EUROPE

Austria

Austrian National Cancer Registry, 1990–2012

Monika Hackl, Henrike Karim-Kos

Austria is located in central Europe. It is bordered by Slovakia and Hungary to the east, Slovenia and Italy to the south, Switzerland to the west, and Germany and the Czech Republic to the north. The well-developed market economy, with a skilled labour force and a high standard of living, is based on a sound balance between a large service sector, a comprehensive industrial sector, and an efficient agricultural sector.

In 2010, Austria had a population of 8.4 million (Table A.7); 21% of the population was younger than 20 years (Table A.6), and 19% was aged 65 years and older. The life expectancy at birth increased, to 78.9 years for men and 83.7 years for women in 2014. The infant mortality rate in 2015 was 3.1 per 1000 live births.

More than 90% of children with cancer are enrolled into centralized clinical trials, resulting from a trend initiated in the early 1980s. Since the early 1990s, treatment of childhood cancer has been centralized in three paediatric haematology and oncology centres (in Vienna, Graz, and Innsbruck) and one specialized centre for brain tumours (in Vienna).

The Austrian National Cancer Registry (ANCR) is located in Vienna and is hosted by the Austrian national statistical institute, Statistics Austria. It is a population-based, epidemiological cancer registry, which is financed by the government. The 1969 Cancer Statistics Act and the 1978 Cancer Statistics Ordinance provide the legal basis for the ANCR and mandate the reporting by hospitals of newly diagnosed cancer cases occurring at any age. In accordance with the 2000 Federal Statistics Act, the Austrian government appointed Statistics Austria as the national provider of cancer statistics. Information collected includes general demographic characteristics (age, sex, residence), date of diagnosis, tumour site, histology, and tumour stage at diagnosis. Annual reports on incidence, prevalence, survival, and mortality contain data for all years after 1983. Registration data and ad hoc analyses are provided to external institutions for research purposes. Population-based data since 1970 are available (Table A.10)

The states of Vorarlberg, Tyrol, Carinthia, and Salzburg have regional cancer registries and provide their quality-assured data to the ANCR. Data from registries and hospitals are stored in an electronic database, and data checks at the national level are performed using the IARC-CHECK program. The registry uses IARC/IACR rules for multiple primary tumours. Data quality and completeness are assessed using data from pathology laboratories and various study groups. Statistics Austria regularly provides quality indicators and indirect measures of completeness. Completeness was estimated to be 94% after a registration period of 5 years after diagnosis. The low rates of retinoblastoma might be because most patients, especially those from Vienna and the surrounding area, are referred to Germany for treatment and thus these cases are not reported to the ANCR.

PUBLICATIONS

Karim-Kos HE, Hackl M, Mann G, Urban C, Woehrer A, Slavc I, et al. (2016). Trends in incidence, survival and mortality of childhood and adolescent cancer in Austria, 1994–2011. Cancer Epidemiol. 42:72–81. https://doi.org/10.1016/j.canep.2016.03.015 PMID:27054577

Hackl M, Waldhoer T (2013). Estimation of completeness of case ascertainment of Austrian cancer incidence data using the flow method. Eur J Public Health. 23(5):889–93. https://doi.org/10.1093/eurpub/cks125 PMID:23002230

POPULATION AT RISK

Population censuses were conducted in 1981, 1991, 2001, and 2011 (Table A.7). Since 2002, data from the Central Register of Residents, which contains registrations of principal residence, have been used by Statistics Austria to produce consistent figures on population at risk, population change, and demographic change for all territorial units. These data were forwarded quarterly from the Central Register of Residents to Statistics Austria, according to the methods described at http://www.statistik.at/web_en/statistics/PeopleSociety/population/index.html. The mid-year population data were provided in the requested detail.

EDITORS' COMMENTS

The proportion of clinically diagnosed cases was less than 1% (Table A.9); some of these cases may be missed by the registry. Non-malignant CNS tumours were reported, and pilocytic astrocytoma was coded with uncertain behaviour according to ICD-O-3 (Table A.10). Skin carcinomas were eligible for registration, but because the completeness of their ascertainment is not checked, they were not submitted to IICC-3. The level of overall incidence rates and the rates of diagnostic group XI are affected by their exclusion. Laterality was provided for 17% of the cases of interest.

AUSTRIA (1990-2012)

	Age group (years)	Males	Females
Person-years	0	972 872	924 049
	1-4	4 033 114	3 833 678
	5-9	5 269 284	5 015 251
	10-14	5 485 130	5 216 444
	15-19	5 705 000	5 439 783
	0-14	15 760 400	14 989 422
	0-19	21 465 400	20 429 205
Average annual population	0-14	685 235	651 714
	0-19	933 278	888 226

Please consult the quality indicators for this registry

AUSTRIA (1990-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	68	646	407	307	289	**1428**	**1717**	31.2	100.0	25.1	100.0	35.8	82.1	39.6	28.7	25.9	**49.4**	**44.1**	707	837	98.4	1.5
	a. Lymphoid	32	534	342	202	165	**1110**	**1275**	24.2	77.7	18.6	74.3	16.9	67.9	33.3	18.9	14.8	**38.6**	**33.3**	550	625	99.2	0.8
	b. Acute myeloid	23	83	43	73	82	**222**	**304**	4.8	15.5	4.4	17.7	12.1	10.6	4.2	6.8	7.4	**7.5**	**7.5**	109	146	97.7	2.3
	c. CMD	7	13	7	23	21	**50**	**71**	1.1	3.5	1.0	4.1	3.7	1.7	0.7	2.1	1.9	**1.6**	**1.7**	24	34	97.2	2.8
	d. MDS & other	1	6	3	5	8	**15**	**23**	0.3	1.1	0.3	1.3	0.5	0.8	0.3	0.5	0.7	**0.5**	**0.6**	7	11	100.0	0.0
	e. Unspecified	5	10	12	4	13	**31**	**44**	0.7	2.2	0.6	2.6	2.6	1.3	1.2	0.4	1.2	**1.1**	**1.1**	15	21	81.8	15.9
II	LYMPHOMA & RELATED	17	68	161	272	531	**518**	**1049**	11.3	100.0	15.3	100.0	9.0	8.6	15.7	25.4	47.6	**15.8**	**23.0**	249	487	98.9	1.0
	a. Hodgkin	2	10	45	149	346	**206**	**552**	4.5	39.8	8.1	52.6	1.1	1.3	4.4	13.9	31.0	**5.9**	**11.6**	98	253	99.3	0.7
	b. Non-Hodgkin except BL	4	33	53	76	132	**166**	**298**	3.6	32.0	4.4	28.4	2.1	4.2	5.2	7.1	11.8	**5.2**	**6.7**	80	139	99.3	0.7
	c. Burkitt (BL)	0	8	36	35	20	**79**	**99**	1.7	15.3	1.4	9.4	-	1.0	3.5	3.3	1.8	**2.4**	**2.3**	38	47	100.0	0.0
	d. Lymphoreticular	10	12	4	6	8	**32**	**40**	0.7	6.2	0.6	3.8	5.3	1.5	0.4	0.6	0.7	**1.2**	**1.1**	16	20	95.0	5.0
	e. Unspecified	1	5	23	6	25	**35**	**60**	0.8	6.8	0.9	5.7	0.5	0.6	2.2	0.6	2.2	**1.1**	**1.4**	17	28	93.3	5.0
III	CNS NEOPLASMS †	81	322	350	326	277	**1079**	**1356**	23.6	100.0	19.8	100.0	42.7	40.9	34.0	30.5	24.9	**35.8**	**33.3**	529	653	92.8	3.4
	a. Ependymoma	16	35	19	29	12	**99**	**111**	2.2	9.2	1.6	8.2	8.4	4.4	1.8	2.7	1.1	**3.4**	**2.9**	49	54	100.0	0.0
	b. Astrocytoma	18	140	149	146	113	**453**	**566**	9.9	42.0	8.3	41.7	9.5	17.8	14.5	13.6	10.1	**14.9**	**13.8**	222	272	98.9	0.0
	c. CNS embryonal	16	77	78	56	37	**227**	**264**	5.0	21.0	3.9	19.5	8.4	9.8	7.6	5.2	3.3	**7.7**	**6.7**	112	128	100.0	0.0
	d. Other gliomas	3	27	44	32	35	**106**	**141**	2.3	9.8	2.1	10.4	1.6	3.4	4.3	3.0	3.1	**3.4**	**3.4**	52	67	81.6	0.0
	e. Other specified	12	13	31	43	49	**99**	**148**	2.2	9.2	2.2	10.9	6.3	1.7	3.0	4.0	4.4	**3.1**	**3.4**	48	70	99.3	0.0
	f. Unspecified CNS	16	30	29	20	31	**95**	**126**	2.1	8.8	1.8	9.3	8.4	3.8	2.8	1.9	2.8	**3.3**	**3.2**	47	61	48.4	36.5
IV	NEUROBLASTOMA	162	144	36	8	12	**350**	**362**	7.6	100.0	5.3	100.0	85.4	18.3	3.5	0.7	1.1	**13.5**	**10.7**	178	183	99.4	0.0
	a. (Ganglio)neuroblastoma	162	142	35	6	9	**345**	**354**	7.5	98.6	5.2	97.8	85.4	18.1	3.4	0.6	0.8	**13.3**	**10.5**	175	180	99.4	0.0
	b. Peripheral nervous	0	2	1	2	3	**5**	**8**	0.1	1.4	0.1	2.2	-	0.3	0.1	0.2	0.3	**0.2**	**0.2**	2	4	100.0	0.0
V	RETINOBLASTOMA	18	27	2	0	0	**47**	**47**	1.0	100.0	0.7	100.0	9.5	3.4	0.2	-	-	**1.8**	**1.4**	24	24	89.4	0.0
VI	RENAL TUMOURS	46	135	49	13	18	**243**	**261**	5.3	100.0	3.8	100.0	24.2	17.2	4.8	1.2	1.6	**9.1**	**7.4**	123	131	97.3	1.1
	a. Nephroblastoma	42	132	45	10	3	**229**	**232**	5.0	94.2	3.4	88.9	22.1	16.8	4.4	0.9	0.3	**8.6**	**6.7**	116	117	98.7	0.0
	b. Renal carcinoma	1	1	3	3	13	**8**	**21**	0.2	3.3	0.3	8.0	0.5	0.1	0.3	0.3	1.2	**0.3**	**0.5**	4	10	100.0	0.0
	c. Unspecified	3	2	1	0	2	**6**	**8**	0.1	2.5	0.1	3.1	1.6	0.3	0.1	-	0.2	**0.2**	**0.2**	3	4	50.0	37.5
VII	HEPATIC TUMOURS	14	13	10	3	9	**40**	**49**	0.9	100.0	0.7	100.0	7.4	1.7	1.0	0.3	0.8	**1.5**	**1.3**	20	24	98.0	2.0
	a. Hepatoblastoma	14	13	7	1	3	**35**	**38**	0.8	87.5	0.6	77.6	7.4	1.7	0.7	0.1	0.3	**1.3**	**1.1**	18	19	100.0	0.0
	b. Hepatic carcinoma	0	0	2	2	6	**4**	**10**	0.1	10.0	0.1	20.4	-	-	0.2	0.2	0.5	**0.1**	**0.2**	2	5	90.0	10.0
	c. Unspecified	0	0	1	0	0	**1**	**1**	0.0	2.5	0.0	2.0	-	-	0.1	-	-	**0.0**	**0.0**	0	0	100.0	0.0
VIII	BONE TUMOURS	3	16	71	174	179	**264**	**443**	5.8	100.0	6.5	100.0	1.6	2.0	6.9	16.3	16.1	**7.7**	**9.6**	126	206	98.9	1.1
	a. Osteosarcoma	1	3	30	98	93	**132**	**225**	2.9	50.0	3.3	50.8	0.5	0.4	2.9	9.2	8.3	**3.8**	**4.8**	62	104	100.0	0.0
	b. Chondrosarcoma	0	0	2	6	14	**8**	**22**	0.2	3.0	0.3	5.0	-	-	0.2	0.6	1.3	**0.2**	**0.5**	4	10	100.0	0.0
	c. Ewing & related	1	11	34	61	55	**107**	**162**	2.3	40.5	2.4	36.6	0.5	1.4	3.3	5.7	4.9	**3.2**	**3.6**	51	76	100.0	0.0
	d. Other specified	0	1	3	5	11	**9**	**20**	0.2	3.4	0.3	4.5	-	0.1	0.3	0.5	1.0	**0.3**	**0.4**	4	9	100.0	0.0
	e. Unspecified	1	1	2	4	6	**8**	**14**	0.2	3.0	0.2	3.2	0.5	0.1	0.2	0.4	0.5	**0.3**	**0.3**	4	7	64.3	35.7
IX	SOFT TISSUE SARCOMA	35	77	69	88	128	**269**	**397**	5.9	100.0	5.8	100.0	18.5	9.8	6.7	8.2	11.5	**9.0**	**9.6**	132	189	100.0	0.0
	a. Rhabdomyosarcoma	15	61	48	28	44	**152**	**196**	3.3	56.5	2.9	49.4	7.9	7.8	4.7	2.6	3.9	**5.3**	**5.0**	75	95	100.0	0.0
	b. Fibrosarcoma	7	5	2	12	21	**26**	**47**	0.6	9.7	0.7	11.8	3.7	0.6	0.2	1.1	1.9	**0.9**	**1.1**	13	22	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	d. Other specified	8	7	15	36	52	**66**	**118**	1.4	24.5	1.7	29.7	4.2	0.9	1.5	3.4	4.7	**2.0**	**2.6**	32	55	100.0	0.0
	e. Unspecified	5	4	4	12	11	**25**	**36**	0.5	9.3	0.5	9.1	2.6	0.5	0.4	1.1	1.0	**0.8**	**0.8**	12	17	100.0	0.0
X	GERM CELL TUMOURS	19	30	19	67	331	**135**	**466**	2.9	100.0	6.8	100.0	10.0	3.8	1.8	6.3	29.7	**4.4**	**10.1**	66	214	99.1	0.4
	a. CNS germ cell	1	1	6	17	14	**25**	**39**	0.5	18.5	0.6	8.4	0.5	0.1	0.6	1.6	1.3	**0.7**	**0.8**	12	18	100.0	0.0
	b. Other extragonadal	9	11	2	10	18	**32**	**50**	0.7	23.7	0.7	10.7	4.7	1.4	0.2	0.9	1.6	**1.1**	**1.2**	16	24	98.0	0.0
	c. Gonadal germ cell	7	14	10	36	238	**67**	**305**	1.5	49.6	4.5	65.5	3.7	1.8	1.0	3.4	21.4	**2.1**	**6.5**	32	139	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	38	**0**	**38**	-	-	0.6	8.2	-	-	-	-	3.4	**-**	**0.8**	-	17	100.0	0.0
	e. Unspecified gonadal	2	4	1	4	23	**11**	**34**	0.2	8.1	0.5	7.3	1.1	0.5	0.1	0.4	2.1	**0.4**	**0.8**	5	16	91.2	5.9
XI	CARCINOMA & MELANOMA	2	4	36	123	468	**165**	**633**	3.6	100.0	9.2	100.0	1.1	0.5	3.5	11.5	42.0	**4.7**	**13.1**	78	288	99.7	0.2
	a. Adrenocortical	1	1	2	1	0	**5**	**5**	0.1	3.0	0.1	0.8	0.5	0.1	0.2	0.1	-	**0.2**	**0.1**	2	2	100.0	0.0
	b. Thyroid	0	1	9	41	136	**51**	**187**	1.1	30.9	2.7	29.5	-	0.1	0.9	3.8	12.2	**1.4**	**3.9**	24	85	100.0	0.0
	c. Nasopharyngeal	0	0	2	6	7	**8**	**15**	0.2	4.8	0.2	2.4	-	-	0.2	0.6	0.6	**0.2**	**0.3**	4	7	100.0	0.0
	d. Melanoma	1	1	15	47	200	**64**	**264**	1.4	38.8	3.9	41.7	0.5	0.1	1.5	4.4	17.9	**1.8**	**5.5**	30	120	99.2	0.4
	e. Skin carcinoma	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	f. Other & unspecified	0	1	8	28	125	**37**	**162**	0.8	22.4	2.4	25.6	-	0.1	0.8	2.6	11.2	**1.1**	**3.3**	17	74	100.0	0.0
XII	OTHER & UNSPECIFIED	8	13	8	11	28	**40**	**68**	0.9	100.0	1.0	100.0	4.2	1.7	0.8	1.0	2.5	**1.4**	**1.6**	20	32	63.2	23.5
	a. Other specified	3	1	0	3	3	**7**	**10**	0.2	17.5	0.1	14.7	1.6	0.1	-	0.3	0.3	**0.2**	**0.2**	3	5	100.0	0.0
	b. Other unspecified	5	12	8	8	25	**33**	**58**	0.7	82.5	0.8	85.3	2.6	1.5	0.8	0.7	2.2	**1.1**	**1.4**	16	28	56.9	27.6
	TOTAL	473	1495	1218	1392	2270	**4578**	**6848**	100.0	100.0	100.0	100.0	249.4	190.0	118.4	130.1	203.7	**154.0**	**165.2**	2250	3269	97.3	1.6

† includes 351 non-malignant

Please consult the quality indicators for this registry

Belarus

National Paediatric Cancer Registry, 1990–2014

Anna Zborovskaya, Olga Aleinikova

Belarus is in eastern Europe. It is bordered by the Russian Federation to the north-east, Ukraine to the south, Poland to the west, and Lithuania and Latvia to the north-west. More than 40% of the area of 207 600 km^2 is covered by forests. In 2010, the estimated population was 9.5 million (Table A.7), and 21% of the population was younger than 20 years (Table A.6). More than 70% of the population lives in urban areas. More than 80% of the population is ethnic Belarusian. There are sizeable minorities of other ethnicities: Russian, Polish, and Ukrainian.

The nationwide Childhood Cancer Sub-Registry of Belarus was established by the Ministry of Health of Belarus in 1999 (Table A.10) and is based at the Department for Clinical and Epidemiological Research of the Belarusian Research Center for Pediatric Oncology, Hematology, and Immunology (BRCPOHI), which is the main clinic in Belarus for patients with cancer aged 0–18 years.

The Childhood Cancer Sub-Registry of Belarus is computerized, with active data collection on cancer cases prospectively in children (ages 0–14 years) since 1999 and in adolescents (ages 15–19 years) since 2004, and with retrospective data collection in children and adolescents since 1986. The information is standardized according to IARC recommendations. Almost all cancer cases (other than CNS tumours) diagnosed after 1990 are MV. The main goals of the registry are to register all cases of malignant neoplasms in children and adolescents in Belarus at the population level in a quality-controlled database, to follow up patients for vital status, and to use the data in clinical and epidemiological studies.

The data sources are BRCPOHI (medical records from inpatient and outpatient departments, the morphology department, and the surgery block), the National Cancer Registry (especially for adolescent cases), specialized clinics (paediatric neurosurgery, thyroid tumour centre), oncology units, morphology laboratories, and pathology laboratories. Information on place of residence of the patients is matched against detailed addresses for Belarusian citizens, and cancers in temporary residents are excluded from incidence studies. Diagnoses are coded according to ICD-10 and ICD-O-3 and are classified using ICCC-3 (Table A.10).

PUBLICATIONS

Savva N, Zborovskaya A, Aleinikova O (2008). Current system of childhood cancer registration in Belarus. Radiol Oncol. 42(1):45–9. https://doi.org/10.2478/v10019-007-0038-1

POPULATION AT RISK

The population figures with distribution by age and region at the beginning of each year are provided by the National Statistical Committee of the Republic of Belarus (https://www.belstat.gov.by/en). They are based on population censuses conducted in 1989, 1999, and 2009 (Table A.7) and account for annual demographic changes. Data were provided in the requested detail.

EDITORS' COMMENTS

Non-malignant CNS tumours were registered (Table A.9), and pilocytic astrocytoma was coded with uncertain behaviour. Skin carcinomas were reportable. Laterality was complete for 97% of relevant cases.

BELARUS, paediatric (1990-2014)

	Age group (years)	Males	Females
Person-years	0	1 397 087	1 313 176
	1-4	5 575 366	5 272 707
	5-9	7 404 162	7 024 163
	10-14	8 455 502	8 054 066
	15-19	9 241 027	8 791 429
	0-14	22 832 117	21 664 112
	0-19	32 073 144	30 455 541
Average annual population	0-14	913 285	866 564
	0-19	1 282 926	1 218 222

Please consult the quality indicators for this registry

BELARUS, paediatric (1990-2014)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	**LEUKAEMIA**	93	789	529	422	422	**1833**	**2255**	26.7	100.0	21.9	100.0	34.3	72.7	36.7	25.6	23.4	**44.4**	**39.7**	636	753	99.8	0.2
	a. Lymphoid	46	684	423	274	198	**1427**	**1625**	20.8	77.9	15.8	72.1	17.0	63.1	29.3	16.6	11.0	**35.1**	**29.7**	499	554	99.9	0.1
	b. Acute myeloid	28	67	79	108	156	**282**	**438**	4.1	15.4	4.3	19.4	10.3	6.2	5.5	6.5	8.7	**6.4**	**6.9**	95	138	99.5	0.5
	c. CMD	1	5	11	25	45	**42**	**87**	0.6	2.3	0.8	3.9	0.4	0.5	0.8	1.5	2.5	**0.9**	**1.2**	14	26	100.0	0.0
	d. MDS & other	8	16	13	10	4	**47**	**51**	0.7	2.6	0.5	2.3	3.0	1.5	0.9	0.6	0.2	**1.2**	**0.9**	16	17	100.0	0.0
	e. Unspecified	10	17	3	5	19	**35**	**54**	0.5	1.9	0.5	2.4	3.7	1.6	0.2	0.3	1.1	**0.9**	**1.0**	13	18	100.0	0.0
II	**LYMPHOMA & RELATED**	7	163	269	410	887	**849**	**1736**	12.4	100.0	16.9	100.0	2.6	15.0	18.6	24.8	49.2	**18.1**	**25.1**	280	526	99.8	0.2
	a. Hodgkin	0	60	106	276	723	**442**	**1165**	6.4	52.1	11.3	67.1	-	5.5	7.3	16.7	40.1	**8.9**	**15.9**	142	343	100.0	0.0
	b. Non-Hodgkin except BL	4	47	72	74	137	**197**	**334**	2.9	23.2	3.2	19.2	1.5	4.3	5.0	4.5	7.6	**4.4**	**5.1**	66	104	99.7	0.3
	c. Burkitt (BL)	0	51	91	59	21	**201**	**222**	2.9	23.7	2.2	12.8	-	4.7	6.3	3.6	1.2	**4.5**	**3.8**	68	74	100.0	0.0
	d. Lymphoreticular	3	4	0	1	1	**8**	**9**	0.1	0.9	0.1	0.5	1.1	0.4	-	0.1	0.1	**0.2**	**0.2**	3	3	88.9	11.1
	e. Unspecified	0	1	0	0	5	**1**	**6**	0.0	0.1	0.1	0.3	-	0.1	-	-	0.3	**0.0**	**0.1**	0	2	83.3	16.7
III	**CNS NEOPLASMS** †	82	407	494	454	307	**1437**	**1744**	20.9	100.0	16.9	100.0	30.3	37.5	34.2	27.5	17.0	**33.0**	**29.4**	489	574	86.1	0.5
	a. Ependymoma	10	52	21	27	23	**110**	**133**	1.6	7.7	1.3	7.6	3.7	4.8	1.5	1.6	1.3	**2.7**	**2.4**	38	45	97.7	2.3
	b. Astrocytoma	18	136	184	194	131	**532**	**663**	7.8	37.0	6.4	38.0	6.6	12.5	12.8	11.8	7.3	**11.9**	**10.9**	179	216	99.5	0.0
	c. CNS embryonal	20	100	125	66	39	**311**	**350**	4.5	21.6	3.4	20.1	7.4	9.2	8.7	4.0	2.2	**7.4**	**6.2**	108	118	99.7	0.3
	d. Other gliomas	4	16	36	56	24	**112**	**136**	1.6	7.8	1.3	7.8	1.5	1.5	2.5	3.4	1.3	**2.4**	**2.1**	37	43	96.3	0.0
	e. Other specified	7	20	58	63	38	**148**	**186**	2.2	10.3	1.8	10.7	2.6	1.8	4.0	3.8	2.1	**3.2**	**2.9**	49	60	98.4	0.0
	f. Unspecified CNS	23	83	70	48	52	**224**	**276**	3.3	15.6	2.7	15.8	8.5	7.7	4.9	2.9	2.9	**5.4**	**4.9**	78	92	17.4	1.8
IV	**NEUROBLASTOMA**	107	168	46	20	18	**341**	**359**	5.0	100.0	3.5	100.0	39.5	15.5	3.2	1.2	1.0	**9.2**	**7.4**	123	128	99.2	0.6
	a. (Ganglio)neuroblastoma	107	167	45	19	8	**338**	**346**	4.9	99.1	3.4	96.4	39.5	15.4	3.1	1.2	0.4	**9.2**	**7.2**	122	125	99.1	0.6
	b. Peripheral nervous	0	1	1	1	10	**3**	**13**	0.0	0.9	0.1	3.6	-	0.1	0.1	0.1	0.6	**0.1**	**0.2**	1	4	100.0	0.0
V	**RETINOBLASTOMA**	50	93	7	0	0	**150**	**150**	2.2	100.0	1.5	100.0	18.4	8.6	0.5	-	-	**4.2**	**3.3**	55	55	82.0	0.7
VI	**RENAL TUMOURS**	50	200	87	21	27	**358**	**385**	5.2	100.0	3.7	100.0	18.4	18.4	6.0	1.3	1.5	**9.5**	**7.7**	129	136	93.5	0.0
	a. Nephroblastoma	50	197	82	8	3	**337**	**340**	4.9	94.1	3.3	88.3	18.4	18.2	5.7	0.5	0.2	**9.0**	**7.0**	122	123	93.2	0.0
	b. Renal carcinoma	0	1	5	13	24	**19**	**43**	0.3	5.3	0.4	11.2	-	0.1	0.3	0.8	1.3	**0.4**	**0.6**	6	13	100.0	0.0
	c. Unspecified	0	2	0	0	0	**2**	**2**	0.0	0.6	0.0	0.5	-	0.2	-	-	-	**0.1**	**0.0**	1	1	0.0	0.0
VII	**HEPATIC TUMOURS**	22	29	10	15	16	**76**	**92**	1.1	100.0	0.9	100.0	8.1	2.7	0.7	0.9	0.9	**1.9**	**1.7**	27	31	97.8	0.0
	a. Hepatoblastoma	22	29	7	4	0	**62**	**62**	0.9	81.6	0.6	67.4	8.1	2.7	0.5	0.2	-	**1.7**	**1.3**	22	22	100.0	0.0
	b. Hepatic carcinoma	0	0	3	10	14	**13**	**27**	0.2	17.1	0.3	29.3	-	-	0.2	0.6	0.8	**0.2**	**0.4**	4	8	100.0	0.0
	c. Unspecified	0	0	0	1	2	**1**	**3**	0.0	1.3	0.0	3.3	-	-	-	0.1	0.1	**0.0**	**0.0**	0	1	33.3	0.0
VIII	**BONE TUMOURS**	1	12	71	197	230	**281**	**511**	4.1	100.0	5.0	100.0	0.4	1.1	4.9	11.9	12.8	**5.4**	**7.1**	89	153	99.2	0.0
	a. Osteosarcoma	0	1	28	99	100	**128**	**228**	1.9	45.6	2.2	44.6	-	0.1	1.9	6.0	5.5	**2.4**	**3.1**	40	68	100.0	0.0
	b. Chondrosarcoma	0	0	2	11	26	**13**	**39**	0.2	4.6	0.4	7.6	-	-	0.1	0.7	1.4	**0.2**	**0.5**	4	11	100.0	0.0
	c. Ewing & related	1	10	38	75	66	**124**	**190**	1.8	44.1	1.8	37.2	0.4	0.9	2.6	4.5	3.7	**2.5**	**2.7**	40	58	100.0	0.0
	d. Other specified	0	1	3	11	24	**15**	**39**	0.2	5.3	0.4	7.6	-	0.1	0.2	0.7	1.3	**0.3**	**0.5**	5	11	100.0	0.0
	e. Unspecified	0	0	0	1	14	**1**	**15**	0.0	0.4	0.1	2.9	-	-	-	0.1	0.8	**0.0**	**0.2**	0	4	73.3	0.0
IX	**SOFT TISSUE SARCOMA**	32	116	74	145	183	**367**	**550**	5.3	100.0	5.3	100.0	11.8	10.7	5.1	8.8	10.1	**8.4**	**8.8**	124	175	99.6	0.2
	a. Rhabdomyosarcoma	17	94	50	55	52	**216**	**268**	3.1	58.9	2.6	48.7	6.3	8.7	3.5	3.3	2.9	**5.3**	**4.7**	75	89	100.0	0.0
	b. Fibrosarcoma	11	6	7	23	26	**47**	**73**	0.7	12.8	0.7	13.3	4.1	0.6	0.5	1.4	1.4	**1.0**	**1.1**	16	23	98.6	1.4
	c. Kaposi sarcoma	0	0	0	1	2	**1**	**3**	0.0	0.3	0.0	0.5	-	-	-	0.1	0.1	**0.0**	**0.0**	0	1	100.0	0.0
	d. Other specified	4	15	17	65	91	**101**	**192**	1.5	27.5	1.9	34.9	1.5	1.4	1.2	3.9	5.0	**2.1**	**2.7**	33	58	99.5	0.0
	e. Unspecified	0	1	0	1	12	**2**	**14**	0.0	0.5	0.1	2.5	-	0.1	-	0.1	0.7	**0.0**	**0.2**	1	4	100.0	0.0
X	**GERM CELL TUMOURS**	30	46	31	88	214	**195**	**409**	2.8	100.0	4.0	100.0	11.1	4.2	2.1	5.3	11.9	**4.4**	**6.1**	65	125	99.3	0.0
	a. CNS germ cell	2	2	9	18	9	**31**	**40**	0.5	15.9	0.4	9.8	0.7	0.2	0.6	1.1	0.5	**0.6**	**0.6**	10	13	100.0	0.0
	b. Other extragonadal	23	30	3	5	17	**61**	**78**	0.9	31.3	0.8	19.1	8.5	2.8	0.2	0.3	0.9	**1.7**	**1.5**	22	27	98.7	0.0
	c. Gonadal germ cell	5	14	17	57	134	**93**	**227**	1.4	47.7	2.2	55.5	1.8	1.3	1.2	3.5	7.4	**1.9**	**3.2**	30	67	100.0	0.0
	d. Gonadal carcinoma	0	0	0	4	27	**4**	**31**	0.1	2.1	0.3	7.6	-	-	-	0.2	1.5	**0.1**	**0.4**	1	9	100.0	0.0
	e. Unspecified gonadal	0	0	2	4	27	**6**	**33**	0.1	3.1	0.3	8.1	-	-	0.1	0.2	1.5	**0.1**	**0.4**	2	9	93.9	0.0
XI	**CARCINOMA & MELANOMA**	2	18	199	741	1084	**960**	**2044**	14.0	100.0	19.9	100.0	0.7	1.7	13.8	44.9	60.1	**18.1**	**27.5**	301	601	100.0	0.0
	a. Adrenocortical	1	3	2	2	4	**8**	**12**	0.1	0.8	0.1	0.6	0.4	0.3	0.1	0.1	0.2	**0.2**	**0.2**	3	4	100.0	0.0
	b. Thyroid	0	7	181	647	821	**835**	**1656**	12.2	87.0	16.1	81.0	-	0.6	12.5	39.2	45.5	**15.6**	**22.4**	261	489	100.0	0.0
	c. Nasopharyngeal	0	1	1	9	14	**11**	**25**	0.2	1.1	0.2	1.2	-	0.1	0.1	0.5	0.8	**0.2**	**0.3**	3	7	100.0	0.0
	d. Melanoma	1	3	9	26	73	**39**	**112**	0.6	4.1	1.1	5.5	0.4	0.3	0.6	1.6	4.0	**0.8**	**1.5**	12	33	99.1	0.9
	e. Skin carcinoma	0	1	1	17	42	**19**	**61**	0.3	2.0	0.6	3.0	-	0.1	0.1	1.0	2.3	**0.3**	**0.8**	6	18	100.0	0.0
	f. Other & unspecified	0	3	5	40	130	**48**	**178**	0.7	5.0	1.7	8.7	-	0.3	0.3	2.4	7.2	**0.9**	**2.3**	15	51	100.0	0.0
XII	**OTHER & UNSPECIFIED**	1	5	4	6	43	**16**	**59**	0.2	100.0	0.6	100.0	0.4	0.5	0.3	0.4	2.4	**0.4**	**0.8**	5	17	54.2	0.0
	a. Other specified	1	1	3	2	3	**7**	**10**	0.1	43.8	0.1	16.9	0.4	0.1	0.2	0.1	0.2	**0.2**	**0.2**	2	3	100.0	0.0
	b. Other unspecified	0	4	1	4	40	**9**	**49**	0.1	56.3	0.5	83.1	-	0.4	0.1	0.2	2.2	**0.2**	**0.7**	3	14	44.9	0.0
	TOTAL	477	2046	1821	2519	3431	**6863**	**10294**	100.0	100.0	100.0	100.0	176.0	188.6	126.2	152.6	190.3	**157.0**	**164.5**	2324	3276	96.7	0.2

