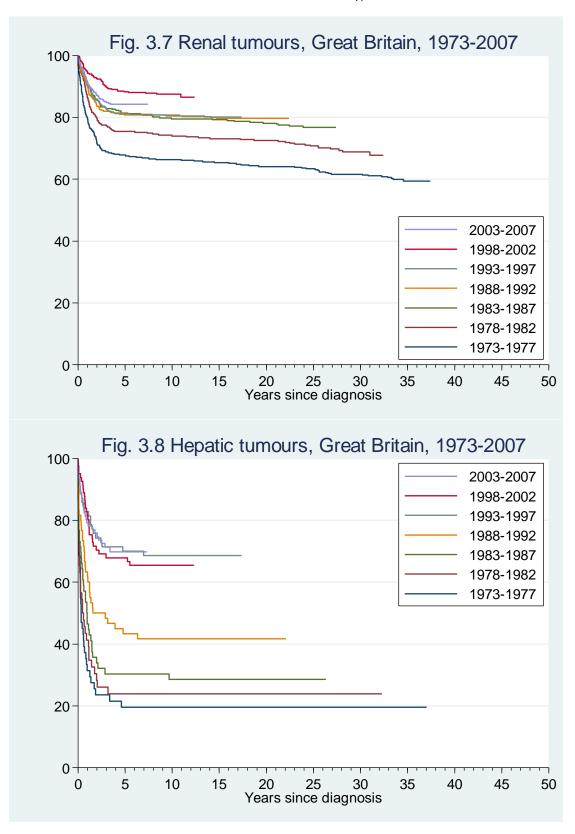


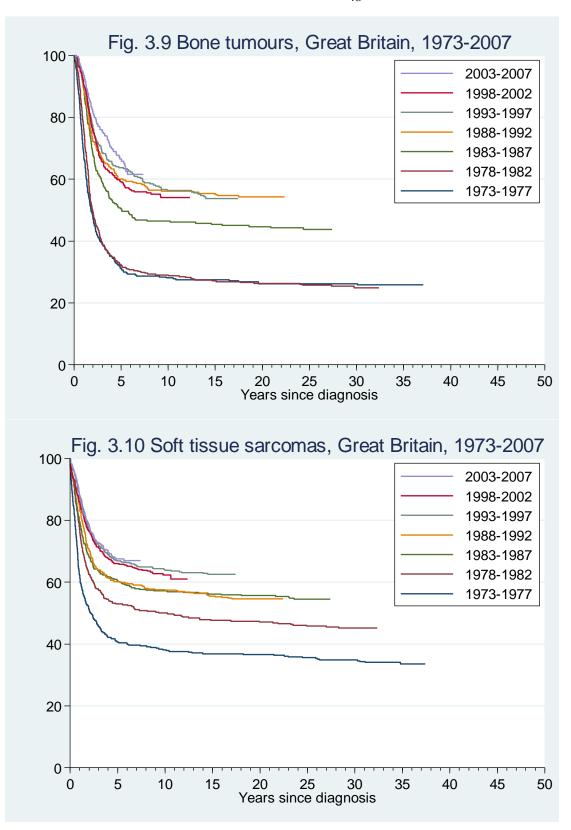


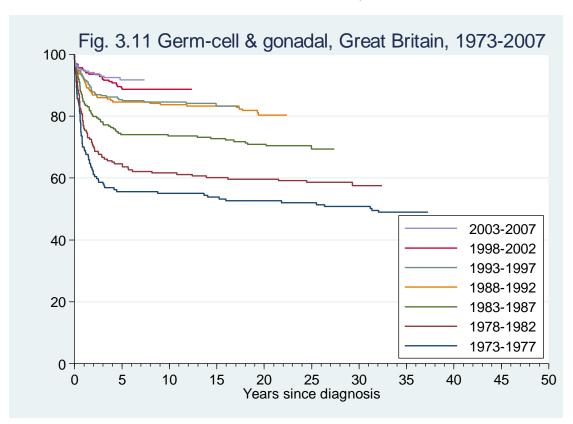




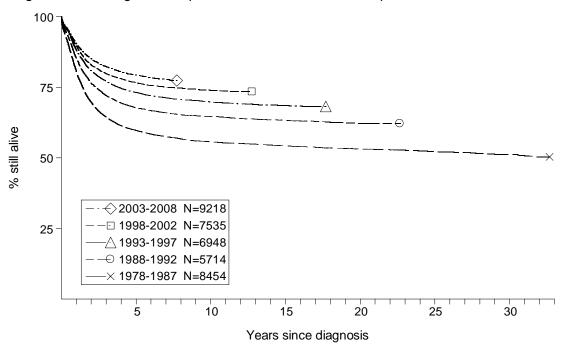




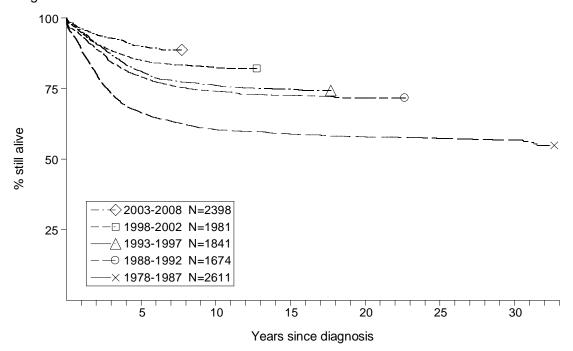




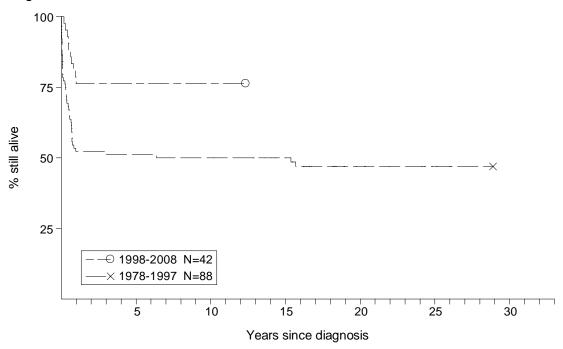
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.12 All Malignant Neoplasms and Other Brain and Spinal Tumours



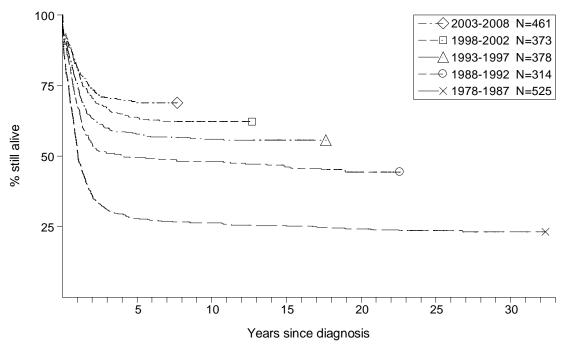
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.13 Precursor-cell ALL



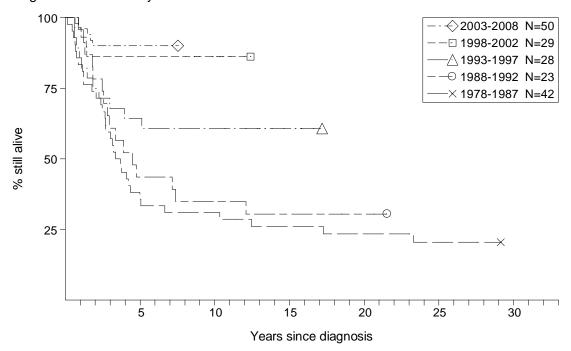
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.14 Mature B-cell Leukaemia



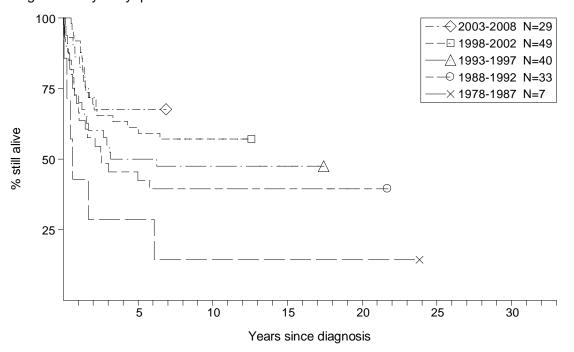
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.15 Acute Myeloid Leukaemia



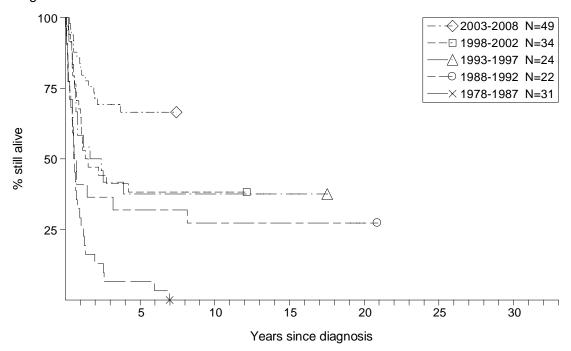
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.16 Chronic Myeloid Leukaemia



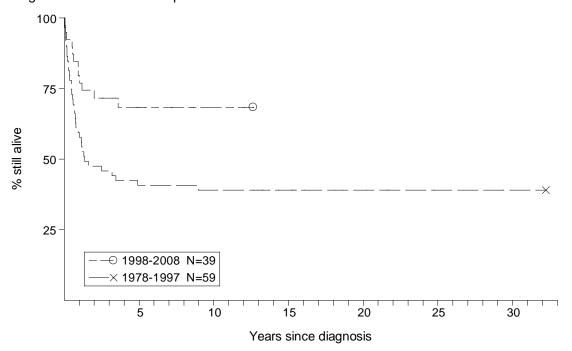
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.17 Myelodysplasia



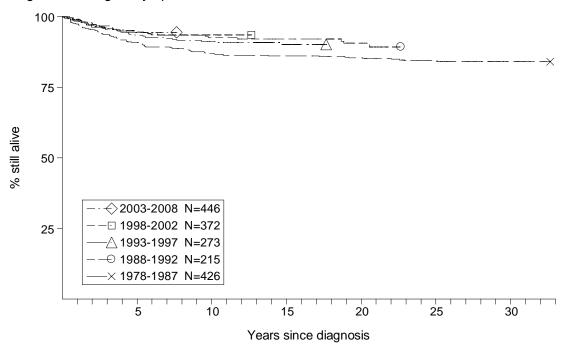
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.18 JMML and CMML



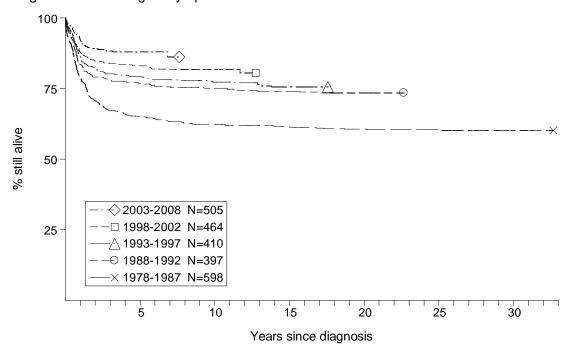
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.19 Other and Unspecified Leukaemia



