**National Registry of Childhood Tumours**

**Progress Report, 2011**

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.

**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.

Table 1.1 shows numbers of registered cases of cancer in the NRCT for children resident in Great Britain at diagnosis from 1962 to 2010. The latest year for which registration is virtually complete from all sources is 2007, but a very high proportion of registrations for 2008-2010 has been received from CCLG centres. Table 1.2 shows the numbers for the whole of the UK for 1993-2010. 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 68,024 registrations for children with cancer in Great Britain over the 49-year period 1962-2010, and 27,919 registrations for the UK over the 18-year period 1993-2010.

At the time of writing, registration data for over 45,000 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 2010 is almost complete. 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, 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 2006-2011. 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 at the NHS Information Centre 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, 1962-2010

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | 1962-2010 | 1991-2000 | 2001-2007 | 2008-2010 |
| Leukaemias, myeloproliferative & myelodysplastic diseases | 22200 | 4723 | 3353 | 1400 |
| Lymphomas & reticuloendothelial neoplasms | 7007 | 1423 | 1108 | 441 |
| CNS & miscellaneous intracranial & intraspinal neoplasms | 16229 | 3618 | 2742 | 1090 |
| Neuroblastoma & other peripheral nervous cell tumours | 4414 | 895 | 641 | 262 |
| Retinoblastoma | 1945 | 429 | 292 | 105 |
| Renal tumours | 3942 | 798 | 606 | 240 |
| Hepatic tumours | 603 | 138 | 130 | 40 |
| Malignant bone tumours | 2930 | 563 | 430 | 190 |
| Soft tissue & other extarosseous sarcomas | 4321 | 1026 | 694 | 299 |
| Germ cell tumours, trophoblastic tumours & neoplasms of gonads | 2089 | 490 | 354 | 158 |
| Other malignant epithelial neoplasms & malignant melanomas | 1967 | 477 | 373 | 94 |
| Other & unspecified malignant neoplasms | 377 | 98 | 64 | 17 |
| Total | 68024 | 14678 | 10787 | 4336 |

Table 1.2 Numbers of registrations by ICCC-3 main diagnostic group. National Registry of Childhood Tumours, United Kingdom, 1993-2010

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | 1993-2010 | 1993-2000 | 2001-2007 | 2008-2010 |
| Leukaemias, myeloproliferative & myelodysplastic diseases | 8868 | 3972 | 3460 | 1436 |
| Lymphomas & reticuloendothelial neoplasms | 2787 | 1185 | 1145 | 457 |
| CNS & miscellaneous intracranial & intraspinal neoplasms | 7034 | 3081 | 2840 | 1113 |
| Neuroblastoma & other peripheral nervous cell tumours | 1666 | 741 | 658 | 267 |
| Retinoblastoma | 756 | 345 | 303 | 108 |
| Renal tumours | 1537 | 664 | 629 | 244 |
| Hepatic tumours | 296 | 116 | 137 | 43 |
| Malignant bone tumours | 1108 | 474 | 441 | 193 |
| Soft tissue & other extarosseous sarcomas | 1875 | 853 | 713 | 309 |
| Germ cell tumours, trophoblastic tumours & neoplasms of gonads | 926 | 400 | 365 | 161 |
| Other malignant epithelial neoplasms & malignant melanomas | 896 | 415 | 385 | 96 |
| Other & unspecified malignant neoplasms | 170 | 83 | 70 | 17 |
| Total | 27919 | 12329 | 11146 | 4444 |

TABLE 1.3 CCLG REGISTRATIONS FOR CHILDREN AGED UNDER 15, BY CENTRE, 1977-2011

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 | 2011 | Total |
| Aberdeen | 1 | 3 | 17 | 25 | 21 | 22 | 36 | 24 | 28 | 15 | 8 | 18 | 21 | 14 | 9 | 11 | 16 | 17 | 15 | 12 | 8 | 10 | 15 | 10 | 9 |  | 385 |
| Barts/RLH | 56 | 65 | 73 | 78 | 126 | 130 | 146 | 166 | 161 | 76 | 79 | 79 | 59 | 74 | 67 | 69 | 55 | 51 | 36 | 6 |  |  |  |  |  |  | 1652 |
| Belfast |  | 41 | 45 | 55 | 53 | 65 | 78 | 70 | 69 | 29 | 37 | 37 | 35 | 30 | 33 | 29 | 33 | 49 | 31 | 36 | 35 | 36 | 30 | 40 | 38 |  | 1034 |
| Birmingham | 95 | 160 | 182 | 188 | 221 | 253 | 279 | 301 | 293 | 170 | 151 | 152 | 161 | 144 | 142 | 140 | 170 | 165 | 191 | 158 | 150 | 175 | 167 | 173 | 164 | 6 | 4551 |
| Bristol | 81 | 101 | 124 | 111 | 123 | 151 | 175 | 146 | 194 | 123 | 114 | 105 | 99 | 110 | 79 | 86 | 103 | 92 | 89 | 90 | 100 | 96 | 113 | 111 | 89 | 3 | 2808 |
| Cambridge |  | 33 | 29 | 39 | 58 | 78 | 96 | 111 | 89 | 60 | 51 | 66 | 73 | 83 | 65 | 71 | 85 | 83 | 99 | 83 | 112 | 101 | 96 | 123 | 125 | 5 | 1914 |
| Cardiff | 45 | 57 | 67 | 72 | 59 | 76 | 82 | 81 | 82 | 53 | 45 | 44 | 56 | 71 | 48 | 57 | 56 | 47 | 33 | 62 | 66 | 55 | 73 | 52 | 49 | 1 | 1489 |
| Dublin |  | 12 | 81 | 100 | 132 | 139 | 132 | 126 | 163 | 82 | 69 | 79 | 98 | 91 | 100 | 119 | 115 | 120 | 129 | 99 | 113 | 122 | 128 | 142 | 84 |  | 2575 |
| Edinburgh | 20 | 25 | 24 | 44 | 63 | 64 | 49 | 54 | 70 | 42 | 36 | 53 | 42 | 44 | 47 | 51 | 68 | 49 | 58 | 47 | 44 | 39 | 53 | 44 | 30 | 1 | 1161 |
| Glasgow | 69 | 76 | 75 | 118 | 111 | 111 | 130 | 125 | 140 | 63 | 53 | 64 | 63 | 60 | 46 | 62 | 61 | 61 | 68 | 63 | 56 | 64 | 87 | 74 | 70 |  | 1970 |
| GOS | 203 | 235 | 309 | 306 | 275 | 281 | 257 | 296 | 381 | 193 | 188 | 210 | 155 | 187 | 157 | 146 | 213 | 176 | 184 | 180 | 196 | 202 | 219 | 181 | 133 |  | 5463 |
| Leeds | 84 | 109 | 109 | 108 | 129 | 150 | 169 | 183 | 187 | 98 | 90 | 91 | 107 | 90 | 97 | 108 | 108 | 92 | 88 | 81 | 97 | 88 | 87 | 89 | 75 | 3 | 2717 |
| Leicester |  |  | 18 | 39 | 51 | 31 | 49 | 36 | 41 | 23 | 19 | 15 | 21 | 15 | 28 | 23 | 26 | 20 | 30 | 23 | 33 | 26 | 24 | 21 | 21 |  | 633 |
| Liverpool | 70 | 94 | 76 | 88 | 101 | 99 | 116 | 124 | 141 | 76 | 89 | 70 | 77 | 85 | 77 | 84 | 100 | 84 | 108 | 90 | 80 | 83 | 82 | 80 | 83 | 5 | 2262 |
| Manchester | 131 | 183 | 177 | 185 | 158 | 183 | 173 | 182 | 229 | 124 | 120 | 122 | 97 | 122 | 111 | 134 | 117 | 136 | 104 | 123 | 112 | 104 | 120 | 104 | 114 |  | 3465 |
| Middlesex/UCLH |  |  |  |  |  | 1 | 4 | 23 | 50 | 25 | 24 | 32 | 46 | 36 | 40 | 30 | 36 | 40 | 44 | 43 | 28 | 39 | 42 | 43 | 35 |  | 661 |
| Newcastle | 55 | 104 | 110 | 110 | 119 | 124 | 120 | 134 | 128 | 69 | 78 | 78 | 71 | 73 | 80 | 91 | 90 | 70 | 86 | 87 | 92 | 65 | 82 | 72 | 71 | 1 | 2260 |
| Nottingham | 28 | 23 | 60 | 47 | 65 | 77 | 90 | 94 | 91 | 61 | 47 | 49 | 72 | 65 | 76 | 62 | 52 | 59 | 60 | 46 | 73 | 50 | 67 | 75 | 73 | 3 | 1565 |
| Oxford |  |  |  | 1 | 2 | 1 | 4 | 32 | 90 | 45 | 52 | 49 | 56 | 57 | 57 | 56 | 55 | 69 | 70 | 76 | 67 | 74 | 71 | 56 | 73 | 11 | 1124 |
| Royal Marsden | 71 | 99 | 83 | 90 | 80 | 113 | 113 | 129 | 115 | 70 | 83 | 83 | 111 | 90 | 116 | 109 | 125 | 84 | 88 | 128 | 109 | 111 | 151 | 148 | 135 |  | 2634 |
| Sheffield | 65 | 76 | 77 | 61 | 80 | 80 | 86 | 83 | 86 | 45 | 50 | 50 | 51 | 58 | 59 | 63 | 69 | 58 | 48 | 56 | 63 | 66 | 49 | 57 | 55 | 2 | 1593 |
| Southampton | 13 | 52 | 59 | 56 | 61 | 77 | 92 | 125 | 129 | 53 | 74 | 70 | 70 | 62 | 59 | 68 | 68 | 73 | 67 | 81 | 61 | 69 | 74 | 70 | 86 | 5 | 1774 |
| Total | 1087 | 1548 | 1795 | 1921 | 2088 | 2306 | 2476 | 2645 | 2957 | 1595 | 1557 | 1616 | 1641 | 1661 | 1593 | 1669 | 1821 | 1695 | 1726 | 1670 | 1695 | 1675 | 1830 | 1765 | 1612 | 46 | 45690 |