† includes 479 non-malignant

Please consult the quality indicators for this registry

Belgium

Belgian Cancer Registry, 2004–2013

Liesbet Van Eycken, Kris Henau, Nancy Van Damme

Belgium covers an area of 30 528 km². It is located in western Europe and is a founding member of the European Union. The economy has a highly productive workforce, a high GDP, and a strong exports sector.

In 2010, the population was 10.9 million, and 23% of the population was younger than 20 years (Table A.6).

Health-care institutions are easily accessible, and oncological care is provided by general and academic hospitals. Belgium has eight paediatric haematology and oncology centres.

The Belgian Cancer Registry was founded in 2005, with coverage of the whole country since 2004 (Table A.10).

Cancer registration is established by law since 2006. It stipulates compulsory notification of cancer. All data are provided electronically to the Belgian Cancer Registry. Hospitals send the standard cancer registration forms, which include a specific set of variables. Tumour characteristics are coded according to ICD-O-3 and the seventh edition of the TNM classification (TNM-7). Pathology files contain specimen data coded according to classification rules and the accompanying text protocols. The specimens are coded at the registry according to ICD-O-3 (Table A.10). In 2009, a supplementary collaboration was established with all eight Belgian paediatric haematology and oncology centres to improve the quality of data on childhood malignancies. Under this collaboration, data have been retrospectively reviewed from the incidence year 2004 onwards.

The law authorizes the use of the national social security number as the unique patient identifier. This enables accurate linkage with other medical or administrative data and, through linkage with the Crossroads Bank for Social Security, it also enables the registry to perform accurate follow-up of patients for vital status and date of death.

Annual incidence data by sex, age, primary site, and geographical unit are routinely tabulated and are electronically available at https://kankerregister.org/. More detailed epidemiological analyses on incidence and survival are regularly made available through other publications, including a detailed overview of cancer incidence and survival in children and adolescents. In addition to producing descriptive statistics, the Belgian Cancer Registry is actively involved in evaluating screening programmes and the analysis of process, structure, and outcome indicators in quality-of-care projects.

PUBLICATIONS

Belgian Cancer Registry (2013). Cancer incidence in Belgium 2010: cancer in children and adolescents. Available from: https://kankerregister.org/en/publicaties/cancer-incidence-belgium-2010-special-issue-cancer-children-and-adolescents.

Belgian Cancer Registry (2012). Cancer survival in Belgium. Available from: https://kankerregister.org/en/publicaties/cancer-survival-belgium.

POPULATION AT RISK

Annual tables of the number of Belgian residents on 1 January are published by the Belgian Directorate-General of Statistics and Economic Information (https://www.statbel.fgov.be/). Population figures are based on the censuses conducted in 2001 and 2011 (Table A.7) and on the National Register, which has real-time, up-to-date data. Data were provided in the requested detail.

EDITORS' COMMENTS

Death certificates were not used for ascertainment of cancer cases because the registry does not have access to identified death certificates (Table A.9). Thus, a small number of new cases may be missed by the registry. The reported proportion of non-malignant CNS tumours is high (Table A.9), because there are strong links with the neurology clinics in the registration area and because all types of CNS tumours are systematically registered. Pilocytic astrocytoma was coded with uncertain behaviour according to ICD-O-3 (Table A.10). This should be considered when interpreting the high incidence rates of CNS tumours and the total. Skin carcinomas are registered, although underreporting is possible, especially before 2006. Laterality is unknown in 20% of relevant cases. All carcinoid tumours of the appendix are coded with malignant behaviour, and they constitute 3.5% of all cases (Table A.11).

BELGIUM (2004-2013)

	Age group (years)	Males	Females
Person-years	0	627 813	599 099
	1-4	2 493 202	2 381 466
	5-9	3 057 447	2 926 677
	10-14	3 148 928	3 013 672
	15-19	3 254 767	3 122 542
	0-14	9 327 390	8 920 914
	0-19	12 582 157	12 043 456
Average annual population	0-14	932 739	892 091
	0-19	1 258 216	1 204 346

Please consult the quality indicators for this registry

BELGIUM (2004-2013)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	58	384	214	202	196	858	1054	25.0	100.0	20.3	100.0	47.3	78.8	35.8	32.8	30.7	49.1	45.0	705	859	100.0	0.0
	a. Lymphoid	22	328	173	132	101	655	756	19.1	76.3	14.5	71.7	17.9	67.3	28.9	21.4	15.8	37.7	32.8	538	618	100.0	0.0
	b. Acute myeloid	24	35	22	35	54	116	170	3.4	13.5	3.3	16.1	19.6	7.2	3.7	5.7	8.5	6.6	7.0	95	137	100.0	0.0
	c. CMD	3	3	3	17	28	26	54	0.8	3.0	1.0	5.1	2.4	0.6	0.5	2.8	4.4	1.3	2.0	21	43	100.0	0.0
	d. MDS & other	6	18	16	17	11	57	68	1.7	6.6	1.3	6.5	4.9	3.7	2.7	2.8	1.7	3.2	2.9	47	55	100.0	0.0
	e. Unspecified	3	0	0	1	2	4	6	0.1	0.5	0.1	0.6	2.4	-	-	0.2	0.3	0.2	0.3	3	5	100.0	0.0
II	LYMPHOMA & RELATED	38	106	149	207	442	500	942	14.6	100.0	18.1	100.0	31.0	21.7	24.9	33.6	69.3	26.9	36.5	410	757	99.7	0.0
	a. Hodgkin	0	5	33	95	282	133	415	3.9	26.6	8.0	44.1	-	1.0	5.5	15.4	44.2	6.6	15.0	109	330	100.0	0.0
	b. Non-Hodgkin except BL	3	18	37	50	118	108	226	3.2	21.6	4.3	24.0	2.4	3.7	6.2	8.1	18.5	5.7	8.6	89	181	100.0	0.0
	c. Burkitt (BL)	0	22	49	28	19	99	118	2.9	19.8	2.3	12.5	-	4.5	8.2	4.5	3.0	5.4	4.8	82	97	100.0	0.0
	d. Lymphoreticular	35	61	29	30	15	155	170	4.5	31.0	3.3	18.0	28.5	12.5	4.8	4.9	2.4	9.1	7.6	127	139	100.0	0.0
	e. Unspecified	0	0	1	4	8	5	13	0.1	1.0	0.2	1.4	-	-	0.2	0.6	1.3	0.2	0.5	4	10	76.9	0.0
III	CNS NEOPLASMS †	73	256	258	257	249	844	1093	24.6	100.0	21.0	100.0	59.5	52.5	43.1	41.7	39.0	46.9	45.1	694	889	87.9	0.0
	a. Ependymoma	18	43	10	18	21	89	110	2.6	10.5	2.1	10.1	14.7	8.8	1.7	2.9	3.3	5.3	4.8	73	89	100.0	0.0
	b. Astrocytoma	26	103	122	113	99	364	463	10.6	43.1	8.9	42.4	21.2	21.1	20.4	18.3	15.5	20.1	19.1	299	377	94.2	0.0
	c. CNS embryonal	11	51	44	34	14	140	154	4.1	16.6	3.0	14.1	9.0	10.5	7.4	5.5	2.2	7.9	6.6	115	126	100.0	0.0
	d. Other gliomas	5	22	34	35	16	96	112	2.8	11.4	2.2	10.2	4.1	4.5	5.7	5.7	2.5	5.2	4.6	79	91	47.3	0.0
	e. Other specified	11	29	39	47	84	126	210	3.7	14.9	4.0	19.2	9.0	5.9	6.5	7.6	13.2	6.9	8.3	103	169	96.2	0.0
	f. Unspecified CNS	2	8	9	10	15	29	44	0.8	3.4	0.8	4.0	1.6	1.6	1.5	1.6	2.4	1.6	1.8	24	36	13.6	0.0
IV	NEUROBLASTOMA	83	108	24	11	6	226	232	6.6	100.0	4.5	100.0	67.6	22.2	4.0	1.8	0.9	13.9	11.0	185	190	99.1	0.0
	a. (Ganglio)neuroblastoma	83	107	23	3	3	216	219	6.3	95.6	4.2	94.4	67.6	22.0	3.8	0.5	0.5	13.4	10.5	177	180	99.1	0.0
	b. Peripheral nervous	0	1	1	8	3	10	13	0.3	4.4	0.2	5.6	-	0.2	0.2	1.3	0.5	0.5	0.5	8	10	100.0	0.0
V	RETINOBLASTOMA	37	62	5	0	0	104	104	3.0	100.0	2.0	100.0	30.2	12.7	0.8	-	-	6.6	5.1	85	85	76.9	0.0
VI	RENAL TUMOURS	24	89	26	10	11	149	160	4.3	100.0	3.1	100.0	19.6	18.3	4.3	1.6	1.7	9.0	7.4	122	131	96.9	0.0
	a. Nephroblastoma	23	88	24	6	5	141	146	4.1	94.6	2.8	91.3	18.7	18.1	4.0	1.0	0.8	8.6	6.9	116	120	97.9	0.0
	b. Renal carcinoma	0	0	2	4	6	6	12	0.2	4.0	0.2	7.5	-	-	0.3	0.6	0.9	0.3	0.4	5	10	100.0	0.0
	c. Unspecified	1	1	0	0	0	2	2	0.1	1.3	0.0	1.3	0.8	0.2	-	-	-	0.1	0.1	2	2	0.0	0.0
VII	HEPATIC TUMOURS	8	15	3	4	4	30	34	0.9	100.0	0.7	100.0	6.5	3.1	0.5	0.6	0.6	1.8	1.5	25	28	100.0	0.0
	a. Hepatoblastoma	8	14	3	2	1	27	28	0.8	90.0	0.5	82.4	6.5	2.9	0.5	0.3	0.2	1.7	1.3	22	23	100.0	0.0
	b. Hepatic carcinoma	0	1	0	2	3	3	6	0.1	10.0	0.1	17.6	-	0.2	-	0.3	0.5	0.2	0.2	2	5	100.0	0.0
	c. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VIII	BONE TUMOURS	2	7	43	113	117	165	282	4.8	100.0	5.4	100.0	1.6	1.4	7.2	18.3	18.3	8.2	10.5	135	227	99.3	0.0
	a. Osteosarcoma	0	0	16	63	64	79	143	2.3	47.9	2.7	50.7	-	-	2.7	10.2	10.0	3.8	5.2	64	115	100.0	0.0
	b. Chondrosarcoma	0	0	2	3	11	5	16	0.1	3.0	0.3	5.7	-	-	0.3	0.5	1.7	0.2	0.6	4	13	100.0	0.0
	c. Ewing & related	2	6	22	43	35	73	108	2.1	44.2	2.1	38.3	1.6	1.2	3.7	7.0	5.5	3.7	4.1	60	87	100.0	0.0
	d. Other specified	0	1	2	4	4	7	11	0.2	4.2	0.2	3.9	-	0.2	0.3	0.6	0.6	0.4	0.4	6	9	100.0	0.0
	e. Unspecified	0	0	1	0	3	1	4	0.0	0.6	0.1	1.4	-	-	0.2	-	0.5	0.1	0.1	1	3	50.0	0.0
IX	SOFT TISSUE SARCOMA	33	51	37	67	124	188	312	5.5	100.0	6.0	100.0	26.9	10.5	6.2	10.9	19.4	10.5	12.5	154	251	99.4	0.0
	a. Rhabdomyosarcoma	13	38	26	14	20	91	111	2.7	48.4	2.1	35.6	10.6	7.8	4.3	2.3	3.1	5.3	4.8	75	91	100.0	0.0
	b. Fibrosarcoma	4	3	3	8	14	18	32	0.5	9.6	0.6	10.3	3.3	0.6	0.5	1.3	2.2	1.0	1.3	15	26	100.0	0.0
	c. Kaposi sarcoma	0	0	0	1	2	1	3	0.0	0.5	0.1	1.0	-	-	-	0.2	0.3	0.0	0.1	1	2	100.0	0.0
	d. Other specified	14	7	8	39	81	68	149	2.0	36.2	2.9	47.8	11.4	1.4	1.3	6.3	12.7	3.6	5.6	56	119	100.0	0.0
	e. Unspecified	2	3	0	5	7	10	17	0.3	5.3	0.3	5.4	1.6	0.6	-	0.8	1.1	0.6	0.7	8	14	88.2	0.0
X	GERM CELL TUMOURS	36	18	16	40	168	110	278	3.2	100.0	5.3	100.0	29.3	3.7	2.7	6.5	26.3	6.2	10.7	90	222	99.3	0.0
	a. CNS germ cell ‡	5	0	7	16	17	28	45	0.8	25.5	0.9	16.2	4.1	-	1.2	2.6	2.7	1.4	1.7	23	36	100.0	0.0
	b. Other extragonadal	22	11	1	1	4	35	39	1.0	31.8	0.7	14.0	17.9	2.3	0.2	0.2	0.6	2.2	1.8	29	32	97.4	0.0
	c. Gonadal germ cell	8	7	7	22	138	44	182	1.3	40.0	3.5	65.5	6.5	1.4	1.2	3.6	21.6	2.4	6.7	36	144	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	7	0	7	-	-	0.1	2.5	-	-	-	-	1.1	-	0.2	-	5	100.0	0.0
	e. Unspecified gonadal	1	0	1	1	2	3	5	0.1	2.7	0.1	1.8	0.8	-	0.2	0.2	0.3	0.2	0.2	2	4	80.0	0.0
XI	CARCINOMA & MELANOMA	2	7	54	179	450	242	692	7.1	100.0	13.3	100.0	1.6	1.4	9.0	29.0	70.6	11.9	25.1	198	551	100.0	0.0
	a. Adrenocortical	1	1	1	1	3	4	7	0.1	1.7	0.1	1.0	0.8	0.2	0.2	0.2	0.5	0.2	0.3	3	6	100.0	0.0
	b. Thyroid	0	0	7	30	84	37	121	1.1	15.3	2.3	17.5	-	-	1.2	4.9	13.2	1.8	4.4	30	96	100.0	0.0
	c. Nasopharyngeal	0	0	1	7	6	8	14	0.2	3.3	0.3	2.0	-	-	0.2	1.1	0.9	0.4	0.5	7	11	100.0	0.0
	d. Melanoma	1	5	11	29	112	46	158	1.3	19.0	3.0	22.8	0.8	1.0	1.8	4.7	17.6	2.3	5.8	38	125	100.0	0.0
	e. Skin carcinoma	0	1	11	33	62	45	107	1.3	18.6	2.1	15.5	-	0.2	1.8	5.4	9.7	2.2	3.9	37	85	100.0	0.0
	f. Other & unspecified	0	0	23	79	183	102	285	3.0	42.1	5.5	41.2	-	-	3.8	12.8	28.7	5.0	10.3	83	227	100.0	0.0
XII	OTHER & UNSPECIFIED	4	2	2	2	8	10	18	0.3	100.0	0.3	100.0	3.3	0.4	0.3	0.3	1.3	0.6	0.7	8	14	77.8	0.0
	a. Other specified	1	1	1	1	7	4	11	0.1	40.0	0.2	61.1	0.8	0.2	0.2	0.2	1.1	0.2	0.4	3	9	100.0	0.0
	b. Other unspecified	3	1	1	1	1	6	7	0.2	60.0	0.1	38.9	2.4	0.2	0.2	0.2	0.2	0.4	0.3	5	6	42.9	0.0
	TOTAL	398	1105	831	1092	1775	3426	5201	100.0	100.0	100.0	100.0	324.4	226.7	138.9	177.2	278.3	191.6	211.1	2812	4204	96.6	0.0

† includes 576 non-malignant ‡ includes 9 non-malignant

Please consult the quality indicators for this registry

Bulgaria

Bulgarian National Cancer Registry, 1990–2013

Zdravka Valerianova, Nadya Dimitrova, Trayan Yordanov, Minka Yordanova

Bulgaria is a southern European country. It is bordered by Romania to the north, Serbia and North Macedonia to the west, Greece and Turkey to the south, and the Black Sea to the east. It covers an area of 110 994 km^2. During the reporting period, the country transformed from a one-party socialist state into a democracy with a market-based economy. The economy is based on heavy industry, power engineering, and agriculture and relies on natural resources. In 2010, the population was 7.4 million (Table A.7), and 19% of the population was younger than 20 years (Table A.6). Most residents live in urban areas. The capital and largest city is Sofia.

Cancer care is funded mainly by the National Health Insurance Fund (NHIF). Use of the NHIF identification number enables follow-up of patients along the pathway from diagnosis to treatment and beyond. Specialized and general hospitals that provide cancer treatment services adhere to the common protocols of care included in the Act for Medical Treatment Facilities, which was most recently amended in 2016. Uniform standards for diagnosis and treatment of patients with cancer are mandatory for all hospitals. Cancer care is coordinated by a council of specialists, composed of a clinical oncologist, a radiotherapist, a surgeon, and a pathologist or other health-care professional, who is nominated according to the cancer type being discussed.

Bulgaria has a separate network for cancer care in children and haematological diseases. Surgery, chemotherapy, radiotherapy, and follow-up of children with malignant tumours are conducted mainly in specialized children's clinics in university hospitals in Sofia, Plovdiv, and Varna. Occasionally, surgical treatment is also provided in some other university hospitals.

Cancer registration has been compulsory since 1952 and is regulated by instructions and orders of the Ministry of Health, which also provides funding based on the number of registered cancer cases.

The Bulgarian National Cancer Registry, which is located in the National Oncology Hospital in Sofia, covers the whole country. The data are collected by 13 regional cancer registries based in the regional oncology centres or hospitals and are recorded in a specialized information system. The main sources of information are hospital discharge records, pathology and other diagnostic units and laboratories, medical records, cancer notification forms, protocols from oncology committees, and reports from the hospital information systems, national and regional health insurance funds, and the national mortality database. Data collection is both passive and active; in recent years, active collection is more prevalent. Based on official agreement, the registry regularly receives data on all deceased people from the Civil Registration System and data on cause of death, population and mortality data, and life tables from the National Statistical Institute. Patients treated abroad may be lost to registration if they are diagnosed abroad and do not seek medical care after returning to Bulgaria.

The Bulgarian National Cancer Registry collects data on all invasive, in situ, and borderline behaviour cases. Information on each cancer case is structured in more than 85 fields and includes the patient's personal information, cancer characteristics, and data on treatment and disease progression. The registry database contains 0.65 million records of cancer cases, diagnosed in 1993–2013, of which 0.5% are for ages 0–14 years and 0.2% are for ages 15–19 years. For IICC-3, all available paper records for 1990–1992 were incorporated into the registry's electronic database.

Multiple primary tumours are defined according to IARC/IACR rules. Since 2005, cancers are coded according to ICD-10 and converted to ICD-O-3 using standard programs (Table A.10). Since 2008, date of incidence has been coded according to ENCR recommendations. Stage is recorded according to the sixth edition of the TNM classification (TNM-6).

POPULATION AT RISK

The official estimates are based on the censuses conducted in1985, 1992, 2001, and 2011 (Table A.7) and were provided by the National Statistical Institute (https://nsi.bg/). The population numbers within age, sex, and administrative units at the end of each year are calculated based on the population data for the previous year and births, deaths, and migration during the current year. Data were provided in the requested detail.

EDITORS' COMMENTS

The registry also participated in IICC-2 (Table A.1). Day of incidence may be unknown for almost 30% of the cases (Table A.8); the missing information pertains mostly to the 1990s. The high DCO% (Table A.9) may suggest that some cases were missed. The precision of diagnosis of the DCO cases is usually limited and is not validated as for other cases. The proportion of cases with unspecified morphology was rather high (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. Pilocytic astrocytoma was originally coded with malignant behaviour and was recoded with uncertain behaviour with the conversion to ICD-O-3 (Table A.10). Other non-malignant CNS tumours were not registered. Some surgical departments (including neurosurgery) do not submit information to the registry; thus, patients treated only surgically are more likely to be missed. The incidence rates increased significantly over the reporting period. According to the registry, this may be explained by gradually solving administrative obstacles to registration from some hospitals and by the addition of death certificates as a routine source of information beginning in 1998. Skin carcinomas are registered, but some cases may have been missed. Laterality was not sufficiently complete for inclusion of this dataset in the relevant tables.

BULGARIA (1990-2013)

	Age group (years)	Males	Females
Person-years	0	909 460	860 422
	1-4	3 818 634	3 617 906
	5-9	5 107 270	4 843 490
	10-14	5 751 506	5 454 223
	15-19	6 495 370	6 174 400
	0-14	15 586 870	14 776 041
	0-19	22 082 240	20 950 441
Average annual population	0-14	649 453	615 668
	0-19	920 093	872 935