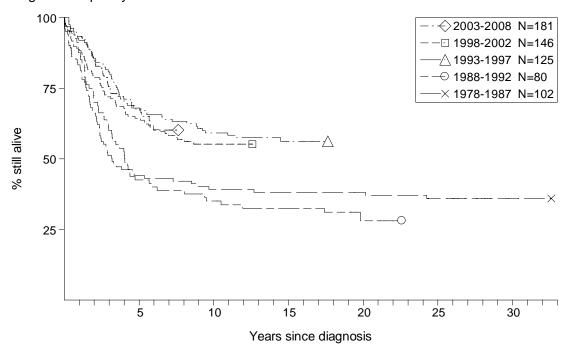
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.20 Hodgkin Lymphoma



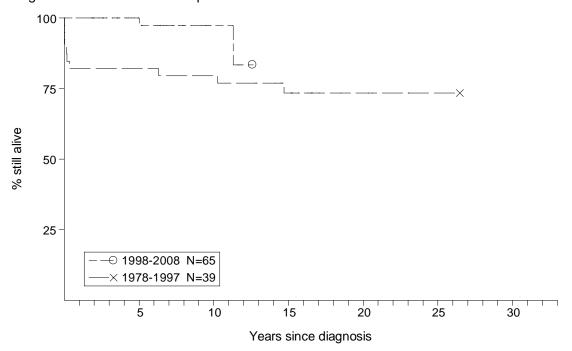
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.21 Non-Hodgkin Lymphoma



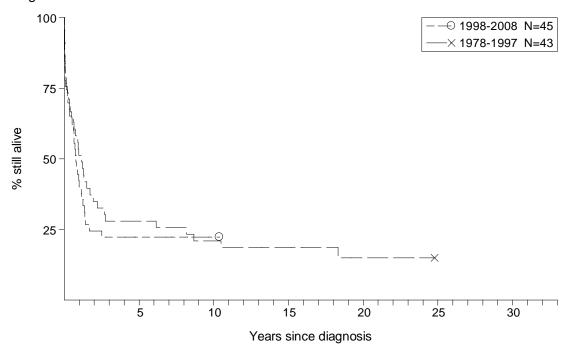
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.22 Ependymoma



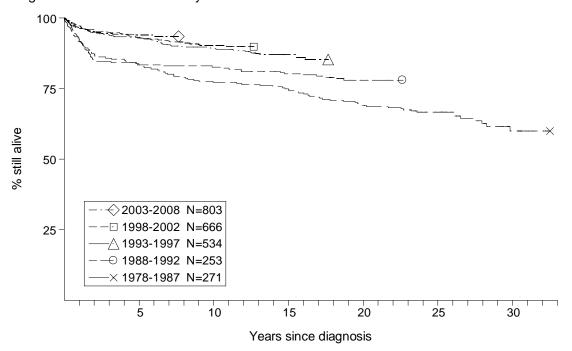
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.23 Choroid Plexus Papilloma



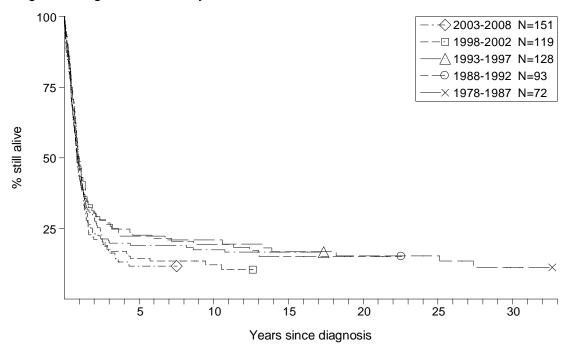
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.24 Choroid Plexus Carcinoma



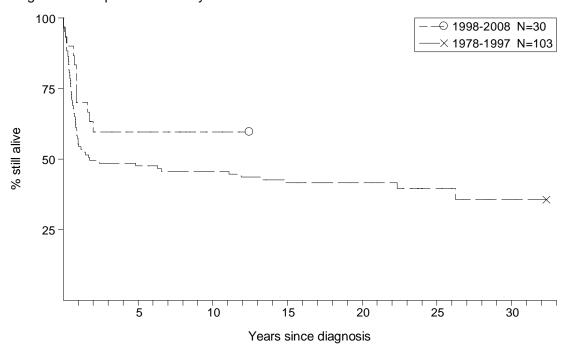
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.25 Low-Grade Astrocytoma



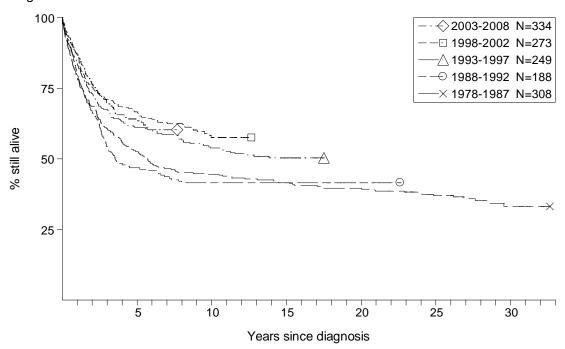
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.26 High-Grade Astrocytoma



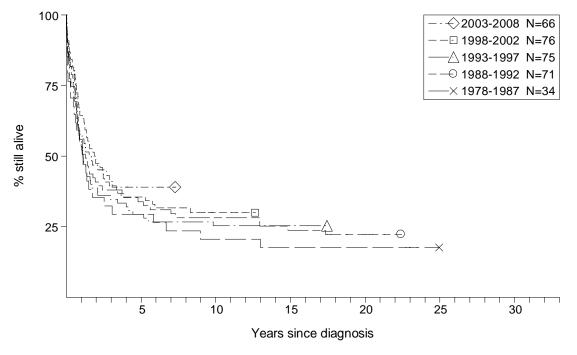
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.27 Unspecified Astrocytoma



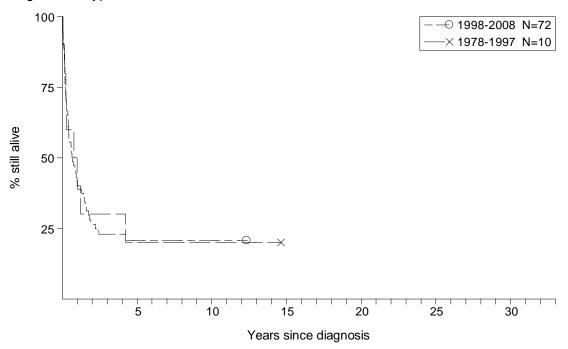
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.28 Medulloblastoma



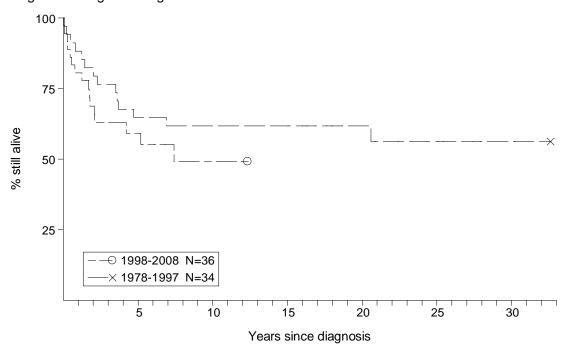
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.29 Other Primitive Neuroectodermal Tumour



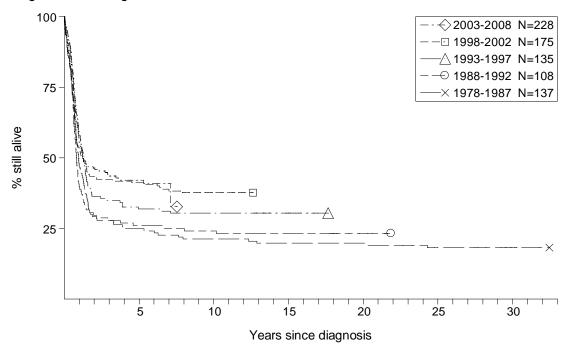
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.30 Atypical Teratoid Rhabdoid Tumour



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.31 Oligodendroglioma



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.32 Other glioma



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.33 Craniopharyngioma

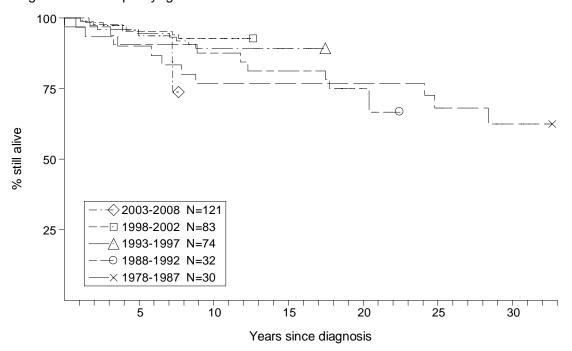
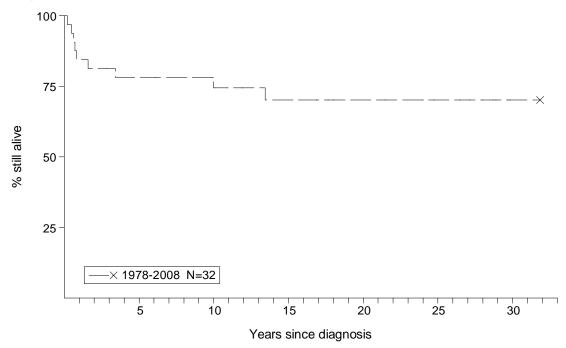
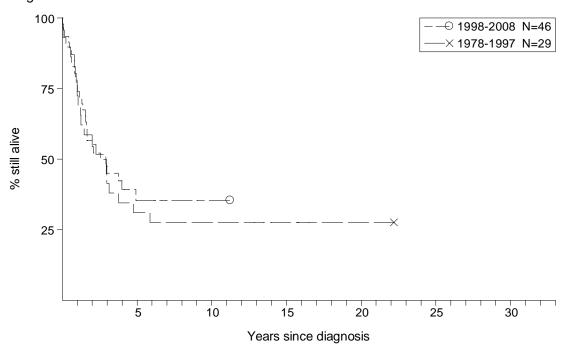