TABLE 1.4 CCLG REGISTRATIONS FOR CHILDREN AGED UNDER 15, BY DIAGNOSTIC GROUP, 1977-2011

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 | 2011 | Total |
| Precursor-cell ALL | 332 | 485 | 531 | 570 | 576 | 631 | 695 | 711 | 763 | 378 | 379 | 377 | 427 | 389 | 377 | 369 | 454 | 394 | 427 | 399 | 403 | 370 | 414 | 431 | 408 | 14 | 11704 |
| Mature B-cell leukaemia |  | 7 | 6 | 11 | 14 | 6 | 5 | 16 | 11 | 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 | 155 | 68 | 81 | 75 | 66 | 85 | 69 | 74 | 81 | 89 | 82 | 70 | 76 | 70 | 75 | 86 | 68 | 3 | 2250 |
| CML | 4 | 7 | 5 | 10 | 15 | 7 | 15 | 5 | 8 | 5 | 6 | 13 | 4 | 6 | 7 | 4 | 8 | 13 | 6 | 4 | 10 | 13 | 5 | 7 | 3 |  | 190 |
| MDS | 1 |  | 3 | 1 | 3 | 6 | 9 | 21 | 11 | 10 | 12 | 7 | 15 | 11 | 5 | 9 | 11 | 3 | 4 | 8 | 3 | 8 | 5 | 5 | 1 |  | 172 |
| JMML/CMML | 2 | 4 | 8 | 6 | 10 | 7 | 8 | 10 | 7 | 2 | 6 | 10 | 4 | 12 | 6 | 7 | 5 | 9 | 10 | 15 | 4 | 5 | 6 | 4 | 2 |  | 169 |
| Other and unspecified leukaemia | 5 | 5 | 6 | 3 | 6 | 5 | 8 | 4 | 5 | 6 | 2 | 7 | 5 | 3 |  | 3 | 5 | 2 | 4 | 4 | 4 | 2 | 5 | 3 | 5 | 1 | 108 |
| Hodgkin lymphoma | 58 | 78 | 90 | 84 | 110 | 72 | 74 | 105 | 95 | 65 | 57 | 61 | 59 | 64 | 69 | 82 | 100 | 55 | 84 | 82 | 79 | 70 | 80 | 78 | 57 | 2 | 1910 |
| NHL | 84 | 115 | 111 | 118 | 132 | 152 | 154 | 162 | 153 | 93 | 74 | 92 | 103 | 93 | 91 | 79 | 100 | 73 | 84 | 82 | 89 | 82 | 100 | 83 | 76 | 2 | 2577 |
| Other lymphoreticular | 5 | 10 | 6 | 3 | 2 | 2 | 3 | 2 |  | 1 |  |  |  | 1 |  |  | 2 |  | 1 | 1 | 1 |  |  |  | 1 |  | 41 |
| Ependymoma | 15 | 19 | 20 | 27 | 23 | 33 | 38 | 35 | 49 | 31 | 22 | 29 | 32 | 27 | 31 | 27 | 31 | 30 | 32 | 22 | 27 | 37 | 36 | 30 | 29 |  | 732 |
| Choroid plexus tumours | 2 |  | 3 | 7 | 2 | 5 | 8 | 10 | 20 | 7 | 10 | 12 | 6 | 10 | 10 | 10 | 8 | 10 | 12 | 13 | 12 | 10 | 12 | 11 | 9 |  | 219 |
| Low-grade astrocytoma | 33 | 58 | 32 | 60 | 86 | 86 | 115 | 133 | 206 | 127 | 109 | 129 | 128 | 132 | 130 | 166 | 126 | 129 | 127 | 143 | 139 | 146 | 141 | 134 | 118 | 2 | 2935 |
| High-grade astrocytoma | 6 | 11 | 8 | 20 | 17 | 27 | 38 | 48 | 48 | 34 | 28 | 25 | 26 | 25 | 19 | 22 | 28 | 30 | 23 | 33 | 18 | 24 | 25 | 16 | 25 | 2 | 626 |
| Unspecified astrocytoma | 11 | 2 | 13 | 8 | 9 | 9 | 7 | 18 | 27 | 6 | 2 | 3 | 4 |  | 3 | 5 | 6 | 2 | 4 | 3 | 2 | 3 | 4 | 18 | 14 |  | 183 |
| Medulloblastoma | 42 | 58 | 65 | 71 | 59 | 66 | 73 | 98 | 100 | 48 | 52 | 51 | 54 | 56 | 49 | 51 | 64 | 60 | 62 | 54 | 62 | 50 | 46 | 52 | 59 | 3 | 1505 |
| Other embryonal CNS |  | 1 | 4 | 7 | 14 | 25 | 33 | 35 | 31 | 18 | 18 | 18 | 22 | 25 | 18 | 22 | 20 | 15 | 15 | 23 | 30 | 13 | 21 | 31 | 20 | 1 | 480 |
| Other glioma | 23 | 25 | 24 | 37 | 38 | 40 | 56 | 53 | 46 | 36 | 30 | 35 | 39 | 37 | 41 | 45 | 35 | 39 | 40 | 26 | 50 | 46 | 43 | 43 | 33 | 1 | 961 |
| Pituitary adenoma and carcinoma |  | 1 | 1 |  |  |  | 2 | 2 | 1 | 4 |  | 1 |  | 2 | 2 | 2 | 2 | 4 | 3 | 4 | 6 | 3 | 5 | 2 | 5 |  | 52 |
| Craniopharyngioma | 10 | 6 | 5 | 4 | 9 | 10 | 13 | 22 | 28 | 20 | 21 | 14 | 18 | 18 | 20 | 13 | 19 | 17 | 21 | 19 | 20 | 17 | 27 | 17 | 16 |  | 404 |
| Pineal parenchymal tumours | 6 | 3 | 6 | 5 | 4 | 6 | 3 | 3 | 9 | 2 | 2 | 5 | 6 | 5 | 4 | 4 | 4 | 4 | 7 | 6 | 6 | 5 | 2 | 3 | 3 |  | 113 |
| Neuronal and neuronal-glial tumours | 1 | 1 | 2 | 1 | 1 | 3 | 3 | 8 | 21 | 12 | 14 | 23 | 16 | 15 | 20 | 11 | 19 | 9 | 20 | 32 | 28 | 16 | 27 | 15 | 18 |  | 336 |
| Meningioma | 1 | 2 | 2 |  | 1 | 2 | 4 | 7 | 9 | 3 | 3 | 4 | 8 |  | 1 | 2 | 1 | 4 | 3 | 4 | 6 | 2 | 7 | 4 | 1 |  | 81 |
| Unspecified CNS tumours | 8 | 4 | 8 | 3 | 7 | 3 | 5 | 5 | 7 | 13 | 2 | 5 | 7 | 6 | 3 | 4 | 8 | 8 | 10 | 9 | 6 | 10 | 13 | 13 | 9 |  | 176 |
| Neuroblastoma | 71 | 106 | 162 | 151 | 149 | 210 | 212 | 195 | 176 | 92 | 101 | 97 | 103 | 110 | 78 | 106 | 106 | 121 | 88 | 104 | 81 | 100 | 94 | 102 | 98 | 6 | 3019 |
| Other malignant peripheral nerve cell |  | 2 | 2 | 2 |  | 3 | 1 | 2 |  | 2 |  | 1 | 2 |  | 3 | 1 | 1 | 1 | 3 |  | 2 | 2 |  |  | 2 |  | 32 |
| Retinoblastoma | 5 | 13 | 14 | 42 | 66 | 74 | 75 | 92 | 109 | 39 | 36 | 43 | 31 | 35 | 42 | 35 | 52 | 42 | 43 | 33 | 41 | 46 | 38 | 42 | 25 |  | 1113 |
| Wilms Tumour | 77 | 97 | 111 | 132 | 130 | 158 | 164 | 146 | 166 | 66 | 83 | 88 | 82 | 66 | 81 | 91 | 98 | 86 | 87 | 83 | 77 | 81 | 83 | 76 | 76 | 2 | 2487 |
| Rhabdoid renal tumour |  | 2 | 6 | 4 | 3 | 4 | 3 | 5 | 4 | 1 | 4 | 5 | 2 | 3 | 1 | 3 | 4 | 5 | 5 | 3 | 5 | 4 | 1 | 2 | 3 |  | 82 |
| Renal sarcomas | 1 | 3 | 3 | 6 | 6 | 9 | 3 | 4 | 8 | 2 | 2 | 4 | 2 | 3 | 5 | 4 | 5 | 4 | 2 | 3 | 4 | 2 | 5 | 6 | 1 |  | 97 |
| Renal pPNET |  |  |  |  |  |  | 1 | 1 | 2 | 2 |  | 2 |  |  | 1 | 2 | 3 | 1 | 1 |  |  | 1 |  |  | 1 |  | 18 |
| 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 |
| Hepatoblastoma | 11 | 8 | 15 | 13 | 15 | 19 | 14 | 21 | 27 | 8 | 16 | 13 | 9 | 9 | 15 | 20 | 16 | 19 | 16 | 15 | 22 | 19 | 11 | 14 | 15 | 1 | 381 |
| Hepatic carcinoma | 2 | 2 | 3 | 6 | 2 | 7 | 4 | 3 | 4 | 2 | 2 | 2 | 2 | 5 | 2 | 1 | 2 | 2 | 7 | 2 |  | 4 | 3 |  | 2 |  | 71 |
| Unspecified malignant hepatic |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | 1 |  |  |  |  |  |  |  |  |  | 1 |
| Osteosarcoma | 12 | 36 | 42 | 33 | 38 | 42 | 35 | 39 | 66 | 47 | 36 | 30 | 28 | 34 | 32 | 34 | 44 | 35 | 28 | 34 | 35 | 29 | 54 | 32 | 33 | 3 | 911 |
| 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 | 40 | 27 | 24 | 20 | 21 | 27 | 25 | 37 | 31 | 42 | 27 | 19 | 30 | 22 | 27 | 20 | 23 |  | 802 |
| Other malignant bone | 4 | 3 | 3 | 4 | 4 | 1 | 2 | 1 | 3 | 3 |  | 3 | 2 | 3 | 1 | 3 | 1 | 3 | 1 | 3 |  | 1 | 2 |  | 1 |  | 52 |
| Rhabdomyosarcoma | 46 | 82 | 100 | 111 | 117 | 124 | 118 | 129 | 134 | 62 | 65 | 55 | 51 | 58 | 55 | 44 | 52 | 71 | 65 | 60 | 38 | 54 | 54 | 62 | 55 | 2 | 1864 |
| Fibrosarcoma, etc. | 4 | 2 | 15 | 4 | 9 | 7 | 8 | 8 | 4 | 3 | 1 | 5 | 1 | 3 | 4 | 4 | 1 | 1 | 6 | 3 | 4 | 1 | 9 | 6 | 7 |  | 120 |