Please consult the quality indicators for this registry

BULGARIA (1990-2013)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	57	499	382	295	241	1233	1474	34.9	100.0	27.9	100.0	32.2	67.1	38.4	26.3	19.0	43.4	37.9	626	721	94.1	5.9
	a. Lymphoid	28	394	303	191	119	916	1035	25.9	74.3	19.6	70.2	15.8	53.0	30.4	17.0	9.4	32.5	27.3	467	514	97.2	2.8
	b. Acute myeloid	14	39	35	54	45	142	187	4.0	11.5	3.5	12.7	7.9	5.2	3.5	4.8	3.6	4.8	4.5	70	88	97.3	2.7
	c. CMD	1	6	13	12	24	32	56	0.9	2.6	1.1	3.8	0.6	0.8	1.3	1.1	1.9	1.0	1.2	16	25	96.4	3.6
	d. MDS & other	1	2	4	4	12	11	23	0.3	0.9	0.4	1.6	0.6	0.3	0.4	0.4	0.9	0.4	0.5	5	10	100.0	0.0
	e. Unspecified	13	58	27	34	41	132	173	3.7	10.7	3.3	11.7	7.3	7.8	2.7	3.0	3.2	4.7	4.4	67	83	70.5	29.5
II	LYMPHOMA & RELATED	11	126	194	233	374	564	938	16.0	100.0	17.8	100.0	6.2	16.9	19.5	20.8	29.5	18.1	20.7	276	423	96.7	3.3
	a. Hodgkin	0	43	98	123	255	264	519	7.5	46.8	9.8	55.3	-	5.8	9.8	11.0	20.1	8.2	10.9	127	228	97.5	2.5
	b. Non-Hodgkin except BL	2	41	65	82	100	190	290	5.4	33.7	5.5	30.9	1.1	5.5	6.5	7.3	7.9	6.0	6.5	93	132	96.6	3.4
	c. Burkitt (BL)	0	16	21	12	6	49	55	1.4	8.7	1.0	5.9	-	2.2	2.1	1.1	0.5	1.7	1.4	25	27	100.0	0.0
	d. Lymphoreticular	9	20	1	6	5	36	41	1.0	6.4	0.8	4.4	5.1	2.7	0.1	0.5	0.4	1.4	1.2	19	21	100.0	0.0
	e. Unspecified	0	6	9	10	8	25	33	0.7	4.4	0.6	3.5	-	0.8	0.9	0.9	0.6	0.8	0.8	12	15	75.8	24.2
III	CNS NEOPLASMS †	33	149	194	188	196	564	760	16.0	100.0	14.4	100.0	18.6	20.0	19.5	16.8	15.5	18.8	18.1	280	358	73.9	11.7
	a. Ependymoma	5	11	7	12	19	35	54	1.0	6.2	1.0	7.1	2.8	1.5	0.7	1.1	1.5	1.2	1.3	18	25	100.0	0.0
	b. Astrocytoma	2	38	72	72	100	184	284	5.2	32.6	5.4	37.4	1.1	5.1	7.2	6.4	7.9	5.9	6.3	90	129	100.0	0.0
	c. CNS embryonal	3	44	52	44	28	143	171	4.0	25.4	3.2	22.5	1.7	5.9	5.2	3.9	2.2	4.8	4.2	71	82	100.0	0.0
	d. Other gliomas	0	3	12	11	10	26	36	0.7	4.6	0.7	4.7	-	0.4	1.2	1.0	0.8	0.8	0.8	13	17	100.0	0.0
	e. Other specified	1	5	2	5	3	13	16	0.4	2.3	0.3	2.1	0.6	0.7	0.2	0.4	0.2	0.4	0.4	6	8	100.0	0.0
	f. Unspecified CNS	22	48	49	44	36	163	199	4.6	28.9	3.8	26.2	12.4	6.5	4.9	3.9	2.8	5.7	5.0	82	96	0.5	44.7
IV	NEUROBLASTOMA	41	102	29	12	15	184	199	5.2	100.0	3.8	100.0	23.2	13.7	2.9	1.1	1.2	7.3	5.9	98	104	99.0	0.0
	a. (Ganglio)neuroblastoma	41	99	28	10	6	178	184	5.0	96.7	3.5	92.5	23.2	13.3	2.8	0.9	0.5	7.1	5.6	95	97	98.9	0.0
	b. Peripheral nervous	0	3	1	2	9	6	15	0.2	3.3	0.3	7.5	-	0.4	0.1	0.2	0.7	0.2	0.3	3	7	100.0	0.0
V	RETINOBLASTOMA	11	52	5	0	0	68	68	1.9	100.0	1.3	100.0	6.2	7.0	0.5	-	-	2.8	2.2	37	37	100.0	0.0
VI	RENAL TUMOURS	22	98	41	14	13	175	188	5.0	100.0	3.6	100.0	12.4	13.2	4.1	1.2	1.0	6.7	5.5	92	97	92.6	3.7
	a. Nephroblastoma	21	88	39	9	2	157	159	4.4	89.7	3.0	84.6	11.9	11.8	3.9	0.8	0.2	6.1	4.7	83	84	98.7	0.0
	b. Renal carcinoma	0	2	1	5	9	8	17	0.2	4.6	0.3	9.0	-	0.3	0.1	0.4	0.7	0.2	0.4	4	7	100.0	0.0
	c. Unspecified	1	8	1	0	2	10	12	0.3	5.7	0.2	6.4	0.6	1.1	0.1	-	0.2	0.4	0.4	5	6	0.0	58.3
VII	HEPATIC TUMOURS	10	17	4	10	14	41	55	1.2	100.0	1.0	100.0	5.7	2.3	0.4	0.9	1.1	1.5	1.4	21	27	69.1	10.9
	a. Hepatoblastoma	4	16	0	3	1	23	24	0.7	56.1	0.5	43.6	2.3	2.2	-	0.3	0.1	0.9	0.7	12	13	100.0	0.0
	b. Hepatic carcinoma	0	0	0	6	8	6	14	0.2	14.6	0.3	25.5	-	-	-	0.5	0.6	0.2	0.3	3	6	100.0	0.0
	c. Unspecified	6	1	4	1	5	12	17	0.3	29.3	0.3	30.9	3.4	0.1	0.4	0.1	0.4	0.4	0.4	6	8	0.0	35.3
VIII	BONE TUMOURS	1	12	47	143	189	203	392	5.7	100.0	7.4	100.0	0.6	1.6	4.7	12.8	14.9	5.8	7.8	94	169	97.2	1.0
	a. Osteosarcoma	0	1	14	61	57	76	133	2.2	37.4	2.5	33.9	-	0.1	1.4	5.4	4.5	2.1	2.6	35	57	100.0	0.0
	b. Chondrosarcoma	0	2	6	19	47	27	74	0.8	13.3	1.4	18.9	-	0.3	0.6	1.7	3.7	0.8	1.4	13	31	100.0	0.0
	c. Ewing & related	0	9	25	56	67	90	157	2.5	44.3	3.0	40.1	-	1.2	2.5	5.0	5.3	2.6	3.2	42	69	100.0	0.0
	d. Other specified	0	0	0	3	12	3	15	0.1	1.5	0.3	3.8	-	-	-	0.3	0.9	0.1	0.3	1	6	100.0	0.0
	e. Unspecified	1	0	2	4	6	7	13	0.2	3.4	0.2	3.3	0.6	-	0.2	0.4	0.5	0.2	0.3	3	6	15.4	30.8
IX	SOFT TISSUE SARCOMA	14	57	51	67	122	189	311	5.3	100.0	5.9	100.0	7.9	7.7	5.1	6.0	9.6	6.4	7.1	94	142	100.0	0.0
	a. Rhabdomyosarcoma	11	42	34	29	32	116	148	3.3	61.4	2.8	47.6	6.2	5.6	3.4	2.6	2.5	4.1	3.7	59	71	100.0	0.0
	b. Fibrosarcoma	2	4	5	13	33	24	57	0.7	12.7	1.1	18.3	1.1	0.5	0.5	1.2	2.6	0.8	1.2	12	25	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Other specified	1	8	9	20	47	38	85	1.1	20.1	1.6	27.3	0.6	1.1	0.9	1.8	3.7	1.2	1.8	18	37	100.0	0.0
	e. Unspecified	0	3	3	5	10	11	21	0.3	5.8	0.4	6.8	-	0.4	0.3	0.4	0.8	0.4	0.5	5	9	100.0	0.0
X	GERM CELL TUMOURS	6	36	10	51	232	103	335	2.9	100.0	6.4	100.0	3.4	4.8	1.0	4.6	18.3	3.4	6.8	51	142	96.7	1.2
	a. CNS germ cell	0	0	1	4	9	5	14	0.1	4.9	0.3	4.2	-	-	0.1	0.4	0.7	0.1	0.3	2	6	100.0	0.0
	b. Other extragonadal	1	10	0	3	9	14	23	0.4	13.6	0.4	6.9	0.6	1.3	-	0.3	0.7	0.5	0.6	7	11	100.0	0.0
	c. Gonadal germ cell	5	26	9	34	158	74	232	2.1	71.8	4.4	69.3	2.8	3.5	0.9	3.0	12.5	2.5	4.7	37	99	100.0	0.0
	d. Gonadal carcinoma	0	0	0	8	39	8	47	0.2	7.8	0.9	14.0	-	-	-	0.7	3.1	0.2	0.9	4	19	100.0	0.0
	e. Unspecified gonadal	0	0	0	2	17	2	19	0.1	1.9	0.4	5.7	-	-	-	0.2	1.3	0.1	0.3	1	8	42.1	21.1
XI	CARCINOMA & MELANOMA	1	7	21	89	292	118	410	3.3	100.0	7.8	100.0	0.6	0.9	2.1	7.9	23.0	3.3	7.8	55	170	100.0	0.0
	a. Adrenocortical	0	0	0	1	8	1	9	0.0	0.8	0.2	2.2	-	-	-	0.1	0.6	0.0	0.2	0	4	100.0	0.0
	b. Thyroid	0	0	5	20	63	25	88	0.7	21.2	1.7	21.5	-	-	0.5	1.8	5.0	0.7	1.6	11	36	100.0	0.0
	c. Nasopharyngeal	0	1	1	23	26	25	51	0.7	21.2	1.0	12.4	-	0.1	0.1	2.1	2.1	0.7	1.0	11	22	100.0	0.0
	d. Melanoma	0	2	7	12	36	21	57	0.6	17.8	1.1	13.9	-	0.3	0.7	1.1	2.8	0.6	1.1	10	24	100.0	0.0
	e. Skin carcinoma	0	0	3	11	33	14	47	0.4	11.9	0.9	11.5	-	-	0.3	1.0	2.6	0.4	0.9	6	19	100.0	0.0
	f. Other & unspecified	1	4	5	22	126	32	158	0.9	27.1	3.0	38.5	0.6	0.5	0.5	2.0	9.9	0.9	3.0	15	65	100.0	0.0
XII	OTHER & UNSPECIFIED	22	30	19	20	53	91	144	2.6	100.0	2.7	100.0	12.4	4.0	1.9	1.8	4.2	3.3	3.5	47	68	15.3	42.4
	a. Other specified	2	3	3	4	8	12	20	0.3	13.2	0.4	13.9	1.1	0.4	0.3	0.4	0.6	0.4	0.5	6	9	100.0	0.0
	b. Other unspecified	20	27	16	16	45	79	124	2.2	86.8	2.4	86.1	11.3	3.6	1.6	1.4	3.6	2.9	3.1	41	58	1.6	49.2
	TOTAL	229	1185	997	1122	1741	3533	5274	100.0	100.0	100.0	100.0	129.4	159.3	100.2	100.1	137.4	120.8	124.6	1770	2457	90.7	5.5

† includes 54 non-malignant

Please consult the quality indicators for this registry

Croatia

Croatian National Cancer Registry, 2001–2014

Mario Šekerija, Ljubica Bubanović, Petra Čukelj

Croatia is located in southern Europe and has two main geographical regions, inland and coastal, with continental and Mediterranean climates, respectively. The economy is based on the service sector, with smaller contributions by industry, agriculture, and tourism, in all of which the state has significant involvement. Croatia has a very high HDI.

In 2010, the population was 4.3 million, and 21% of the population was younger than 20 years (Table A.6). Administratively, the country is divided into 20 counties and the capital city of Zagreb. The population is covered by the social health insurance scheme operated by the Croatian Health Insurance Fund, the sole insurer for mandatory health insurance; it covers about 99% of citizens. The main regional oncology centres with a full range of services for treating childhood cancer are located in the university hospitals in Zagreb, Split, and Rijeka. Croatia has two referral centres for childhood cancer: one for solid tumours and one for haematological malignancies. Both centres are located in Zagreb.

The Croatian National Cancer Registry was founded in 1959 and began collecting incidence data in 1962 (Table A.10). It operates within the Croatian Institute of Public Health in Zagreb and is funded by the Ministry of Health and the Croatian Health Insurance Fund. The registry covers the whole of Croatia.

Sources of cancer cases are notifications from hospitals and primary care providers, pathology reports, and mortality databases. Notifications include the name of the health-care provider (hospital or physician), so that they can be contacted for additional information. Electronic hospital discharge records are a supplementary data source. In IICC-3, data topography and morphology were coded according to ICD-O-2 (Table A.10). The registry is currently being restructured to incorporate the increasing proportion of electronic notifications and ICD-O-3 coding, and it aims to increase the percentage of histologically confirmed cases.

Cancer incidence data have been published in an annual report since 1976. The data have been used for scientific and public health purposes, including CI5 Volumes VII–X, CONCORD-2, and EUROCARE-5 cancer survival studies, and in several other scientific projects.

PUBLICATIONS

Karalexi MA, Papathoma P, Thomopoulos TP, Ryzhov A, Zborovskaya A, Dimitrova N, et al. (2015). Childhood central nervous system tumour mortality and survival in Southern and Eastern Europe (1983–2014): gaps persist across 14 cancer registries. Eur J Cancer. 51(17):2665–77. https://doi.org/10.1016/j.ejca.2015.08.018 PMID:26343313

Vučemilo L, Znaor T, Kuliš T, Šekerija M, Znaor A (2015). Thyroid cancer incidence and mortality trends in Croatia 1988–2010. Acta Clin Croat. 54(1):30–7. PMID:26058240

POPULATION AT RISK

The population data are based on decennial censuses conducted in 2001 and 2011 and intercensal estimates provided by the National Bureau of Statistics (https://www.dzs.hr/). Data were provided in the requested detail.

EDITORS' COMMENTS

The registry also participated in IICC-2 (Table A.1). The proportion of cases with unspecified morphology is rather high (Table A.9), especially for CNS tumours (35%), bone tumours (30%), and soft tissue sarcomas (21%). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. Non-malignant CNS tumours defined by the ICD-10 codes D32, D33.0-D33.2, D42, and D43 are registered. Pilocytic astrocytoma was originally coded with malignant behaviour and was recoded with uncertain behaviour for IICC-3. Skin carcinomas are not registered, which affected the incidence of diagnostic group XI and overall. The high incidence rate is influenced by a marked increase in the incidence of thyroid cancer over the reporting period. The registry attributes this increase to more pronounced diagnostic efforts and increased awareness resulting from several recent public service campaigns. Information on laterality is not systematically collected; thus, this dataset was not included in the laterality tables.

CROATIA (2001-2014)

	Age group (years)	Males	Females
Person-years	0	295 350	278 923
	1-4	1 210 061	1 146 109
	5-9	1 586 671	1 507 284
	10-14	1 694 912	1 615 228
	15-19	1 822 453	1 743 536
	0-14	4 786 994	4 547 544
	0-19	6 609 447	6 291 080
Average annual population	0-14	341 928	324 825
	0-19	472 103	449 363

Please consult the quality indicators for this registry

CROATIA (2001-2014)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	21	242	142	123	87	528	615	30.4	100.0	23.9	100.0	36.6	102.7	45.9	37.2	24.4	60.3	52.2	864	986	99.8	0.0
	a. Lymphoid	15	208	123	94	52	440	492	25.3	83.3	19.1	80.0	26.1	88.3	39.8	28.4	14.6	50.5	42.4	721	794	100.0	0.0
	b. Acute myeloid	6	26	17	19	22	68	90	3.9	12.9	3.5	14.6	10.4	11.0	5.5	5.7	6.2	7.7	7.3	111	142	100.0	0.0
	c. CMD	0	3	0	5	6	8	14	0.5	1.5	0.5	2.3	-	1.3	-	1.5	1.7	0.8	1.0	13	21	100.0	0.0
	d. MDS & other	0	1	0	2	0	3	3	0.2	0.6	0.1	0.5	-	0.4	-	0.6	-	0.3	0.2	5	5	100.0	0.0
	e. Unspecified	0	4	2	3	7	9	16	0.5	1.7	0.6	2.6	-	1.7	0.6	0.9	2.0	1.0	1.2	15	24	93.8	0.0
II	LYMPHOMA & RELATED	15	43	61	104	192	223	415	12.8	100.0	16.1	100.0	26.1	18.2	19.7	31.4	53.8	23.1	30.1	355	624	100.0	0.0
	a. Hodgkin	0	6	16	54	119	76	195	4.4	34.1	7.6	47.0	-	2.5	5.2	16.3	33.4	7.2	13.1	118	285	100.0	0.0
	b. Non-Hodgkin except BL	0	16	25	35	63	76	139	4.4	34.1	5.4	33.5	-	6.8	8.1	10.6	17.7	7.8	10.0	121	209	100.0	0.0
	c. Burkitt (BL)	0	6	11	11	6	28	34	1.6	12.6	1.3	8.2	-	2.5	3.6	3.3	1.7	2.9	2.6	45	53	100.0	0.0
	d. Lymphoreticular	15	15	9	2	3	41	44	2.4	18.4	1.7	10.6	26.1	6.4	2.9	0.6	0.8	5.1	4.1	69	73	100.0	0.0
	e. Unspecified	0	0	0	2	1	2	3	0.1	0.9	0.1	0.7	-	-	-	0.6	0.3	0.2	0.2	3	4	100.0	0.0
III	CNS NEOPLASMS †	25	132	130	128	158	415	573	23.9	100.0	22.3	100.0	43.5	56.0	42.0	38.7	44.3	45.5	45.2	671	893	68.4	0.3
	a. Ependymoma	4	24	5	7	5	40	45	2.3	9.6	1.7	7.9	7.0	10.2	1.6	2.1	1.4	4.8	4.1	66	73	100.0	0.0
	b. Astrocytoma	3	32	35	41	32	111	143	6.4	26.7	5.6	25.0	5.2	13.6	11.3	12.4	9.0	11.9	11.2	178	223	95.8	0.0
	c. CNS embryonal	3	28	29	19	13	79	92	4.5	19.0	3.6	16.1	5.2	11.9	9.4	5.7	3.6	8.8	7.6	128	147	100.0	0.0
	d. Other gliomas	0	13	12	5	11	30	41	1.7	7.2	1.6	7.2	-	5.5	3.9	1.5	3.1	3.4	3.3	49	65	97.6	0.0
	e. Other specified	2	6	14	12	19	34	53	2.0	8.2	2.1	9.2	3.5	2.5	4.5	3.6	5.3	3.6	4.0	54	81	100.0	0.0
	f. Unspecified CNS	13	29	35	44	78	121	199	7.0	29.2	7.7	34.7	22.6	12.3	11.3	13.3	21.9	13.1	15.0	195	304	12.6	1.0
IV	NEUROBLASTOMA	31	57	15	3	2	106	108	6.1	100.0	4.2	100.0	54.0	24.2	4.8	0.9	0.6	13.5	10.6	179	182	95.4	0.0
	a. (Ganglio)neuroblastoma	30	57	15	2	2	104	106	6.0	98.1	4.1	98.1	52.2	24.2	4.8	0.6	0.6	13.2	10.4	176	179	95.3	0.0
	b. Peripheral nervous	1	0	0	1	0	2	2	0.1	1.9	0.1	1.9	1.7	-	-	0.3	-	0.2	0.2	3	3	100.0	0.0
V	RETINOBLASTOMA	4	19	2	0	0	25	25	1.4	100.0	1.0	100.0	7.0	8.1	0.6	-	-	3.2	2.5	42	42	100.0	0.0
VI	RENAL TUMOURS	12	66	14	6	12	98	110	5.6	100.0	4.3	100.0	20.9	28.0	4.5	1.8	3.4	12.3	10.3	165	182	91.8	0.0
	a. Nephroblastoma	12	64	13	0	0	89	89	5.1	90.8	3.5	80.9	20.9	27.2	4.2	-	-	11.4	8.8	151	151	95.5	0.0
	b. Renal carcinoma	0	0	0	6	10	6	16	0.3	6.1	0.6	14.5	-	-	-	1.8	2.8	0.5	1.0	9	23	100.0	0.0
	c. Unspecified	0	2	1	0	2	3	5	0.2	3.1	0.2	4.5	-	0.8	0.3	-	0.6	0.4	0.4	5	8	0.0	0.0
VII	HEPATIC TUMOURS	4	15	0	4	3	23	26	1.3	100.0	1.0	100.0	7.0	6.4	-	1.2	0.8	2.9	2.4	38	43	100.0	0.0
	a. Hepatoblastoma	4	15	0	0	0	19	19	1.1	82.6	0.7	73.1	7.0	6.4	-	-	-	2.5	1.9	32	32	100.0	0.0
	b. Hepatic carcinoma	0	0	0	4	3	4	7	0.2	17.4	0.3	26.9	-	-	-	1.2	0.8	0.4	0.5	6	10	100.0	0.0
	c. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VIII	BONE TUMOURS	2	10	37	63	74	112	186	6.4	100.0	7.2	100.0	3.5	4.2	12.0	19.0	20.8	11.0	13.2	175	279	97.8	1.1
	a. Osteosarcoma	0	0	13	24	30	37	67	2.1	33.0	2.6	36.0	-	-	4.2	7.3	8.4	3.5	4.6	57	99	100.0	0.0
	b. Chondrosarcoma	0	0	0	1	5	1	6	0.1	0.9	0.2	3.2	-	-	-	0.3	1.4	0.1	0.4	2	9	100.0	0.0
	c. Ewing & related	0	5	11	19	19	35	54	2.0	31.3	2.1	29.0	-	2.1	3.6	5.7	5.3	3.5	3.9	55	82	100.0	0.0
	d. Other specified	0	0	0	1	3	1	4	0.1	0.9	0.2	2.2	-	-	-	0.3	0.8	0.1	0.3	2	6	100.0	0.0
	e. Unspecified	2	5	13	18	17	38	55	2.2	33.9	2.1	29.6	3.5	2.1	4.2	5.4	4.8	3.9	4.1	60	84	92.7	3.6
IX	SOFT TISSUE SARCOMA	12	40	31	22	42	105	147	6.0	100.0	5.7	100.0	20.9	17.0	10.0	6.6	11.8	12.0	12.0	172	231	99.3	0.0
	a. Rhabdomyosarcoma	4	27	21	9	8	61	69	3.5	58.1	2.7	46.9	7.0	11.5	6.8	2.7	2.2	7.1	6.0	100	112	98.6	0.0
	b. Fibrosarcoma	2	5	2	4	2	13	15	0.7	12.4	0.6	10.2	3.5	2.1	0.6	1.2	0.6	1.5	1.3	21	24	100.0	0.0
	c. Kaposi sarcoma	0	0	0	1	0	1	1	0.1	1.0	0.0	0.7	-	-	-	0.3	-	0.1	0.1	2	2	100.0	0.0
	d. Other specified	1	1	5	4	20	11	31	0.6	10.5	1.2	21.1	1.7	0.4	1.6	1.2	5.6	1.1	2.1	18	46	100.0	0.0
	e. Unspecified	5	7	3	4	12	19	31	1.1	18.1	1.2	21.1	8.7	3.0	1.0	1.2	3.4	2.2	2.5	31	48	100.0	0.0
X	GERM CELL TUMOURS	4	5	10	24	97	43	140	2.5	100.0	5.4	100.0	7.0	2.1	3.2	7.3	27.2	4.3	9.5	68	204	88.6	0.0
	a. CNS germ cell	0	0	3	2	1	5	6	0.3	11.6	0.2	4.3	-	-	1.0	0.6	0.3	0.5	0.4	8	9	100.0	0.0
	b. Other extragonadal	0	0	0	3	0	3	3	0.2	7.0	0.1	2.1	-	-	-	0.9	-	0.3	0.2	5	5	100.0	0.0
	c. Gonadal germ cell	3	5	6	18	75	32	107	1.8	74.4	4.2	76.4	5.2	2.1	1.9	5.4	21.0	3.3	7.3	51	156	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	2	0	2	-	-	0.1	1.4	-	-	-	-	0.6	-	0.1	-	3	100.0	0.0
	e. Unspecified gonadal	1	0	1	1	19	3	22	0.2	7.0	0.9	15.7	1.7	-	0.3	0.3	5.3	0.3	1.4	5	31	27.3	0.0
XI	CARCINOMA & MELANOMA	0	2	7	40	154	49	203	2.8	100.0	7.9	100.0	-	0.8	2.3	12.1	43.2	4.5	13.2	75	291	100.0	0.0
	a. Adrenocortical	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Thyroid	0	1	3	28	88	32	120	1.8	65.3	4.7	59.1	-	0.4	1.0	8.5	24.7	2.9	7.8	49	172	100.0	0.0
	c. Nasopharyngeal	0	0	0	1	5	1	6	0.1	2.0	0.2	3.0	-	-	-	0.3	1.4	0.1	0.4	2	9	100.0	0.0
	d. Melanoma	0	1	4	9	30	14	44	0.8	28.6	1.7	21.7	-	0.4	1.3	2.7	8.4	1.3	2.9	22	64	100.0	0.0
	e. Skin carcinoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	f. Other & unspecified	0	0	0	2	31	2	33	0.1	4.1	1.3	16.3	-	-	-	0.6	8.7	0.2	2.1	3	46	100.0	0.0
XII	OTHER & UNSPECIFIED	2	2	3	4	13	11	24	0.6	100.0	0.9	100.0	3.5	0.8	1.0	1.2	3.6	1.2	1.7	18	36	16.7	4.2
	a. Other specified	0	0	0	0	2	0	2	-	-	0.1	8.3	-	-	-	-	0.6	-	0.1	-	3	100.0	0.0
	b. Other unspecified	2	2	3	4	11	11	22	0.6	100.0	0.9	91.7	3.5	0.8	1.0	1.2	3.1	1.2	1.6	18	33	9.1	4.5
	TOTAL	132	633	452	521	834	1738	2572	100.0	100.0	100.0	100.0	229.9	268.7	146.1	157.4	233.9	193.9	202.9	2823	3992	90.8	0.2

† includes 199 non-malignant

Please consult the quality indicators for this registry

Cyprus

South-West, Cyprus Cancer Registry, 1998–2012

Pavlos Pavlou, Anna Demetriou

Cyprus is an island country in the eastern Mediterranean. It is located south of Turkey, west of the Syrian Arab Republic and Lebanon, north-west of Israel, and south-east of Greece. The island is a major tourist destination. The advanced market economy is based on the service sector, including tourism, finance, shipping, and real estate.

The area covered by the Cyprus Cancer Registry is the Cyprus Government-controlled area of 6060 km^2. It is divided into five districts: Nicosia, Larnaca, Limassol, Paphos, and Famagusta. In 2010, the resident population was 0.8 million, and 24% of the population was younger than 20 years (Table A.6).

General health care in Cyprus is provided by the Ministry of Health through district hospitals, primary health-care centres, and the private sector. The Bank of Cyprus Oncology Centre, a government-funded non-profit organization, provides health-care services – notably, radiotherapy and chemotherapy – to patients with cancer. Makarios III Hospital in Nicosia has a paediatric oncology unit. Children with retinoblastoma are usually diagnosed and treated in Birmingham, United Kingdom.

The Cyprus Cancer Registry is part of the Health Monitoring Unit of the Ministry of Health. Direct responsibility for the registry is shared by the unit's coordinator and the Permanent Secretary of the Ministry of Health.

Cases are actively identified based on various sources, mainly inpatient records from general hospitals, inpatient and outpatient facilities in each district, the Bank of Cyprus Oncology Centre, private-sector hospitals, pathology laboratories, haematology laboratories, cytology departments, and the death registry. The cases notified from death certificates were imported from the electronic Causes of Death Database that was created in 2004.

Registry staff members visit all sources and scrutinize the records kept in the medical records departments and registers of individual departments concerned with diagnosis and treatment of cancers, to identify and abstract information on cancer cases diagnosed by all methods among residents of the registry's coverage area. Cancer is not a notifiable disease in Cyprus, but legislation is being introduced. Since 2010, data collection procedures have included electronic data transfer of all data available electronically, such as demographic data and type of therapy.

POPULATION AT RISK

The source of the population data is the Statistical Service of Cyprus, specifically, the Demographic Report of 2014 (https://library.cystat.gov.cy/Documents/Publication/DEMOGRAPHIC_REPORT-2014-271115.pdf). Population estimates are based on the censuses conducted in 1992, 2001, and 2011 and are updated annually to account for demographic changes due to births, deaths, and net migration. Data were provided in the requested detail.

EDITORS' COMMENTS

The proportion of cases aged 0–14 years in the age group 0–19 years is lower than expected (Table A.9), possibly because of high rates of tumours that predominantly affect adolescents (ages 15–19 years), such as thyroid cancer. Non-malignant CNS tumours were not registered during the reporting period (Table A.9), and there were no cases of pilocytic astrocytoma in the dataset. The incidence rates for retinoblastoma are lower than expected. Children with this tumour are routinely referred to the United Kingdom for treatment, and the registry confirmed that it is not possible to obtain information on cases initially diagnosed abroad. The incidence rates of diagnostic group XI and overall are affected by the ineligibility of basal and squamous cell tumours of the skin for registration. Laterality was not sufficiently complete for inclusion of the dataset in the laterality tables.