Fig. 3.34 Pinealoma and Pineocytoma



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.35 Pineoblastoma



# SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.36 Ganglioglioma

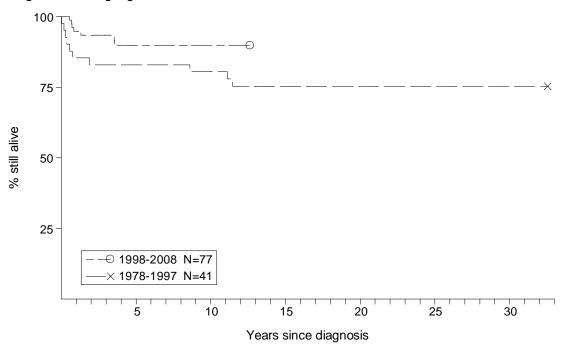
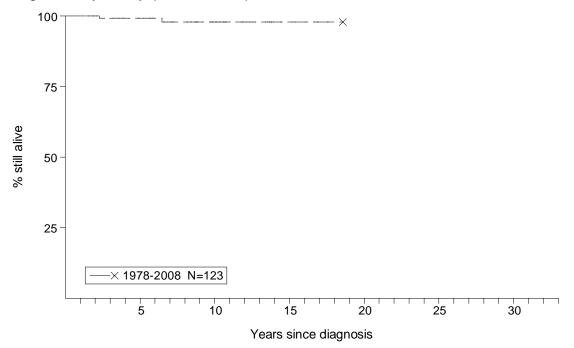
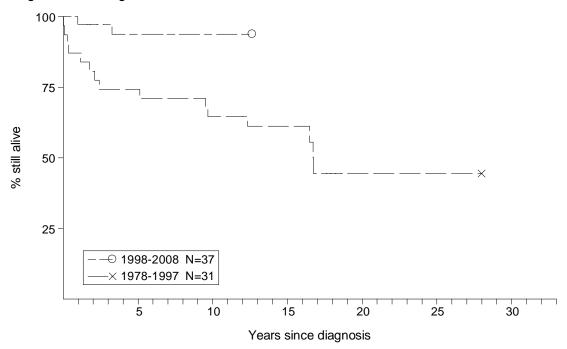


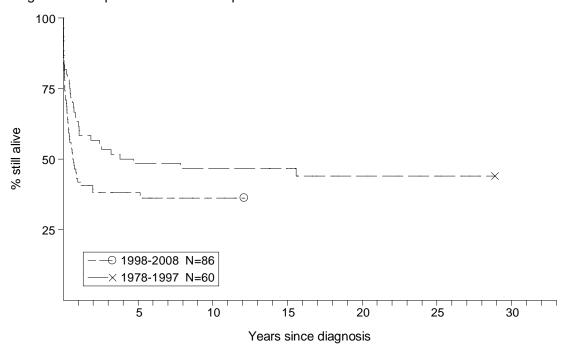
Fig. 3.37 Dysembryoplastic Neuroepithelial Tumour



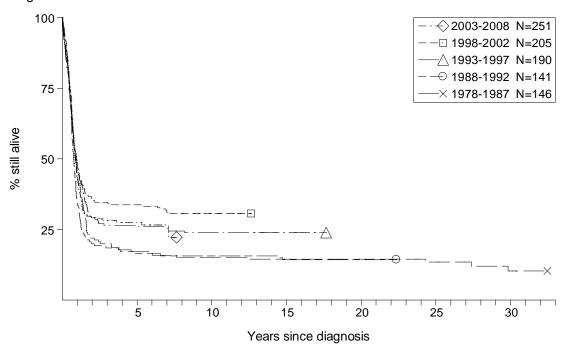
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.38 Meningioma



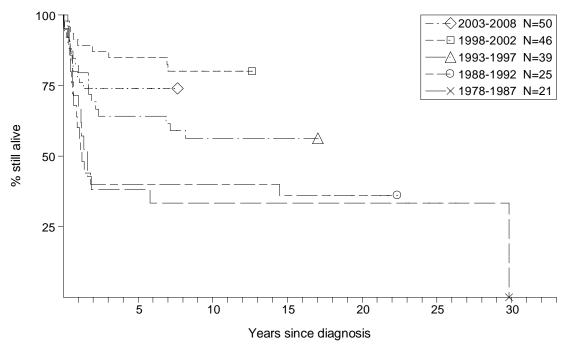
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.39 Unspecified Brain and Spinal



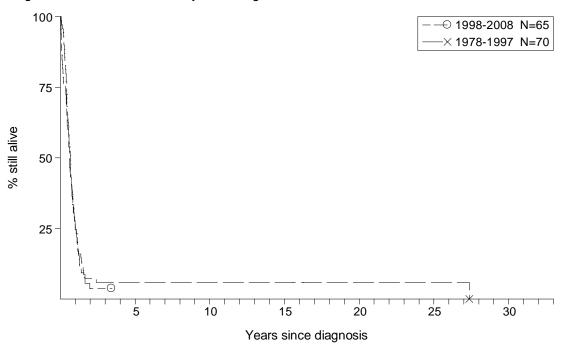
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.40 Brain Stem Tumours



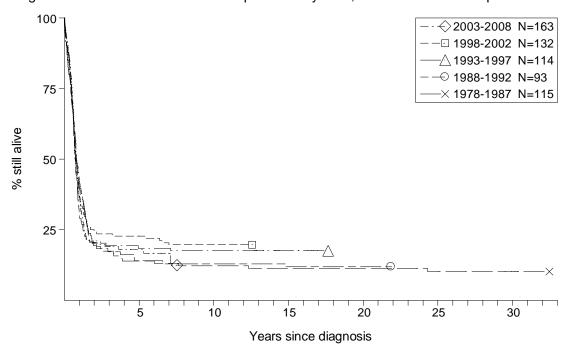
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.41 Brain Stem Astrocytoma, Low Grade



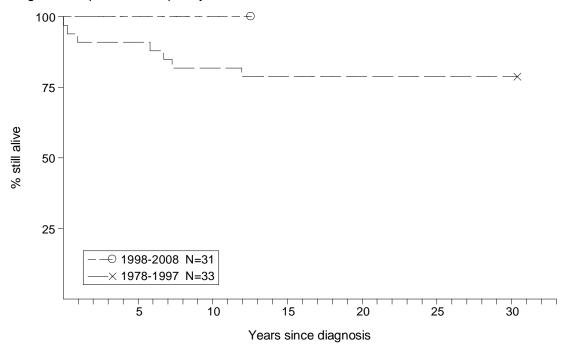
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.42 Brain Stem Astrocytoma, High Grade



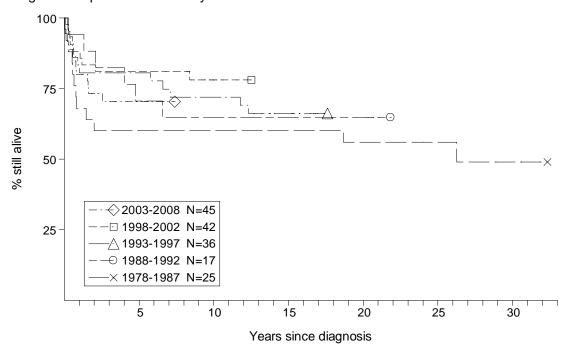
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.43 Brain Stem Tumours: Unspec Astrocytoma, Other Glioma & Unspec Tumou



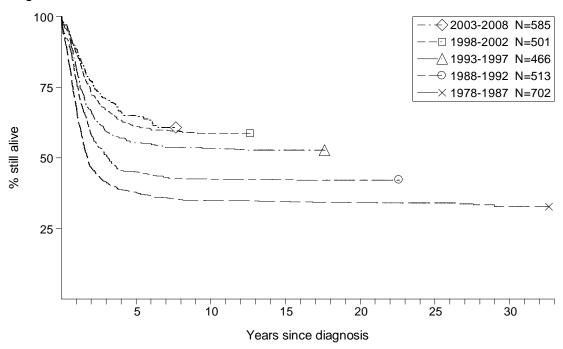
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.44 Spinal Cord Ependymoma



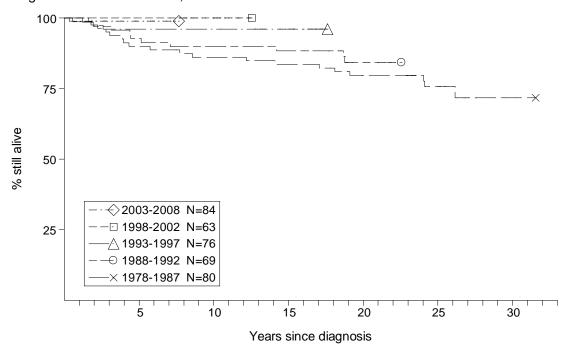
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.45 Spinal Cord Astrocytoma



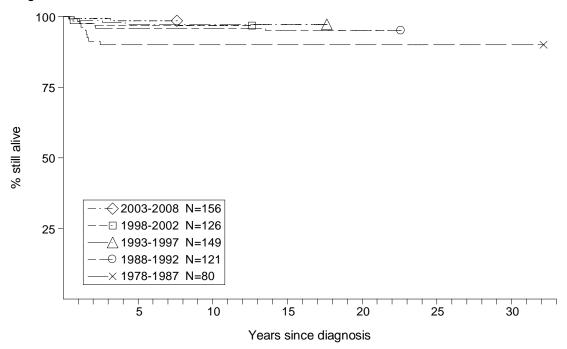
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.46 Neuroblastoma



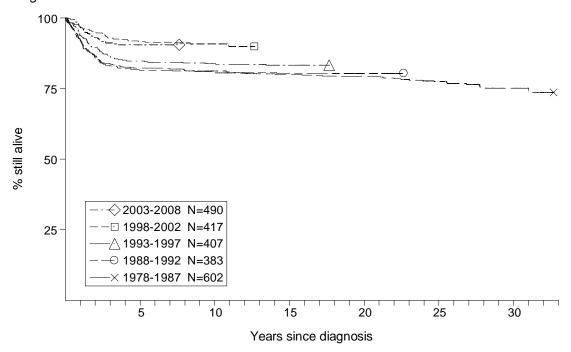
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.47 Retinoblastoma, Bilateral



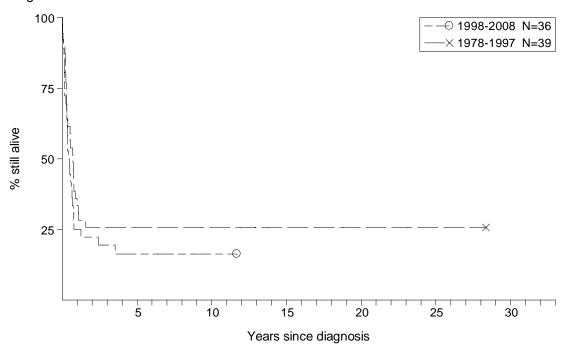
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.48 Retinoblastoma, Unilateral



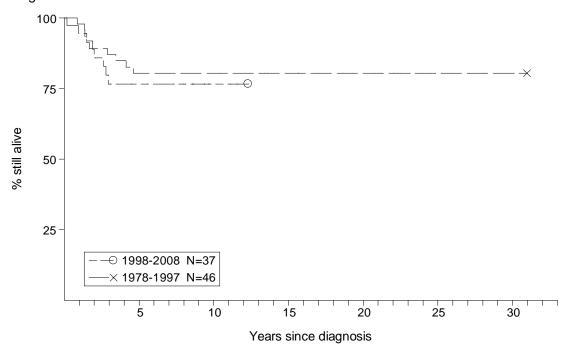
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.49 Wilms' Tumour