TABLE 1.4 CCLG REGISTRATIONS FOR CHILDREN AGED UNDER 15, BY DIAGNOSTIC GROUP, 1977-2011

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 | 2011 | Total |
| MPNST | 1 | 1 | 2 | 3 | 1 | 3 | 5 | 5 | 3 | 6 | 3 | 4 | 3 | 6 | 2 | 3 | 1 | 5 | 4 | 2 | 2 | 3 | 3 | 2 | 2 |  | 75 |
| Kaposi sarcoma | 1 |  |  |  |  |  |  |  |  |  |  | 1 |  |  |  |  |  |  |  |  |  | 3 |  |  |  |  | 5 |
| Extraosseous ESFT | 2 | 7 | 4 | 8 | 10 | 15 | 20 | 29 | 30 | 16 | 14 | 22 | 17 | 13 | 15 | 21 | 19 | 18 | 19 | 10 | 15 | 11 | 16 | 16 | 16 |  | 383 |
| Extrarenal rhabdoid tumour |  |  |  |  | 2 | 2 | 3 | 3 | 6 | 3 | 4 | 2 |  | 3 |  | 2 |  | 2 | 1 | 3 | 3 | 6 | 8 | 11 | 4 |  | 68 |
| Fibrohistiocytic sarcomas | 1 | 1 | 5 |  | 1 | 3 | 3 | 2 | 4 | 1 |  |  | 2 | 2 | 1 | 2 | 3 |  | 1 | 2 |  |  | 3 | 4 | 2 |  | 43 |
| Synovial sarcoma |  | 3 | 2 | 2 | 3 | 6 | 5 | 6 | 12 | 9 | 1 | 5 | 6 | 9 | 5 | 5 | 7 | 4 | 8 | 4 | 8 | 7 | 7 | 7 | 4 |  | 135 |
| Other specified soft-tissue sarcomas | 5 | 9 | 4 | 6 | 6 | 9 | 6 | 10 | 13 | 11 | 3 | 7 | 1 | 4 | 8 | 11 | 7 | 4 | 8 | 5 | 10 | 5 | 7 | 2 | 1 |  | 162 |
| Unspecified soft-tissue sarcoma | 8 | 8 | 2 | 11 | 6 | 11 | 10 | 6 | 6 | 9 | 6 | 10 | 3 | 5 | 4 | 9 | 6 | 6 | 7 | 5 | 3 | 8 | 7 | 5 | 4 |  | 165 |
| Intracranial & intraspinal germ cell tumours | 6 | 10 | 9 | 9 | 16 | 9 | 12 | 35 | 29 | 9 | 20 | 9 | 11 | 18 | 16 | 17 | 14 | 19 | 17 | 14 | 16 | 22 | 13 | 17 | 17 |  | 384 |
| Other malignant extragonadal germ cell tumours | 11 | 8 | 18 | 10 | 11 | 26 | 24 | 14 | 22 | 9 | 13 | 7 | 12 | 12 | 12 | 14 | 15 | 11 | 15 | 17 | 17 | 13 | 16 | 15 | 16 |  | 358 |
| Gonadal germ cell tumours | 18 | 23 | 27 | 30 | 46 | 37 | 26 | 26 | 35 | 26 | 21 | 22 | 14 | 21 | 22 | 20 | 14 | 12 | 14 | 17 | 19 | 23 | 24 | 19 | 23 |  | 579 |
| 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 | 2 | 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 | 3 | 2 | 7 | 2 | 7 | 5 | 7 | 13 | 6 | 6 | 9 | 11 | 8 | 11 | 10 | 10 | 10 |  | 151 |
| Nasopharyngeal carcinoma | 4 | 6 | 7 | 5 | 5 | 5 | 1 | 7 | 3 | 3 | 4 | 2 | 3 | 3 | 3 | 1 |  | 5 | 4 | 1 | 5 | 4 | 2 | 3 | 1 |  | 87 |
| Malignant melanoma | 2 | 6 | 2 | 4 | 3 | 4 | 1 | 7 | 10 | 7 | 4 | 3 | 3 | 7 | 4 | 3 | 9 | 3 | 6 | 3 | 4 | 7 | 5 | 3 | 1 |  | 111 |
| Skin carcinoma | 1 | 1 | 1 |  | 1 |  |  |  | 2 |  |  | 1 | 2 |  | 1 |  |  | 1 |  | 2 | 1 | 1 |  |  | 1 |  | 16 |
| Other carcinomas | 5 | 2 | 7 | 8 | 4 | 10 | 8 | 4 | 11 | 6 | 9 | 6 | 7 | 5 | 6 | 4 | 8 | 1 | 8 | 6 | 5 | 7 | 7 | 4 | 9 |  | 157 |
| 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 |  |  | 28 |
| Lymphoproliferative disease |  |  | 1 |  |  |  |  |  | 1 | 4 | 3 | 3 | 3 | 4 | 4 | 3 | 3 | 4 | 3 | 4 |  | 1 | 3 | 1 |  | 1 | 46 |
| LCH single system | 10 | 15 | 20 | 22 | 27 | 26 | 30 | 33 | 47 | 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 | 17 | 5 | 6 | 11 | 10 | 9 | 8 | 7 | 8 | 3 | 9 | 3 | 3 | 2 | 12 | 8 | 1 |  | 266 |
| LCH unspecified | 2 |  | 2 |  |  | 4 | 1 |  |  | 4 | 2 |  |  | 1 |  |  | 2 |  | 4 | 4 | 1 | 3 | 4 | 34 | 33 |  | 101 |
| HLH | 3 | 2 |  | 2 | 3 | 2 | 6 | 6 | 12 | 9 | 5 | 10 | 5 | 14 | 4 | 5 | 6 | 13 | 6 | 11 | 18 | 10 | 14 | 14 | 8 |  | 188 |
| Ganglioneuroma | 1 | 1 | 3 | 7 | 7 | 6 | 13 | 10 | 9 | 7 | 3 | 6 | 10 | 7 | 12 | 10 | 5 | 12 | 5 | 9 | 5 | 4 | 10 | 11 | 2 |  | 175 |
| Other non-malignant peripheral nervous cell |  |  | 3 | 1 | 2 | 3 | 5 | 2 | 3 | 3 | 4 | 6 | 5 | 2 |  | 2 | 2 | 4 | 2 | 2 | 2 | 3 | 1 | 4 | 5 |  | 66 |
| Non-malignant embryonal renal | 2 | 6 | 7 | 11 | 6 | 5 | 5 | 9 | 12 | 7 | 5 | 3 | 7 | 7 | 4 | 3 | 6 | 7 | 4 | 5 | 9 | 11 | 5 | 7 | 14 |  | 167 |
| Non-malignant bone |  | 1 | 1 | 1 | 5 | 3 | 3 | 3 | 4 | 2 | 2 | 1 | 1 | 5 | 1 | 3 | 1 | 5 | 2 | 4 | 1 | 2 | 4 | 6 | 7 |  | 68 |
| Fibromatosis |  |  | 1 | 4 | 3 | 4 | 6 | 7 | 10 | 3 | 6 | 10 | 4 | 5 | 7 | 5 | 6 | 10 | 5 | 5 | 4 | 3 | 10 | 8 | 7 |  | 133 |
| NF & neurofibromatosis |  | 3 | 4 | 3 | 4 | 13 | 8 | 9 | 11 | 11 | 6 | 5 | 11 | 12 | 7 | 8 | 7 | 12 | 7 | 2 | 9 | 10 | 12 | 6 | 12 |  | 192 |
| Other non-malignant soft-tissue | 3 | 3 | 8 | 4 | 12 | 9 | 8 | 13 | 22 | 8 | 6 | 11 | 22 | 14 | 19 | 11 | 14 | 11 | 15 | 20 | 19 | 30 | 35 | 24 | 39 |  | 380 |
| Non-CNS non-gonadal non-malignant germ cell | 5 | 10 | 17 | 8 | 13 | 10 | 13 | 17 | 27 | 16 | 16 | 7 | 13 | 15 | 18 | 13 | 18 | 13 | 19 | 10 | 13 | 24 | 18 | 23 | 16 |  | 372 |
| Gonadal non-malignant germ-cell | 1 | 1 | 6 | 4 | 7 | 6 | 17 | 12 | 13 | 12 | 15 | 14 | 13 | 15 | 16 | 18 | 11 | 20 | 14 | 12 | 17 | 13 | 21 | 14 | 14 |  | 306 |
| Other non-malignant gonadal | 1 |  | 2 | 2 |  | 2 | 3 | 5 | 7 | 4 | 8 | 4 | 4 | 8 | 5 | 6 | 4 | 7 | 5 | 4 | 6 | 8 | 7 | 7 | 12 |  | 121 |
| Adrenocortical adenoma |  | 2 | 2 | 2 |  |  | 1 | 2 | 2 | 2 | 3 | 3 | 1 | 3 | 1 |  | 3 | 2 | 2 | 4 | 2 | 2 | 2 | 2 | 1 |  | 44 |
| Other non-malignant |  | 1 | 3 | 2 | 4 | 4 | 7 | 5 | 7 | 3 | 12 | 7 | 16 | 6 | 12 | 10 | 10 | 4 | 8 | 11 | 6 | 9 | 13 | 14 | 7 |  | 181 |
| Total | 1087 | 1548 | 1795 | 1921 | 2088 | 2306 | 2475 | 2645 | 2957 | 1595 | 1557 | 1616 | 1641 | 1661 | 1593 | 1669 | 1821 | 1695 | 1726 | 1670 | 1694 | 1675 | 1830 | 1764 | 1612 | 46 | 45687 |