CYPRUS, South-West (1998-2012)

	Age group (years)	Males	Females
Person-years	0	69 172	65 409
	1-4	278 254	263 705
	5-9	372 257	352 611
	10-14	411 597	389 534
	15-19	454 622	432 056
	0-14	1 131 280	1 071 259
	0-19	1 585 902	1 503 315
Average annual population	0-14	75 419	71 417
	0-19	105 727	100 221

Please consult the quality indicators for this registry

CYPRUS, South-West (1998-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	5	49	38	28	36	120	156	33.3	100.0	25.4	100.0	37.2	90.4	52.4	35.0	40.6	58.0	54.1	836	1039	97.4	2.6
	a. Lymphoid	3	42	25	21	21	91	112	25.3	75.8	18.2	71.8	22.3	77.5	34.5	26.2	23.7	44.5	39.8	636	755	99.1	0.9
	b. Acute myeloid	2	5	8	7	9	22	31	6.1	18.3	5.0	19.9	14.9	9.2	11.0	8.7	10.2	10.1	10.1	151	201	100.0	0.0
	c. CMD	0	0	1	0	5	1	6	0.3	0.8	1.0	3.8	-	-	1.4	-	5.6	0.4	1.6	7	35	100.0	0.0
	d. MDS & other	0	0	3	0	0	3	3	0.8	2.5	0.5	1.9	-	-	4.1	-	-	1.3	1.0	21	21	66.7	33.3
	e. Unspecified	0	2	1	0	1	3	4	0.8	2.5	0.7	2.6	-	3.7	1.4	-	1.1	1.6	1.5	22	27	50.0	50.0
II	LYMPHOMA & RELATED	0	3	22	34	80	59	139	16.4	100.0	22.6	100.0	-	5.5	30.4	42.4	90.2	23.8	38.8	386	837	98.6	1.4
	a. Hodgkin	0	2	5	24	58	31	89	8.6	52.5	14.5	64.0	-	3.7	6.9	30.0	65.4	12.1	24.1	199	526	100.0	0.0
	b. Non-Hodgkin except BL	0	1	12	9	17	22	39	6.1	37.3	6.3	28.1	-	1.8	16.6	11.2	19.2	9.2	11.4	146	242	97.4	2.6
	c. Burkitt (BL)	0	0	4	0	2	4	6	1.1	6.8	1.0	4.3	-	-	5.5	-	2.3	1.8	1.9	28	39	100.0	0.0
	d. Lymphoreticular	0	0	0	0	1	0	1	-	-	0.2	0.7	-	-	-	-	1.1	-	0.3	-	6	100.0	0.0
	e. Unspecified	0	0	1	1	2	2	4	0.6	3.4	0.7	2.9	-	-	1.4	1.2	2.3	0.8	1.1	13	24	75.0	25.0
III	CNS NEOPLASMS	7	17	16	12	12	52	64	14.4	100.0	10.4	100.0	52.0	31.4	22.1	15.0	13.5	25.2	22.6	363	430	62.5	3.1
	a. Ependymoma	0	5	0	0	0	5	5	1.4	9.6	0.8	7.8	-	9.2	-	-	-	2.9	2.2	37	37	100.0	0.0
	b. Astrocytoma	3	4	3	5	5	15	20	4.2	28.8	3.3	31.3	22.3	7.4	4.1	6.2	5.6	7.2	6.8	104	132	75.0	0.0
	c. CNS embryonal	2	5	3	4	2	14	16	3.9	26.9	2.6	25.0	14.9	9.2	4.1	5.0	2.3	6.8	5.8	97	109	87.5	0.0
	d. Other gliomas	1	1	7	1	2	10	12	2.8	19.2	2.0	18.8	7.4	1.8	9.7	1.2	2.3	4.6	4.1	69	81	33.3	0.0
	e. Other specified	0	1	0	0	1	1	2	0.3	1.9	0.3	3.1	-	1.8	-	-	1.1	0.6	0.7	7	13	100.0	0.0
	f. Unspecified CNS	1	1	3	2	2	7	9	1.9	13.5	1.5	14.1	7.4	1.8	4.1	2.5	2.3	3.2	3.0	48	59	0.0	22.2
IV	NEUROBLASTOMA	12	11	3	1	1	27	28	7.5	100.0	4.6	100.0	89.2	20.3	4.1	1.2	1.1	14.9	11.8	197	203	100.0	0.0
	a. (Ganglio)neuroblastoma	12	11	3	1	1	27	28	7.5	100.0	4.6	100.0	89.2	20.3	4.1	1.2	1.1	14.9	11.8	197	203	100.0	0.0
	b. Peripheral nervous	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
V	RETINOBLASTOMA	1	0	0	0	0	1	1	0.3	100.0	0.2	100.0	7.4	-	-	-	-	0.6	0.4	7	7	0.0	0.0
VI	RENAL TUMOURS	5	10	1	2	2	18	20	5.0	100.0	3.3	100.0	37.2	18.5	1.4	2.5	2.3	9.8	8.1	130	142	90.0	5.0
	a. Nephroblastoma	5	10	1	2	0	18	18	5.0	100.0	2.9	90.0	37.2	18.5	1.4	2.5	-	9.8	7.6	130	130	88.9	5.6
	b. Renal carcinoma	0	0	0	0	2	0	2	-	-	0.3	10.0	-	-	-	-	2.3	-	0.5	-	11	100.0	0.0
	c. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VII	HEPATIC TUMOURS	1	0	3	0	1	4	5	1.1	100.0	0.8	100.0	7.4	-	4.1	-	1.1	1.9	1.7	28	34	100.0	0.0
	a. Hepatoblastoma	1	0	3	0	0	4	4	1.1	100.0	0.7	80.0	7.4	-	4.1	-	-	1.9	1.5	28	28	100.0	0.0
	b. Hepatic carcinoma	0	0	0	0	1	0	1	-	-	0.2	20.0	-	-	-	-	1.1	-	0.3	-	6	100.0	0.0
	c. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VIII	BONE TUMOURS	0	0	4	22	19	26	45	7.2	100.0	7.3	100.0	-	-	5.5	27.5	21.4	9.8	12.4	165	272	97.8	2.2
	a. Osteosarcoma	0	0	0	14	9	14	23	3.9	53.8	3.7	51.1	-	-	-	17.5	10.2	5.1	6.2	87	138	95.7	4.3
	b. Chondrosarcoma	0	0	1	0	1	1	2	0.3	3.8	0.3	4.4	-	-	1.4	-	1.1	0.4	0.6	7	13	100.0	0.0
	c. Ewing & related	0	0	3	7	8	10	18	2.8	38.5	2.9	40.0	-	-	4.1	8.7	9.0	3.9	5.0	64	109	100.0	0.0
	d. Other specified	0	0	0	1	1	1	2	0.3	3.8	0.3	4.4	-	-	-	1.2	1.1	0.4	0.5	6	12	100.0	0.0
	e. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
IX	SOFT TISSUE SARCOMA	1	7	4	9	11	21	32	5.8	100.0	5.2	100.0	7.4	12.9	5.5	11.2	12.4	9.6	10.2	143	205	100.0	0.0
	a. Rhabdomyosarcoma	0	5	4	4	2	13	15	3.6	61.9	2.4	46.9	-	9.2	5.5	5.0	2.3	6.1	5.2	90	101	100.0	0.0
	b. Fibrosarcoma	1	0	0	1	2	2	4	0.6	9.5	0.7	12.5	7.4	-	-	1.2	2.3	0.9	1.2	14	25	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	1	0	1	-	-	0.2	3.1	-	-	-	-	1.1	-	0.3	-	6	100.0	0.0
	d. Other specified	0	0	0	3	6	3	9	0.8	14.3	1.5	28.1	-	-	-	3.7	6.8	1.1	2.4	19	53	100.0	0.0
	e. Unspecified	0	2	0	1	0	3	3	0.8	14.3	0.5	9.4	-	3.7	-	1.2	-	1.5	1.2	21	21	100.0	0.0
X	GERM CELL TUMOURS	2	2	0	5	32	9	41	2.5	100.0	6.7	100.0	14.9	3.7	-	6.2	36.1	4.1	11.3	61	241	100.0	0.0
	a. CNS germ cell	1	1	0	1	0	3	3	0.8	33.3	0.5	7.3	7.4	1.8	-	1.2	-	1.5	1.2	21	21	100.0	0.0
	b. Other extragonadal	1	0	0	0	1	1	2	0.3	11.1	0.3	4.9	7.4	-	-	-	1.1	0.6	0.7	7	13	100.0	0.0
	c. Gonadal germ cell	0	1	0	4	29	5	34	1.4	55.6	5.5	82.9	-	1.8	-	5.0	32.7	2.0	8.9	32	196	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	2	0	2	-	-	0.3	4.9	-	-	-	-	2.3	-	0.5	-	11	100.0	0.0
	e. Unspecified gonadal	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
XI	CARCINOMA & MELANOMA	0	0	3	16	60	19	79	5.3	100.0	12.8	100.0	-	-	4.1	20.0	67.7	7.1	20.8	121	459	98.7	0.0
	a. Adrenocortical	0	0	0	1	0	1	1	0.3	5.3	0.2	1.3	-	-	-	1.2	-	0.4	0.3	6	6	100.0	0.0
	b. Thyroid	0	0	1	12	40	13	53	3.6	68.4	8.6	67.1	-	-	1.4	15.0	45.1	4.8	13.9	82	307	100.0	0.0
	c. Nasopharyngeal	0	0	0	1	0	1	1	0.3	5.3	0.2	1.3	-	-	-	1.2	-	0.4	0.3	6	6	100.0	0.0
	d. Melanoma	0	0	2	1	6	3	9	0.8	15.8	1.5	11.4	-	-	2.8	1.2	6.8	1.3	2.5	20	54	100.0	0.0
	e. Skin carcinoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	f. Other & unspecified	0	0	0	1	14	1	15	0.3	5.3	2.4	19.0	-	-	-	1.2	15.8	0.4	3.8	6	85	93.3	0.0
XII	OTHER & UNSPECIFIED	1	1	1	1	1	4	5	1.1	100.0	0.8	100.0	7.4	1.8	1.4	1.2	1.1	2.0	1.8	28	34	20.0	60.0
	a. Other specified	0	1	0	0	0	1	1	0.3	25.0	0.2	20.0	-	1.8	-	-	-	0.6	0.4	7	7	100.0	0.0
	b. Other unspecified	1	0	1	1	1	3	4	0.8	75.0	0.7	80.0	7.4	-	1.4	1.2	1.1	1.4	1.3	21	26	0.0	75.0
	TOTAL	35	100	95	130	255	360	615	100.0	100.0	100.0	100.0	260.1	184.5	131.1	162.3	287.6	166.6	193.8	2464	3902	93.7	2.1

Please consult the quality indicators for this registry

Czech Republic

Czech National Cancer Registry, 1990–2012

Daniel Klimeš, Jan Mužík, Denisa Malúšková, Michaela Kučerová, Miroslav Zvolský

The Czech Republic is located in central Europe and has a temperate continental climate. It is bordered by Slovakia to the east, Austria to the south, Germany to the west, and Poland to the north. During the reporting period, the country transformed from a one-party socialist state to a democracy with an advanced, fast-growing economy and a high standard of living. The largest industry is automobile manufacturing. The Czech Republic became a member of the European Union in 2004.

In 2010, the total population was 10.5 million (Table A.7). The age structure is weighted towards older age groups; 20% of the population is younger than 20 years (Table A.6), and 15% is aged 65 years and older.

The health-care system in the Czech Republic is well developed, with mandatory public health insurance. Cancer care is centralized in a network of 13 comprehensive cancer care centres. Health care for childhood cancer is provided by two specialized hospitals: Motol University Hospital in Prague and the University Hospital in Brno.

The Czech National Cancer Registry is a national population-based registry. The reporting of cancer cases to the registry is required by law. Paper forms are completed by clinicians in health-care facilities and sent to registry offices on a county level, where trained staff members validate information and complete the treatment data. Annual linkage with the administrative registry of death certificates enables completion of the registry database. The cases identified from death certificates are traced back and coded as death-certificate-initiated cases if more details on the diagnosis are found, or as DCO cases if no additional details are found.

Cancer diagnoses were coded according to ICD-9 before 1994 and according to ICD-10 since 1994. In addition, ICD-O-1 was used before 1994, ICD-O-2 was used in 1994–2004, and ICD-O-3 has been used since 2005 (Table A.10). The TNM-7 staging system has been used since 2010.

For IICC-3, the Czech National Cancer Registry validated and completed diagnostic information for childhood cancer cases through linkage with the clinical registry of childhood cancer maintained by the two childhood cancer care centres, in Prague and Brno.

PUBLICATIONS

Bajciova V (2011). Paediatric oncology must be based on reliable data. [in Czech] Onkologie. 7(3):C2–3.

POPULATION AT RISK

The population data were provided by the Czech Statistical Office (https://www.czso.cz/csu/czso/home) through the inter-organizational information system and are based on the censuses conducted in 1980, 1991, 2001, and 2011 (Table A.7). Data were provided in the requested detail.

EDITORS' COMMENTS

The registry also participated in IICC-2 (Table A.1). Non-malignant CNS tumours were registered, and pilocytic astrocytoma was originally coded according to the ICD-O edition in use and was recoded with uncertain behaviour with the conversion to ICD-O-3 (Table A.10). Skin carcinomas were reportable (Table A.9). Laterality was complete and is provided for retinoblastoma.

CZECH REPUBLIC (1990-2012)

	Age group (years)	Males	Females
Person-years	0	1 246 921	1 182 733
	1-4	5 079 372	4 820 185
	5-9	6 597 686	6 265 667
	10-14	7 417 709	7 058 093
	15-19	8 527 180	8 138 092
	0-14	20 341 688	19 326 678
	0-19	28 868 868	27 464 770
Average annual population	0-14	884 421	840 290
	0-19	1 255 168	1 194 120

Please consult the quality indicators for this registry

CZECH REPUBLIC (1990-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	**LEUKAEMIA**	98	812	450	391	393	**1751**	**2144**	27.8	100.0	22.2	100.0	40.3	82.0	35.0	27.0	23.6	**47.7**	**42.3**	679	797	93.1	0.9
	a. Lymphoid	56	692	342	258	206	**1348**	**1554**	21.4	77.0	16.1	72.5	23.0	69.9	26.6	17.8	12.4	**37.2**	**31.6**	525	587	93.6	0.6
	b. Acute myeloid	28	81	67	90	111	**266**	**377**	4.2	15.2	3.9	17.6	11.5	8.2	5.2	6.2	6.7	**6.9**	**6.9**	101	135	91.2	2.1
	c. CMD	2	4	14	23	32	**43**	**75**	0.7	2.5	0.8	3.5	0.8	0.4	1.1	1.6	1.9	**1.0**	**1.2**	16	25	93.3	0.0
	d. MDS & other	6	14	14	10	20	**44**	**64**	0.7	2.5	0.7	3.0	2.5	1.4	1.1	0.7	1.2	**1.2**	**1.2**	17	23	100.0	0.0
	e. Unspecified	6	21	13	10	24	**50**	**74**	0.8	2.9	0.8	3.5	2.5	2.1	1.0	0.7	1.4	**1.4**	**1.4**	19	27	85.1	2.7
II	**LYMPHOMA & RELATED**	24	156	258	405	896	**843**	**1739**	13.4	100.0	18.0	100.0	9.9	15.8	20.1	28.0	53.8	**20.2**	**27.8**	313	582	97.2	1.0
	a. Hodgkin	1	36	88	219	647	**344**	**991**	5.5	40.8	10.3	57.0	0.4	3.6	6.8	15.1	38.8	**7.8**	**14.7**	125	319	99.0	0.5
	b. Non-Hodgkin except BL	2	57	99	130	188	**288**	**476**	4.6	34.2	4.9	27.4	0.8	5.8	7.7	9.0	11.3	**6.9**	**7.9**	107	164	94.3	1.9
	c. Burkitt (BL)	0	26	41	35	18	**102**	**120**	1.6	12.1	1.2	6.9	-	2.6	3.2	2.4	1.1	**2.5**	**2.2**	39	44	96.7	1.7
	d. Lymphoreticular	21	29	12	11	13	**73**	**86**	1.2	8.7	0.9	4.9	8.6	2.9	0.9	0.8	0.8	**2.1**	**1.8**	29	33	97.7	1.2
	e. Unspecified	0	8	18	10	30	**36**	**66**	0.6	4.3	0.7	3.8	-	0.8	1.4	0.7	1.8	**0.9**	**1.1**	14	23	92.4	0.0
III	**CNS NEOPLASMS** †	80	390	435	418	351	**1323**	**1674**	21.0	100.0	17.4	100.0	32.9	39.4	33.8	28.9	21.1	**34.0**	**31.1**	504	609	84.3	3.0
	a. Ependymoma	22	62	40	41	36	**165**	**201**	2.6	12.5	2.1	12.0	9.1	6.3	3.1	2.8	2.2	**4.5**	**3.9**	64	75	96.5	0.0
	b. Astrocytoma	22	162	185	188	162	**557**	**719**	8.8	42.1	7.5	43.0	9.1	16.4	14.4	13.0	9.7	**14.2**	**13.2**	211	260	97.2	0.1
	c. CNS embryonal	12	67	95	71	29	**245**	**274**	3.9	18.5	2.8	16.4	4.9	6.8	7.4	4.9	1.7	**6.3**	**5.3**	93	102	98.2	0.0
	d. Other gliomas	3	8	10	22	28	**43**	**71**	0.7	3.3	0.7	4.2	1.2	0.8	0.8	1.5	1.7	**1.0**	**1.2**	16	24	98.6	0.0
	e. Other specified	4	14	33	35	31	**86**	**117**	1.4	6.5	1.2	7.0	1.6	1.4	2.6	2.4	1.9	**2.1**	**2.0**	32	42	96.6	0.0
	f. Unspecified CNS	17	77	72	61	65	**227**	**292**	3.6	17.2	3.0	17.4	7.0	7.8	5.6	4.2	3.9	**6.0**	**5.5**	87	107	22.6	17.1
IV	**NEUROBLASTOMA**	189	209	59	26	21	**483**	**504**	7.7	100.0	5.2	100.0	77.8	21.1	4.6	1.8	1.3	**14.5**	**11.5**	193	200	98.0	0.2
	a. (Ganglio)neuroblastoma	188	207	55	17	13	**467**	**480**	7.4	96.7	5.0	95.2	77.4	20.9	4.3	1.2	0.8	**14.1**	**11.1**	187	191	97.9	0.2
	b. Peripheral nervous	1	2	4	9	8	**16**	**24**	0.3	3.3	0.2	4.8	0.4	0.2	0.3	0.6	0.5	**0.4**	**0.4**	6	8	100.0	0.0
V	**RETINOBLASTOMA**	48	86	3	2	0	**139**	**139**	2.2	100.0	1.4	100.0	19.8	8.7	0.2	0.1	-	**4.3**	**3.3**	56	56	99.3	0.7
VI	**RENAL TUMOURS**	44	217	78	16	27	**355**	**382**	5.6	100.0	4.0	100.0	18.1	21.9	6.1	1.1	1.6	**10.5**	**8.5**	142	150	95.5	0.8
	a. Nephroblastoma	40	207	66	11	10	**324**	**334**	5.1	91.3	3.5	87.4	16.5	20.9	5.1	0.8	0.6	**9.6**	**7.6**	130	133	98.2	0.0
	b. Renal carcinoma	0	3	6	4	17	**13**	**30**	0.2	3.7	0.3	7.9	-	0.3	0.5	0.3	1.0	**0.3**	**0.5**	5	10	96.7	0.0
	c. Unspecified	4	7	6	1	0	**18**	**18**	0.3	5.1	0.2	4.7	1.6	0.7	0.5	0.1	-	**0.5**	**0.4**	7	7	44.4	16.7
VII	**HEPATIC TUMOURS**	34	38	8	14	14	**94**	**108**	1.5	100.0	1.1	100.0	14.0	3.8	0.6	1.0	0.8	**2.7**	**2.3**	37	41	84.3	2.8
	a. Hepatoblastoma	27	29	6	2	0	**64**	**64**	1.0	68.1	0.7	59.3	11.1	2.9	0.5	0.1	-	**1.9**	**1.5**	26	26	95.3	1.6
	b. Hepatic carcinoma	2	4	1	12	10	**19**	**29**	0.3	20.2	0.3	26.9	0.8	0.4	0.1	0.8	0.6	**0.5**	**0.5**	7	10	96.6	0.0
	c. Unspecified	5	5	1	0	4	**11**	**15**	0.2	11.7	0.2	13.9	2.1	0.5	0.1	-	0.2	**0.3**	**0.3**	4	6	13.3	13.3
VIII	**BONE TUMOURS**	3	21	77	182	219	**283**	**502**	4.5	100.0	5.2	100.0	1.2	2.1	6.0	12.6	13.1	**6.3**	**7.9**	103	168	93.8	2.4
	a. Osteosarcoma	0	3	33	83	82	**119**	**201**	1.9	42.0	2.1	40.0	-	0.3	2.6	5.7	4.9	**2.6**	**3.1**	43	67	99.0	0.0
	b. Chondrosarcoma	0	0	1	10	16	**11**	**27**	0.2	3.9	0.3	5.4	-	-	0.1	0.7	1.0	**0.2**	**0.4**	4	9	96.3	0.0
	c. Ewing & related	2	16	38	71	89	**127**	**216**	2.0	44.9	2.2	43.0	0.8	1.6	3.0	4.9	5.3	**2.9**	**3.5**	47	73	99.1	0.0
	d. Other specified	0	0	2	7	10	**9**	**19**	0.1	3.2	0.2	3.8	-	-	0.2	0.5	0.6	**0.2**	**0.3**	3	6	100.0	0.0
	e. Unspecified	1	2	3	11	22	**17**	**39**	0.3	6.0	0.4	7.8	0.4	0.2	0.2	0.8	1.3	**0.4**	**0.6**	6	13	33.3	30.8
IX	**SOFT TISSUE SARCOMA**	59	100	94	130	165	**383**	**548**	6.1	100.0	5.7	100.0	24.3	10.1	7.3	9.0	9.9	**10.0**	**9.9**	146	195	99.3	0.0
	a. Rhabdomyosarcoma	22	71	54	44	30	**191**	**221**	3.0	49.9	2.3	40.3	9.1	7.2	4.2	3.0	1.8	**5.2**	**4.4**	74	83	99.1	0.0
	b. Fibrosarcoma	15	4	7	12	14	**38**	**52**	0.6	9.9	0.5	9.5	6.2	0.4	0.5	0.8	0.8	**1.0**	**1.0**	15	19	100.0	0.0
	c. Kaposi sarcoma	0	1	0	1	0	**2**	**2**	0.0	0.5	0.0	0.4	-	0.1	-	0.1	-	**0.1**	**0.0**	1	1	100.0	0.0
	d. Other specified	10	14	23	55	94	**102**	**196**	1.6	26.6	2.0	35.8	4.1	1.4	1.8	3.8	5.6	**2.4**	**3.2**	38	66	100.0	0.0
	e. Unspecified	12	10	10	18	27	**50**	**77**	0.8	13.1	0.8	14.1	4.9	1.0	0.8	1.2	1.6	**1.3**	**1.4**	19	27	97.4	0.0
X	**GERM CELL TUMOURS**	29	42	31	92	495	**194**	**689**	3.1	100.0	7.1	100.0	11.9	4.2	2.4	6.4	29.7	**4.9**	**10.4**	73	221	96.7	0.3
	a. CNS germ cell ‡	4	8	5	24	16	**41**	**57**	0.7	21.1	0.6	8.3	1.6	0.8	0.4	1.7	1.0	**1.0**	**1.0**	15	20	96.5	0.0
	b. Other extragonadal	17	19	5	3	18	**44**	**62**	0.7	22.7	0.6	9.0	7.0	1.9	0.4	0.2	1.1	**1.3**	**1.3**	18	23	96.8	0.0
	c. Gonadal germ cell	6	13	16	53	395	**88**	**483**	1.4	45.4	5.0	70.1	2.5	1.3	1.2	3.7	23.7	**2.1**	**6.9**	32	151	98.3	0.0
	d. Gonadal carcinoma	0	0	1	8	48	**9**	**57**	0.1	4.6	0.6	8.3	-	-	0.1	0.6	2.9	**0.2**	**0.8**	3	18	100.0	0.0
	e. Unspecified gonadal	2	2	4	4	18	**12**	**30**	0.2	6.2	0.3	4.4	0.8	0.2	0.3	0.3	1.1	**0.3**	**0.5**	5	10	63.3	6.7
XI	**CARCINOMA & MELANOMA**	5	22	76	244	711	**347**	**1058**	5.5	100.0	11.0	100.0	2.1	2.2	5.9	16.9	42.7	**7.6**	**15.5**	125	338	99.1	0.0
	a. Adrenocortical	2	5	0	2	6	**9**	**15**	0.1	2.6	0.2	1.4	0.8	0.5	-	0.1	0.4	**0.3**	**0.3**	4	5	100.0	0.0
	b. Thyroid	0	2	20	101	244	**123**	**367**	2.0	35.4	3.8	34.7	-	0.2	1.6	7.0	14.6	**2.6**	**5.3**	43	117	99.5	0.0
	c. Nasopharyngeal	0	0	1	4	18	**5**	**23**	0.1	1.4	0.2	2.2	-	-	0.1	0.3	1.1	**0.1**	**0.3**	2	7	95.7	0.0
	d. Melanoma	3	8	19	52	182	**82**	**264**	1.3	23.6	2.7	25.0	1.2	0.8	1.5	3.6	10.9	**1.9**	**3.9**	30	84	98.9	0.0
	e. Skin carcinoma	0	2	16	34	79	**52**	**131**	0.8	15.0	1.4	12.4	-	0.2	1.2	2.3	4.7	**1.1**	**2.0**	19	42	99.2	0.0
	f. Other & unspecified	0	5	20	51	182	**76**	**258**	1.2	21.9	2.7	24.4	-	0.5	1.6	3.5	10.9	**1.7**	**3.8**	27	82	99.2	0.0
XII	**OTHER & UNSPECIFIED**	25	35	22	24	49	**106**	**155**	1.7	100.0	1.6	100.0	10.3	3.5	1.7	1.7	2.9	**2.9**	**2.9**	41	56	40.6	18.1
	a. Other specified	1	8	3	3	10	**15**	**25**	0.2	14.2	0.3	16.1	0.4	0.8	0.2	0.2	0.6	**0.4**	**0.5**	6	9	100.0	0.0
	b. Other unspecified	24	27	19	21	39	**91**	**130**	1.4	85.8	1.3	83.9	9.9	2.7	1.5	1.5	2.3	**2.5**	**2.5**	35	47	29.2	21.5
	TOTAL	638	2128	1591	1944	3341	**6301**	**9642**	100.0	100.0	100.0	100.0	262.6	215.0	123.7	134.3	200.5	**165.7**	**173.5**	2412	3414	93.1	1.4

† includes 418 non-malignant ‡ includes 3 non-malignant

Please consult the quality indicators for this registry

Estonia

Estonian Cancer Registry, 1990–2012

Margit Mägi, Pille Härmaorg, Mari-Liis Zimmermann

Estonia is located on the eastern shores of the Baltic Sea and covers an area of 45 227 km^2. It is bordered to the south by Latvia and to the east by the Russian Federation. Estonia is located in a transition zone between maritime and continental climates. During the reporting period, the country transformed from a regulated socialist economy as a republic of the former Soviet Union to a free market advanced, high-income economy with a very high HDI. Estonians benefit from free education, universal health care, and paid maternity leave of 1.5 years.

In 2010, the population was 1.3 million (Table A.7), and 21% of the population was younger than 20 years (Table A.6). The major nationalities were Estonian (69%) and Russian (25%). About 68% of the population lived in urban areas. The life expectancy at birth was 71.4 years for men and 81.2 years for women.

The Estonian health-care system is based on a compulsory, solidarity-based insurance scheme, which covers about 94% of the population. Patients with cancer are referred mainly to two specialized hospitals, which provide radiotherapy, surgical oncology, and chemotherapy services. Estonia has two specialized departments for paediatric and adolescent oncology: one in Tartu University Hospital and one in Tallinn Children's Hospital.

The Estonian Cancer Registry was founded in 1978, and reliable incidence data are available beginning from 1968 (Table A.10). The registry is state-funded and operates as a subunit of the National Institute for Health Development. Cancer reporting is mandated by a decree issued by the Minister of Social Affairs. In 2011, the new Public Health Act came into force and cancer reporting became compulsory by law. The registry covers the whole country.

A list of reportable diseases includes all malignant tumours and in situ carcinomas. CNS tumours with benign and uncertain behaviour are reportable since 1998. Diagnosis is coded using ICD-O. The registry is notified by treating physicians and by pathology and haematology laboratories. Registry staff members code and input the data.

Cancer cases are followed up until death or emigration. The registry receives death certificate data and performs trace-back procedure for cases first notified from death certificates. Since 2000, the registry has performed regular linkage with the Estonian Population Registry (https://www.tallinn.ee/en/population-register).

The registry routinely produces cancer incidence statistics. The data have been used for several epidemiological studies, including international comparisons and registry-based clinical research. A special study of childhood cancer data quality in the registry was recently conducted.

PUBLICATIONS

Paapsi K, Mägi M, Mikkel S, Saks K, Aareleid T, Innos K (2017). The impact of under-reporting of cases on the estimates of childhood cancer incidence and survival in Estonia. Eur J Cancer Prev. 26:S147–52. https://doi.org/10.1097/CEJ.0000000000000377 PMID:28604420

POPULATION AT RISK

The official estimates are based on the 1989, 2000, and 2011 censuses (Table A.7), making allowances for births, deaths, and migration. The source of the population data is Statistics Estonia (https://www.stat.ee/). Data were provided in the requested detail.

EDITORS' COMMENTS

The registry also participated in IICC-2 (Table A.1). Day of incidence is missing for 27% of cases (Table A.8), mostly because it was not collected during the first half of the 1990s. Non-malignant CNS tumours were present in the database since 1993; thus, their proportion and the reported incidence rates are likely to be underestimated for the diagnostic groups III and Xa and the total. Pilocytic astrocytoma has been coded with uncertain behaviour since 2008; in the same year, the earlier malignant cases were recoded with uncertain behaviour. Skin carcinomas are recorded, and laterality is complete.