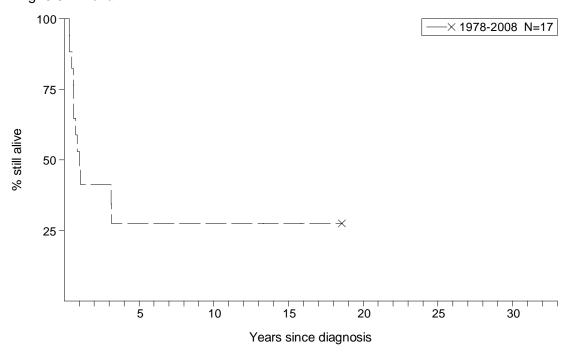
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.50 Rhabdoid Renal Tumour

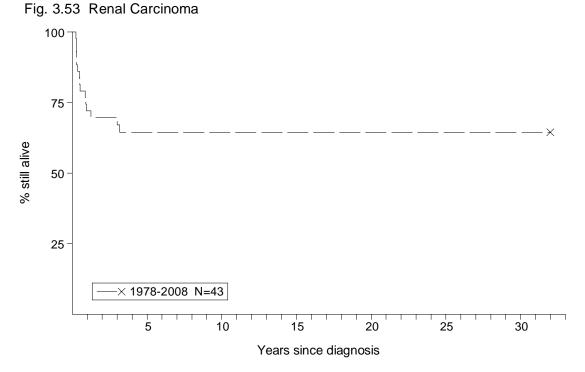


SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.51 Renal Clear-Cell Sarcoma

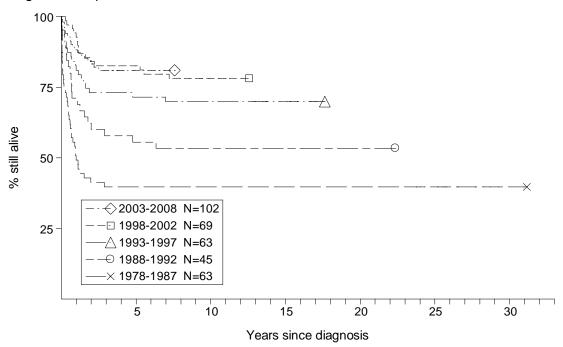


# SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008 Fig. 3.52 Renal PNET

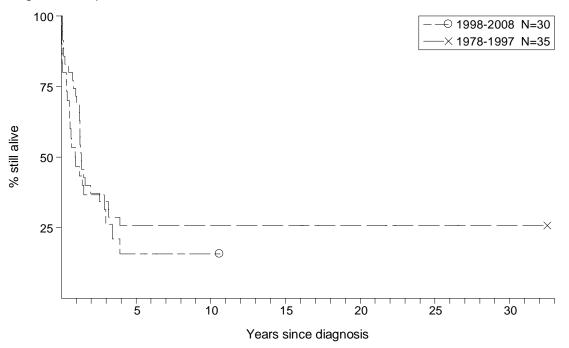




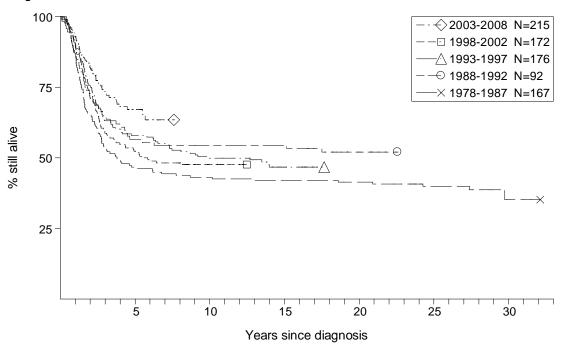
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.54 Hepatoblastoma

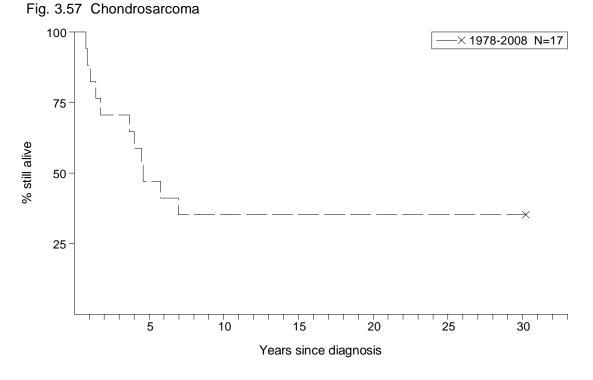


SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.55 Hepatic Carcinoma

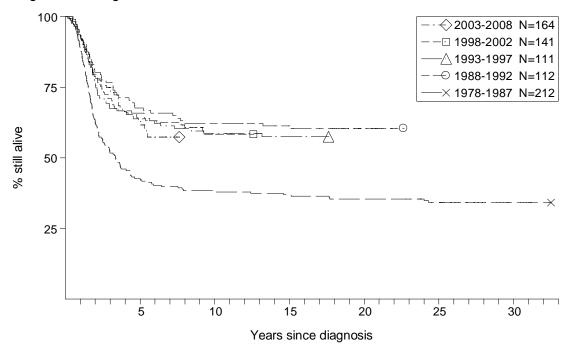


SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.56 Osteosarcoma

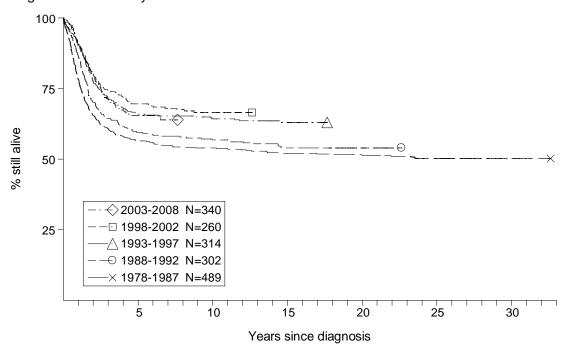




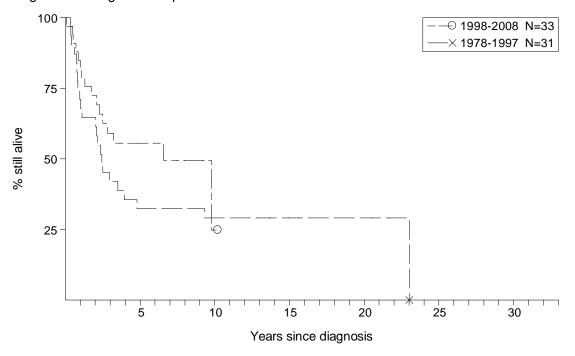
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.58 Ewing Sarcoma of Bone



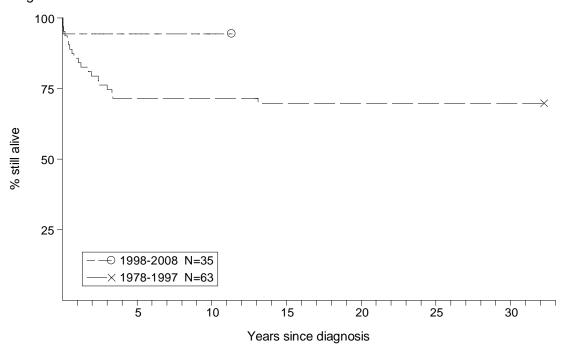
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.59 Rhabdomyosarcoma



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.60 Malignant Peripheral Nerve Sheath Tumour



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.61 Other Fibrosarcoma etc



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.62 Extraosseous Ewing Sarcoma Family Tumours

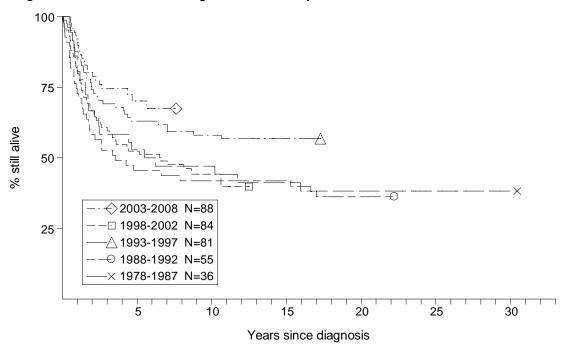
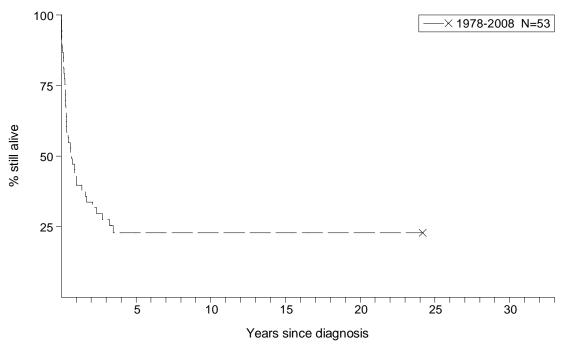


Fig. 3.63 Extrarenal Rhabdoid Tumour



## SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.64 Synovial Sarcoma

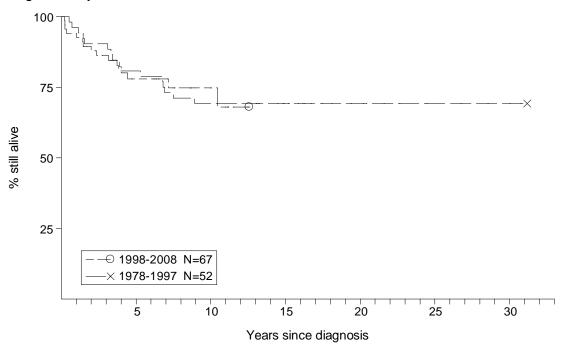
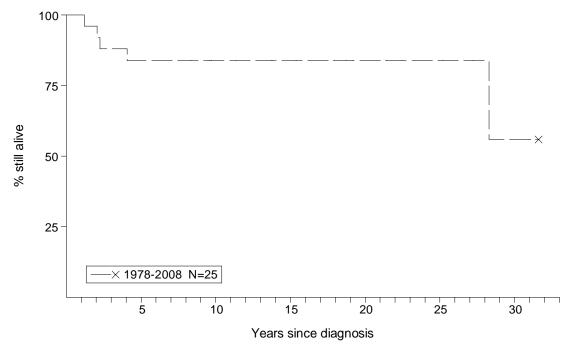
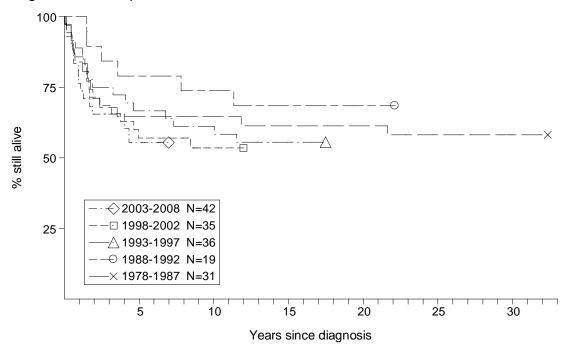