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 | 37 | 9 | 2 | 20 | 3 | 7 | 12 | 3 | 1 | 1 | 6 | 178 |
| Birmingham | 244 | 64 | 163 | 40 | 79 | 41 | 11 | 25 | 45 | 25 | 17 |  | 70 | 824 |
| Bristol | 124 | 43 | 109 | 29 | 2 | 33 | 5 | 15 | 24 | 15 | 11 | 2 | 48 | 460 |
| Cambridge | 128 | 39 | 109 | 23 | 4 | 23 | 3 | 12 | 32 | 13 | 4 | 1 | 30 | 421 |
| Cardiff | 80 | 22 | 57 | 13 | 2 | 13 | 1 | 8 | 19 | 9 | 2 | 1 | 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 | 112 | 899 |
| Glasgow | 112 | 39 | 56 | 19 | 2 | 12 | 4 | 16 | 34 | 4 | 2 | 1 | 14 | 315 |
| Leeds | 144 | 61 | 100 | 24 | 4 | 19 | 5 | 20 | 23 | 15 | 8 |  | 54 | 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 | 136 | 32 | 3 | 40 | 6 | 30 | 37 | 17 | 13 | 1 | 65 | 614 |
| Middlesex/UCLH | 55 | 40 | 4 | 4 |  | 5 | 1 | 59 | 13 | 3 | 4 |  | 5 | 193 |
| Newcastle | 115 | 43 | 120 | 25 | 5 | 17 | 6 | 15 | 30 | 13 | 10 |  | 25 | 424 |
| Nottingham | 67 | 34 | 101 | 13 |  | 7 | 1 | 9 | 13 | 5 | 3 | 1 | 25 | 279 |
| Oxford | 101 | 25 | 91 | 24 |  | 22 | 1 | 11 | 21 | 6 | 6 |  | 18 | 326 |
| Royal Marsden | 152 | 73 | 141 | 36 |  | 40 | 9 | 16 | 26 | 18 | 10 |  | 13 | 534 |
| Sheffield | 81 | 26 | 69 | 15 | 11 | 18 | 4 | 14 | 12 | 12 | 7 |  | 25 | 294 |
| Southampton | 114 | 33 | 68 | 22 |  | 26 | 6 | 16 | 27 | 14 | 5 |  | 26 | 357 |
| Total | 2594 | 825 | 1886 | 531 | 205 | 499 | 101 | 345 | 521 | 232 | 124 | 12 | 706 | 8581 |

TABLE 1.5(ii) CCLG REGISTRATIONS FOR CHILDREN AGED UNDER 15, BY CENTRE AND DIAGNOSTIC GROUP, 2006-2011

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Centre | Leukaemia | Lymphomas | CNS | SNS | Retino- blastoma | Renal | Hepatic | Bone | Soft tissue sarcoma | Germ-cell etc | Epithelial | Other malignant | Other non- malignant | **Total** |
| Aberdeen | 13 | 4 | 10 | 7 |  | 4 | 1 | 2 | 4 | 1 |  | 1 | 5 | 52 |
| Belfast | 59 | 27 | 33 | 9 | 8 | 7 | 5 | 7 | 13 | 6 | 3 |  | 2 | 179 |
| Birmingham | 228 | 67 | 172 | 29 | 97 | 37 | 8 | 22 | 44 | 26 | 11 | 1 | 93 | 835 |
| Bristol | 142 | 39 | 115 | 37 | 4 | 24 | 6 | 27 | 41 | 20 | 9 |  | 48 | 512 |
| Cambridge | 161 | 45 | 114 | 32 | 6 | 28 | 2 | 11 | 33 | 27 | 9 | 1 | 93 | 562 |
| Cardiff | 98 | 16 | 77 | 14 | 1 | 13 | 2 | 9 | 23 | 6 | 8 |  | 29 | 296 |
| Dublin | 185 | 53 | 133 | 46 | 13 | 35 | 7 | 13 | 43 | 15 | 4 | 2 | 40 | 589 |
| Edinburgh | 65 | 10 | 60 | 11 | 1 | 13 | 1 | 6 | 8 | 3 | 3 |  | 30 | 211 |
| GOS | 252 | 61 | 266 | 62 | 9 | 64 | 11 | 2 | 47 | 28 | 3 | 1 | 125 | 931 |
| Glasgow | 109 | 27 | 70 | 22 | 5 | 14 | 4 | 15 | 25 | 11 | 3 |  | 46 | 351 |
| Leeds | 117 | 46 | 91 | 34 | 2 | 18 | 7 | 21 | 24 | 23 | 6 |  | 50 | 439 |
| Leicester | 62 | 11 | 7 | 7 | 2 | 5 |  | 5 | 10 |  | 2 |  | 14 | 125 |
| Liverpool | 112 | 40 | 103 | 21 | 9 | 15 | 4 | 17 | 22 | 15 | 5 | 1 | 49 | 413 |
| Manchester | 149 | 60 | 122 | 30 | 5 | 22 | 6 | 25 | 38 | 17 | 10 |  | 70 | 554 |
| Middlesex/UCLH | 33 | 36 | 14 | 2 |  | 1 |  | 51 | 16 | 11 | 10 |  | 13 | 187 |
| Newcastle | 104 | 35 | 103 | 25 | 2 | 16 | 2 | 18 | 22 | 13 | 10 |  | 33 | 383 |
| Nottingham | 89 | 44 | 101 | 13 | 3 | 27 | 7 | 9 | 15 | 11 | 4 | 1 | 17 | 341 |
| Oxford | 110 | 35 | 92 | 18 | 7 | 13 | 2 | 10 | 11 | 12 | 4 |  | 37 | 351 |
| Royal Marsden | 227 | 76 | 151 | 38 |  | 43 | 7 | 15 | 37 | 17 | 11 | 3 | 28 | 653 |
| Sheffield | 93 | 35 | 62 | 12 | 3 | 17 | 3 | 9 | 13 | 5 | 4 |  | 36 | 292 |
| Southampton | 119 | 33 | 64 | 18 | 15 | 26 | 6 | 18 | 18 | 10 | 5 | 1 | 32 | 365 |
| Total | 2527 | 800 | 1960 | 487 | 192 | 442 | 91 | 312 | 507 | 277 | 124 | 12 | 890 | 8621 |

**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 CCLG (formerly UKCCSG) registrations 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 with a CCLG registration who 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 1998-2002, 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 85% 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 and Scotland 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 2008-2011. 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 by Cancer Network (England and Wales)**

Since 2001, England has been covered by Cancer Networks, numbering 28 at the end of 2011, whose areas are each comprised of those of several Primary Care Trusts. A further three Cancer Networks cover Wales. Table 2.6 shows the CCLG centres from which children resident in each Cancer Network area were registered during 2001-2010. Retinoblastoma is excluded from this table because many children are registered from the two supraregional referral centres for this tumour. Thirteen of the 28 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 2006-2010 there were a number of changes in referral from 2001-2005, many of which were direct, or presumed indirect, consequences of the cessation of paediatric oncology at Barts/RLH. In 2001-2005, Barts/RLH accounted for 37% of referrals in NE London and 6-11% of those in North London and Essex. In 2006-2010, those components of referral seem largely to have moved to GOS in North East and North London and to UCLH in Essex. For NW London, GOS and UCLH both saw increases in registrations while registration of children from this Network ceased at Royal Marsden. The increase in referrals to GOS from the Networks mentioned above was offset by reductions in referrals from Anglia (with corresponding increase at Cambridge) and from SE London, 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.

