Methodology for Data Briefing 'Occurrence of cancer among five-year survivors of childhood cancer'

Data Source

The National Registry of Childhood Tumours (NRCT) is the population-based registry of cancer diagnosed before the age of 15 years in residents of Great Britain (England, Scotland and Wales) during 1962-92 and the UK (Great Britain and Northern Ireland) from 1993 onwards. The NRCT includes all malignant neoplasms, and non-malignant CNS tumours. Cases are notified direct from all paediatric oncology principal treatment centres throughout the UK, and are also ascertained from the all-ages national and regional cancer registries for the whole of the UK and from death certificates in Great Britain.

Methods for identifying five-year survivors and new primary tumours.

Children who were residents of Great Britain when first diagnosed with childhood cancer and who are not already known to have died within 5 years from diagnosis while still aged under 15 years have been flagged in the NHS Central Registers. Copies of cancer registrations (regardless of age at diagnosis) and death certificates (regardless of age at death and cause of death) for flagged patients are sent to the NRCT. New primary tumours occurring before the 15th birthday are identified from routine notifications to the NRCT, and some subsequent primaries are also notified direct from paediatric oncology principal treatment centres.

Criteria for second cancer inclusion

Cancer registries in the UK follow UKACR rules for registering multiple primary tumours in any one individual. Relapses and recurrences of a primary tumour are not usually recorded, but when recorded, are not counted as a second primary tumour. Bilateral occurrences of childhood tumours of the same type are not considered second primaries. Non-malignant CNS tumours following childhood cancer were counted as subsequent primaries. Skin carcinomas were excluded because registration is known to be incomplete.

Classification of first and subsequent cancers

First cancers were classified according to the 12 main groups of the International Classification of Childhood Cancer, Third Edition[1], as shown in Table 1. Subsequent cancers, which could occur at any age within the range 5-39 years, were classified according to the broad grouping shown in Table 2, derived from the Birch classification of cancer for adolescents and young adults[2].

Patterns of second cancer diagnosis in childhood cancer survivors

Subjects were all children in the NRCT who were diagnosed during 1980-99 with a cancer other than skin carcinoma included in ICCC-3, were resident in Great Britain at diagnosis, and were known to have survived at least five years from diagnosis. Second cancers were all cancers in the Birch classification except skin carcinoma diagnosed before the age of 40 years during 1985-2009. Third or later cancers were excluded.

Subsequent cancer diagnoses in childhood cancer survivors as a proportion of all cancers diagnosed at 5-39 years of age

Subjects were all persons who had a childhood cancer diagnosed during 1963-2004 while resident in Great Britain, survived at least five years following their original diagnosis, and had a subsequent cancer diagnosed at age under 40 years during 2003-09.

References

1. Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, third edition. *Cancer* 2005; **103**: 1457-67.

2. Barr RD, Holowaty EJ, Birch JM. Classification schemes for tumours diagnosed in adolescents and young adults. *Cancer* 2006; **106**: 1425-30.

For any queries regarding this methodology or the results contained within the data briefing please contact Charles Stiller at NRCT (charles.stiller@ccrg.ox.ac.uk)

Table 1: The 12 main groups of the International Classification of Childhood Cancer, Third Edition

Group	Title	Short title
I	Leukaemias, myeloproliferative diseases and myelodysplastic diseases	Leukaemias
II	Lymphomas and reticuloendothelial neoplasms	Lymphomas
III	CNS and miscellaneous intracranial and intraspinal neoplasms	CNS tumours
IV	Neuroblastoma and other peripheral nervous cell tumours	Neuroblastoma etc
V	Retinoblastoma	Retinoblastoma
VI	Renal tumours	Renal tumours
VII	Hepatic tumours	Hepatic tumours
VIII	Malignant bone tumours	Bone tumours
IX	Soft tissue and other extraosseous sarcomas	Soft-tissue sarcomas
X	Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	Germ-cell tumours etc
XI*	Other malignant epithelial neoplasms and malignant melanomas	Carcinoma and melanoma
XII	Other and unspecified malignant neoplasms	Other and unspecified

*Subgroup XIe, skin carcinoma, is excluded

Table 2: Broad grouping of subsequent cancers based on Birch classification

Groups and subgroups of Birch classification	Title	Short title
1	Leukaemias	Leukaemias
2	Lymphomas	Lymphomas
3.5.5	Meningioma	Meningioma
3, except 3.5.5.	CNS and other intracranial and intraspinal neoplasms except meningioma	Other CNS tumours
4	Osseous and chondromatous neoplasms, Ewing tumour and other neoplasms of bone	Bone tumours
5	Soft tissue sarcomas	Soft tissue sarcomas
6	Germ cell and trophoblastic neoplasms	Germ-cell tumours
7.1*	Melanoma	Melanoma
8.1	Carcinoma of thyroid	Carcinoma: thyroid
8.2	Other carcinoma of head and neck	Carcinoma: other head and neck
8.4	Carcinoma of breast	Carcinoma: breast
8.5	Carcinoma of genito-urinary tract	Carcinoma: genito-urinary
8.6	Carcinoma of gastro-intestinal tract	Carcinoma: gastro-intestinal
8.3, 8.7, 9, 10	Carcinoma of trachea, bronchus, lung, pleura and other and ill-defined sites not elsewhere classified (NEC); miscellaneous specified neoplasms NEC; unspecified malignant neoplasms NEC	Other and unspecified

*Subgroup 7.2, skin carcinoma, is excluded