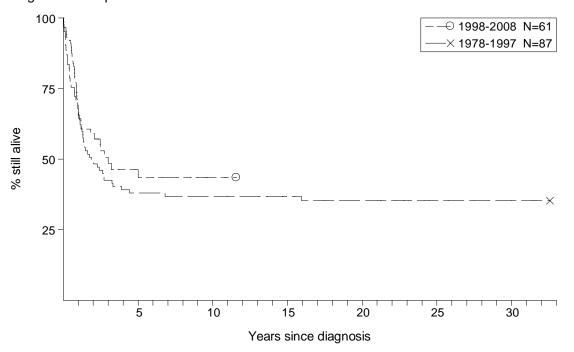
Fig. 3.65 Leiomyosarcoma



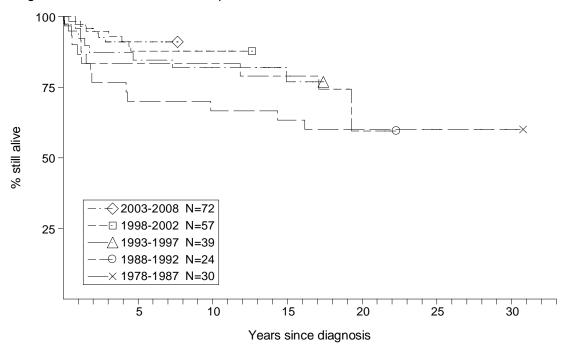
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.66 Other Specified Soft-Tissue Sarcoma



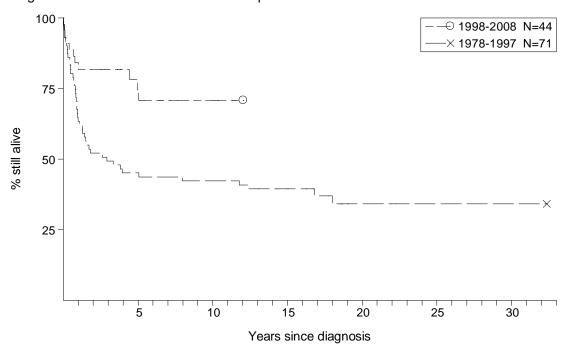
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.67 Unspecified Soft-Tissue Sarcoma



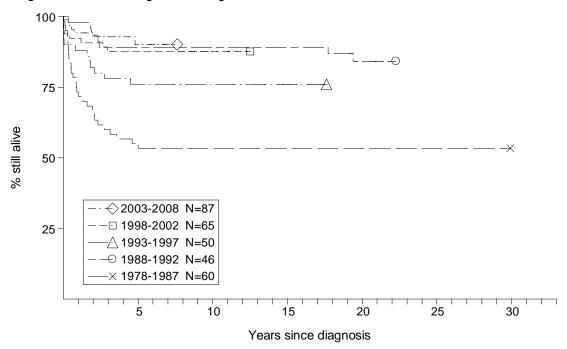
## SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.68 Intracranial and Intraspinal Germinoma



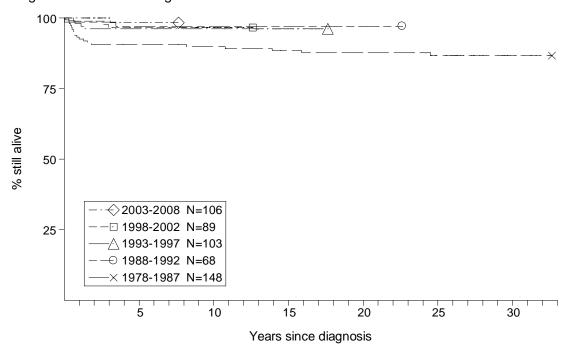
## SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.69 Other Intracranial and Intraspinal Germ-Cell Tumours



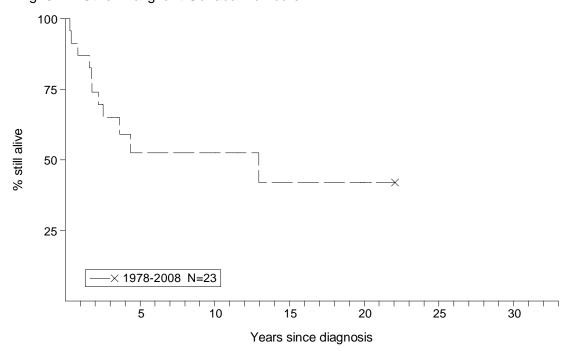
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.70 Other Malignant Extragonadal Germ-Cell Tumours



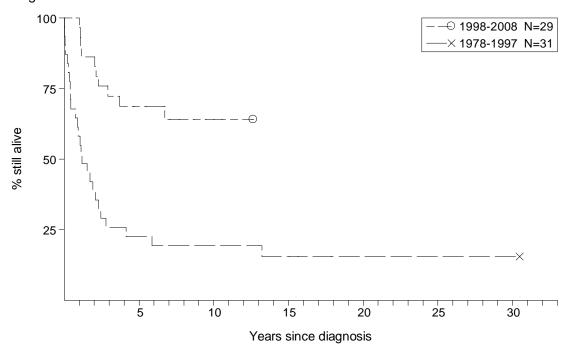
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.71 Gonadal Malignant Germ-Cell Tumours



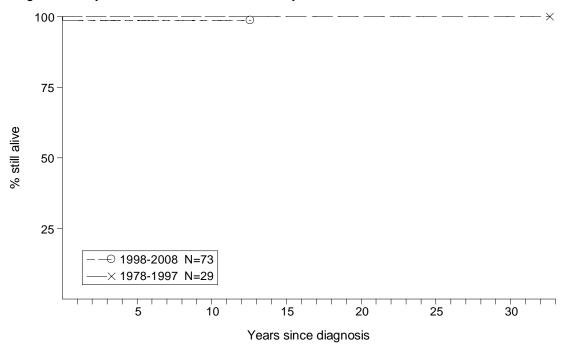
# SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008 Fig. 3.72 Other Malignant Gonadal Tumours



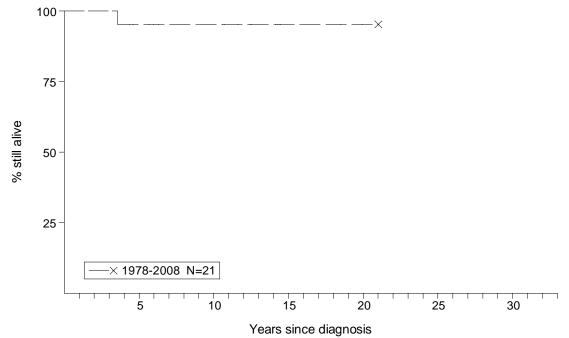
# SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.73 Adrenocortical Carcinoma



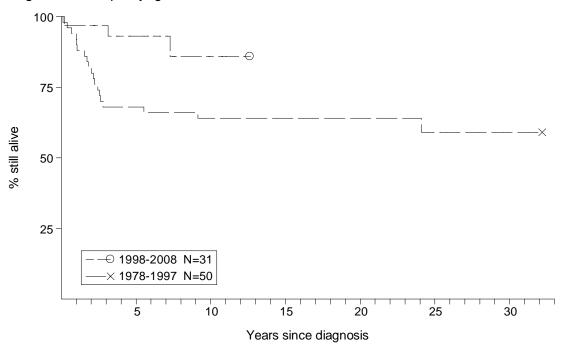
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.74 Thyroid Carcinoma, Non-Medullary







SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.76 Nasopharyngeal Carcinoma



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.77 Malignant Melanoma

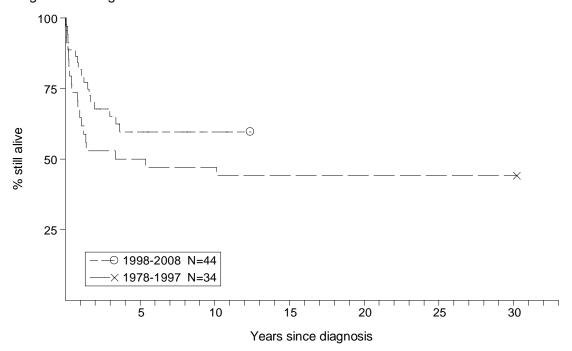


Fig. 3.78 Salivary Gland Carcinoma

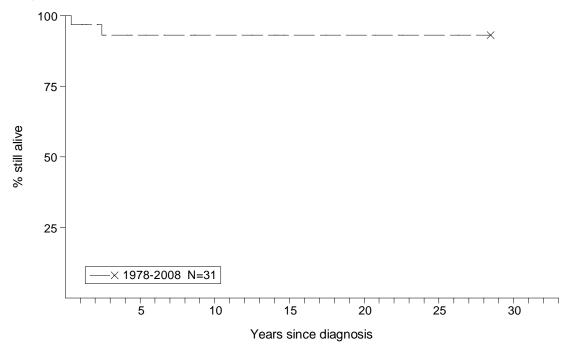
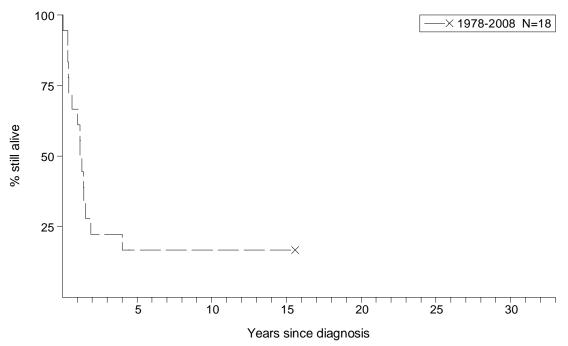


Fig. 3.79 Colorectal Carcinoma



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.80 Miscellaneous Other Carcinoma

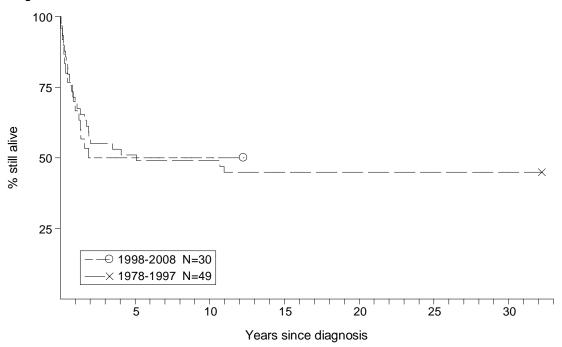
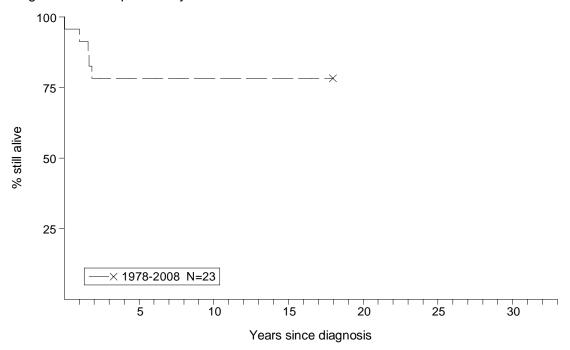
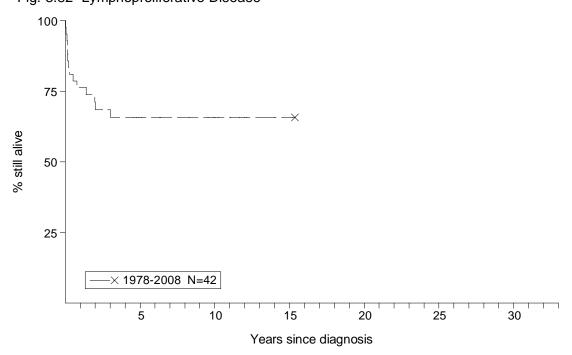