**Referral by Health Board (Scotland)**

Table 2.7 shows CCLG centre of non-retinoblastoma registrations by Health Board for 2001-2010. 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 neuroblastoma etc., 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 | 69 | 81 | 86 | 92 | 94 | 96 |
|  | Lymphoid | 70 | 83 | 88 | 92 | 95 | 98 |
|  | AML | 71 | 81 | 87 | 98 | 96 | 95 |
|  | CML | 43 | 66 | 68 | 69 | 75 | 95 |
|  | JMML/CMML | 65 | 100 | 100 | 100 | 94 | 98 |
|  | Myelodysplasia | - | - | 78 | 70 | 69 | 63 |
|  | Other & unspecified | 43 | 31 | 38 | 63 | 79 | 67 |
|  |  |  |  |  |  |  |  |
| II | Lymphomas | 69 | 78 | 84 | 91 | 92 | 91 |
|  | Hodgkin lymphoma | 64 | 71 | 77 | 89 | 93 | 96 |
|  | NHL & other lymphoma | 74 | 83 | 88 | 92 | 92 | 88 |
|  |  |  |  |  |  |  |  |
| III | CNS etc | 32 | 41 | 56 | 77 | 89 | 89 |
|  | Choroid plexus tumours | 16 | 44 | 59 | 88 | 89 | 95 |
|  | Ependymoma | 30 | 47 | 63 | 90 | 93 | 93 |
|  | Astrocytoma | 26 | 40 | 55 | 82 | 90 | 91 |
|  | Embryonal | 49 | 56 | 71 | 94 | 98 | 96 |
|  | Other gliomas | 31 | 39 | 55 | 81 | 92 | 92 |
|  | Craniopharyngioma | 22 | 15 | 40 | 72 | 86 | 92 |
|  | Other CNS | 27 | 21 | 27 | 55 | 62 | 69 |
|  |  |  |  |  |  |  |  |
| IV | SNS etc | 79 | 93 | 95 | 99 | 99 | 98 |
|  | Neuroblastoma | 81 | 93 | 95 | 99 | 99 | 98 |
|  |  |  |  |  |  |  |  |
| V | Retinoblastoma | 10 | 68 | 84 | 94 | 92 | 91 |
|  |  |  |  |  |  |  |  |
| VI | Renal tumours | 75 | 91 | 93 | 97 | 98 | 99 |
|  | Wilms’ tumour etc | 75 | 91 | 93 | 97 | 99 | 99 |
|  | Renal carcinoma | - | - | - | 83 | - | 73 |
|  |  |  |  |  |  |  |  |
| VII | Hepatic tumours | 65 | 75 | 83 | 96 | 93 | 95 |
|  | Hepatoblastoma | 71 | 83 | 91 | 98 | 97 | 100 |
|  | Hepatic carcinoma | 45 | 53 | 63 | - | 71 | 88 |
|  |  |  |  |  |  |  |  |
| VIII | Bone tumours | 48 | 66 | 66 | 91 | 94 | 95 |
|  | Osteosarcoma | 41 | 58 | 57 | 92 | 95 | 96 |
|  | Ewing sarcoma of bone | 59 | 78 | 83 | 97 | 97 | 98 |
|  | All other malignant bone | 33 | 48 | 25 | 53 | 63 | 50 |
|  |  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |

* 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 | 81 | 84 | 88 | 89 | 88 |
|  | Rhabdomyosarcoma | 77 | 90 | 94 | 98 | 98 | 98 |
|  | Fibrosarcoma etc | 51 | 49 | 61 | 63 | 72 | 68 |
|  | Extraosseous ESFT | 85 | 88 | 89 | 96 | 99 | 97 |
|  | Synovial sarcoma | 33 | 60 | 75 | 81 | 82 | 78 |
|  | All other specified | 47 | 50 | 55 | 68 | 59 | 67 |
|  | Unspecified | 40 | 73 | 74 | 78 | 75 | 75 |
|  |  |  |  |  |  |  |  |
| X | Germ-cell and gonadal | 49 | 63 | 71 | 84 | 87 | 86 |
|  | CNS germ-cell | 39 | 36 | 63 | 88 | 85 | 95 |
|  | Other non-gonadal  germ cell | 69 | 94 | 82 | 85 | 92 | 85 |
|  | Malignant gonadal germ-cell | 50 | 76 | 75 | 81 | 86 | 80 |
|  | All other malignant gonadal | - | 21 | - | - | - | - |
|  |  |  |  |  |  |  |  |
| XI | Epithelial | 27 | 19 | 23 | 27 | 41 | 42 |
|  | Adrenocortical  Carcinoma | 77 | 42 | - | - | 100 | - |
|  | Thyroid carcinoma | 21 | 19 | 36 | 41 | 56 | 69 |
|  | Nasopharyngeal  Carcinoma | 58 | 86 | 58 | 92 | - | 95 |
|  | Malignant melanoma | 10 | 6 | 11 | 13 | 33 | 28 |
|  | Skin carcinoma | 9 | 2 | 0 | 5 | 4 | 5 |
|  | Other carcinoma | 29 | 22 | 28 | 35 | 39 | 39 |
|  |  |  |  |  |  |  |  |
| XII | Other & unspecified | 33 | 43 | 15 | 13 | 33 | 17 |
|  |  |  |  |  |  |  |  |
|  | Total | 57 | 69 | 76 | 87 | 90 | 91 |

- 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 | 90 | 93 | 93 |
|  |  |  |  |  |  |  |
| 10-12 | 54 | 63 | 68 | 81 | 88 | 86 |
|  |  |  |  |  |  |  |
| 13-14 | 35 | 45 | 51 | 70 | 79 | 83 |
|  |  |  |  |  |  |  |
| Total | 57 | 69 | 76 | 87 | 90 | 91 |

**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 | 48 | 75 | 82 | 88 | 92 | 92 |
| West Midlands | 55 | 75 | 83 | 92 | 95 | 95 |
| East of England | 58 | 65 | 74 | 89 | 92 | 91 |
| London | 50 | 59 | 62 | 81 | 85 | 88 |
| South East Coast | 53 | 64 | 68 | 81 | 88 | 86 |
| South Central | 40 | 46 | 57 | 79 | 88 | 88 |
| South West | 52 | 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 | 43 | 74 | 75 | 83 | 87 | 91 |
| Great Britain | 57 | 69 | 76 | 87 | 90 | 91 |
| N Ireland |  |  |  | 60 | 63 | 72 |
| UK |  |  |  | 86 | 90 | 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

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 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 |  |  |  |  |  |  |  |  |  |  |  | 148 |  |  |  |  |  | 148 |
| Barts/RLH | 8 | 38 | 24 | 29 | 14 | 201 | 241 | 106 | 79 | 27 | 19 | 8 | 12 | 2 |  | 7 | 5 | 820 |
| Belfast |  | 1 |  |  |  |  |  |  | 1 |  |  |  | 405 |  |  |  |  | 407 |
| Birmingham | 1 | 5 |  | 68 | 1536 | 3 | 2 | 1 | 5 | 5 | 18 | 1 | 1 |  |  | 1 |  | 1647 |
| Bristol |  |  |  | 1 | 3 |  | 1 |  | 7 | 960 | 4 |  |  | 2 |  | 1 | 3 | 982 |
| Cambridge |  |  |  | 16 |  | 417 |  |  | 4 |  |  |  |  |  |  |  | 1 | 438 |
| Cardiff |  | 1 |  |  |  |  |  |  |  | 1 | 526 |  |  |  |  |  |  | 528 |
| Dublin |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | 722 |  | 722 |
| Edinburgh | 2 | 1 |  |  |  |  |  |  |  |  |  | 335 |  |  |  |  | 2 | 340 |
| Glasgow |  |  | 1 |  | 1 |  | 1 |  |  |  |  | 788 |  |  |  | 2 | 1 | 794 |
| GOS |  | 2 | 2 | 40 | 2 | 575 | 770 | 460 | 155 | 33 |  | 1 |  | 10 |  | 1 | 31 | 2082 |
| Leeds | 8 | 6 | 987 | 4 |  |  |  |  |  |  |  |  |  |  |  |  | 1 | 1006 |
| Leicester |  |  |  | 221 | 1 | 1 |  |  |  |  |  | 1 |  |  |  |  |  | 224 |
| Liverpool |  | 565 | 1 |  | 3 |  |  |  |  |  | 145 |  |  |  | 22 |  | 2 | 738 |
| Manchester |  | 1279 | 6 | 27 | 2 |  | 1 |  | 1 |  | 4 |  |  |  |  |  |  | 1320 |
| Middlesex/UCLH |  |  |  | 1 |  | 7 | 15 | 5 |  |  |  |  |  |  |  |  |  | 28 |
| Newcastle | 753 | 104 | 12 | 1 |  |  |  |  |  |  |  | 3 |  |  |  |  |  | 873 |
| Nottingham |  |  | 6 | 469 | 1 | 1 |  | 1 |  |  |  |  |  |  |  |  |  | 478 |
| Oxford |  |  |  | 3 | 1 |  |  |  | 35 | 1 |  |  |  |  |  |  |  | 40 |
| Royal Marsden |  | 1 | 1 | 6 | 5 | 23 | 296 | 312 | 88 | 13 | 2 | 1 |  | 1 |  | 11 | 1 | 761 |
| Sheffield |  |  | 446 | 142 |  |  |  |  |  |  |  | 1 |  |  |  |  | 2 | 591 |
| Southampton |  |  |  |  | 1 | 1 | 1 | 16 | 364 | 131 |  |  |  | 17 |  |  | 4 | 535 |
| **Total** | 772 | 2003 | 1486 | 1028 | 1570 | 1229 | 1328 | 901 | 739 | 1171 | 718 | 1287 | 418 | 32 | 22 | 745 | 53 | 15502 |

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

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 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 |  |  |  |  |  |  |  |  |  |  |  | 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 |  | 222 |  |  |  |  |  | 1 | 224 |
| 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 | 320 | 595 | 181 | 12 | 5 | 395 | 16 | 7722 |

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

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 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 | 667 | 1 | 2 | 1 | 3 | 7 | 12 | 3 | 1 |  |  |  |  | 757 |
| 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 | 711 | 699 | 955 | 539 | 476 | 605 | 387 | 627 | 164 | 14 | 7 | 524 | 3 | 8381 |