ESTONIA (1990-2012)

	Age group (years)	Males	Females
Person-years	0	175 964	166 131
	1-4	739 138	700 274
	5-9	991 578	943 728
	10-14	1 071 716	1 017 942
	15-19	1 142 511	1 083 673
	0-14	2 978 396	2 828 075
	0-19	4 120 907	3 911 748
Average annual population	0-14	129 495	122 960
	0-19	179 170	170 076

Please consult the quality indicators for this registry

ESTONIA (1990-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	10	105	58	56	58	229	287	28.0	100.0	23.2	100.0	29.2	72.9	30.0	26.8	26.1	42.4	38.7	607	737	99.7	0.3
	a. Lymphoid	4	89	44	38	27	175	202	21.4	76.4	16.3	70.4	11.7	61.8	22.7	18.2	12.1	32.8	28.2	466	526	100.0	0.0
	b. Acute myeloid	5	5	9	16	21	35	56	4.3	15.3	4.5	19.5	14.6	3.5	4.7	7.7	9.4	5.9	6.7	90	137	100.0	0.0
	c. CMD	0	2	1	1	7	4	11	0.5	1.7	0.9	3.8	-	1.4	0.5	0.5	3.1	0.7	1.3	11	26	100.0	0.0
	d. MDS & other	1	4	2	0	0	7	7	0.9	3.1	0.6	2.4	2.9	2.8	1.0	-	-	1.4	1.1	19	19	100.0	0.0
	e. Unspecified	0	5	2	1	3	8	11	1.0	3.5	0.9	3.8	-	3.5	1.0	0.5	1.3	1.6	1.5	22	28	90.9	9.1
II	LYMPHOMA & RELATED	5	13	34	54	118	106	224	12.9	100.0	18.1	100.0	14.6	9.0	17.6	25.8	53.0	17.1	25.2	268	533	98.7	0.0
	a. Hodgkin	0	3	10	24	90	37	127	4.5	34.9	10.3	56.7	-	2.1	5.2	11.5	40.4	5.7	13.5	92	294	100.0	0.0
	b. Non-Hodgkin except BL	2	6	13	19	22	40	62	4.9	37.7	5.0	27.7	5.8	4.2	6.7	9.1	9.9	6.5	7.3	102	151	100.0	0.0
	c. Burkitt (BL)	0	1	9	5	2	15	17	1.8	14.2	1.4	7.6	-	0.7	4.7	2.4	0.9	2.4	2.1	38	43	100.0	0.0
	d. Lymphoreticular	3	3	2	3	1	11	12	1.3	10.4	1.0	5.4	8.8	2.1	1.0	1.4	0.4	2.1	1.7	29	31	100.0	0.0
	e. Unspecified	0	0	0	3	3	3	6	0.4	2.8	0.5	2.7	-	-	-	1.4	1.3	0.4	0.6	7	14	50.0	0.0
III	CNS NEOPLASMS †	12	67	68	80	75	227	302	27.7	100.0	24.4	100.0	35.1	46.5	35.1	38.3	33.7	39.6	38.3	589	757	85.4	0.3
	a. Ependymoma	6	14	7	3	2	30	32	3.7	13.2	2.6	10.6	17.5	9.7	3.6	1.4	0.9	5.9	4.8	81	86	100.0	0.0
	b. Astrocytoma	2	25	31	40	28	98	126	12.0	43.2	10.2	41.7	5.8	17.4	16.0	19.1	12.6	16.6	15.7	252	314	100.0	0.0
	c. CNS embryonal	2	20	17	8	9	47	56	5.7	20.7	4.5	18.5	5.8	13.9	8.8	3.8	4.0	8.7	7.7	125	145	100.0	0.0
	d. Other gliomas	1	1	3	4	2	9	11	1.1	4.0	0.9	3.6	2.9	0.7	1.6	1.9	0.9	1.5	1.4	23	27	100.0	0.0
	e. Other specified	0	3	1	14	17	18	35	2.2	7.9	2.8	11.6	-	2.1	0.5	6.7	7.6	2.8	3.9	45	83	88.6	0.0
	f. Unspecified CNS	1	4	9	11	17	25	42	3.1	11.0	3.4	13.9	2.9	2.8	4.7	5.3	7.6	4.1	4.9	64	102	4.8	2.4
IV	NEUROBLASTOMA	16	22	4	9	4	51	55	6.2	100.0	4.4	100.0	46.8	15.3	2.1	4.3	1.8	10.2	8.3	139	148	98.2	0.0
	a. (Ganglio)neuroblastoma	16	22	4	8	2	50	52	6.1	98.0	4.2	94.5	46.8	15.3	2.1	3.8	0.9	10.0	8.0	136	141	98.1	0.0
	b. Peripheral nervous	0	0	0	1	2	1	3	0.1	2.0	0.2	5.5	-	-	-	0.5	0.9	0.1	0.3	2	7	100.0	0.0
V	RETINOBLASTOMA	5	10	0	0	0	15	15	1.8	100.0	1.2	100.0	14.6	6.9	-	-	-	3.3	2.5	42	42	100.0	0.0
VI	RENAL TUMOURS	9	26	16	2	4	53	57	6.5	100.0	4.6	100.0	26.3	18.1	8.3	1.0	1.8	10.5	8.6	144	153	94.7	0.0
	a. Nephroblastoma	9	25	15	2	1	51	52	6.2	96.2	4.2	91.2	26.3	17.4	7.8	1.0	0.4	10.2	8.0	139	141	98.1	0.0
	b. Renal carcinoma	0	0	0	0	3	0	3	-	-	0.2	5.3	-	-	-	-	1.3	-	0.3	-	7	100.0	0.0
	c. Unspecified	0	1	1	0	0	2	2	0.2	3.8	0.2	3.5	-	0.7	0.5	-	-	0.4	0.3	5	5	0.0	0.0
VII	HEPATIC TUMOURS	4	4	2	2	2	12	14	1.5	100.0	1.1	100.0	11.7	2.8	1.0	1.0	0.9	2.3	2.0	32	37	100.0	0.0
	a. Hepatoblastoma	4	4	2	1	1	11	12	1.3	91.7	1.0	85.7	11.7	2.8	1.0	0.5	0.4	2.2	1.8	30	32	100.0	0.0
	b. Hepatic carcinoma	0	0	0	1	1	1	2	0.1	8.3	0.2	14.3	-	-	-	0.5	0.4	0.1	0.2	2	5	100.0	0.0
	c. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VIII	BONE TUMOURS	1	2	12	18	39	33	72	4.0	100.0	5.8	100.0	2.9	1.4	6.2	8.6	17.5	5.2	7.9	82	170	94.4	1.4
	a. Osteosarcoma	0	0	8	3	20	11	31	1.3	33.3	2.5	43.1	-	-	4.1	1.4	9.0	1.8	3.4	28	73	100.0	0.0
	b. Chondrosarcoma	0	0	0	1	7	1	8	0.1	3.0	0.6	11.1	-	-	-	0.5	3.1	0.1	0.8	2	18	100.0	0.0
	c. Ewing & related	0	2	4	11	8	17	25	2.1	51.5	2.0	34.7	-	1.4	2.1	5.3	3.6	2.6	2.8	42	60	100.0	0.0
	d. Other specified	1	0	0	0	2	1	3	0.1	3.0	0.2	4.2	2.9	-	-	-	0.9	0.2	0.4	3	7	100.0	0.0
	e. Unspecified	0	0	0	3	2	3	5	0.4	9.1	0.4	6.9	-	-	-	1.4	0.9	0.4	0.5	7	12	20.0	20.0
IX	SOFT TISSUE SARCOMA	2	13	8	11	21	34	55	4.2	100.0	4.4	100.0	5.8	9.0	4.1	5.3	9.4	6.1	6.9	89	136	100.0	0.0
	a. Rhabdomyosarcoma	2	8	5	2	1	17	18	2.1	50.0	1.5	32.7	5.8	5.6	2.6	1.0	0.4	3.3	2.6	46	48	100.0	0.0
	b. Fibrosarcoma	0	3	0	2	9	5	14	0.6	14.7	1.1	25.5	-	2.1	-	1.0	4.0	0.9	1.6	13	33	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Other specified	0	2	2	7	11	11	22	1.3	32.4	1.8	40.0	-	1.4	1.0	3.3	4.9	1.7	2.5	28	52	100.0	0.0
	e. Unspecified	0	0	1	0	0	1	1	0.1	2.9	0.1	1.8	-	-	0.5	-	-	0.2	0.1	3	3	100.0	0.0
X	GERM CELL TUMOURS	7	7	6	14	39	34	73	4.2	100.0	5.9	100.0	20.5	4.9	3.1	6.7	17.5	6.0	8.6	88	176	98.6	0.0
	a. CNS germ cell	0	0	3	1	3	4	7	0.5	11.8	0.6	9.6	-	-	1.6	0.5	1.3	0.6	0.8	10	17	100.0	0.0
	b. Other extragonadal	7	4	2	3	3	16	19	2.0	47.1	1.5	26.0	20.5	2.8	1.0	1.4	1.3	3.1	2.7	43	50	100.0	0.0
	c. Gonadal germ cell	0	3	1	8	29	12	41	1.5	35.3	3.3	56.2	-	2.1	0.5	3.8	13.0	1.9	4.4	30	95	100.0	0.0
	d. Gonadal carcinoma	0	0	0	1	2	1	3	0.1	2.9	0.2	4.1	-	-	-	0.5	0.9	0.1	0.3	2	7	100.0	0.0
	e. Unspecified gonadal	0	0	0	1	2	1	3	0.1	2.9	0.2	4.1	-	-	-	0.5	0.9	0.1	0.3	2	7	66.7	0.0
XI	CARCINOMA & MELANOMA	0	1	1	18	57	20	77	2.4	100.0	6.2	100.0	-	0.7	0.5	8.6	25.6	2.9	8.0	48	176	98.7	0.0
	a. Adrenocortical	0	1	0	0	1	1	2	0.1	5.0	0.2	2.6	-	0.7	-	-	0.4	0.2	0.3	3	5	100.0	0.0
	b. Thyroid	0	0	1	6	15	7	22	0.9	35.0	1.8	28.6	-	-	0.5	2.9	6.7	1.0	2.3	17	51	100.0	0.0
	c. Nasopharyngeal	0	0	0	1	3	1	4	0.1	5.0	0.3	5.2	-	-	-	0.5	1.3	0.1	0.4	2	9	100.0	0.0
	d. Melanoma	0	0	0	6	17	6	23	0.7	30.0	1.9	29.9	-	-	-	2.9	7.6	0.8	2.4	14	53	100.0	0.0
	e. Skin carcinoma	0	0	0	2	6	2	8	0.2	10.0	0.6	10.4	-	-	-	1.0	2.7	0.3	0.8	5	18	87.5	0.0
	f. Other & unspecified	0	0	0	3	15	3	18	0.4	15.0	1.5	23.4	-	-	-	1.4	6.7	0.4	1.8	7	41	100.0	0.0
XII	OTHER & UNSPECIFIED	0	3	2	0	3	5	8	0.6	100.0	0.6	100.0	-	2.1	1.0	-	1.3	1.0	1.1	14	20	50.0	37.5
	a. Other specified	0	1	1	0	1	2	3	0.2	40.0	0.2	37.5	-	0.7	0.5	-	0.4	0.4	0.4	5	8	100.0	0.0
	b. Other unspecified	0	2	1	0	2	3	5	0.4	60.0	0.4	62.5	-	1.4	0.5	-	0.9	0.6	0.7	8	13	20.0	60.0
	TOTAL	71	273	211	264	420	819	1239	100.0	100.0	100.0	100.0	207.5	189.7	109.0	126.3	188.7	146.6	156.1	2142	3086	95.0	0.5

† includes 105 non-malignant

Please consult the quality indicators for this registry

France

The territory of France comprises metropolitan France, in western Europe, and several overseas regions and territories. Metropolitan France has a temperate climate and covers an area of 551 500 km^2. France is a developed country with a very high HDI.

The population of metropolitan France was estimated to be 63.0 million (Table A.7); 19% of the population was younger than 15 years, and 25% was younger than 20 years (Table A.6). In 2010, the average population density was 115 per km^2, with marked variations throughout the country. The area of Paris, the capital city, is by far the most densely populated, and one quarter of the population lives there. The average urban-to-rural ratio was 3 (compared with > 5 in the areas of Paris, Lille, and Marseille), with marked between-region variations. Of children younger than 15 years, 34% lived in a highly urbanized region and 18% lived in a low urbanization region. Overall, 5.6% of the population was of foreign nationality (4.3% for children aged 0–14 years), but this percentage was higher in the eastern half of the country and in the Parisian region, where the foreign population accounted for 12% of the total (8.5% for children aged 0–14 years).

France has a universal health-care system that covers the entire population. The French social security system provides basic coverage (70%) for all employees, and the complementary regimens provide additional coverage. Other schemes are available for the remainder of the residents (self-employed, foreign-born). All children younger than 16 years are covered by the French social security system, which includes health insurance, regardless of their nationality. Also, cancer is one of the 30 long-duration diseases for which patients' health-care costs are covered entirely (100%) by the French social security system.

Children who are ill are treated by both general practitioners and paediatricians; the numbers of paediatricians vary by region and patient age, from 45 to 60 per 100 000 children. The treatment of children with cancer is highly concentrated in specialized paediatric oncology departments or units located in teaching hospitals or comprehensive cancer centres. Most of these specialized units treat solid tumours and haematopoietic malignancies, but 33% of solid tumours are treated in four comprehensive cancer centres located in Paris, Lyon, and Lille, whereas leukaemia is treated only in the teaching hospitals.

Cancer registration in France started in 1975 in the department of Bas-Rhin as an interest-driven individual initiative to monitor the cancer burden and to conduct research. The National Committee of Registries was created in 1986. Since 1991, the registries qualified by the National Committee of Registries are affiliated with the French Network of Cancer Registries (FRANCIM; France cancer incidence et mortalité), which coordinates research using the data collected by the registries. The common database is managed by the biostatistics unit of the Hospices Civils de Lyon (HCL) and administered by a steering committee composed of representatives of four institutions: FRANCIM, HCL, Public Health France (SPF; Santé publique France), and the National Cancer Institute (InCa; Institut national du Cancer). SPF was established in 2016 by merging the National Institute for Public Health Surveillance with other public health institutions. The Registries Evaluation Committee (CER; Comité d'evaluation des registres) assesses the work of each registry every 4–5 years and is authorized to certify the registry with respect to data quality and research activities. The accredited registries receive funding from SPF and INCa. Activities of the cancer registries are also approved by the National Commission on Informatics and Liberty (CNIL; Commission nationale de l'informatique et des libertés), which is responsible for the protection of personal data.

Cancer registration coverage is split between the two national paediatric cancer registries described below, 19 general subnational registries that cover about 24% of the population in metropolitan France, 10 subnational registries that specialize in the collection of data on selected neoplasms, and one mesothelioma registry that covers 22 departments and has the goal of achieving national coverage. In the areas covered by more than one registry, each registry may collect data on a restricted section of the population of patients with cancer. The data are annually cross-linked to identify potential tumour duplicates between registries.

Cancer is not a reportable disease in France; therefore, data collection is mainly active. The cancer registries in France do not have access to the nominal death certificates, because cause of death information is confidential. The international recommendations for data collection, registration, and coding formulated by IARC are followed. Registries also use the number of data sources per patient as an indicator of data quality and completeness. The registration of non-malignant CNS tumours was limited by time period in some registries, whereas data on pilocytic astrocytoma were collected for the entire reporting period in all registries. Most registries recorded squamous cell skin carcinomas but not basal cell skin carcinomas.

The registries participate in data exchange agreements and subnational, national, and international research. The data and statistics produced by the registries are disseminated online by SPF (https://www.santepubliquefrance.fr/maladies-et-traumatismes/cancers) and INCa (https://www.e-cancer.fr/Expertises-et-publications/Les-donnees-sur-les-cancers/Les-registres-des-cancers).

PUBLICATIONS

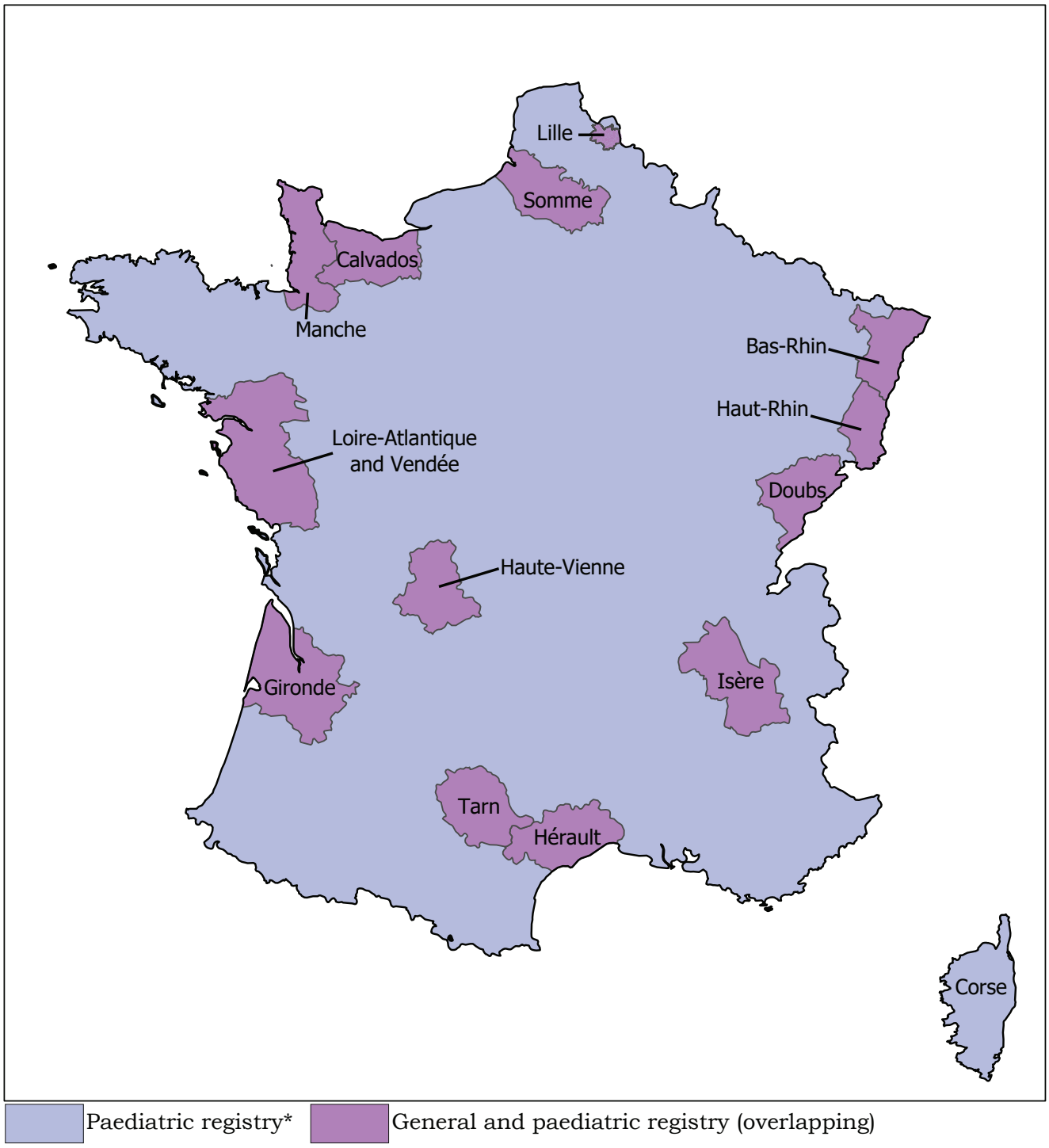
Desandes E, Lacour B, Belot A, Molinie F, Delafosse P, Tretarre B, et al. (2013). Cancer incidence and survival in adolescents and young adults in France, 2000–2008. Pediatr Hematol Oncol. 30(4):291–306. https://doi.org/10.3109/08880018.2012.762569 PMID:23363314

Lacour B, Goujon S, Guissou S, Guyot-Goubin A, Desmée S, Désandes E, et al. (2014). Childhood cancer survival in France, 2000–2008. Eur J Cancer Prev. 23(5):449–57. https://doi.org/10.1097/CEJ.0000000000000006 PMID:25010837

Lacour B, Guyot-Goubin A, Guissou S, Bellec S, Désandes E, Clavel J (2010). Incidence of childhood cancer in France: National Children Cancer Registries, 2000–2004. Eur J Cancer Prev. 19(3):173–81. https://doi.org/10.1097/CEJ.0b013e32833876c0 PMID:20361423

POPULATION AT RISK

During the reporting period, national censuses were conducted in 1990 and 1999; from 2004, the population data are derived from annual surveys (Table A.7). Annual population data are provided by the French National



*Haematopoietic neoplasms only for the period 1990-1999

Institute of Statistics and Economic Studies (INSEE; Institut national de la statistique et des études économiques) (https://www.insee.fr/). These mid-year estimates are based on data on births, deaths, and migration. All registries provided data in the requested detail, by sex and single year of age for each calendar year of the reporting period. The decimal numbers provided for some subnational population counts within sex and age categories were rounded to the nearest integer at IARC.

EDITORS' COMMENTS

The cancer data for France presented here were combined into three tables: (i) the data collected over the common recording period (2000–2012) in the two national paediatric registries, (ii) the data on haematopoietic malignancies collected in 1990–1999, and (iii) the data pooled from 12 subnational areas covered by the general or specialized cancer registries. Data for the third dataset were provided by HCL and were complemented by the individual cancer registries if required. Additional full incidence tables are available online for 10 individual general cancer registries, and abbreviated tables are available for two registries

(Lille and Tarn). Data for Haute-Vienne were not tabulated, because the dataset was small (Table A.12). All registries included in IICC-3 were accredited by CER. The Bas-Rhin Cancer Registry contributed to all three IICC volumes, and the registries of Doubs, Haut-Rhin, Hérault, Isère, and Tarn contributed to IICC-2 (Table A.1).

Death certificates were not available for ascertainment of cancer cases (Table A.9); thus, a proportion of new cases may have been missed. Day of birth and day of incidence were not provided by FRANCIM for the general cancer registries (Table A.8), so precise age could not be verified at IARC. The unexpectedly high proportion of patients in age 0 years or aged 19 years observed in some general cancer registries (Table A.9) may be attributed in part to the imprecise dates and in part to the high incidence rates of tumours that predominantly affect these years of age. Collection and reporting of non-malignant CNS tumours varied by registry (see below); nevertheless, their overall incidence in the pooled dataset was relatively high (Table A.9). Pilocytic astrocytoma was originally coded according to the ICD-O edition in use and recoded with uncertain behaviour with the conversion to ICD-O-3 (Table A.10). The exclusion of basal cell skin carcinomas in many registries may affect the incidence rates of skin carcinomas; however, the effect is expected to be minimal because of the low incidence in children. Information on laterality was complete, unless otherwise specified below for individual registries.

French National Childhood Cancer Registries, 2000–2012: National Registry of Childhood Haematological Malignancies, 1990–1999

National Registry of Childhood Solid Tumours and National Registry of Childhood Haematological Malignancies, 2000–2012

Jacqueline Clavel, Brigitte Lacour, Stéphanie Goujon, Emmanuel Désandes, Laure Faure, Sandra Guissou

The French National Registry of Childhood Haematological Malignancies (RNHE) and the French National Registry of Childhood Solid Tumours (RNTSE) jointly ensure the surveillance of cancer in children younger than 15 years in metropolitan France. RNHE has specifically recorded haematological malignancies since 1990, and RNTSE has recorded malignant solid tumours, including benign tumours of the CNS, since 2000 (Table A.10). The registries receive national public funding, which covers data collection and quality control.

Data are actively collected by trained investigators in all paediatric haematology and oncology departments and paediatric neurosurgery departments (~40 centres). Active registration is supplemented by an annual request for data from the Medical Information System Programme of the teaching hospitals and comprehensive cancer centres, which lists all children younger than 15 years who have been admitted to any department with a diagnosis of cancer, a brain tumour, or any of a few borderline diagnoses. Additional data sources are the long-duration disease database derived from health insurance organizations and therapeutic networks. The medical causes of death are matched against the cancer cases that are fatal before the patient is transferred to a specialized department (mainly neonatal cases), using probabilistic methods within the CépiDc database of the National Institute of Health and Medical Research (INSERM). Because this database is anonymous, no cases can be registered on the basis of a death certificate only.

The registration form is common to both registries and includes identification data (first and last names, sex, date and place of birth, address at diagnosis), diagnostic data (date of incidence, basis of diagnosis, method of first detection, site of primary tumour, histological type, immunophenotype and genetics, stage at diagnosis, laterality, histological grade), patient pathway from diagnosis to treatment, initial treatment (date of treatment initiation, cancer treatment type), vital status, and date of last contact. Vital status is updated every 2 years by comparing the registry files with the central population register.

The two national registries work closely together and have used a common database since 2012. They comply with the international recommendations for data collection, registration, and coding formulated by IARC. Data quality is regularly monitored by searching for duplicates and conducting consistency checks. Data are used for surveillance and research. Paediatric registries provide the national figures of cancer incidence and survival in

FRANCE, paediatric (2000-2012)

	Age group (years)	Males	Females
Person-years	0	5 026 801	4 801 810
	1-4	20 057 157	19 141 302
	5-9	25 020 356	23 829 425
	10-14	25 345 283	24 141 436
	0-14	75 449 597	71 913 973
Average annual population	0-14	5 803 815	5 531 844

Please consult the quality indicators for this registry

FRANCE, paediatric, haematological malignancies (1990-1999)

	Age group (years)	Males	Females
Person-years	0	3 712 566	3 535 545
	1-4	14 985 758	14 306 315
	5-9	19 439 096	18 555 160
	10-14	19 659 716	18 753 230
	0-14	57 797 136	55 150 250
Average annual population	0-14	5 779 714	5 515 025

Please consult the quality indicators for this registry

FRANCE, paediatric (2000-2012)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	366	2833	1833	1411	**6443**	28.5	100.0	37.2	72.3	37.5	28.5	**45.6**	656	99.9	0.0
	a. Lymphoid	150	2397	1518	968	**5033**	22.3	78.1	15.3	61.2	31.1	19.6	**35.8**	513	100.0	0.0
	b. Acute myeloid	146	312	214	289	**961**	4.3	14.9	14.9	8.0	4.4	5.8	**6.7**	98	100.0	0.0
	c. CMD	3	17	30	81	**131**	0.6	2.0	0.3	0.4	0.6	1.6	**0.8**	13	99.2	0.0
	d. MDS & other	50	76	39	33	**198**	0.9	3.1	5.1	1.9	0.8	0.7	**1.4**	20	99.5	0.0
	e. Unspecified	17	31	32	40	**120**	0.5	1.9	1.7	0.8	0.7	0.8	**0.8**	12	100.0	0.0
II	LYMPHOMA & RELATED	52	336	771	1409	**2568**	11.4	100.0	5.3	8.6	15.8	28.5	**16.4**	261	99.7	0.0
	a. Hodgkin	0	32	217	843	**1092**	4.8	42.5	-	0.8	4.4	17.0	**6.6**	111	99.9	0.0
	b. Non-Hodgkin except BL	8	121	256	370	**755**	3.3	29.4	0.8	3.1	5.2	7.5	**4.9**	77	99.5	0.0
	c. Burkitt (BL)	1	139	292	187	**619**	2.7	24.1	0.1	3.5	6.0	3.8	**4.1**	63	99.8	0.0
	d. Lymphoreticular	43	44	6	6	**99**	0.4	3.9	4.4	1.1	0.1	0.1	**0.8**	10	99.0	0.0
	e. Unspecified	0	0	0	3	**3**	0.0	0.1	-	-	-	0.1	**0.0**	0	100.0	0.0
III	CNS NEOPLASMS †	384	1733	1787	1522	**5426**	24.0	100.0	39.1	44.2	36.6	30.8	**37.4**	553	85.2	0.0
	a. Ependymoma	83	223	116	108	**530**	2.3	9.8	8.4	5.7	2.4	2.2	**3.8**	54	98.5	0.0
	b. Astrocytoma	116	701	646	525	**1988**	8.8	36.6	11.8	17.9	13.2	10.6	**13.8**	202	81.5	0.0
	c. CNS embryonal	100	406	373	201	**1080**	4.8	19.9	10.2	10.4	7.6	4.1	**7.6**	110	99.2	0.0
	d. Other gliomas	29	196	306	232	**763**	3.4	14.1	3.0	5.0	6.3	4.7	**5.2**	78	63.7	0.0
	e. Other specified	41	190	330	425	**986**	4.4	18.2	4.2	4.8	6.8	8.6	**6.5**	100	91.7	0.0
	f. Unspecified CNS	15	17	16	31	**79**	0.3	1.5	1.5	0.4	0.3	0.6	**0.5**	8	26.6	0.0
IV	NEUROBLASTOMA	720	876	208	66	**1870**	8.3	100.0	73.3	22.3	4.3	1.3	**14.4**	191	96.7	0.0
	a. (Ganglio)neuroblastoma	718	872	205	52	**1847**	8.2	98.8	73.1	22.2	4.2	1.1	**14.2**	188	96.6	0.0
	b. Peripheral nervous	2	4	3	14	**23**	0.1	1.2	0.2	0.1	0.1	0.3	**0.1**	2	100.0	0.0
V	RETINOBLASTOMA	281	339	23	1	**644**	2.9	100.0	28.6	8.6	0.5	0.0	**5.1**	66	63.5	0.0
VI	RENAL TUMOURS	191	770	263	46	**1270**	5.6	100.0	19.4	19.6	5.4	0.9	**9.6**	130	98.2	0.0
	a. Nephroblastoma	191	768	241	26	**1226**	5.4	96.5	19.4	19.6	4.9	0.5	**9.3**	125	98.1	0.0
	b. Renal carcinoma	0	2	22	20	**44**	0.2	3.5	-	0.1	0.5	0.4	**0.3**	4	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VII	HEPATIC TUMOURS	60	122	33	31	**246**	1.1	100.0	6.1	3.1	0.7	0.6	**1.8**	25	97.2	0.0
	a. Hepatoblastoma	60	118	24	8	**210**	0.9	85.4	6.1	3.0	0.5	0.2	**1.6**	21	96.7	0.0
	b. Hepatic carcinoma	0	4	9	23	**36**	0.2	14.6	-	0.1	0.2	0.5	**0.2**	4	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VIII	BONE TUMOURS	3	61	323	682	**1069**	4.7	100.0	0.3	1.6	6.6	13.8	**6.6**	108	99.9	0.0
	a. Osteosarcoma	1	10	137	360	**508**	2.2	47.5	0.1	0.3	2.8	7.3	**3.1**	52	99.8	0.0
	b. Chondrosarcoma	0	1	5	23	**29**	0.1	2.7	-	0.0	0.1	0.5	**0.2**	3	100.0	0.0
	c. Ewing & related	2	46	163	266	**477**	2.1	44.6	0.2	1.2	3.3	5.4	**3.0**	48	100.0	0.0
	d. Other specified	0	2	13	23	**38**	0.2	3.6	-	0.1	0.3	0.5	**0.2**	4	100.0	0.0
	e. Unspecified	0	2	5	10	**17**	0.1	1.6	-	0.1	0.1	0.2	**0.1**	2	100.0	0.0
IX	SOFT TISSUE SARCOMA	144	434	404	439	**1421**	6.3	100.0	14.7	11.1	8.3	8.9	**9.8**	145	99.9	0.0
	a. Rhabdomyosarcoma	50	328	243	142	**763**	3.4	53.7	5.1	8.4	5.0	2.9	**5.4**	78	100.0	0.0
	b. Fibrosarcoma	45	11	15	34	**105**	0.5	7.4	4.6	0.3	0.3	0.7	**0.7**	11	100.0	0.0
	c. Kaposi sarcoma	1	1	2	0	**4**	0.0	0.3	0.1	0.0	0.0	-	**0.0**	0	75.0	0.0
	d. Other specified	37	77	113	216	**443**	2.0	31.2	3.8	2.0	2.3	4.4	**2.9**	45	100.0	0.0
	e. Unspecified	11	17	31	47	**106**	0.5	7.5	1.1	0.4	0.6	0.9	**0.7**	11	100.0	0.0
X	GERM CELL TUMOURS	203	170	123	351	**847**	3.8	100.0	20.7	4.3	2.5	7.1	**5.8**	86	92.1	0.0
	a. CNS germ cell ‡	30	59	67	160	**316**	1.4	37.3	3.1	1.5	1.4	3.2	**2.1**	32	86.4	0.0
	b. Other extragonadal	139	61	6	26	**232**	1.0	27.4	14.1	1.6	0.1	0.5	**1.8**	24	90.9	0.0
	c. Gonadal germ cell	33	49	46	151	**279**	1.2	32.9	3.4	1.3	0.9	3.1	**1.8**	28	98.9	0.0
	d. Gonadal carcinoma	0	0	0	8	**8**	0.0	0.9	-	-	-	0.2	**0.0**	1	100.0	0.0
	e. Unspecified gonadal	1	1	4	6	**12**	0.1	1.4	0.1	0.0	0.1	0.1	**0.1**	1	100.0	0.0
XI	CARCINOMA & MELANOMA	26	62	159	484	**731**	3.2	100.0	2.6	1.6	3.3	9.8	**4.6**	74	99.6	0.0
	a. Adrenocortical	16	18	7	8	**49**	0.2	6.7	1.6	0.5	0.1	0.2	**0.4**	5	100.0	0.0
	b. Thyroid	7	21	68	235	**331**	1.5	45.3	0.7	0.5	1.4	4.7	**2.0**	34	99.7	0.0
	c. Nasopharyngeal	0	1	6	37	**44**	0.2	6.0	-	0.0	0.1	0.7	**0.3**	4	100.0	0.0
	d. Melanoma	3	19	36	81	**139**	0.6	19.0	0.3	0.5	0.7	1.6	**0.9**	14	99.3	0.0
	e. Skin carcinoma	0	2	16	16	**34**	0.2	4.7	-	0.1	0.3	0.3	**0.2**	3	97.1	0.0
	f. Other & unspecified	0	1	26	107	**134**	0.6	18.3	-	0.0	0.5	2.2	**0.8**	14	100.0	0.0
XII	OTHER & UNSPECIFIED	7	25	8	9	**49**	0.2	100.0	0.7	0.6	0.2	0.2	**0.4**	5	100.0	0.0
	a. Other specified	7	23	7	9	**46**	0.2	93.9	0.7	0.6	0.1	0.2	**0.3**	5	100.0	0.0
	b. Other unspecified	0	2	1	0	**3**	0.0	6.1	-	0.1	0.0	-	**0.0**	0	100.0	0.0
	TOTAL	2437	7761	5935	6451	**22584**	100.0	100.0	247.9	198.0	121.5	130.4	**157.6**	2299	94.6	0.0