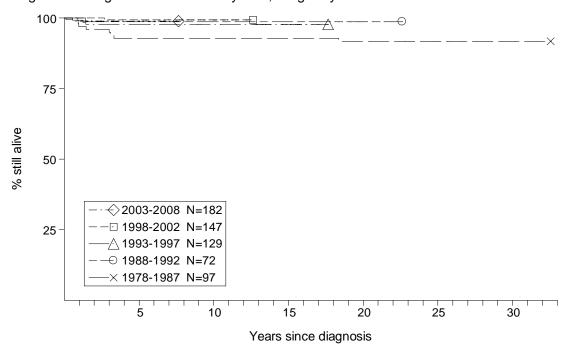
Fig. 3.81 Pleuropulmonary Blastoma



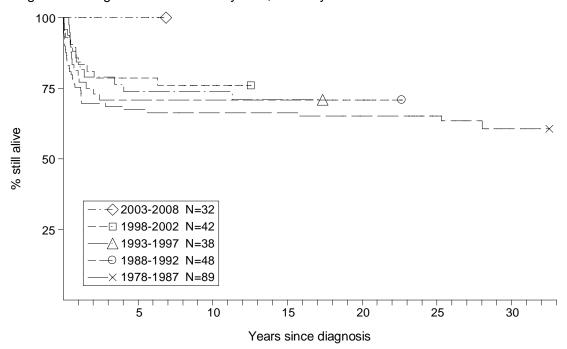
## SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008 Fig. 3.82 Lymphoproliferative Disease



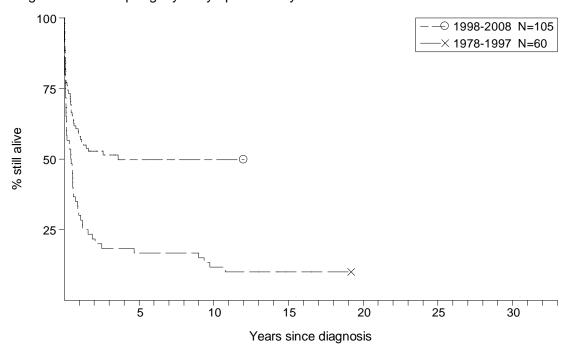
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.83 Langerhans Cell Histiocytosis, Single System



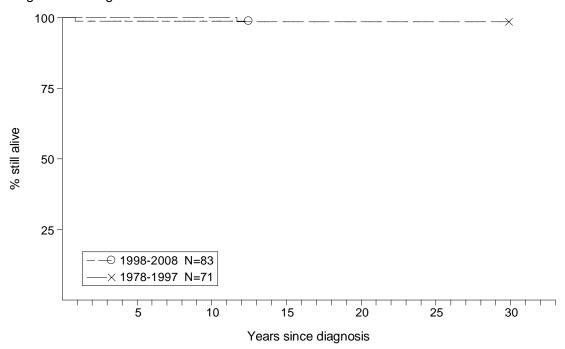
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.84 Langerhans Cell Histiocytosis, Multi System



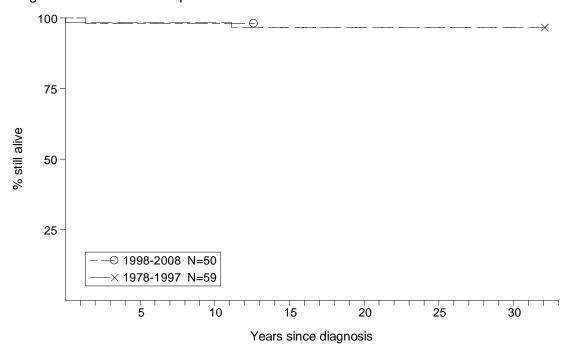
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.85 Haemophagocytic Lymphohistiocytosis



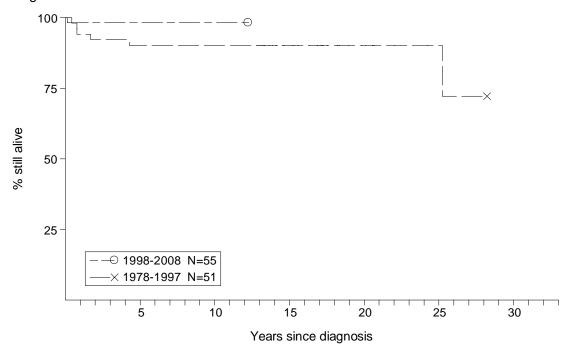
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.86 Ganglioneuroma



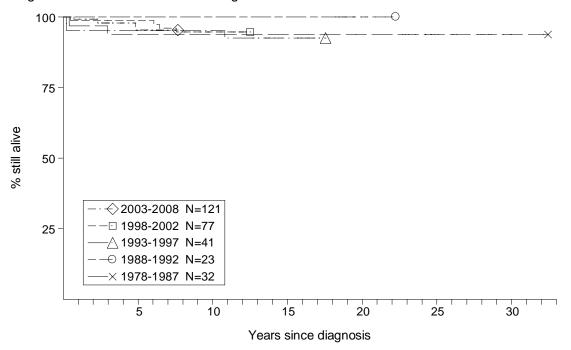
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.87 Mesoblastic Nephroma



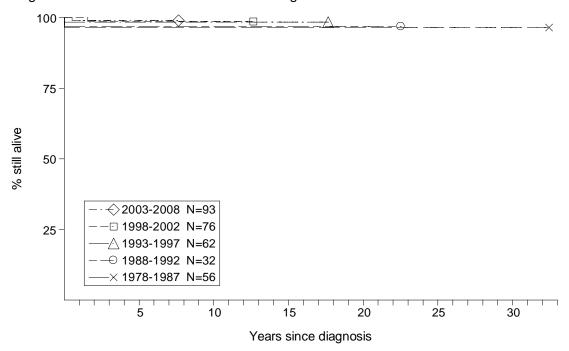
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.88 Fibromatosis



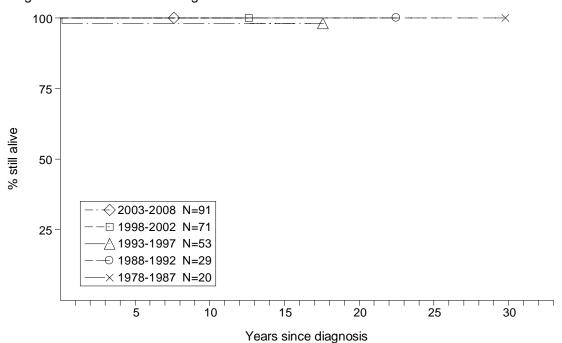
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.89 Miscellaneous Non-Malignant Soft-Tissue Tumours



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.90 Non-Gonadal Non-CNS Non-Malignant Germ-Cell Tumours



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.91 Gonadal Non-Malignant Germ-Cell Tumours



## SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY CALENDAR PERIOD Fig. 3.92 Other Non-Malignant Gonadal Tumours

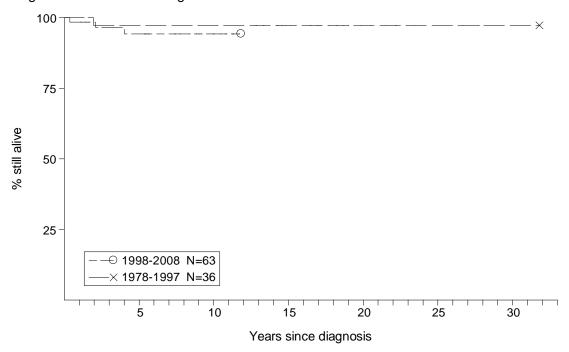
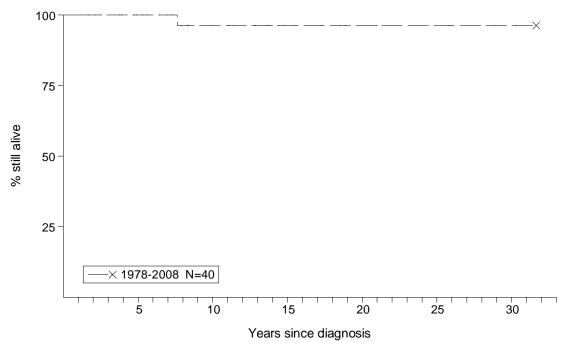
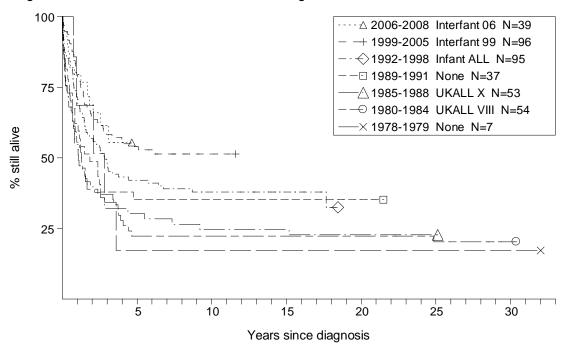


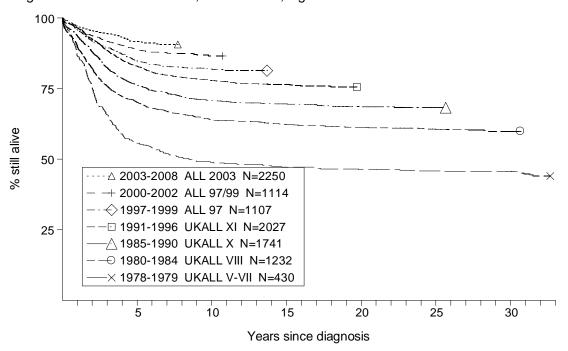
Fig. 3.93 Adrenocortical Adenoma



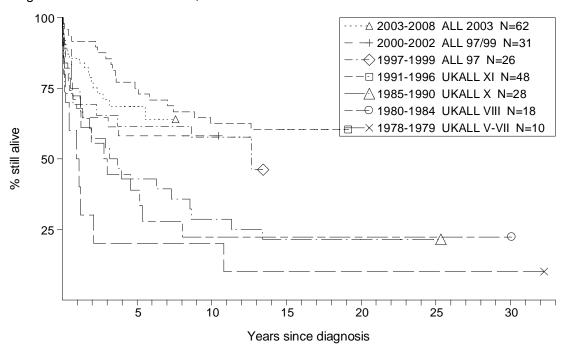
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.94 Precursor-cell ALL, Non-Down's, Age < 1 Year