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

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 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 |  |  |  |  |  |  |  |  |  |  |  | 62 |  |  |  |  |  | 62 |
| Barts/RLH |  | 4 | 2 | 1 |  | 14 | 54 | 8 | 4 | 3 | 1 | 1 | 1 |  |  |  |  | 93 |
| Belfast |  |  |  |  |  |  | 1 |  |  |  |  |  | 186 |  |  |  |  | 187 |
| Birmingham | 11 | 17 | 7 | 62 | 695 | 4 | 1 |  | 4 | 8 | 17 | 12 |  |  |  | 1 |  | 839 |
| Bristol |  |  |  |  | 6 | 1 |  | 1 |  | 458 | 1 |  |  |  |  |  |  | 467 |
| Cambridge |  |  |  | 14 |  | 455 | 2 | 2 | 2 |  |  |  |  |  |  |  |  | 475 |
| Cardiff | 1 |  |  |  |  |  |  |  |  | 2 | 260 |  |  |  |  |  |  | 263 |
| Dublin |  |  |  |  |  | 1 |  |  |  |  |  |  |  |  |  | 582 |  | 583 |
| Edinburgh | 1 |  |  |  |  |  |  |  |  |  |  | 236 |  |  |  |  |  | 237 |
| Glasgow |  |  |  |  |  |  |  |  | 1 |  |  | 311 |  |  |  |  |  | 312 |
| GOS |  | 2 | 2 | 3 | 1 | 209 | 579 | 122 | 11 |  | 1 | 2 | 2 | 1 |  | 3 |  | 938 |
| Leeds | 1 | 2 | 438 | 2 |  | 1 |  |  |  |  |  |  |  |  |  |  | 1 | 445 |
| Leicester |  |  |  | 121 | 7 | 3 |  | 1 |  |  |  |  |  |  |  |  |  | 132 |
| Liverpool |  | 339 |  |  | 6 |  |  |  |  |  | 86 |  |  |  | 13 |  | 1 | 445 |
| Manchester |  | 565 |  | 9 | 3 |  |  |  |  |  | 2 |  |  |  |  |  |  | 579 |
| Middlesex/UCLH |  |  |  |  |  | 42 | 126 | 21 | 4 | 1 |  |  |  |  |  |  |  | 194 |
| Newcastle | 350 | 40 | 7 |  | 1 |  |  |  |  |  |  | 1 |  |  |  |  | 1 | 400 |
| Nottingham |  |  |  | 271 | 17 |  |  |  |  |  |  |  |  |  |  |  |  | 288 |
| Oxford |  | 1 |  | 21 | 3 | 5 | 5 |  | 285 | 35 |  |  |  |  |  |  | 1 | 356 |
| Royal Marsden |  |  |  |  |  | 2 | 184 | 304 | 30 |  |  |  |  |  |  |  |  | 520 |
| Sheffield | 1 |  | 224 | 63 | 1 | 1 |  |  | 1 |  |  |  |  |  |  |  |  | 291 |
| Southampton |  |  |  |  |  |  | 1 | 23 | 212 | 104 |  |  |  | 11 |  |  |  | 351 |
| **Total** | 365 | 970 | 680 | 567 | 740 | 738 | 953 | 482 | 554 | 611 | 368 | 625 | 189 | 12 | 13 | 586 | 4 | 8457 |

Table 2.5(v) Region of residence by centre for children in CCLG Register 2008-2011

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 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 |  |  |  |  |  |  |  |  |  |  |  | 34 |  |  |  |  |  | 34 |
| Barts/RLH |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Belfast |  |  |  |  |  |  |  |  |  |  |  |  | 108 |  |  |  |  | 108 |
| Birmingham | 3 | 14 | 16 | 38 | 414 |  |  |  | 4 | 3 | 11 | 3 |  |  |  |  | 1 | 507 |
| Bristol |  |  |  |  |  |  |  |  |  | 311 | 1 |  |  |  |  |  |  | 312 |
| Cambridge |  |  |  | 4 | 1 | 327 | 4 | 1 |  |  |  |  |  |  |  |  |  | 337 |
| Cardiff |  |  |  |  |  |  |  |  |  | 1 | 174 |  |  |  |  |  |  | 175 |
| Dublin |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | 354 |  | 354 |
| Edinburgh |  |  |  |  |  |  |  |  |  | 1 |  | 127 |  |  |  |  |  | 128 |
| Glasgow |  |  |  |  |  |  |  |  |  |  |  | 231 |  |  |  |  |  | 231 |
| GOS |  | 1 | 1 | 3 | 1 | 126 | 337 | 48 | 10 | 2 | 1 | 1 | 1 | 1 |  |  |  | 533 |
| Leeds |  | 2 | 237 |  |  |  | 1 |  |  |  |  |  |  |  |  |  |  | 240 |
| Leicester |  |  |  | 58 | 5 | 2 | 1 |  |  |  |  |  |  |  |  |  |  | 66 |
| Liverpool |  | 168 |  | 1 | 9 |  |  |  |  |  | 60 |  |  |  | 5 | 2 |  | 245 |
| Manchester |  | 325 | 3 | 7 | 2 |  |  |  | 1 |  |  |  |  |  |  |  |  | 338 |
| Middlesex/UCLH |  |  |  |  |  | 34 | 51 | 16 | 1 |  |  |  |  |  |  |  |  | 102 |
| Newcastle | 198 | 19 | 6 |  |  |  |  |  |  |  |  | 1 |  |  |  |  |  | 224 |
| Nottingham |  |  | 1 | 205 | 8 | 1 |  |  |  |  |  |  |  |  |  |  |  | 215 |
| Oxford |  |  |  | 5 | 1 | 7 | 5 | 1 | 161 | 24 |  |  |  |  |  |  |  | 204 |
| Royal Marsden |  |  |  |  |  | 7 | 163 | 251 | 13 |  |  |  |  |  |  |  |  | 434 |
| Sheffield |  |  | 129 | 32 | 1 |  |  |  |  |  |  |  |  |  |  |  |  | 162 |
| Southampton |  |  |  |  |  |  |  | 14 | 126 | 70 |  |  |  | 19 |  |  |  | 229 |
| **Total** | 201 | 529 | 393 | 353 | 442 | 504 | 562 | 331 | 316 | 412 | 247 | 397 | 109 | 20 | 5 | 356 | 1 | 5178 |

**Table 2.6 CCLG registrations for all diagnoses except retinoblastoma by Cancer Network and CCLG centre, 2001-2005 and 2006-2010. 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 registrations** | |
|  |  | **2001-2005** | **2006-2010** |
| Lancashire & South Cumbria | Manchester | 86 | 93 |
|  | Liverpool | 10 | 6 |
| Greater Manchester & Cheshire | Manchester | 91 | 93 |
|  | Liverpool | 9 | 7 |
| Merseyside & Cheshire | Liverpool | 99 | 99 |
| North of England | Newcastle | 97 | 98 |
| Yorkshire | Leeds | 98 | 98 |
| Humber & Yorkshire Coast | Leeds | 68 | 77 |
|  | Sheffield | 31 | 23 |
| North Trent | Sheffield | 94 | 93 |
| Greater Midlands | Birmingham | 92 | 91 |
| Pan Birmingham | Birmingham | 98 | 99 |
| Arden (Warwickshire) | Birmingham | 92 | 92 |
| East Midlands | Nottingham | 53 | 61 |
|  | Leicester | 22 | 22 |
|  | Birmingham | 15 | 10 |
| Anglia | Cambridge | 74 | 83 |
|  | GOS | 18 | 12 |
| Essex | GOS | 74 | 71 |
|  | UCLH | 12 | 22 |
|  | Barts/RLH | 11 |  |
| Mount Vernon (Beds, Herts) | GOS | 52 | 44 |
|  | Cambridge | 36 | 43 |
|  | UCLH | 11 | 8 |
| NW London | GOS | 73 | 83 |
|  | UCLH | 13 | 12 |
|  | R Marsden | 8 |  |
| North London | GOS | 72 | 86 |
|  | UCLH | 23 | 10 |
|  | Barts/RLH | 6 |  |
| NE London | GOS | 50 | 82 |
|  | Barts/RLH | 37 |  |
|  | UCLH | 12 | 15 |
| SE London | GOS | 50 | 31 |
|  | R Marsden | 34 | 61 |
|  | UCLH | 13 | 7 |
| SW London | R Marsden | 65 | 74 |
|  | GOS | 30 | 22 |
| Peninsula (Devon, Cornwall) | Bristol | 98 | 99 |
| Dorset | Southampton | 96 | 96 |
| Avon, Somerset & Wilts | Bristol | 88 | 84 |
|  | Oxford | 10 | 12 |
| Three Counties (Herefs, Worcs, Gloucs) | Bristol | 49 | 52 |
|  | Birmingham | 47 | 42 |
| Thames Valley | Oxford | 91 | 92 |
| Central South Coast | Southampton | 93 | 97 |
| Surrey, W Sussex & Hants | R Marsden | 72 | 78 |
|  | GOS | 18 | 17 |
|  | Southampton | 5 |  |
| Sussex | R Marsden | 67 | 80 |
|  | GOS | 22 | 13 |
|  | Southampton | 7 |  |
| Kent & Medway | R Marsden | 51 | 65 |
|  | GOS | 39 | 24 |
|  | UCLH | 7 | 9 |
| North Wales | Liverpool | 97 | 100 |
| Mid & West Wales | Cardiff | 91 | 88 |
|  | Birmingham | 8 | 9 |
| SE Wales | Cardiff | 99 | 98 |

**Table 2.7 CCLG registrations for all diagnoses except retinoblastoma by Scottish Health Board and CCLG centre, 2001-2010. 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 | 75 |
|  | Edinburgh | 13 |
|  | Aberdeen | 11 |
| Grampian | Aberdeen | 89 |
|  | Edinburgh | 7 |
| Tayside | Edinburgh | 99 |
| Fife | Edinburgh | 100 |
| Lothian | Edinburgh | 98 |
| Borders | Edinburgh | 93 |
| Central (Forth Valley) | Glasgow | 69 |
|  | Edinburgh | 29 |
| Argyll & Clyde | Glasgow | 99 |
| Greater Glasgow | Glasgow | 100 |
| Lanark | Glasgow | 95 |
| Ayrshire & Arran | Glasgow | 100 |
| Dumfries & Galloway | Glasgow | 79 |
|  | Edinburgh | 17 |
| Orkney | Aberdeen | 67 |
|  | Glasgow | 17 |
|  | Edinburgh | 17 |
| Shetland | Aberdeen | 83 |
|  | Edinburgh | 17 |
| 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** | **UKCCSG/CCLG** | | **UKCCSG** | **Cancer registrations** |
|  | **2001-2007** | | **1994-2000** | **1994-2000** |
|  | **Total** | **Annual** | **Annual** | **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 from Great Britain who were diagnosed during 1973-2007 and included in the National Registry of Childhood Tumours. Most survivors have been followed up until the end of August 2011. 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 these 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 (21%) 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 (29%), retinoblastoma (43%) and hepatic tumours (46%) and in 2003-07 for leukaemia (29%). The largest reduction for renal tumours was in 1998-2002 (36%), but this was followed by a rise of 36% 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 14%. 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 1978-2009

Tables 3.2-3.4 and Figures 3.12-3.132 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 (1978-89, 1990-94, 1995-99, 2000-2004, 2005-2009) while for the remainder they are shown for two periods (1978-99, 2000-2009). 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 3.13-3.41, 3.48-3.99). 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 3.42-3.45. 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 3.46 and 3.47 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 3.100-3.132. In the keys to these graphs, calendar periods with no trial open are shown in brackets.