† includes 2414 non-malignant ‡ includes 119 non-malignant

Please consult the quality indicators for this registry

FRANCE, paediatric, haematological malignancies (1990-1999)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	265	2060	1370	945	**4640**	73.9	100.0	36.6	70.3	36.1	24.6	**43.4**	621	98.7	0.0
	a. Lymphoid	107	1744	1121	669	**3641**	58.0	78.5	14.8	59.5	29.5	17.4	**34.2**	488	99.3	0.0
	b. Acute myeloid	124	240	185	216	**765**	12.2	16.5	17.1	8.2	4.9	5.6	**7.1**	102	95.9	0.0
	c. CMD	0	7	25	31	**63**	1.0	1.4	-	0.2	0.7	0.8	**0.5**	8	96.8	0.0
	d. MDS & other	23	49	20	17	**109**	1.7	2.3	3.2	1.7	0.5	0.4	**1.1**	15	98.2	0.0
	e. Unspecified	11	20	19	12	**62**	1.0	1.3	1.5	0.7	0.5	0.3	**0.6**	8	100.0	0.0
II	LYMPHOMA & RELATED	9	250	565	819	**1643**	26.1	100.0	1.2	8.5	14.9	21.3	**13.7**	216	85.0	0.0
	a. Hodgkin	0	46	168	428	**642**	10.2	39.1	-	1.6	4.4	11.1	**5.1**	84	94.7	0.0
	b. Non-Hodgkin except BL	6	98	187	236	**527**	8.4	32.1	0.8	3.3	4.9	6.1	**4.5**	70	80.8	0.0
	c. Burkitt (BL)	1	106	208	151	**466**	7.4	28.4	0.1	3.6	5.5	3.9	**4.0**	62	76.8	0.0
	d. Lymphoreticular	2	0	0	0	**2**	0.0	0.1	0.3	-	-	-	**0.0**	0	100.0	0.0
	e. Unspecified	0	0	2	4	**6**	0.1	0.4	-	-	0.1	0.1	**0.0**	1	33.3	0.0
III	CNS NEOPLASMS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	a. Ependymoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Astrocytoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	c. CNS embryonal	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Other gliomas	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	e. Other specified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	f. Unspecified CNS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
IV	NEUROBLASTOMA	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	a. (Ganglio)neuroblastoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Peripheral nervous	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
V	RETINOBLASTOMA	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VI	RENAL TUMOURS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	a. Nephroblastoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Renal carcinoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	c. Unspecified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VII	HEPATIC TUMOURS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	a. Hepatoblastoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Hepatic carcinoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	c. Unspecified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VIII	BONE TUMOURS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	a. Osteosarcoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Chondrosarcoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	c. Ewing & related	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Other specified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	e. Unspecified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
IX	SOFT TISSUE SARCOMA	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	a. Rhabdomyosarcoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Fibrosarcoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	c. Kaposi sarcoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Other specified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	e. Unspecified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
X	GERM CELL TUMOURS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	a. CNS germ cell	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Other extragonadal	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	c. Gonadal germ cell	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Gonadal carcinoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	e. Unspecified gonadal	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
XI	CARCINOMA & MELANOMA	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	a. Adrenocortical	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Thyroid	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	c. Nasopharyngeal	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Melanoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	e. Skin carcinoma	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	f. Other & unspecified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
XII	OTHER & UNSPECIFIED	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	a. Other specified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Other unspecified	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	TOTAL	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Please consult the quality indicators for this registry

the childhood population; these data are disseminated by SPF and INCa. They also participate in various research projects (https://rnce.inserm.fr).

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

The first incidence table in this section presents a combined dataset provided by both registries (RNHE and RNTSE) for 2000–2012, and the second table shows the data for haematopoietic malignancies only, collected by RNHE in 1990–1999. In both registries, registration focused on the age range 0–14 years during the reporting period. Therefore, data for the age groups 15–19 years and 0–19 years are not shown in the tables.

As expected, the incidence rate and the proportion of infants among children reported in Table A.9 for RNHE are low, because only leukaemia and lymphoma were included in this dataset. The reported proportion of non-malignant CNS tumours in the pooled dataset is high (Table A.9), because of strong links with neurology clinics throughout the country and systematic registration of all types of CNS tumours during the entire recording period. Pilocytic astrocytoma was coded with uncertain behaviour, but one case was coded with malignant behaviour. Skin carcinomas are recorded, but cases diagnosed in private hospitals or by dermatologists providing outpatient treatment may be missed. Laterality information collected by RNTSE was almost complete and is included in the relevant tables. See also France, above.

FRANCE, 13 registries (1993-2012)

Registry	Period	Cases	%	Person-years	%
Bas-Rhin	1993-2011	872	12.1	5 035 555	11.9
Calvados	1993-2012	564	7.8	3 464 517	8.2
Doubs	1993-2012	462	6.4	2 682 953	6.3
Gironde	2008-2012	317	4.4	1 728 884	4.1
Haut-Rhin	1993-2012	594	8.2	3 688 407	8.7
Haute-Vienne	2009-2011	43	0.6	237 246	0.6
Hérault	1993-2012	821	11.4	4 594 978	10.8
Isère	1993-2012	1100	15.3	6 086 411	14.4
Lille	2008-2012	192	2.7	1 018 249	2.4
Loire-Atlantique and Vendée	1998-2012	1181	16.4	6 958 225	16.4
Manche	1994-2012	370	5.1	2 322 619	5.5
Somme	1993-2012	425	5.9	2 937 532	6.9
Tarn	1993-2012	263	3.7	1 618 280	3.8
FRANCE	**1993-2012**	**7204**	**100.0**	**42 373 856**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

Bas-Rhin Cancer Registry, 1993–2011

Michel Velten

The department of Bas-Rhin, located in eastern France, is the more populous and more densely populated of the two departments that form the Alsace region. In 2010, the population was 1.1 million, and 24% of the population was younger than 20 years (Table A.6). The capital city is Strasbourg.

The Bas-Rhin Cancer Registry was created in 1974 to collect data for use in epidemiological research and evaluation. It was inspired by international trends and the high cancer mortality in Alsace. The first year with complete data is 1975 (Table A.10).

All diagnosed malignant or in situ tumours are registered for patients residing in the Bas-Rhin department at the time of diagnosis, regardless of where they are treated. Multiple tumours in the same subject are registered, regardless of whether they occur simultaneously in paired organs or in sublocations of the same organ.

Data are collected actively from clinical records either on-site or electronically. Vital status of the patient is based on a sample follow-up with a frequency of one or two large anatomical localizations per year with an average rotation period of 5 years.

The registry provides data and estimates of cancer incidence, prevalence, and survival for the department of Bas-Rhin and participates in national and international studies.

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

The proportion of cases aged 19 years in the age group 15–19 years was 25.4% (Table A.9); the excess was seen for lymphomas and germ cell tumours. The reported proportion of non-malignant CNS tumours is high (Table A.9) because of systematic registration of all types of CNS tumours since 2000. Laterality was complete for retinoblastoma and nephroblastoma. See also France, above.

Calvados, 1990–2012
Calvados General Tumours Registry
Calvados Registry of Digestive Tumours
Lower Normandy Haemopathy Registry

Anne-Valérie Guizard, Guy Launoy, Véronique Bouvier, Xavier Troussard, Edouard Cornet

The department of Calvados is located in the region of Normandy in north-western France. It covers an area of 5548 km^2 and is bordered by the English Channel. The population was 0.7 million, and 25% of the total population was younger than 20 years (Table A.6); 64% of people live in urban areas.

In 2013, there were 607 general practitioners and 92 paediatricians in the department. The major city of Caen has a university hospital and a comprehensive cancer centre. Of the 12 general public and private hospitals, one has radiotherapy facilities.

Three cancer registries operate in the department, all three targeting patients in the entire age range. A general registry and a registry of digestive tumours were started in 1978, and a regional registry of haematological malignancies was started in 2002. These registries are supported mainly by INCa and the Ministry of Health.

Population-based cancer registration has been conducted in the department using data from public and private medical facilities.

Registration is active; information is collected from the medical and pathology records in Calvados and neighbouring areas. Completeness is ensured by linking the information collected from all sources. Follow-up for vital status is updated at regular intervals for all cases. Data from registries are linked periodically to exclude duplicate cases.

The registry data are used to analyse socioeconomic and geographical determinants of incidence and time trends, evaluate mass screening, report on survival, assess the impact of treatment on survival trends, and measure quality of life.

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

A remarkable peak in cancer incidence in 2009 was ascribed by the general registry to random variation due to the small number of cases. Non-malignant CNS tumours were registered from 2000 (Table A.9). Pilocytic astrocytoma was coded with malignant behaviour until 2000 and was coded with uncertain behaviour beginning in 2001, but all cases were recoded with uncertain behaviour for submission to IICC-3. See also France, above.

Doubs Cancer Registry, 1993–2012

Anne-Sophie Woronoff

The Doubs Cancer Registry covers the population of the department of Doubs, which covers an area of 5234 km^2 and is located in the Bourgogne Franche-Comté region of eastern France. The covered population was 0.5 million (0.8% of the national population), and 25% of the population was younger than 20 years (Table A.6). Almost 80% of people live in urban areas. In 2014, the average population density was 102 per km^2.

The numbers of paediatricians per 100 000 children are close to the national averages. The department has five public hospitals (including one university hospital) and four private care facilities but no specialized cancer centre. In 2009, a regional infrastructure for the coordination of multidisciplinary service to provide cancer care was established and centralized at the regional level of Franche-Comté.

The Doubs Cancer Registry is one of the oldest general cancer registries in France; its activities began in 1976, and data were provided from 1978 (Table A.10). The registry is located in the University Hospital of Besançon. The registry staff consists of seven people, who conduct both registration and research activities. The registry received national public funding for data collection and quality control.

The main sources of information are the regional pathology and cytology laboratories (pathology records), medical information systems in public and private care facilities (medical files), records of multidisciplinary team meetings, screening facilities, and health insurance notifications. The registry staff members visit the sources and consult medical records to collect and validate data. The international recommendations for data collection, registration, and coding formulated by IARC are followed. Data quality is regularly monitored by searching for duplicates and conducting consistency checks.

The registry regularly publishes descriptive statistics, conducts studies in collaboration with local clinicians and epidemiologists, and participates in activities with other registries at the national level (in FRANCIM) and the international level (https://www.chu-besancon.fr/registretumeursdoubs). Registry data are used in numerous epidemiological studies, including incidence, prevalence, survival, and evaluation-of-care studies, and for public health assessments.

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

The proportion of cases aged 19 years in the age group 15–19 years was high (26.8%) (Table A.9), mainly because of the high incidence in the diagnostic groups II, X, and XI. The reported proportion of non-malignant CNS tumours is high (Table A.9) because of systematic registration of all types of CNS tumours since 2003. The high proportion of malignant carcinoid tumours of the appendix (Table A.11) was based on nine cases. See also France, above.

Gironde, 2008–2012
General Cancer Registry of Gironde
Registry of CNS Tumours of Gironde
Registry of Haematological Malignancies of Gironde
Mesothelioma Registry

Brice Amadeo, Gaëlle Coureau, Simone Mathoulin-Pélissier, Sylvain Maurisset, Marianne Saves, Isabelle Baldi, Camille Pouchieu, Anne Cantagrel-Gruber, Sandra Le Guyader, Alain Monnereau, Sébastien Orazio, Patrick Brochard, Céline Gramond

The department of Gironde is part of the Aquitaine region, located in south-western France. It covers an area of 9975 km^2 and is the largest department in France. The population was 1.5 million (2.3% of the national population), and 23% of the population was younger than 20 years (Table A.6). The population density is 149 per km^2. Almost 80% of the population lives in urban areas.

Gironde has 30 public and private hospitals with acute care services, including a teaching hospital and a comprehensive cancer centre. The medical coverage in Gironde is above the national average. There are 67 paediatricians per 100 000 children younger than 15 years.

Gironde is covered by four cancer registries that target cancers in patients of all ages: a general population-based registry and three specialized registries that collect data on CNS tumours, haematological malignancies, and mesothelioma. All these registries are located in Bordeaux and are supported mainly by SPF and INCa. Cancer records are based on notifications from four types of data sources: pathology and cytology laboratories, hospital medical information programmes, health insurance notifications for cancer, and multidisciplinary team meetings. Registry staff members systematically check and validate notifications by consulting medical records in hospitals.

The Gironde registries collaborate to provide indicators such as incidence and survival in the department. They also participate in various research projects to study the effects of environmental exposures, socioeconomic determinants

of cancer occurrence, and survivorship. Data and research projects are regularly updated online (http://etudes.isped.u-bordeaux2.fr/registres-cancers-aquitaine).

POPULATION AT RISK
See France, above.

EDITORS' COMMENTS
The proportion of cases aged 19 years in the age group 15–19 years was 32.1% (Table A.9), mainly because of a high incidence of tumours in the diagnostic group XI. The reported proportion of non-malignant CNS tumours is high (Table A.9) because of systematic registration of all types of CNS tumours over the entire reporting period. Skin carcinomas are reportable, but their registration may be incomplete. See also France, above.

Haut-Rhin Cancer Registry, 1993–2012

Emilie Marrer, Antoine Buemi

The department of Haut-Rhin covers an area of 3525 km^2 and is located in north-eastern France. It is bordered by the department of Bas-Rhin to the north (with which it constitutes the Alsace region), the department of Vosges to the west, Germany to the east, and the Franche-Comté region and Switzerland to the south.

In 2010, the total population of Haut-Rhin was 0.8 million (1.2% of the French population), and 24% of the population was younger than 20 years (Table A.6). Haut-Rhin is divided into 377 communes, of which 82% have a population of less than 2000. The average population density is 214 per km^2.

With 83 general practitioners and 140 specialists per 100 000 residents, the medical coverage of the Haut-Rhin population is below the national average. Cancer care for children living in the department is organized in collaboration with the regional specialized reference centre for paediatric oncology, which is located outside the department, in Strasbourg (the capital of the Bas-Rhin department). Haut-Rhin has two radiotherapy wards: one in the south, in Mulhouse, and one in the north, in Colmar.

The Haut-Rhin Cancer Registry was established in 1989 to obtain data on the cancer burden in the department. Data from the registry are used to evaluate public health measures in cancer prevention, screening, and treatment. The registry actively collects information on all new cases of cancer in Haut-Rhin, including on patients diagnosed and treated elsewhere. The main sources of information are pathology and cytology laboratories, hospital discharge data, and radiotherapy, oncology, paediatrics, and haematology services. The data are systematically verified, completed, or modified using secondary sources (hospitalization services, general practitioners). Paediatric cases are also linked annually with the database of the French National Childhood Cancer Registries. Data are collected according to standardized procedures (IARC, ENCR) and maintained using IARC CanReg software. The registry provides data and estimates of cancer incidence and survival for the department and participates in national and international studies.

POPULATION AT RISK
See France, above.

EDITORS' COMMENTS
The MV% is 98% (Table A.9), which may indicate that some clinically diagnosed cases were missed. The high proportion of cases aged 19 years in the age group 15–19 years resulted from the high incidence of tumours in the diagnostic groups XI, II, and X. Non-malignant CNS tumours were registered for the entire reporting period (Table A.9). All skin carcinomas were reportable. See also France, above.

Haute-Vienne, Limousin Cancer Registry, 2009–2011

Tania d'Almeida

The Limousin Cancer Registry covers the population of the department of Haute-Vienne, which is located in the Limousin region of south-western France and covers an area of 5520 km^2. The population was 0.4 million (0.6% of the national population), and 21% of the population was younger than 20 years (Table A.6). Almost 80% of people live in urban areas. In 2010, the ageing index (the ratio of population aged 65 years and older to population younger than 15 years) was higher in Haute-Vienne (99.2%) than the national average (69.4%).

The department has five public hospitals (including one university hospital) and three private care facilities but no specialized cancer centre. Haute-Vienne has two radiotherapy units – one in the university hospital and one in a private care facility – and four pathology laboratories. The numbers of general practitioners and specialists per 100 000 residents are 140 and 81, respectively.

The Limousin Cancer Registry is located in Limoges, the department capital, within the university hospital. Registration activities are funded by SPF, INCa, and the University Hospital of Limoges. The registry staff consists of five people: a medical epidemiologist, a data manager, and three trained registrars.

Cancer cases are found by active searching in the medical records from several sources. The main sources of information are pathology and cytology laboratories, medical information systems in hospitals and private care facilities, and health insurance notifications.

The registry publishes basic descriptive statistics and participates in collaborative studies at the national and international levels. Registry data are included in the FRANCIM database and are used to estimate national incidence and survival.

POPULATION AT RISK
See France, above.

EDITORS' COMMENTS

The number of incident cases during the reporting period was not sufficiently large for presentation of the data in a full table, but the registry contributed to the national pool. Non-malignant CNS tumours were registered for the entire reporting period. There were no cases of pilocytic astrocytoma in the dataset. See also France, above.

Hérault Cancer Registry, 1993–2012

Brigitte Trétarre

The department of Hérault is located in the Languedoc-Roussillon region of southern France, on the Mediterranean Sea. The department covers an area of 6101 km^2. The population is 1.0 million, and 23% of the population is younger than 20 years (Table A.6). The urban population is 4.9 times the rural population, and this ratio is growing.

Residents of the department have good access to medicosocial facilities; Hérault has one specialized cancer hospital, 10 public hospitals (including one academic hospital, in Montpellier), and 16 private clinics. Radiotherapy is available at three main centres. The numbers of general practitioners, specialists, and paediatricians per 100 000 residents are higher than the national averages.

The general population-based cancer registry of the Hérault department was established in 1985 (http://www.registre-tumeurs-herault.fr). The registry has six employees: a medical epidemiologist, a biostatistician, a secretary, and three trained investigators.

The registry relies on several information sources, such as the medical informatics systems of individual hospitals, pathology records, and health insurance databases. Each new case of cancer diagnosed in a resident of the department of Hérault and identified via these sources is verified and updated through systematic checking of source medical files and is then recorded in the registry database. All invasive cancers (except basal cell skin carcinomas), all benign tumours of the CNS, and some in situ cancers are registered. The international recommendations for data collection, registration, and coding formulated by IARC are followed. Active follow-up is performed for all registered cases.

The registry collaborates with other registries at the national level (in FRANCIM) and the international level.

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

All non-malignant CNS tumours were registered during the entire reporting period. Laterality was complete for 84% of the cases of interest. See also France, above.

Isère Cancer Registry, 1993–2012

Marc Colonna

The Isère Cancer Registry covers the population of the department of Isère, which covers an area of 7431 km^2 and is located in the Auvergne-Rhône-Alpes region of south-eastern France. In 2013, the average population density was 166 per km^2. The population is 1.2 million (1.9% of the national population), and 26% of the population is younger than 20 years (Table A.6).

The numbers of paediatricians per 100 000 children younger than 15 years are close to the national average. Isère has public hospitals (including one university hospital) and private care facilities but no specialized cancer centre.

The Isère Cancer Registry began its activities in 1979 (Table A.10). It is one of the oldest general cancer registries in France and is affiliated with FRANCIM. The registry is located in the University Hospital of Grenoble. The registry has 10 staff members, who conduct both registration and research activities. The registry receives national public funding for data collection and quality control.

The main sources of information are the regional pathology and cytology laboratories (pathology records), medical information systems in public and private care facilities (medical files), records of multidisciplinary team meetings, screening facilities, and health insurance notifications. The registry staff members visit the sources and consult medical records to collect and validate data. Data quality is regularly monitored by searching for duplicates and conducting consistency checks.

The registry regularly publishes basic descriptive epidemiological studies, conducts studies with local clinicians and epidemiologists, and collaborates with other registries at the national level (in FRANCIM) and the international level. Registry data are used in numerous epidemiological studies, including incidence, prevalence, survival, evaluation-of-care studies, and for public health assessments.

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

The reported proportion of non-malignant CNS tumours is high (Table A.9) because of systematic registration of all types of CNS tumours over the entire reporting period. Laterality was complete for retinoblastoma and nephroblastoma. See also France, above.

Lille Cancer Registry, 2008–2012

Sandrine Plouvier, Karine Ligier

The cancer registry of Lille and the surrounding area is a general population-based cancer registry that covered a population of 788 877 in 2011. Lille is located in northern France, near the border with Belgium. The city of Lille is both the capital of the Hauts-de-France region in the Nord department and the major city in the European Metropolis of Lille. The covered population includes the residents of Lille and 100 surrounding communities. This population is about 30% of the population of the Nord department, and 27% of the population is younger than 20 years (Table A.6). Lille and the surrounding area has a high population density of 1175 per km^2 and is affected by socioeconomic deprivation and environmental pollution.

There are two teaching hospitals, 10 general public and private hospitals, a regional cancer care centre, and three radiotherapy centres within the study area.

The registry was established in 2005 following the first national cancer plan of France (2003–2007). It is part of the Centre de Référence Régional en Cancérologie – a structure of cooperation in oncology between the University Hospital of Lille and the cancer care centre of Lille.

The registry has nine staff members, some of whom work part-time. Cancer cases are identified from several sources: hospital and radiotherapy centre discharge records, pathology records, health insurance notifications, haematology laboratories, and multidisciplinary team meetings. Information from these sources is systematically checked by registry staff members, and medical files are consulted to validate the registration records. Registration follows international rules (IACR, ENCR). Data completeness and quality and completeness of registration are regularly checked.

The registry regularly publishes incidence and survival data and participates in studies conducted by FRANCIM and in national studies on survival.

PUBLICATIONS

Ligier K, Plouvier S, Danzon A, Martin P, Benoît E, Molinié F, et al. (2012). Éléments d'exhaustivité et résultats pour la première année d'enregistrement du Registre général des cancers de Lille et de sa région. [in French] Rev Epidemiol Sante Publique. 60(2):131–9. https://doi.org/10.1016/j.respe.2011.10.006 PMID:22424751

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

The small numbers of cases may explain the unexpected age distribution (Table A.9); the dates of birth and incidence are considered to be incomplete (Table A.8). Non-malignant CNS tumours were included, except pituitary adenoma. See also France, above.

Loire-Atlantique and Vendée Cancer Registry, 1998–2012

Florence Molinié, Anne Cowppli-Bony, Solenne Billon-Delacour

The registration area consists of the departments of Loire-Atlantique and Vendée, located in western France. The total population is 1.9 million (3% of the national population), and 25% of the population is younger than 20 years (Table A.6). The population density of Loire-Atlantique and Vendée is 187 per km^2 and 94 per km^2, respectively. About 54% of the Loire-Atlantique population and 25% of the Vendée population lives in urban areas (≥ 10 000 inhabitants).

There are 23 public and 37 private hospitals in the two departments, including one university hospital and two cancer centres. The two departments have 2750 general practitioners and 2730 specialists.

The Loire-Atlantique and Vendée Cancer Registry is one of the largest registries in France. It was created in 1998 as a legal association. It is financed entirely by SFP, INCa, and local organizations. The registry is staffed by two medical epidemiologists, a part-time pathologist, and 12.4 full-time equivalent positions.

Data are actively collected from the medical records of several data sources, including pathology departments, medical information systems of hospitals and clinics, and health insurance notifications, to identify and abstract information on cancer diagnosis and treatment. Cancer is not a notifiable disease; however, a few registration forms are received from private practitioners.

Data registration follows the ENCR and IACR recommendations. Data are checked for duplicates and inconsistencies twice a year, using IARCcrgTools.

The registry produces basic descriptive data in annual reports and participates in collaborative studies at the national level (https://www.santepaysdelaloire.com/registre-des-cancers).

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

The reported proportion of non-malignant CNS tumours is high (Table A.9); all types of CNS tumours were systematically registered from 2005. Skin carcinomas were not reportable. Laterality was complete for retinoblastoma and nephroblastoma. See also France, above.

Manche, 1994–2012
Manche General Cancer Registry
Lower Normandy Haemopathy Registry

Simona Bara, Xavier Troussard, Edouard Cornet

The department of Manche covers an area of 5938 km^2 and is located in the region of Normandy, in north-western France. The total population is 0.5 million, and 24% of the population is younger than 20 years (Table A.6). The average population density is 84 per km^2. The population is mainly rural; only 48% of residents live in the five urban areas of Manche.

The level of medical coverage in Manche is relatively low compared with the national average. There are 11 public hospitals (general and local) and seven private care facilities. There are no specialized cancer centres in the department, but there are two radiotherapy units: a private unit in the south and a public unit in the north. The public unit is an external facility of the regional cancer care centre in the neighbouring department of Calvados.

Manche is covered by two cancer registries targeting patients in the entire age range: a general registry and a regional registry of haematological malignancies.

The Manche General Cancer Registry began in 1994. It is based in the general hospital of Cherbourg and was created by an association of practitioners in the department. To reflect a specific interest in malignant haemopathy, the registry established – in collaboration with the haematology laboratory of the regional university hospital – a specific methodology for recording haematological malignancies. The resulting Lower Normandy Haemopathy Registry started operating in 2002. Both registries receive national public funding for data collection and quality control. Data are actively collected from regional sources, including pathology and cytology laboratories, oncology and radiotherapy services, records of multidisciplinary team meetings, screening facilities, health insurance notifications, and the medical records departments of hospitals. After initial notification, every file is checked in regional (private and public) medical facilities and then coded (Table A.10). The international recommendations for data collection, registration, and coding formulated by IARC are followed. Follow-up for vital status is updated at regular intervals for all cases.

The two registries collaborate to provide indicators such as incidence and survival in the department. They also regularly publish basic descriptive epidemiological studies and collaborate with other registries and FRANCIM in national and international studies (https://www.registrecancermanche.org/).

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

The proportion of cases aged 19 years in the age group 15–19 years was 27.0% (Table A.9), because of an increase in incidence in the diagnostic group XI. All non-malignant CNS tumours are systematically registered, and their proportion was relatively high (Table A.9). See also France, above.

Somme Cancer Registry, 1993–2012

Olivier Ganry, Bénédicte Lapôtre-Ledoux, Pascal Caillet

The Somme Cancer Registry covers the population of the department of Somme, located in the Hauts-de-France region. The topography is relatively flat, and the department covers an area of 6170 km^2. Amiens is the capital city. The population is 0.6 million, and almost 25% of the population is younger than 20 years (Table A.6). Cancer diagnostic and treatment services are provided by public and private hospitals. The area has nine public hospitals (including one university hospital), four private care facilities, and two radiotherapy centres but no specialized cancer centre.

Since 1982, the registry has recorded incident cancer cases (Table A.10) occurring in residents even if they are diagnosed or treated outside the registration area. The registry is a department of the University Hospital of Amiens and is funded by SPF, INCa, and the regional health agency. Cancer cases are ascertained actively from multiple medical records of several sources located within and outside the covered area. For paediatric and adolescent cases, the main sources of data are pathology laboratories and the medical information departments in public hospitals or in cancer centres located in neighbouring regions. All incident cases are validated after active consultation of all relevant medical and administrative records. The registry follows international guidelines for cancer registration. Regular checks are performed to ensure data completeness (in particular, cases are linked annually with the French National Childhood Cancer Registries database), quality, and internal consistency and to eliminate duplicates. Descriptive epidemiological studies are conducted and published in collaboration with FRANCIM and other European registries.