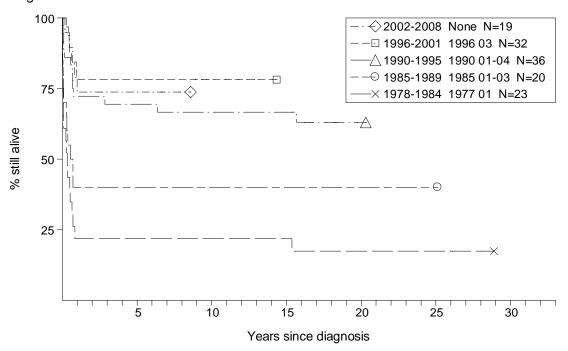
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.95 Precursor-cell ALL, Non-Down's, Age 1-14 Years



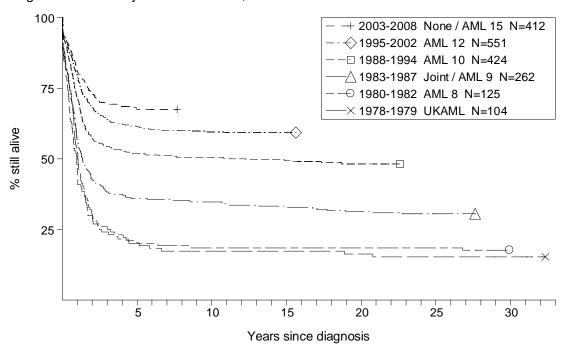
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.96 Precursor-cell ALL, Down's



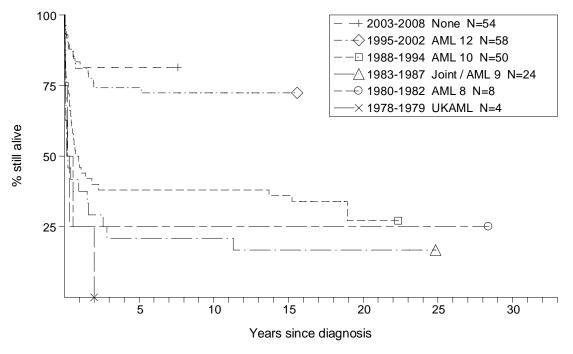
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.97 Mature B-cell Leukaemia



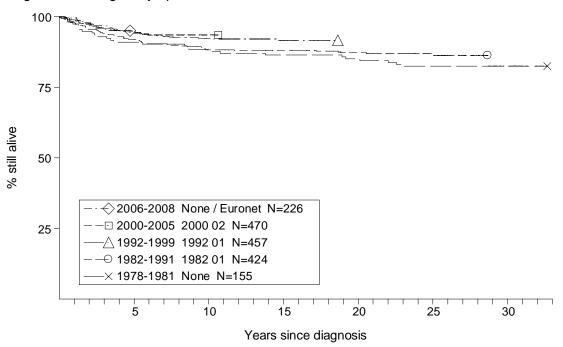
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.98 Acute Myeloid Leukaemia, Non-Down's



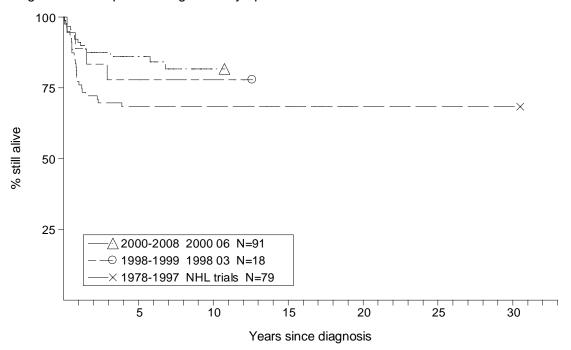
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.99 Myeloid Leukaemia of Down's Syndrome



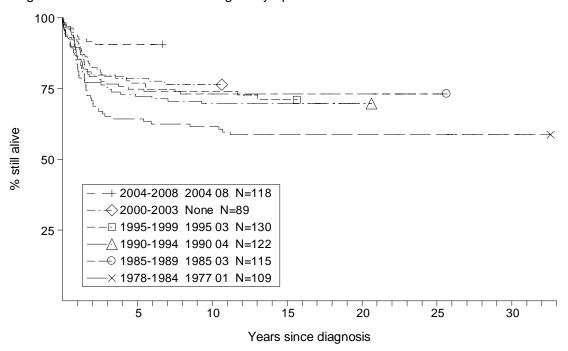
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.100 Hodgkin Lymphoma



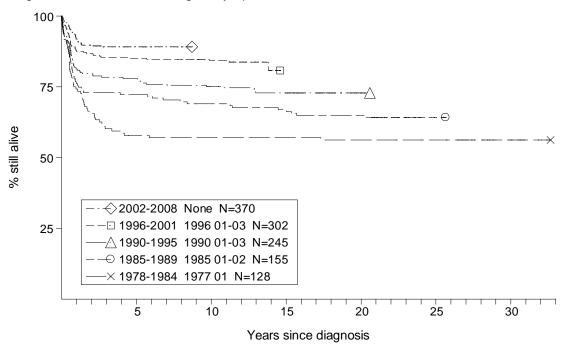
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.101 Anaplastic Large-Cell Lymphoma



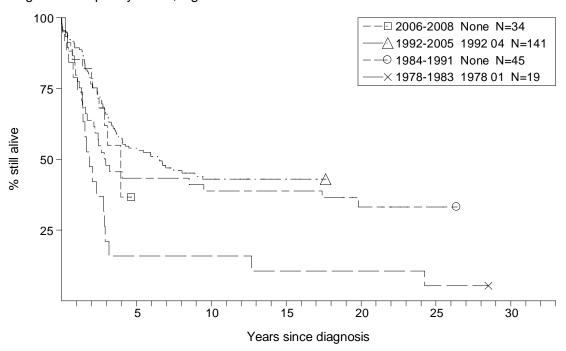
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.102 Other T-Cell Non-Hodgkin Lymphoma



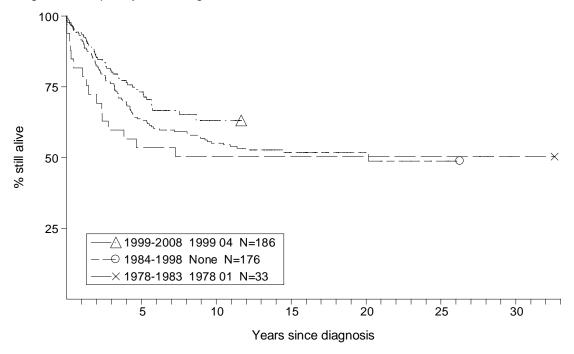
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.103 B-Cell Non-Hodgkin Lymphoma



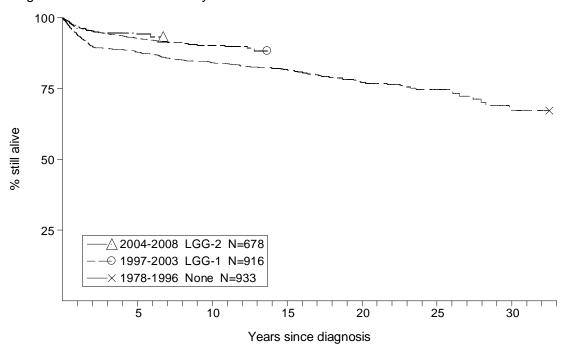
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.104 Ependymoma, Age 0-2 Years



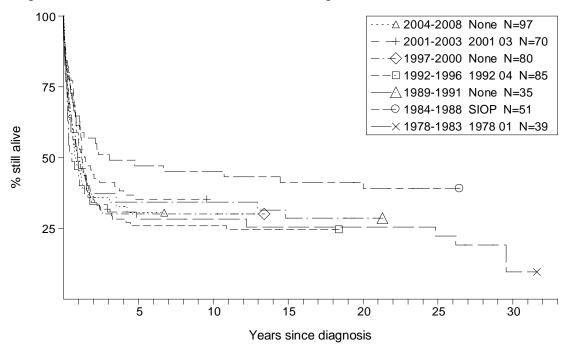
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.105 Ependymoma, Age 3-14 Years



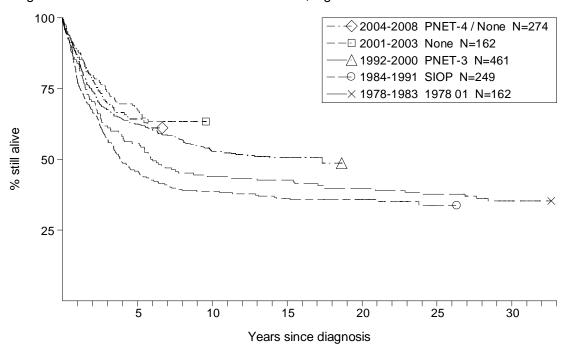
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.106 Low-Grade Astrocytoma



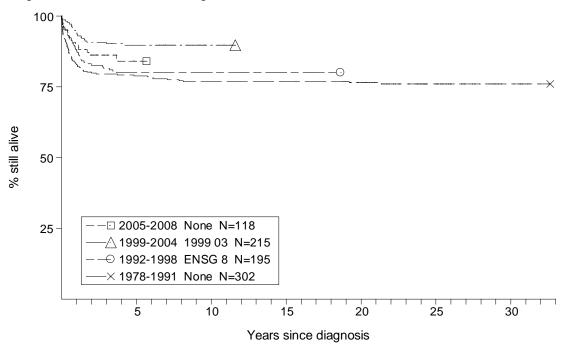
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.107 Primitive Neuroectodermal Tumour, Age 0-2 Years



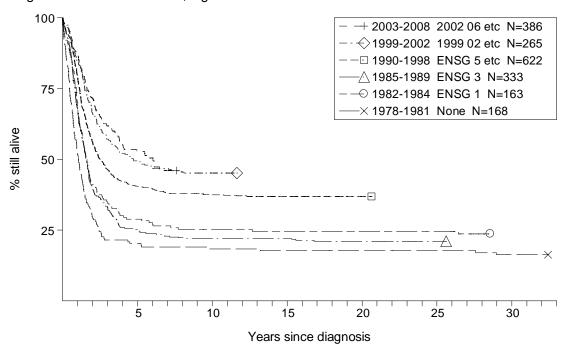
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.108 Primitive Neuroectodermal Tumour, Age 3-14 Years