Results for ALL are presented separately according to Down syndrome (DS) 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. DS is an adverse prognostic factor in ALL, and DS have sometimes been less likely to be entered in national trials.

Among non-DS children with precursor-cell ALL, survival of infants remained fairly constant throughout 1978-88. Survival increased successively thereafter and in 2006 onwards, the era of the INTERFANT 2005 trial, five-year survival exceeded 60% for the first time.

Survival of older non-DS 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 DS 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 DS and non-DS 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 2003-09 (era of ALL 2003) one-year survival increased to 86% and five-year survival was 68%.

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 (1985-89 and 1990-95), five-year survival increased dramatically from 40% to 69%. Five-year survival since 1996 has been above 75%.

For AML, survival has also been analysed separately for children with and without DS. Among non-DS children, survival has increased steadily since 1983. During 2005 onwards (era of AML15), five year survival was 68%. Survival of DS 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-DS patients, but during 1995-2002 (AML 12), DS children had the better prognosis, with five-year survival of 74% compared with 61% for non-DS children. This improvement was maintained during 2003-09, with five-year survival reaching 83%. From the mid 1990s onwards, DS 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 in 1982; 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 2004-2009 (era of the 2004/08 trial and subsequent non-trial period), when five-year survival was over 85% 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. During 1992-2005, children under 3 years of age were eligible for the infant brain tumour study, and 5-year survival in that period was 54%. Survival of older children with ependymoma has also increased, exceeding 70% during 1999 onwards.

Survival from low-grade astrocytoma was higher during the era of LGG-1 (1997-2003) than previously. The small further increase since then was non-significant.

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. Five-year survival in 1992-2000 (era of the international PNET-3 trial) was 62%; it increased further, to 67%, during 2001-09, which included the era of PNET-4.

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 (1992-98) was hardly different from earlier years. Five-year survival rose to 90% during 1999-2004 (1999 03 study era), followed by a non-significant decrease to 82% during 2005-09. 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 55% 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 most recent SIOP trial (2002 onwards) the risk of death within one year from diagnosis was 3.3%, a one-third reduction from the one-year mortality rate of 5.0% 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 (1990-94) were substantially higher than before but there was no further increase in the period of SIOPEL-2 (1995-97). Survival has increased again since the opening of SIOPEL-3 in 1998, with five year survival reaching 83%. 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 69% in the era of the EURAMOS-1 trial from 2005 onwards. Survival rates for Ewing sarcoma of bone were markedly higher than previously during the era of the second UKCCSG study (1987-92) 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 throughout 1989-2005 (including the eras of MMT-89 and MMT-95) was 64-68%. In 2006 onwards (era of RMS 2005) there was a substantial increase in 5-year survival to 76%.

There was a major change in the chemotherapy protocol for germ-cell tumours in 1983, 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 in 1989 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 from 1978-90 until the era of the third trial, starting in 2002, since when five-year survival has been above 95%. 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 (1995-2003). Survival increased further since then, to 55% during 2006 onwards.

**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** | **X2 (1df) for trend** |
| Leukaemias | 40 | 51 | 63 | 72 | 76 | 80 | 86 | 2073\*\*\* |
| Lymphomas | 50 | 67 | 77 | 84 | 85 | 87 | 89 | 580.6\*\*\* |
| CNS tumours | 43 | 49 | 57 | 58 | 70 | 72 | 71 | 665.7\*\*\* |
| Neuroblastoma etc | 20 | 37 | 40 | 44 | 55 | 63 | 64 | 439.6\*\*\* |
| Retinoblastoma | 85 | 90 | 92 | 95 | 97 | 98 | 99 | 48.9\*\*\* |
| Renal tumours | 68 | 74 | 81 | 81 | 82 | 88 | 84 | 67.0\*\*\* |
| Hepatic tumours | 20 | 24 | 30 | 44 | 70 | 68 | 71 | 99.8\*\*\* |
| Bone tumours | 31 | 32 | 51 | 60 | 64 | 59 | 66 | 208.0\*\*\* |
| Soft tissue sarcomas | 41 | 53 | 60 | 60 | 67 | 66 | 68 | 130.6\*\*\* |
| Germ cell & gonadal tumours | 56 | 65 | 74 | 85 | 86 | 89 | 92 | 150.4\*\*\* |
| All cancers | 44 | 54 | 63 | 68 | 75 | 77 | 80 | 3852\*\*\* |

\*\*\*p<0.001

**Table 3.2 Survival of CCLG patients diagnosed 1978-2009 by period of diagnosis. In the test for trend by year of diagnosis, brackets around the X2 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** | **2003-2009** | **1978-97** | **1998-2009** | **X2 (1df) for trend** |
| Precursor ALL | 66 | 79 | 81 | 85 | 91 |  |  | 596.4\*\*\* |
| Mature B-cell leukaemia |  |  |  |  |  | 51 | 77 | 30.3\*\*\* |
| AML | 28 | 49 | 58 | 64 | 70 |  |  | 242.1\*\*\* |
| CML | 36 | 43 | 64 | 86 | 89 |  |  | 43.4\*\*\* |
| *Myelodysplasia* | *29* | *42* | *49* | *61* | *64* |  |  | *9.10\*\** |
| *JMML & CMML* | *6* | *32* | *40* | *38* | *69* |  |  | *44.8\*\*\** |
| *Other & unspecified leukaemia* |  |  |  |  |  | *41* | *60* | *17.6\*\*\** |
| Hodgkin lymphoma | 91 | 94 | 93 | 95 | 95 |  |  | 11.3\*\* |
| NHL | 65 | 77 | 79 | 83 | 87 |  |  | 105.8\*\*\* |
| Ependymoma | 45 | 43 | 68 | 64 | 70 |  |  | 21.9\*\*\* |
| Choroid plexus papilloma |  |  |  |  |  | 82 | 98 | 19.6\*\*\* |
| Choroid plexus carcinoma |  |  |  |  |  | 26 | 21 | (0.01) |
| Low grade astrocytoma | 83 | 83 | 93 | 93 | 95 |  |  | 52.9\*\*\* |
| High grade astrocytoma | 22 | 23 | 19 | 14 | 13 |  |  | (3.22) |
| *Unspec. Astrocytoma* | *58* | *40* | *40* | *59* | *62* |  |  | *1.24* |
| Medulloblastoma | 53 | 47 | 61 | 67 | 66 |  |  | 30.0\*\*\* |
| CNS PNET | 29 | 34 | 29 | 36 | 41 |  |  | 3.64 |
| ATRT |  |  |  |  |  | 20 | 22 | 0.24 |
| Oligodendroglioma |  |  |  |  |  | 65 | 62 | (0.36) |
| Other glioma | 25 | 26 | 32 | 42 | 43 |  |  | 18.6\*\*\* |
| **Diagnostic Group** | **1978-87** | **1988-92** | **1993-97** | **1998-2002** | **2003-2009** | **1978-97** | **1998-2009** | **X2 (1df) for trend** |
| Craniopharyngioma | 90 | 91 | 95 | 95 | 95 |  |  | 2.82 |
| Pineoblastoma |  |  |  |  |  | 31 | 37 | 6.63\* |
| Ganglioglioma |  |  |  |  |  | 83 | 91 | 2.57 |
| Meningioma |  |  |  |  |  | 74 | 95 | 11.5\*\* |
| *Unspecified CNS* | *37* | *44* | *63* | *44* | *39* |  |  | *0.00* |
| Neuroblastoma | 38 | 45 | 55 | 61 | 66 |  |  | 173.3\*\*\* |
| Retinoblastoma bilateral | 90 | 93 | 96 | 100 | 99 |  |  | 17.1\*\*\* |
| Retinoblastoma unilateral | 90 | 96 | 97 | 97 | 98 |  |  | 7.95\*\* |
| Wilms tumour | 82 | 81 | 85 | 92 | 90 |  |  | 34.9\*\*\* |
| Rhabdoid renal tumour |  |  |  |  |  | 24 | 16 | (1.07) |
| Renal clear cell sarcoma |  |  |  |  |  | 80 | 80 | (0.03) |
| Hepatoblastoma | 40 | 56 | 71 | 83 | 83 |  |  | 48.0\*\*\* |
| Hepatic carcinoma |  |  |  |  |  | 26 | 20 | (0.00) |
| Osteosarcoma | 47 | 57 | 58 | 52 | 66 |  |  | 14.2\*\*\* |
| Ewing sarcoma of bone | 42 | 68 | 66 | 64 | 64 |  |  | 27.4\*\*\* |
| Rhabdomyosarcoma | 57 | 59 | 66 | 70 | 69 |  |  | 30.8\*\*\* |
| MPNST |  |  |  |  |  | 32 | 54 | 2.22 |
| Other fibrosarcoma etc |  |  |  |  |  | 71 | 89 | 12.4\*\*\* |
| Extraosseous ESFT | 53 | 45 | 63 | 52 | 68 |  |  | 5.74\* |
| Synovial sarcoma |  |  |  |  |  | 81 | 81 | 1.18 |
| *Other specified soft tissue sarcoma* |  |  |  |  |  | *66* | *65* | *0.00* |
| *Unspecified soft-tissue sarcoma* | *39* | *45* | *32* | *44* | *52* |  |  | *0.46* |
| Hepatic sarcoma, all types |  |  |  |  |  | 43 | 59 | 0.57 |
| Intracranial & intra-spinal germinoma | 70 | 83 | 85 | 88 | 93 |  |  | 9.42\* |
| Other CNS germ-cell |  |  |  |  |  | 45 | 71 | 10.8\*\* |
| Other malig. extra-gonadal germ-cell | 55 | 89 | 76 | 88 | 90 |  |  | 30.4\*\*\* |
| Gonadal malig. germ-cell | 91 | 97 | 96 | 97 | 98 |  |  | 18.8\*\*\* |
| Adrenocortical carcinoma |  |  |  |  |  | 23 | 67 | 15.8\*\*\* |
| Thyroid carcinoma, non-medullary |  |  |  |  |  | 100 | 99 | - |
|  |  |  |  |  |  |  |  |  |
| **Diagnostic Group** | **1978-87** | **1988-92** | **1993-97** | **1998-2002** | **2003-2009** | **1978-97** | **1998-2009** | **X2 (1df) for trend** |
| Nasopharyngeal carcinoma |  |  |  |  |  | 68 | 91 | 5.81\* |
| Malignant melanoma |  |  |  |  |  | 50 | 63 | 4.29\* |
| *Misc. other carcinoma* |  |  |  |  |  | *52* | *58* | *1.72* |
| LCH single system | 93 | 99 | 98 | 99 | 99 |  |  | 9.51\*\* |
| LCH multi system | 67 | 71 | 74 | 79 | 98 |  |  | 10.6\*\* |
| HLH | 0 | 15 | 22 | 40 | 58 |  |  | 32.1\*\*\* |
| Ganglioneuroma | 100 | 100 | 100 | 98 | 100 |  |  | - |
| Mesoblastic nephroma |  |  |  |  |  | 98 | 98 | - |
| Fibromatosis |  |  |  |  |  | 90 | 98 | 2.52 |
| *Misc non-malig soft tissue* | *94* | *100* | *95* | *99* | *99* |  |  | *1.23* |
| Other non-gonadal non-malig. germ-cell | 96 | 97 | 98 | 99 | 99 |  |  | 1.73 |
| Gonadal non-malig. germ-cell | 100 | 100 | 98 | 100 | 100 |  |  | - |
| Non-malignant specialised gonadal |  |  |  |  |  | 97 | 94 | (0.00) |