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

The proportion of cases aged 19 years in the age group 15–19 years was 27.1% (Table A.9), because of the increase in incidence in the diagnostic groups II, XI, and X. Non-malignant CNS tumours are registered, but data were not provided. There were no cases of pilocytic astrocytoma in the dataset. Thus, the reported incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. Malignant carcinoid tumours of the appendix constituted 1.6% of the total dataset (Table A.11). See also France, above.

Tarn Cancer Registry, 1993–2012

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The department of Tarn is administratively part of the Midi-Pyrénées region of southern France. The population is 0.4 million; 22% of the population is younger than 20 years (Table A.6), and 30% is aged 60 years and older.

The registration area is fairly autonomous in its provision of cancer care facilities, which are staffed by five pathologists, six oncologists, and five radiotherapists. These services are complemented by a regional cancer network, which consists of four public hospitals and four private clinics. However, some cancers, and particularly childhood cancers, are treated in the regional university hospital or in the regional cancer centre, both of which are located in Toulouse, the capital of the neighbouring department of Haute-Garonne.

The Tarn Cancer Registry has been in operation since 1982 (Table A.10); it operates as a non-profit association. The registry committee comprises representatives of the medical and university sectors and elected officials of the department of Tarn and the Midi-Pyrénées region. The registry is funded by the General Council of Tarn, the departmental committee of the National League Against Cancer, and INCa. Research is funded by grants. The registry staff of nine (6.3 full-time equivalent positions) is responsible for both registration and research activities. Notifications are systematically checked and completed by consulting the medical files. The medical information is coded by trained encoders. Information is collected by active case finding; four investigators visit the data sources. Laboratory services, private and public hospitals, administrative services, and medical specialists in Tarn are regularly visited. The most significant data sources are the regional university hospital and the regional cancer centre. In hospitals cases are ascertained from electronic databases of medical information departments. The registry also receives information annually from multidisciplinary team meetings of the entire Midi-Pyrénées region and uses the national hospital database to improve completeness. Insufficient information is completed in collaboration with general practitioners. Paediatric cases are also linked annually with the database of the French National Childhood Cancer Registries.

Active follow-up for vital status is conducted by consulting the national identification registry of physical persons or by writing to the town of birth every 5 years for all relevant survival studies.

The Tarn Cancer Registry conducts several studies, alone or in collaboration with other registries (FRANCIM and ENCR). These include estimates of cancer incidence, time trends, and prevalence and evaluation of diagnostic and therapeutic practices for selected sites.

POPULATION AT RISK

See France, above.

EDITORS' COMMENTS

The small numbers of cases may explain the unexpected age distribution of the cases (Table A.9). The reported proportion of non-malignant CNS tumours is high (Table A.9) because of systematic registration of all types of CNS tumours over the entire reporting period. Laterality was complete for retinoblastoma and gonadal tumours. See also France, above.

FRANCE, 13 registries (1993-2012)

	Age group (years)	Males	Females
Person-years	0	1 039 125	989 269
	1-4	4 216 929	4 014 207
	5-9	5 354 538	5 090 479
	10-14	5 433 345	5 178 088
	15-19	5 616 077	5 441 799
	0-14	16 043 937	15 272 043
	0-19	21 660 014	20 713 842

Please consult the quality indicators for this pool and its constituent registries

FRANCE, 13 registries (1993-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	84	603	390	265	316	1342	1658	27.8	100.0	23.0	100.0	41.4	73.3	37.3	25.0	28.6	45.2	41.5	646	789	99.6	0.0
	a. Lymphoid	32	488	320	182	154	1022	1176	21.2	76.2	16.3	70.9	15.8	59.3	30.6	17.2	13.9	34.5	29.9	492	562	99.7	0.0
	b. Acute myeloid	36	79	40	50	101	205	306	4.3	15.3	4.2	18.5	17.7	9.6	3.8	4.7	9.1	6.9	7.4	99	144	99.7	0.0
	c. CMD	0	5	10	17	41	32	73	0.7	2.4	1.0	4.4	-	0.6	1.0	1.6	3.7	1.0	1.6	15	34	98.6	0.0
	d. MDS & other	13	20	10	3	14	46	60	1.0	3.4	0.8	3.6	6.4	2.4	1.0	0.3	1.3	1.6	1.6	22	29	100.0	0.0
	e. Unspecified	3	11	10	13	6	37	43	0.8	2.8	0.6	2.6	1.5	1.3	1.0	1.2	0.5	1.2	1.0	18	20	97.7	0.0
II	LYMPHOMA & RELATED	21	95	191	354	611	661	1272	13.7	100.0	17.7	100.0	10.4	11.5	18.3	33.4	55.3	20.0	27.9	315	591	100.0	0.0
	a. Hodgkin	0	9	44	197	434	250	684	5.2	37.8	9.5	53.8	-	1.1	4.2	18.6	39.2	7.1	14.3	118	315	100.0	0.0
	b. Non-Hodgkin except BL	4	34	69	97	146	204	350	4.2	30.9	4.9	27.5	2.0	4.1	6.6	9.1	13.2	6.2	7.8	97	163	100.0	0.0
	c. Burkitt (BL)	0	34	73	51	24	158	182	3.3	23.9	2.5	14.3	-	4.1	7.0	4.8	2.2	4.9	4.3	76	86	100.0	0.0
	d. Lymphoreticular	17	18	2	5	5	42	47	0.9	6.4	0.7	3.7	8.4	2.2	0.2	0.5	0.5	1.5	1.3	20	23	100.0	0.0
	e. Unspecified	0	0	3	4	2	7	9	0.1	1.1	0.1	0.7	-	-	0.3	0.4	0.2	0.2	0.2	3	4	100.0	0.0
III	CNS NEOPLASMS †	52	333	364	322	245	1071	1316	22.2	100.0	18.3	100.0	25.6	40.5	34.8	30.3	22.2	34.6	31.8	514	624	86.9	0.0
	a. Ependymoma	12	41	27	14	19	94	113	1.9	8.8	1.6	8.6	5.9	5.0	2.6	1.3	1.7	3.2	2.9	45	54	100.0	0.0
	b. Astrocytoma	16	121	124	125	80	386	466	8.0	36.0	6.5	35.4	7.9	14.7	11.9	11.8	7.2	12.4	11.3	185	221	90.3	0.0
	c. CNS embryonal	15	86	89	45	27	235	262	4.9	21.9	3.6	19.9	7.4	10.4	8.5	4.2	2.4	7.8	6.6	113	125	100.0	0.0
	d. Other gliomas	1	43	63	56	41	163	204	3.4	15.2	2.8	15.5	0.5	5.2	6.0	5.3	3.7	5.1	4.8	78	97	69.6	0.0
	e. Other specified	7	32	43	62	71	144	215	3.0	13.4	3.0	16.3	3.5	3.9	4.1	5.8	6.4	4.5	4.9	69	101	94.4	0.0
	f. Unspecified CNS	1	10	18	20	7	49	56	1.0	4.6	0.8	4.3	0.5	1.2	1.7	1.9	0.6	1.5	1.3	23	27	3.6	0.0
IV	NEUROBLASTOMA	151	187	35	20	10	393	403	8.2	100.0	5.6	100.0	74.4	22.7	3.4	1.9	0.9	14.4	11.3	191	195	98.8	0.0
	a. (Ganglio)neuroblastoma	150	186	33	19	6	388	394	8.0	98.7	5.5	97.8	74.0	22.6	3.2	1.8	0.5	14.2	11.1	188	191	98.7	0.0
	b. Peripheral nervous	1	1	2	1	4	5	9	0.1	1.3	0.1	2.2	0.5	0.1	0.2	0.1	0.4	0.2	0.2	2	4	100.0	0.0
V	RETINOBLASTOMA	53	71	1	1	0	126	126	2.6	100.0	1.7	100.0	26.1	8.6	0.1	0.1	-	4.7	3.7	61	61	70.6	0.0
VI	RENAL TUMOURS	54	158	56	10	21	278	299	5.8	100.0	4.2	100.0	26.6	19.2	5.4	0.9	1.9	10.0	8.2	135	144	97.7	0.0
	a. Nephroblastoma	54	158	56	7	7	275	282	5.7	98.9	3.9	94.3	26.6	19.2	5.4	0.7	0.6	9.9	7.8	133	137	97.5	0.0
	b. Renal carcinoma	0	0	0	3	14	3	17	0.1	1.1	0.2	5.7	-	-	-	0.3	1.3	0.1	0.3	1	8	100.0	0.0
	c. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VII	HEPATIC TUMOURS	12	28	7	6	17	53	70	1.1	100.0	1.0	100.0	5.9	3.4	0.7	0.6	1.5	1.9	1.8	26	33	97.1	0.0
	a. Hepatoblastoma	12	25	6	4	2	47	49	1.0	88.7	0.7	70.0	5.9	3.0	0.6	0.4	0.2	1.7	1.4	23	24	100.0	0.0
	b. Hepatic carcinoma	0	2	1	2	14	5	19	0.1	9.4	0.3	27.1	-	0.2	0.1	0.2	1.3	0.2	0.4	2	9	100.0	0.0
	c. Unspecified	0	1	0	0	1	1	2	0.0	1.9	0.0	2.9	-	0.1	-	-	0.1	0.0	0.0	0	1	0.0	0.0
VIII	BONE TUMOURS	0	11	56	161	221	228	449	4.7	100.0	6.2	100.0	-	1.3	5.4	15.2	20.0	6.5	9.6	108	208	99.8	0.0
	a. Osteosarcoma	0	1	26	78	111	105	216	2.2	46.1	3.0	48.1	-	0.1	2.5	7.4	10.0	3.0	4.6	50	100	100.0	0.0
	b. Chondrosarcoma	0	0	0	9	21	9	30	0.2	3.9	0.4	6.7	-	-	-	0.8	1.9	0.2	0.6	4	14	100.0	0.0
	c. Ewing & related	0	10	30	64	73	104	177	2.2	45.6	2.5	39.4	-	1.2	2.9	6.0	6.6	3.1	3.9	49	82	100.0	0.0
	d. Other specified	0	0	0	6	11	6	17	0.1	2.6	0.2	3.8	-	-	-	0.6	1.0	0.2	0.4	3	8	100.0	0.0
	e. Unspecified	0	0	0	4	5	4	9	0.1	1.8	0.1	2.0	-	-	-	0.4	0.5	0.1	0.2	2	4	88.9	0.0
IX	SOFT TISSUE SARCOMA	20	100	76	91	139	287	426	6.0	100.0	5.9	100.0	9.9	12.1	7.3	8.6	12.6	9.4	10.1	138	201	100.0	0.0
	a. Rhabdomyosarcoma	10	74	45	33	23	162	185	3.4	56.4	2.6	43.4	4.9	9.0	4.3	3.1	2.1	5.5	4.7	78	88	100.0	0.0
	b. Fibrosarcoma	5	3	3	6	16	17	33	0.4	5.9	0.5	7.7	2.5	0.4	0.3	0.6	1.4	0.6	0.8	8	15	100.0	0.0
	c. Kaposi sarcoma	0	0	0	1	2	1	3	0.0	0.3	0.0	0.7	-	-	-	0.1	0.2	0.0	0.1	0	1	100.0	0.0
	d. Other specified	4	18	23	43	83	88	171	1.8	30.7	2.4	40.1	2.0	2.2	2.2	4.1	7.5	2.7	3.8	42	80	100.0	0.0
	e. Unspecified	1	5	5	8	15	19	34	0.4	6.6	0.5	8.0	0.5	0.6	0.5	0.8	1.4	0.6	0.8	9	16	100.0	0.0
X	GERM CELL TUMOURS	35	32	22	59	272	148	420	3.1	100.0	5.8	100.0	17.3	3.9	2.1	5.6	24.6	4.8	9.3	71	194	97.9	0.0
	a. CNS germ cell ‡	6	5	10	20	25	41	66	0.9	27.7	0.9	15.7	3.0	0.6	1.0	1.9	2.3	1.3	1.5	20	31	90.9	0.0
	b. Other extragonadal	21	14	2	2	16	39	55	0.8	26.4	0.8	13.1	10.4	1.7	0.2	0.2	1.4	1.4	1.4	19	26	98.2	0.0
	c. Gonadal germ cell	8	13	10	31	213	62	275	1.3	41.9	3.8	65.5	3.9	1.6	1.0	2.9	19.3	1.9	5.8	30	126	99.3	0.0
	d. Gonadal carcinoma	0	0	0	5	16	5	21	0.1	3.4	0.3	5.0	-	-	-	0.5	1.4	0.1	0.4	2	10	100.0	0.0
	e. Unspecified gonadal	0	0	0	1	2	1	3	0.0	0.7	0.0	0.7	-	-	-	0.1	0.2	0.0	0.1	0	1	100.0	0.0
XI	CARCINOMA & MELANOMA	2	16	45	163	515	226	741	4.7	100.0	10.3	100.0	1.0	1.9	4.3	15.4	46.6	6.5	15.5	107	340	99.9	0.0
	a. Adrenocortical	1	2	2	3	2	8	10	0.2	3.5	0.1	1.3	0.5	0.2	0.2	0.3	0.2	0.3	0.2	4	5	100.0	0.0
	b. Thyroid	0	7	17	62	198	86	284	1.8	38.1	3.9	38.3	-	0.9	1.6	5.8	17.9	2.5	6.0	41	130	100.0	0.0
	c. Nasopharyngeal	0	0	2	6	11	8	19	0.2	3.5	0.3	2.6	-	-	0.2	0.6	1.0	0.2	0.4	4	9	100.0	0.0
	d. Melanoma	1	3	13	43	179	60	239	1.2	26.5	3.3	32.3	0.5	0.4	1.2	4.1	16.2	1.7	5.0	28	109	99.6	0.0
	e. Skin carcinoma	0	2	2	3	13	7	20	0.1	3.1	0.3	2.7	-	0.2	0.2	0.3	1.2	0.2	0.4	3	9	100.0	0.0
	f. Other & unspecified	0	2	9	46	112	57	169	1.2	25.2	2.3	22.8	-	0.2	0.9	4.3	10.1	1.6	3.5	27	78	100.0	0.0
XII	OTHER & UNSPECIFIED	3	4	2	0	15	9	24	0.2	100.0	0.3	100.0	1.5	0.5	0.2	-	1.4	0.3	0.6	4	11	87.5	0.0
	a. Other specified	3	4	1	0	8	8	16	0.2	88.9	0.2	66.7	1.5	0.5	0.1	-	0.7	0.3	0.4	4	8	100.0	0.0
	b. Other unspecified	0	0	1	0	7	1	8	0.0	11.1	0.1	33.3	-	-	0.1	-	0.6	0.0	0.2	0	4	62.5	0.0
	TOTAL	487	1638	1245	1452	2382	4822	7204	100.0	100.0	100.0	100.0	240.1	199.0	119.2	136.8	215.4	158.4	171.2	2316	3393	96.6	0.0

† includes 530 non-malignant ‡ includes 11 non-malignant

Please consult the quality indicators for this pool and its constituent registries

Germany

Germany is located in central Europe. It is bordered by Poland and the Czech Republic to the east, Austria and Switzerland to the south, France, Luxembourg, Belgium, and the Netherlands to the west, and the North Sea, Denmark, and the Baltic Sea to the north. It covers an area of 357 386 km^2, which slowly declines from the high peaks of Alps in the south to a massive lowland plain in the north and is traversed by major rivers: the Rhine, Danube, and Elbe. The climate is temperate. Significant natural resources include iron ore, coal, potash, timber, lignite, uranium, copper, natural gas, salt, nickel, arable land, and water.

Germany was divided into eastern and western parts after the Second World War and was reunified on 3 October 1990. Currently, the country has a strong social market economy with a highly skilled labour force, a very high standard of living, a social security system with universal health care, and comprehensive environmental protection. The service sector (including information technology) contributes 71% of the GDP, industry 28%, and agriculture 1%. The unemployment rate is relatively low, and labour productivity is high. Exports include vehicles, machinery, chemical goods, electronic products, electrical equipment, pharmaceuticals, transport equipment, basic metals, food products, and rubber and plastics.

In 2010, the population was 80.4 million (Table A.7), and 19% of the population was younger than 20 years (Table A.6). The population density is 227 per km^2, and 75% of the population lives in urban areas. The overall life expectancy at birth is 80.19 years, and the fertility rate is low, at 1.41 children per woman. The death rate has exceeded the birth rate since the early 1970s. Immigration has been considerable over the past few decades. The immigrants are often well educated and tend to settle in urban areas in the west of the country. The largest national groups are from Turkey, Poland, the Russian Federation, Italy, and African countries. About two thirds of the total population are Christian, and one third does not claim any religious affiliation. Germany is made up of 16 federal states (Bundesländer). Each state has its own constitution and is largely autonomous in its internal organization. Three of the states are city-states, which consist of just one city: Berlin, Bremen, and Hamburg.

In Germany all residents have access to health care; health insurance is almost universal. Specialized paediatric and adolescent oncology services are centralized in about 80 facilities. No other facilities can collect payment from health insurance for the treatment of paediatric oncology patients. Therapy is thus standardized nationwide and clinical trials are optimized centrally for each major disease entity.

Although cancer registration in Germany dates back to 1927, when registration started in Hamburg, most of the modern cancer registries were established relatively recently (Table A.10). In 1996, the Working Group of Population-Based Cancer Registries in Germany was founded by all population-based cancer registries and the federal cancer surveillance unit of the Robert Koch Institute, in response to the Agenda for Cancer Control of the Federal Ministry of Health. In April 2004, this working group engendered the Association of Population-Based Cancer Registries in Germany (GEKID) (https://www.gekid.de/). The main task of GEKID is to achieve nationwide methodological uniformity of cancer registration standards despite different registration laws in the federal states. GEKID also responds to interstate questions related to data generated from population-based cancer registration. GEKID comprises 10 statewide cancer registries operating in the states of western Germany, one cancer registry operating in the six states of eastern Germany, and one nationwide cancer registry: the German Childhood Cancer Registry (GCCR). In addition, the operations of large clinical cancer registries are also regulated on a federal level. Data from clinical cancer registries are not included in IICC-3; however, their existence may explain why the term "epidemiological" is included in the names of some population-based cancer registries in Germany. In 2008, a national cancer control plan was initiated, one goal of which was to foster collaboration between clinical and epidemiological cancer registries. A law passed in 2013 mandated the implementation of clinical cancer registration in all federal states.

The Federal Cancer Registry Act of 1993 mandated a double-unit model for each registry, composed of a trust unit and a registry unit. The trust unit maintains close connection with the data providers: physicians and dentists, tumour centres and the health authorities that report on their behalf, and autopsy reports. Cancer is reported using a registration form or by providing an electronic record. These registrations are checked for completeness and plausibility, and disagreements are clarified with the reporting physician or tumour centre. After validation, the personal identifying data are encrypted and control numbers are generated. The anonymized data records are provided to the registrar. The trust unit holds data for only a 6-month processing period, after which all notifications in the trust unit are deleted or destroyed.

The registrar uses the control numbers to compare the anonymized data with the existing database. Using a probabilistic matching procedure, records of people or tumours are combined. The data are subsequently subjected to comprehensive plausibility checks, and staff at the trust office clarify any discrepancies with the reporting physician or tumour centre. The anonymous cancer database is permanently kept in the registry unit. The data are used for scientific studies, regular reports, and responding to relevant inquiries.

PUBLICATIONS

Haberland J, Bertz J, Wolf U, Ziese T, Kurth BM (2010). German cancer statistics 2004. BMC Cancer. 10(1):52. https://doi.org/10.1186/1471-2407-10-52 PMID:20175882

POPULATION AT RISK

The most recent separate censuses were conducted in 1981 in eastern Germany and in 1987 in western Germany (Table A.7). A census to be conducted in both western Germany and eastern Germany had been planned for 1991, but it was replaced by a micro census population sample of 1% of households. The 2011 census for the whole country was based on data stored in the registers of the administrative authorities, in municipal population registers, and in the Federal Employment Agency registers; this census was conducted by the Federal Statistical Office (https://www.destatis.de/EN/Home/_node.html). Population data were provided by the registries in the requested detail, unless otherwise specified below; some data were provided by federal or state statistical offices.

EDITORS' COMMENTS

The cancer data from Germany are included in the IICC-3 book in three standard incidence tables: one table for GCCR, a pooled table for the common registry of the six eastern states supplied in a single dataset (Berlin, Brandenburg, Mecklenburg-Vorpommern, Saxony-Anhalt, Saxony, and Thuringia), and a table for the combined data of five western registries (Bavaria, Rhineland-Palatinate, Saarland, Lower Saxony, and Schleswig-Holstein). The standard incidence tables for the individual western registries are available online (Table A.12). Of the included registries, only the registry of the six eastern states contributed to all three IICC volumes; GCCR contributed to IICC-2, and the Saarland Cancer Registry contributed to IICC-1 (Table A.1).

The strict system of privacy preservation is described above for the general cancer registries. Informed consent is required for registration in GCCR; thus, the completeness of registration can be ensured up to the level of compliance with the registration request. Most German registries were unable to provide full dates of birth and incidence (Table A.8).

German Childhood Cancer Registry, 1996–2012

Peter Kaatsch, Desiree Grabow, Claudia Spix

The German Childhood Cancer Registry (GCCR) was founded in 1980 by the Society for Paediatric Oncology and Haematology. The registry is located in the Institute of Medical Biostatistics, Epidemiology, and Informatics at the University Medical Centre in Mainz. In 1980–2008, information on all patients younger than 15 years was systematically collected; in 2009, the registry was expanded to cover patients aged up to 18 years.

GCCR initially covered only western Germany, including West Berlin, but since 1991 it has covered the entire national childhood population. The records of cases registered in eastern Germany (including East Berlin) before 1991 are not included in GCCR. Therefore, a subsequent tumour of a patient first diagnosed before age 15 years before 1991 in eastern Germany (or elsewhere outside of western Germany) would count as the first primary in GCCR.

GCCR is funded jointly by the Federal Ministry of Health and the 16 state ministries of health. The data sources include 80 specialized treatment centres, centralized therapy trials, and centralized reference laboratories for cytology.

Diagnoses are coded using ICD-O-3 (Table A.10), with additional codes for CNS tumours from ICD-O-3.1. Registration is more than 95% complete from 1987.

Follow-up information is provided soon after treatment by the treatment centres, after which GCCR performs active follow-up through population registries to ascertain the vital status of registered patients and through direct access to patients.

Registration is slightly incomplete for benign CNS tumours and adult-type carcinomas, because some of these patients are treated outside of paediatric oncology facilities. Thyroid carcinoma reporting was incomplete before 1997. The data are used for reporting and scientific studies (https://www.kinderkrebsregister.de/dkkr/ueber-uns/uebersicht.html).

POPULATION AT RISK

The source of the population data is the Federal Statistical Office (Statistisches Bundesamt, Wiesbaden). See also Germany, above.

EDITORS' COMMENTS

The years 1996–2012 selected for IICC-3 follow on from the period published for this registry in IICC-2 (Table A.1). Because registration during the reporting period focused on the age range 0–14 years, data for the age groups 15–19 years and 0–19 years are not shown in the tables. The rate of parental or patient consent to registration at diagnosis is more than 99%. The underestimation of cancer incidence may be the result of older patients receiving treatment outside of paediatric oncology units. The diagnoses affected by underregistration are mostly benign CNS tumours (treated in neurosurgery units), skin carcinoma, malignant melanoma, and germ cell carcinoma.

Although full dates are recorded in the registry, day of birth was not provided (Table A.8) because of data protection requirements. Death certificates were not available for ascertainment of cancer cases, because the registry does not have access to identified death certificates. Thus, a proportion of new cases may be missed. The MV% decreased during the reporting period, from almost 100% to about 95%, and the proportion of clinically diagnosed cases increased accordingly, which attests to the inclusion of a larger number of data sources for ascertainment of cancer cases. This trend was accompanied by an increase in the proportion of non-malignant CNS tumours registered.

Despite the possible underreporting suggested by the registry, the reported proportion of non-malignant CNS tumours is high (Table A.9) because of strong links with neurology clinics throughout the country and the systematic registration of all types of CNS tumours. Pilocytic astrocytoma was mostly coded with uncertain behaviour, although a few cases were coded with malignant behaviour. Skin carcinomas are systematically recorded in the age group 0–14 years, and no skin carcinomas are excluded; however, underregistration is possible if cases were treated outside the paediatric oncology network. Laterality was sufficiently complete for all diagnoses of interest to be included in the laterality tables. See also Germany, above.

GERMANY, paediatric (1996-2012)

	Age group (years)	Males	Females
Person-years	0	6 286 065	5 963 105
	1-4	25 945 271	24 616 512
	5-9	34 958 094	33 170 732
	10-14	37 661 887	35 725 756
	0-14	104 851 317	99 476 105
Average annual population	0-14	6 167 725	5 851 536