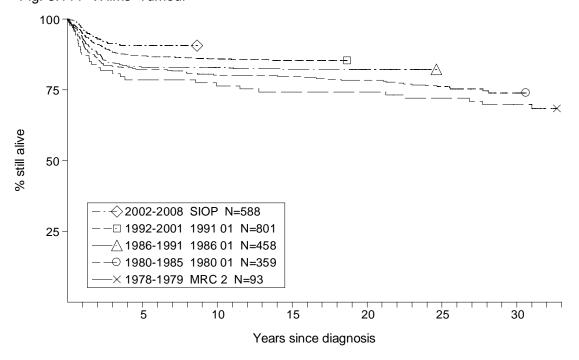
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.109 Neuroblastoma, Age < 1 Year



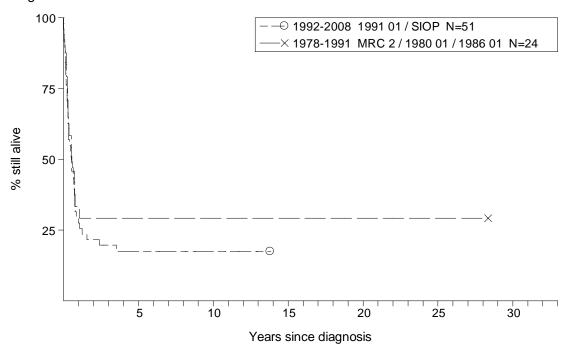
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.110 Neuroblastoma, Age 1-14 Years



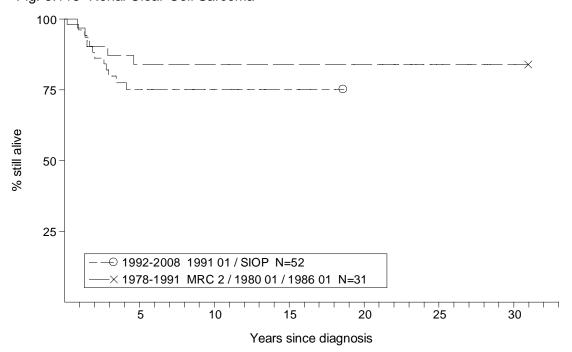
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.111 Wilms' Tumour



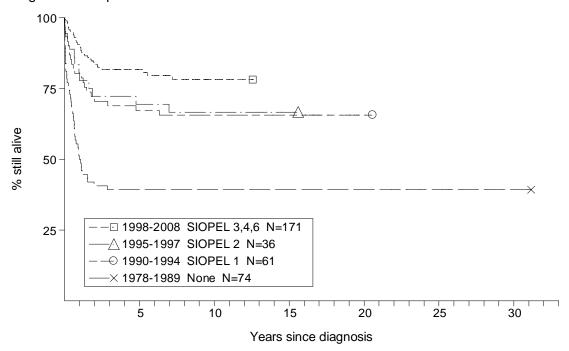
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.112 Rhabdoid Renal Tumour



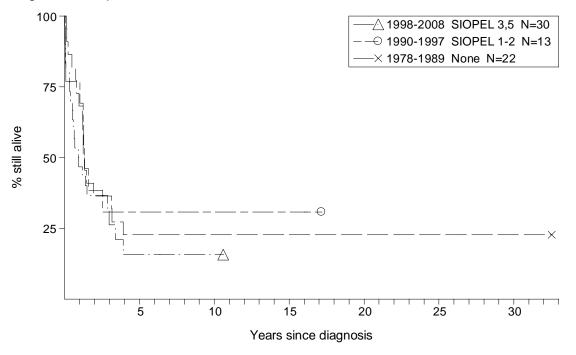
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.113 Renal Clear-Cell Sarcoma



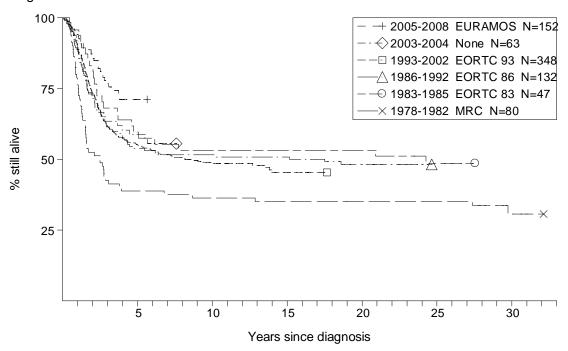
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.114 Hepatoblastoma



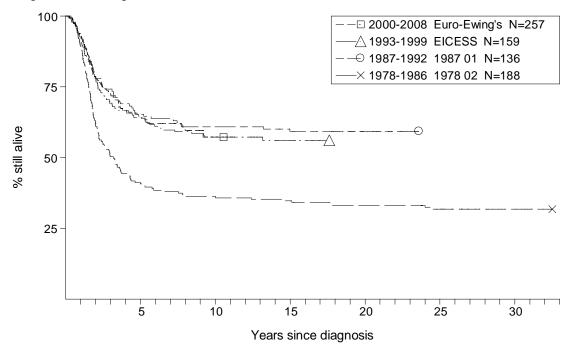
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.115 Hepatic Carcinoma



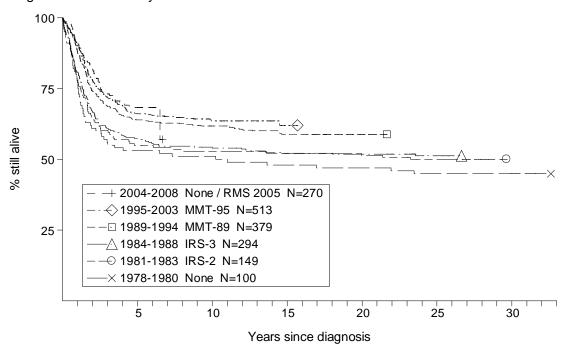
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.116 Osteosarcoma



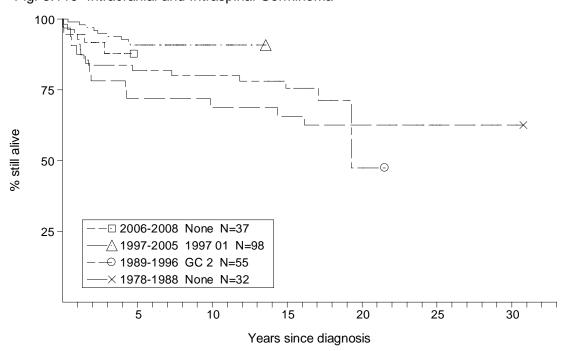
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.117 Ewing Sarcoma of Bone



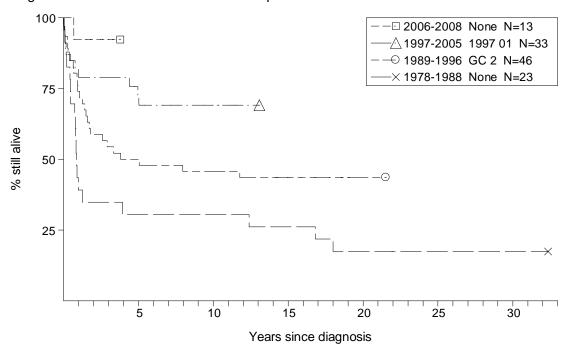
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.118 Rhabdomyosarcoma



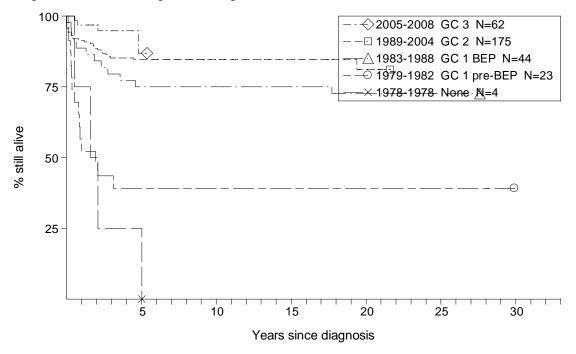
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.119 Intracranial and Intraspinal Germinoma



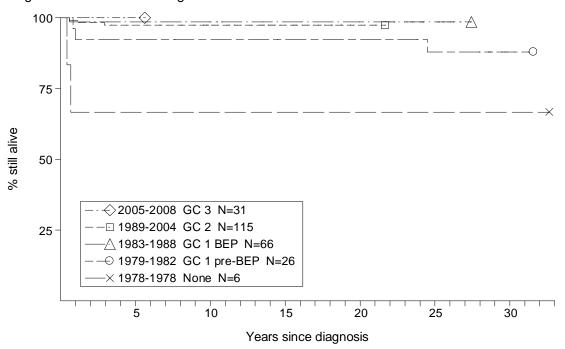
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.120 Other Intracranial and Intraspinal Germ-Cell Tumours



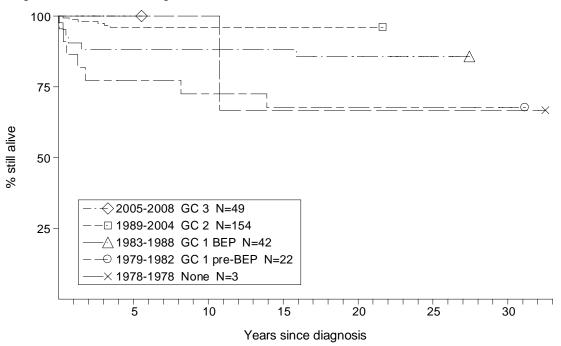
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.121 Other Malignant Extragonadal Germ-Cell Tumours



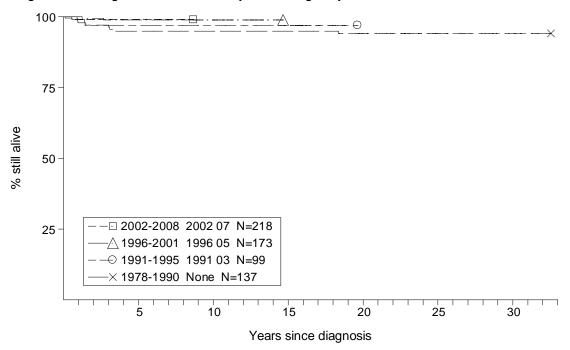
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.122 Testicular Malignant Germ-Cell Tumours



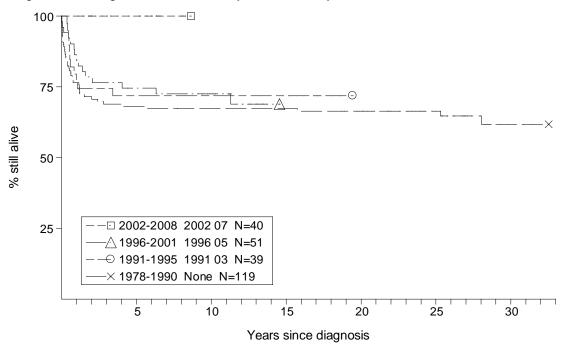
SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.123 Ovarian Malignant Germ-Cell Tumours



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.124 Langerhans Cell Histiocytosis, Single System



SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.125 Langerhans Cell Histiocytosis, Multi System



# SURVIVAL OF CCLG PATIENTS DIAGNOSED 1978-2008, BY TRIAL ENTRY PERIOD Fig. 3.126 Haemophagocytic Lymphohistiocytosis