\* P<0.05

\*\* P<0.01

\*\*\* P<0.001

**Table 3.3 Survival of CCLG patients diagnosed 1978-2009**

|  |  |
| --- | --- |
| Diagnostic group | Five-year actuarial survival % |
|  |  |
| Pituitary carcinoma & adenoma | 98 |
|  |  |
| Pinealoma & Pineocytoma | 79 |
|  |  |
| Desmoplastic infantile astrocytoma | 93 |
|  |  |
| DNET | 99 |
|  |  |
| Renal PNET | 29 |
|  |  |
| Renal carcinoma | 64 |
|  |  |
| Chondrosarcoma | 47 |
|  |  |
| Extrarenal rhabdoid tumour | 21 |
|  |  |
| Leiomyosarcoma | 84 |
|  |  |
| Fibrohistiocytic tumours | 91 |
|  |  |
| Alveolar soft part sarcoma | 95 |
|  |  |
| Desmoplastic small round cell tumour | 25 |
|  |  |
| Other malignant gonadal tumours | 56 |
|  |  |
| Thyroid carcinoma, medullary | 95 |
|  |  |
| Salivary gland carcinoma | 94 |
|  |  |
| Colorectal carcinoma | 17 |
|  |  |
| Pleuropulmonary blastoma | 76 |
|  |  |
| Lymphoproliferative disease | 66 |
|  |  |
| Adrenocortical adenoma | 100 |

**Table 3.4 Survival of CCLG patients diagnosed 1978-2009 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** | **2003-2009** | **1978-97** | **1998-2009** | **X2 (1df) for trend** |
| (i) | Astrocytoma, glioma or  unspecified tumour of brain stem |  |  |  |  |  |  |  |  |
|  | Total | 17 | 16 | 26 | 34 | 28 |  |  | 6.72\* |
|  | Low-grade astrocytoma | 38 | 40 | 64 | 85 | 75 |  |  | 15.1\*\*\* |
|  | High-grade astrocytoma |  |  |  |  |  | 6 | 0 | 0.00 |
|  | *Unspec astrocytoma, other*  *glioma & unspecified* | *14* | *14* | *18* | *23* | *19* |  |  | *0.77* |
| (ii) | Spinal cord |  |  |  |  |  |  |  |  |
|  | Ependymoma |  |  |  |  |  | 91 | 100 | 7.75\* |
|  | Astrocytoma | 60 | 71 | 81 | 81 | 75 |  |  | 1.25 |

an1surv19732007regreport1.wmf

an1surv19732007regreport2.wmfan1surv19732007regreport3.wmfan1surv19732007regreport4.wmfan1surv19732007regreport5.wmfan1surv19732007regreport6.wmfan1surv19732007regreport7.wmfan1surv19732007regreport8.wmfan1surv19732007regreport9.wmfan1surv19732007regreport10.wmfan1surv19732007regreport11.wmfan1surv19782009cclg12.wmfan1surv19782009cclg13.wmfan1surv19782009cclg14.wmfan1surv19782009cclg15.wmfan1surv19782009cclg16.wmfan1surv19782009cclg17.wmfan1surv19782009cclg18.wmfan1surv19782009cclg19.wmfan1surv19782009cclg20.wmfan1surv19782009cclg21.wmfan1surv19782009cclg22.wmfan1surv19782009cclg23.wmfan1surv19782009cclg24.wmfan1surv19782009cclg25.wmfan1surv19782009cclg26.wmfan1surv19782009cclg27.wmfan1surv19782009cclg28.wmfan1surv19782009cclg29.wmfan1surv19782009cclg30.wmfan1surv19782009cclg31.wmfan1surv19782009cclg32.wmfan1surv19782009cclg33.wmfan1surv19782009cclg34.wmfan1surv19782009cclg35.wmfan1surv19782009cclg36.wmfan1surv19782009cclg37.wmfan1surv19782009cclg38.wmfan1surv19782009cclg39.wmfan1surv19782009cclg40.wmfan1surv19782009cclg41.wmfan1surv19782009cclg42.wmfan1surv19782009cclg43.wmfan1surv19782009cclg44.wmfan1surv19782009cclg45.wmfan1surv19782009cclg46.wmfan1surv19782009cclg47.wmfan1surv19782009cclg48.wmfan1surv19782009cclg49.wmfan1surv19782009cclg50.wmfan1surv19782009cclg51.wmfan1surv19782009cclg52.wmfan1surv19782009cclg53.wmfan1surv19782009cclg54.wmfan1surv19782009cclg55.wmfan1surv19782009cclg56.wmfan1surv19782009cclg57.wmfan1surv19782009cclg58.wmfan1surv19782009cclg59.wmfan1surv19782009cclg60.wmfan1surv19782009cclg61.wmfan1surv19782009cclg62.wmfan1surv19782009cclg63.wmfan1surv19782009cclg64.wmfan1surv19782009cclg65.wmfan1surv19782009cclg66.wmfan1surv19782009cclg67.wmfan1surv19782009cclg68.wmfan1surv19782009cclg69.wmfan1surv19782009cclg70.wmfan1surv19782009cclg71.wmfan1surv19782009cclg72.wmfan1surv19782009cclg73.wmfan1surv19782009cclg74.wmfan1surv19782009cclg75.wmfan1surv19782009cclg76.wmfan1surv19782009cclg77.wmfan1surv19782009cclg78.wmfan1surv19782009cclg79.wmfan1surv19782009cclg80.wmfan1surv19782009cclg81.wmfan1surv19782009cclg82.wmfan1surv19782009cclg83.wmfan1surv19782009cclg84.wmfan1surv19782009cclg85.wmfan1surv19782009cclg86.wmfan1surv19782009cclg87.wmfan1surv19782009cclg88.wmfan1surv19782009cclg89.wmfan1surv19782009cclg90.wmfan1surv19782009cclg91.wmfan1surv19782009cclg92.wmfan1surv19782009cclg93.wmfan1surv19782009cclg94.wmfan1surv19782009cclg95.wmfan1surv19782009cclg96.wmfan1surv19782009cclg97.wmfan1surv19782009cclg98.wmfan1surv19782009cclg99.wmfan1surv19782009cclg100.wmfan1surv19782009cclg101.wmfan1surv19782009cclg102.wmfan1surv19782009cclg103.wmfan1surv19782009cclg104.wmfan1surv19782009cclg105.wmfan1surv19782009cclg106.wmfan1surv19782009cclg107.wmfan1surv19782009cclg108.wmfan1surv19782009cclg109.wmfan1surv19782009cclg110.wmfan1surv19782009cclg111.wmfan1surv19782009cclg112.wmfan1surv19782009cclg113.wmfan1surv19782009cclg114.wmfan1surv19782009cclg115.wmfan1surv19782009cclg116.wmfan1surv19782009cclg117.wmfan1surv19782009cclg118.wmfan1surv19782009cclg119.wmfan1surv19782009cclg120.wmfan1surv19782009cclg121.wmfan1surv19782009cclg122.wmfan1surv19782009cclg123.wmfan1surv19782009cclg124.wmfan1surv19782009cclg125.wmfan1surv19782009cclg126.wmfan1surv19782009cclg127.wmfan1surv19782009cclg128.wmfan1surv19782009cclg129.wmfan1surv19782009cclg130.wmfan1surv19782009cclg131.wmfan1surv19782009cclg132.wmf

**Authorship and Acknowledgements**

This report was written by Charles Stiller, many of the analyses and tabulations were done by Nicole Diggens and Tim Vincent, 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.