Please consult the quality indicators for this registry

GERMANY, paediatric (1996-2012)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	505	4647	2945	2239	**10336**	33.6	100.0	41.2	91.9	43.2	30.5	**54.6**	779	100.0	0.0
	a. Lymphoid	202	3981	2425	1516	**8124**	26.4	78.6	16.5	78.7	35.6	20.7	**43.3**	614	100.0	0.0
	b. Acute myeloid	212	460	296	431	**1399**	4.5	13.5	17.3	9.1	4.3	5.9	**7.2**	105	100.0	0.0
	c. CMD	4	14	46	74	**138**	0.4	1.3	0.3	0.3	0.7	1.0	**0.6**	10	100.0	0.0
	d. MDS & other	69	180	154	191	**594**	1.9	5.7	5.6	3.6	2.3	2.6	**3.0**	44	100.0	0.0
	e. Unspecified	18	12	24	27	**81**	0.3	0.8	1.5	0.2	0.4	0.4	**0.4**	6	100.0	0.0
II	LYMPHOMA & RELATED	25	399	1134	1884	**3442**	11.2	100.0	2.0	7.9	16.6	25.7	**15.4**	245	100.0	0.0
	a. Hodgkin	0	66	332	1075	**1473**	4.8	42.8	-	1.3	4.9	14.6	**6.2**	103	100.0	0.0
	b. Non-Hodgkin except BL	16	197	486	584	**1283**	4.2	37.3	1.3	3.9	7.1	8.0	**5.9**	92	100.0	0.0
	c. Burkitt (BL)	1	132	312	221	**666**	2.2	19.3	0.1	2.6	4.6	3.0	**3.2**	49	100.0	0.0
	d. Lymphoreticular	8	3	3	3	**17**	0.1	0.5	0.7	0.1	0.0	0.0	**0.1**	1	100.0	0.0
	e. Unspecified	0	1	1	1	**3**	0.0	0.1	-	0.0	0.0	0.0	**0.0**	0	100.0	0.0
III	CNS NEOPLASMS †	512	2073	2478	2136	**7199**	23.4	100.0	41.8	41.0	36.4	29.1	**36.1**	533	85.9	0.0
	a. Ependymoma	116	307	136	146	**705**	2.3	9.8	9.5	6.1	2.0	2.0	**3.8**	54	100.0	0.0
	b. Astrocytoma	168	941	1198	1060	**3367**	10.9	46.8	13.7	18.6	17.6	14.4	**16.7**	248	88.5	0.0
	c. CNS embryonal	152	493	559	278	**1482**	4.8	20.6	12.4	9.8	8.2	3.8	**7.7**	111	100.0	0.0
	d. Other gliomas	25	120	235	180	**560**	1.8	7.8	2.0	2.4	3.4	2.5	**2.7**	41	25.9	0.0
	e. Other specified	35	184	315	435	**969**	3.1	13.5	2.9	3.6	4.6	5.9	**4.6**	70	87.7	0.0
	f. Unspecified CNS	16	28	35	37	**116**	0.4	1.6	1.3	0.6	0.5	0.5	**0.6**	9	20.7	0.0
IV	NEUROBLASTOMA	999	1074	193	64	**2330**	7.6	100.0	81.6	21.2	2.8	0.9	**13.9**	184	99.6	0.0
	a. (Ganglio)neuroblastoma	999	1068	190	57	**2314**	7.5	99.3	81.6	21.1	2.8	0.8	**13.9**	182	99.6	0.0
	b. Peripheral nervous	0	6	3	7	**16**	0.1	0.7	-	0.1	0.0	0.1	**0.1**	1	100.0	0.0
V	RETINOBLASTOMA	309	331	27	4	**671**	2.2	100.0	25.2	6.5	0.4	0.1	**4.1**	53	48.9	0.0
VI	RENAL TUMOURS	261	1004	370	83	**1718**	5.6	100.0	21.3	19.9	5.4	1.1	**9.9**	134	98.8	0.0
	a. Nephroblastoma	261	1001	360	55	**1677**	5.5	97.6	21.3	19.8	5.3	0.7	**9.7**	131	98.7	0.0
	b. Renal carcinoma	0	3	10	27	**40**	0.1	2.3	-	0.1	0.1	0.4	**0.2**	3	100.0	0.0
	c. Unspecified	0	0	0	1	**1**	0.0	0.1	-	-	-	0.0	**0.0**	0	100.0	0.0
VII	HEPATIC TUMOURS	100	173	38	50	**361**	1.2	100.0	8.2	3.4	0.6	0.7	**2.1**	28	100.0	0.0
	a. Hepatoblastoma	100	170	14	14	**298**	1.0	82.5	8.2	3.4	0.2	0.2	**1.8**	23	100.0	0.0
	b. Hepatic carcinoma	0	3	24	35	**62**	0.2	17.2	-	0.1	0.4	0.5	**0.3**	4	100.0	0.0
	c. Unspecified	0	0	0	1	**1**	0.0	0.3	-	-	-	0.0	**0.0**	0	100.0	0.0
VIII	BONE TUMOURS	8	84	354	906	**1352**	4.4	100.0	0.7	1.7	5.2	12.3	**5.8**	95	100.0	0.0
	a. Osteosarcoma	0	17	162	505	**684**	2.2	50.6	-	0.3	2.4	6.9	**2.9**	48	100.0	0.0
	b. Chondrosarcoma	0	1	4	17	**22**	0.1	1.6	-	0.0	0.1	0.2	**0.1**	2	100.0	0.0
	c. Ewing & related	8	63	181	367	**619**	2.0	45.8	0.7	1.2	2.7	5.0	**2.7**	44	100.0	0.0
	d. Other specified	0	3	6	11	**20**	0.1	1.5	-	0.1	0.1	0.1	**0.1**	1	100.0	0.0
	e. Unspecified	0	0	1	6	**7**	0.0	0.5	-	-	0.0	0.1	**0.0**	0	100.0	0.0
IX	SOFT TISSUE SARCOMA	195	545	492	592	**1824**	5.9	100.0	15.9	10.8	7.2	8.1	**9.2**	135	100.0	0.0
	a. Rhabdomyosarcoma	84	422	305	202	**1013**	3.3	55.5	6.9	8.3	4.5	2.8	**5.4**	76	100.0	0.0
	b. Fibrosarcoma	49	24	33	71	**177**	0.6	9.7	4.0	0.5	0.5	1.0	**0.9**	13	100.0	0.0
	c. Kaposi sarcoma	0	0	0	1	**1**	0.0	0.1	-	-	-	0.0	**0.0**	0	100.0	0.0
	d. Other specified	43	74	125	261	**503**	1.6	27.6	3.5	1.5	1.8	3.6	**2.3**	36	100.0	0.0
	e. Unspecified	19	25	29	57	**130**	0.4	7.1	1.6	0.5	0.4	0.8	**0.6**	10	100.0	0.0
X	GERM CELL TUMOURS	242	165	155	417	**979**	3.2	100.0	19.8	3.3	2.3	5.7	**4.9**	72	100.0	0.0
	a. CNS germ cell ‡	13	10	74	170	**267**	0.9	27.3	1.1	0.2	1.1	2.3	**1.2**	19	100.0	0.0
	b. Other extragonadal	174	83	5	21	**283**	0.9	28.9	14.2	1.6	0.1	0.3	**1.7**	22	100.0	0.0
	c. Gonadal germ cell	55	70	73	216	**414**	1.3	42.3	4.5	1.4	1.1	2.9	**2.0**	30	100.0	0.0
	d. Gonadal carcinoma	0	0	3	9	**12**	0.0	1.2	-	-	0.0	0.1	**0.0**	1	100.0	0.0
	e. Unspecified gonadal	0	2	0	1	**3**	0.0	0.3	-	0.0	-	0.0	**0.0**	0	100.0	0.0
XI	CARCINOMA & MELANOMA	11	46	114	350	**521**	1.7	100.0	0.9	0.9	1.7	4.8	**2.3**	37	99.2	0.0
	a. Adrenocortical	5	19	12	9	**45**	0.1	8.6	0.4	0.4	0.2	0.1	**0.2**	3	100.0	0.0
	b. Thyroid	2	9	54	172	**237**	0.8	45.5	0.2	0.2	0.8	2.3	**1.0**	17	100.0	0.0
	c. Nasopharyngeal	0	1	0	40	**41**	0.1	7.9	-	0.0	-	0.5	**0.2**	3	100.0	0.0
	d. Melanoma	4	15	20	32	**71**	0.2	13.6	0.3	0.3	0.3	0.4	**0.3**	5	94.4	0.0
	e. Skin carcinoma	0	0	5	7	**12**	0.0	2.3	-	-	0.1	0.1	**0.1**	1	100.0	0.0
	f. Other & unspecified	0	2	23	90	**115**	0.4	22.1	-	0.0	0.3	1.2	**0.5**	8	100.0	0.0
XII	OTHER & UNSPECIFIED	2	16	10	9	**37**	0.1	100.0	0.2	0.3	0.1	0.1	**0.2**	3	97.3	0.0
	a. Other specified	2	15	9	6	**32**	0.1	86.5	0.2	0.3	0.1	0.1	**0.2**	2	100.0	0.0
	b. Other unspecified	0	1	1	3	**5**	0.0	13.5	-	0.0	0.0	0.0	**0.0**	0	80.0	0.0
	TOTAL	3169	10557	8310	8734	**30770**	100.0	100.0	258.7	208.8	122.0	119.0	**158.5**	2298	95.5	0.0

† includes 2973 non-malignant ‡ includes 28 non-malignant

Please consult the quality indicators for this registry

Common Cancer Registry of the Federal States Berlin, Brandenburg, Mecklenburg-Vorpommern, Saxony-Anhalt and the Free States Saxony and Thuringia (6 eastern states), 2001–2007

Roland Stabenow

The combined territory covered by the federal states Berlin, Brandenburg, Mecklenburg-Vorpommern, Saxony-Anhalt, and the Free States Saxony and Thuringia corresponds to that of the former German Democratic Republic, which ceased to exist in 1990 upon the reunification of Germany. The region covers an area of 108 000 km^2 and is bordered by the Baltic Sea to the north, Poland to the east, and the Czech Republic to the south-east. Compared with the rest of Germany, the combined six states lag behind in terms of industry, average income, and productivity, with only education keeping the pace. In 2010, the population was 16.3 million, and 17% of the population was younger than 20 years (Table A.6). The proportion of immigrants (<10%) is lower than in some other regions, where it may be more than 20%.

Until 1989, the former German Democratic Republic was covered by a national cancer registry, which was established in 1953 (Table A.10) and was sustained by mandatory notification of cancer. The registry was an integral part of a network of medical and social services for patients with cancer provided or coordinated by the Cancer Control Agency. After the reunification of Germany in 1990, the six states were constituted on the territory of the former German Democratic Republic. Concurrently, the statutory reporting requirement was waived, which resulted in a significant drop in reporting. To alleviate this situation, the six states decided to continue registration as a Joint Cancer Registry (GKR) and to include the western part of Berlin in the covered area. A treaty was validated in 1999 between the federal states participating in GKR, and cancer registration was enforced as state law. Thus, the activities of GKR have been secured for the long term since 2000, and the registry became the largest epidemiological cancer registry in Germany.

In concordance with the cancer registration law, new cases can be reported to GKR directly or through a clinical centre. Such channelling of notifications helps to reduce strain on the reporting physicians and to avoid multiple notifications of a case. Cancer cases are reported by 30 regional tumour centres (> 90% of reports), clinical cancer registries, aftercare centres, and oncological surveillance units.

GKR was based in Berlin until its dissolution at the end of 2022. It was a non-statutory institution under public law and was administered by the Senate Department for Health, Care, and Equality in Berlin. Each state had a representative on the management committee, which ensured their participation in the operation of the registry. GKR periodically published reports on cancer incidence and mortality and participated in national and international research.

POPULATION AT RISK

Population data were provided by sex and 5-year age groups by the Federal Statistical Office. The data for the missing year–age–sex categories were estimated at IARC using the methods described in Chapter 2.

EDITORS' COMMENTS

The data used in IICC-3 were extracted at IARC from the submission to CI5 Volume X, in agreement with the registry. The registry was unable to supply data for other years (because of the data protection law) or to assist with data validation. The low proportion of children aged 0–14 years within the age group 0–19 years (Table A.9) probably reflects the low proportion of children in the underlying population (Table A.6). Day of birth and day of incidence were not provided (Table A.8); this may have affected the age-specific rates. Non-malignant CNS tumours were not provided (Table A.9), and there are no cases of pilocytic astrocytoma in the dataset; thus, the incidence rates for the relevant tumour groups and overall are lower than those for registries in which these cases are included. Laterality was complete for 80% of the cases of interest. See also Germany, above.

GERMANY, 6 Eastern states (2001-2007)

	Age group (years)	Males	Females
Person-years	0	430 961	409 543
	1-4	1 821 165	1 732 011
	5-9	2 056 697	1 950 762
	10-14	2 620 011	2 480 665
	15-19	3 889 902	3 648 310
	0-14	6 928 834	6 572 981
	0-19	10 818 736	10 221 291
Average annual population	0-14	989 833	938 997
	0-19	1 545 534	1 460 184

Please consult the quality indicators for this registry

GERMANY, 6 Eastern states (2001-2007)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	45	291	151	145	184	632	816	34.4	100.0	25.3	100.0	53.5	81.9	37.7	28.4	24.4	50.0	44.3	713	835	96.3	3.2
	a. Lymphoid	24	253	121	102	110	500	610	27.2	79.1	18.9	74.8	28.6	71.2	30.2	20.0	14.6	40.0	34.2	566	639	97.4	2.1
	b. Acute myeloid	20	30	21	36	49	107	156	5.8	16.9	4.8	19.1	23.8	8.4	5.2	7.1	6.5	8.1	7.8	118	151	96.2	3.2
	c. CMD	0	0	3	4	13	7	20	0.4	1.1	0.6	2.5	-	-	0.7	0.8	1.7	0.5	0.8	8	16	95.0	5.0
	d. MDS & other	0	4	2	0	0	6	6	0.3	0.9	0.2	0.7	-	1.1	0.5	-	-	0.5	0.4	7	7	100.0	0.0
	e. Unspecified	1	4	4	3	12	12	24	0.7	1.9	0.7	2.9	1.2	1.1	1.0	0.6	1.6	0.9	1.1	14	22	70.8	29.2
II	LYMPHOMA & RELATED	7	30	59	119	370	215	585	11.7	100.0	18.1	100.0	8.3	8.4	14.7	23.3	49.1	14.8	22.5	232	478	97.9	1.2
	a. Hodgkin	0	4	15	81	258	100	358	5.4	46.5	11.1	61.2	-	1.1	3.7	15.9	34.2	6.2	12.5	103	274	99.2	0.0
	b. Non-Hodgkin except BL	4	13	29	30	98	76	174	4.1	35.3	5.4	29.7	4.8	3.7	7.2	5.9	13.0	5.5	7.2	85	150	98.3	0.6
	c. Burkitt (BL)	0	9	12	6	5	27	32	1.5	12.6	1.0	5.5	-	2.5	3.0	1.2	0.7	2.1	1.8	31	34	100.0	0.0
	d. Lymphoreticular	2	0	0	0	5	2	7	0.1	0.9	0.2	1.2	2.4	-	-	-	0.7	0.2	0.3	2	6	100.0	0.0
	e. Unspecified	1	4	3	2	4	10	14	0.5	4.7	0.4	2.4	1.2	1.1	0.7	0.4	0.5	0.8	0.7	11	14	57.1	42.9
III	CNS NEOPLASMS	30	79	99	87	111	295	406	16.0	100.0	12.6	100.0	35.7	22.2	24.7	17.1	14.7	22.5	20.8	333	406	90.1	4.9
	a. Ependymoma	4	19	3	11	14	37	51	2.0	12.5	1.6	12.6	4.8	5.3	0.7	2.2	1.9	2.9	2.7	41	50	100.0	0.0
	b. Astrocytoma	9	16	36	28	47	89	136	4.8	30.2	4.2	33.5	10.7	4.5	9.0	5.5	6.2	6.7	6.6	101	132	98.5	0.0
	c. CNS embryonal	9	23	38	17	21	87	108	4.7	29.5	3.3	26.6	10.7	6.5	9.5	3.3	2.8	6.8	5.9	100	114	100.0	0.0
	d. Other gliomas	2	9	13	15	14	39	53	2.1	13.2	1.6	13.1	2.4	2.5	3.2	2.9	1.9	2.9	2.6	43	53	96.2	0.0
	e. Other specified	0	3	2	2	8	7	15	0.4	2.4	0.5	3.7	-	0.8	0.5	0.4	1.1	0.5	0.7	8	13	100.0	0.0
	f. Unspecified CNS	6	9	7	14	7	36	43	2.0	12.2	1.3	10.6	7.1	2.5	1.7	2.7	0.9	2.7	2.3	40	44	16.3	46.5
IV	NEUROBLASTOMA	50	69	10	3	6	132	138	7.2	100.0	4.3	100.0	59.5	19.4	2.5	0.6	0.8	11.5	9.1	151	155	97.1	0.0
	a. (Ganglio)neuroblastoma	50	67	9	3	2	129	131	7.0	97.7	4.1	94.9	59.5	18.9	2.2	0.6	0.3	11.2	8.7	147	149	96.9	0.0
	b. Peripheral nervous	0	2	1	0	4	3	7	0.2	2.3	0.2	5.1	-	0.6	0.2	-	0.5	0.3	0.3	4	6	100.0	0.0
V	RETINOBLASTOMA	16	21	1	2	1	40	41	2.2	100.0	1.3	100.0	19.0	5.9	0.2	0.4	0.1	3.5	2.7	45	46	85.4	0.0
VI	RENAL TUMOURS	19	64	33	7	13	123	136	6.7	100.0	4.2	100.0	22.6	18.0	8.2	1.4	1.7	10.4	8.4	142	151	80.1	1.5
	a. Nephroblastoma	18	63	32	5	4	118	122	6.4	95.9	3.8	89.7	21.4	17.7	8.0	1.0	0.5	10.0	7.9	137	140	80.3	0.0
	b. Renal carcinoma	1	0	1	1	8	3	11	0.2	2.4	0.3	8.1	1.2	-	0.2	0.2	1.1	0.2	0.4	3	9	100.0	0.0
	c. Unspecified	0	1	0	1	1	2	3	0.1	1.6	0.1	2.2	-	0.3	-	0.2	0.1	0.1	0.1	2	3	0.0	66.7
VII	HEPATIC TUMOURS	9	8	3	2	6	22	28	1.2	100.0	0.9	100.0	10.7	2.3	0.7	0.4	0.8	1.9	1.6	25	29	82.1	10.7
	a. Hepatoblastoma	8	7	2	0	1	17	18	0.9	77.3	0.6	64.3	9.5	2.0	0.5	-	0.1	1.5	1.2	20	20	88.9	5.6
	b. Hepatic carcinoma	0	1	1	2	4	4	8	0.2	18.2	0.2	28.6	-	0.3	0.2	0.4	0.5	0.3	0.3	4	7	87.5	12.5
	c. Unspecified	1	0	0	0	1	1	2	0.1	4.5	0.1	7.1	1.2	-	-	-	0.1	0.1	0.1	1	2	0.0	50.0
VIII	BONE TUMOURS	1	11	26	85	112	123	235	6.7	100.0	7.3	100.0	1.2	3.1	6.5	16.7	14.9	8.0	9.5	129	204	97.9	1.7
	a. Osteosarcoma	0	2	11	44	57	57	114	3.1	46.3	3.5	48.5	-	0.6	2.7	8.6	7.6	3.6	4.5	59	97	100.0	0.0
	b. Chondrosarcoma	0	1	0	6	5	7	12	0.4	5.7	0.4	5.1	-	0.3	-	1.2	0.7	0.4	0.5	7	10	100.0	0.0
	c. Ewing & related	1	6	13	31	44	51	95	2.8	41.5	2.9	40.4	1.2	1.7	3.2	6.1	5.8	3.4	4.0	55	84	100.0	0.0
	d. Other specified	0	2	0	1	2	3	5	0.2	2.4	0.2	2.1	-	0.6	-	0.2	0.3	0.2	0.2	3	5	100.0	0.0
	e. Unspecified	0	0	2	3	4	5	9	0.3	4.1	0.3	3.8	-	-	0.5	0.6	0.5	0.3	0.4	5	8	44.4	44.4
IX	SOFT TISSUE SARCOMA	16	32	25	37	88	110	198	6.0	100.0	6.1	100.0	19.0	9.0	6.2	7.3	11.7	8.3	9.1	122	180	99.5	0.0
	a. Rhabdomyosarcoma	4	24	16	18	24	62	86	3.4	56.4	2.7	43.4	4.8	6.8	4.0	3.5	3.2	4.8	4.4	69	85	100.0	0.0
	b. Fibrosarcoma	3	1	3	4	8	11	19	0.6	10.0	0.6	9.6	3.6	0.3	0.7	0.8	1.1	0.8	0.9	12	18	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Other specified	6	4	5	12	51	27	78	1.5	24.5	2.4	39.4	7.1	1.1	1.2	2.4	6.8	2.0	3.0	29	63	98.7	0.0
	e. Unspecified	3	3	1	3	5	10	15	0.5	9.1	0.5	7.6	3.6	0.8	0.2	0.6	0.7	0.8	0.8	11	14	100.0	0.0
X	GERM CELL TUMOURS	16	8	2	19	216	45	261	2.4	100.0	8.1	100.0	19.0	2.3	0.5	3.7	28.7	3.4	9.0	48	192	97.7	0.8
	a. CNS germ cell	0	0	2	9	11	11	22	0.6	24.4	0.7	8.4	-	-	0.5	1.8	1.5	0.7	0.9	11	19	95.5	0.0
	b. Other extragonadal	10	4	0	0	5	14	19	0.8	31.1	0.6	7.3	11.9	1.1	-	-	0.7	1.2	1.1	16	19	100.0	0.0
	c. Gonadal germ cell	6	4	0	10	179	20	199	1.1	44.4	6.2	76.2	7.1	1.1	-	2.0	23.7	1.5	6.5	21	140	99.0	0.0
	d. Gonadal carcinoma	0	0	0	0	12	0	12	-	-	0.4	4.6	-	-	-	-	1.6	-	0.4	-	8	100.0	0.0
	e. Unspecified gonadal	0	0	0	0	9	0	9	-	-	0.3	3.4	-	-	-	-	1.2	-	0.3	-	6	66.7	22.2
XI	CARCINOMA & MELANOMA	3	4	13	53	269	73	342	4.0	100.0	10.6	100.0	3.6	1.1	3.2	10.4	35.7	4.7	11.7	76	255	99.7	0.0
	a. Adrenocortical	1	2	2	1	1	6	7	0.3	8.2	0.2	2.0	1.2	0.6	0.5	0.2	0.1	0.5	0.4	7	8	100.0	0.0
	b. Thyroid	0	2	4	25	85	31	116	1.7	42.5	3.6	33.9	-	0.6	1.0	4.9	11.3	1.9	4.0	32	88	100.0	0.0
	c. Nasopharyngeal	0	0	0	3	4	3	7	0.2	4.1	0.2	2.0	-	-	-	0.6	0.5	0.2	0.3	3	6	100.0	0.0
	d. Melanoma	2	0	4	4	71	10	81	0.5	13.7	2.5	23.7	2.4	-	1.0	0.8	9.4	0.7	2.7	11	58	100.0	0.0
	e. Skin carcinoma	0	0	2	1	25	3	28	0.2	4.1	0.9	8.2	-	-	0.5	0.2	3.3	0.2	0.9	3	20	100.0	0.0
	f. Other & unspecified	0	0	1	19	83	20	103	1.1	27.4	3.2	30.1	-	-	0.2	3.7	11.0	1.2	3.4	20	75	99.0	0.0
XII	OTHER & UNSPECIFIED	14	5	5	5	15	29	44	1.6	100.0	1.4	100.0	16.7	1.4	1.2	1.0	2.0	2.4	2.3	33	43	34.1	47.7
	a. Other specified	0	0	2	1	6	3	9	0.2	10.3	0.3	20.5	-	-	0.5	0.2	0.8	0.2	0.3	3	7	100.0	0.0
	b. Other unspecified	14	5	3	4	9	26	35	1.4	89.7	1.1	79.5	16.7	1.4	0.7	0.8	1.2	2.1	1.9	29	35	17.1	60.0
	TOTAL	226	622	427	564	1391	1839	3230	100.0	100.0	100.0	100.0	268.9	175.1	106.6	110.6	184.5	141.2	150.9	2051	2973	94.9	2.6

Please consult the quality indicators for this registry

GERMANY, 6 Eastern states (2001-2007)

Registry	Period	Cases	%	Person-years	%
Berlin	2001-2007	704	21.8	4 196 909	19.9
Brandenburg	2001-2007	566	17.5	3 335 147	15.9
Mecklenburg	2001-2007	312	9.7	2 279 737	10.8
Saxony	2001-2007	802	24.8	5 203 200	24.7
Saxony-Anhalt	2001-2007	478	14.8	3 096 658	14.7
Thüringen	2001-2007	368	11.4	2 928 376	13.9
GERMANY	**2001-2007**	**3230**	**100.0**	**21 040 027**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

GERMANY, 5 Western registries (1994-2012)

Registry	Period	Cases	%	Person-years	%
Bavaria	2002-2012	4695	40.9	27 913 471	40.9
Lower Saxony	2003-2012	2726	23.7	16 444 446	24.1
Rhineland-Palatinate	1998-2012	2079	18.1	12 555 083	18.4
Saarland	1994-2012	659	5.7	3 846 375	5.6
Schleswig-Holstein	2000-2012	1321	11.5	7 470 147	10.9
GERMANY	**1994-2012**	**11480**	**100.0**	**68 229 522**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

Bavarian Cancer Registry, 2002–2012

Martin Meyer

Bavaria is one of the 16 federal states of Germany. It is located in south-eastern Germany and is bordered by the Czech Republic to the east and Austria to the south. Bavaria has both rural areas and urban environments and has several big cities, including the capital city of Munich. The population was 12.5 million, and 20% of the population was younger than 20 years (Table A.6). Five university hospitals and more than 300 other hospitals provide high-level health care for the entire population. There are 17 hospitals with facilities for specialist paediatric and adolescent oncology diagnostic and treatment services.

The population-based Bavarian Cancer Registry is funded by the Bavarian State Ministry of Health and Care.

Cancer is notified by all physicians and hospitals in Bavaria, and death certificates are also ascertained for new cancer cases. Information on childhood cancer cases is collected from these same sources and from GCCR.

Staff members at six regional cancer registry sites in Bavaria collect the individual data on cancer cases reported by physicians, check the data for completeness and consistency, and evaluate therapy progress and long-term outcomes to facilitate quality assurance of the reporting sites. The epidemiological portion of the collected data is submitted at regular intervals to the central Bavarian Cancer Registry.

Cancers are coded to ICD-10 and ICD-O-3 topography for all cases in the registry, but only histologically verified cancer cases are coded to ICD-O-3 morphology (Table A.10). TNM is also recorded.

The completeness of registration is at least 94% since 2003; this is checked annually by the Robert Koch Institute. The completeness is estimated by applying the incidence-to-mortality ratio to each of the federal states.

The collected data are used for epidemiological studies and public health surveillance. Registry tasks include monitoring trends over time, analysing the regional distribution of cancers, and providing information for health services planning and epidemiological research.

The registry helps to monitor and assess the effectiveness of preventive and treatment measures.

POPULATION AT RISK

The population data are provided by the Statistical Office of the Federal State of Bavaria and are updated annually with information on births, deaths, and migration. The decimal portions of the estimated counts provided for some sex and age categories were rounded to the nearest integer at IARC (Table A.8). See also Germany, above.

EDITORS' COMMENTS

Although the registry started in 1998 (Table A.10), only the data for 2002–2012 were deemed to be of sufficient quality for submission to IICC-3. For data protection reasons, the registry is not permitted to collect exact dates of birth and diagnosis (Table A.8); as a result, age is calculated based on month and year, with day of diagnosis coded to 15. Thus, age-specific rates may be affected.

The registry collects CNS tumours with uncertain behaviour, and pilocytic astrocytoma was coded with uncertain behaviour. Registration of benign CNS tumours started in 2017. Skin carcinomas are registered, although they may have been underreported in the early years of the reporting period. Laterality was complete for 91% of the cases of interest. See also Germany, above.

Epidemiological Cancer Registry of Lower Saxony, 2003–2012

Joachim Kieschke, Eunice Sirri

Lower Saxony is located in north-western Germany. It is the second largest federal state and covers an area of 47 641 km^2. It is bordered by nine other German states, as well as the Netherlands to the west and the North Sea to the north. The population is 7.9 million, and 20% of the population is younger than 20 years (Table A.6). Most of the population is of northern European descent, with about 5.7% foreign nationals.

Cancer care facilities are incorporated into the general health-care system. Private practitioners and hospitals provide health care. In 2012, there were 198 hospitals with more than 42 000 beds, 91 certified oncology centres with about 130 oncologists, and six cancer aftercare facilities in the registration area. Childhood and adult cancer care are all integrated within the same oncological facilities. The entire population is covered by either public or private health insurance.

Since 2000, the Epidemiological Cancer Registry of Lower Saxony has operated under the law funded by the State Ministry of Social Affairs, Health, and Equality. Complete coverage of the registration area was achieved in 2003. Cancer cases in patients of all ages were voluntarily notified by physicians, based on an informed consent model, until the end of 2012. In 2013, notification became compulsory. Notification from pathologists has always been compulsory. Cancer registration is based on multiple data sources, to ensure completeness and quality. These sources include hospital departments (especially pathology departments), general practitioners, and death certificates. After the initial notification, clinical information is abstracted from case notes and anonymized in the trust unit of the registry. Data are further processed and stored in the registry database for statistical analysis and cancer research.

Follow-up of patients is largely passive. The registry database is routinely linked with all death certificates from the regional governmental health departments, with mortality and migration data from the regional population registry, and with cause-of-death information from the regional statistical office. Cases initially identified by a death certificate are traced back to document additional relevant clinical data.

The registry regularly prepares reports of cancer incidence, mortality, and survival, and has an interactive database (https://www.krebsregister-niedersachsen.de/). It provides information to assist public health officials in planning for cancer prevention and care. Staff engage in evaluating breast cancer screening, perform cancer care research, and participate in national and international projects.

POPULATION AT RISK

The source of the population data is the State Office for Statistics of Lower Saxony (https://www.statistik.niedersachsen.de/), making allowances for births, deaths, and migration. See also Germany, above.

EDITORS' COMMENTS

Although the registry started in 2000 (Table A.10), only the data for 2003–2012 were deemed to be sufficiently complete for submission to IICC-3. For data protection reasons, the registry is not permitted to collect exact dates of birth and diagnosis (Table A.8), and age is calculated using imprecise dates. Thus, age-specific rates may be affected. Non-malignant CNS tumours and pilocytic astrocytoma were not registered during the reporting period. Therefore, reported incidence rates are underestimated for diagnostic categories III and Xa and the total. Skin carcinomas are reportable, but according to the registry their registration may represent less than 90% of the true incidence. Laterality was complete. See also Germany, above.

Rhineland-Palatinate Cancer Registry, 1998–2012

Sylke Zeißig, Katharina Emrich

The federal state of Rhineland-Palatinate is located in south-western Germany and covers an area of 19 847 km^2. It has a population density of 204 per km^2. In 2010, the population was 4 million, and 19% of the population was younger than 20 years (Table A.6). Most of the population (75%) lives in primarily rural areas. The population is predominantly White and Christian. Foreign nationals constitute 7.7% of the population.

Cancer diagnosis and treatment are conducted by resident physicians in about 100 hospitals, one of which is the University Medical Centre in Mainz. An increasing number of tumour centres that specialize in diagnosis, research, and treatment of certain cancer types (Organtumorzentren) offer highly specialized medical care to patients with cancer. There are five centres for children with cancer in Rhineland-Palatinate. However, because of strong centralization of treatment by cancer type, a proportion of children with cancer living in Rhineland-Palatinate are treated in other federal states.

The Rhineland-Palatinate Cancer Registry was officially established 1998. The legal framework was set by federal law in 1999, and notification has been compulsory since 2000. Patients must be informed about the registry, and they have the right to withhold the notification of their disease or to withdraw from the registry. The registry is funded by the Federal Ministry of Health. The registry has 4.5 full-time equivalent scientist positions and 6.5 full-time equivalent data manager positions.

GCCR is an important source of data on childhood cancer cases. Other data sources are hospitals, resident physicians, and pathologists. Data collection is passive, through paper or electronic notification, and follow-up for vital status and migration is passive, through the population registry. Cases are coded to ICD-10, ICD-O-3, and TNM-7.

The estimated completeness of registration for all cancers was 93% in 2008.

POPULATION AT RISK

Data were provided by sex and 5-year age groups for each calendar year. These are intercensal estimates generated by the Federal Statistical Office. The data for the missing year–age–sex categories were estimated at IARC using the methods described in Chapter 2. See also Germany, above.

EDITORS' COMMENTS

For data protection reasons, the registry is not permitted to store exact dates of birth and diagnosis (Table A.8), and age is calculated based on only month and year. Thus, age-specific rates may be affected. Sex was unknown in 0.1% of all cases (Table A.8).

The registry was unable to supply information on basis of diagnosis for 4.7% of cases (Table A.9). In many instances, information on these cases was obtained by data exchange with other cancer registries, and the basis of diagnosis could not be retrieved. The reported proportion of non-malignant CNS tumours was high, presumably because of systematic registration of all types of CNS tumours. Pilocytic astrocytoma was coded with behaviour according to the ICD-O edition in use (Table A.10) and converted to uncertain behaviour during the implementation of ICD-O-3. Registration of skin carcinomas is considered complete. Laterality was complete for nephroblastoma. See also Germany, above.

Saarland Cancer Registry, 1994–2012

Bernd Holleczek

The federal state of Saarland is located in south-western Germany and is bordered by France and Luxembourg. Saarland is the second smallest state in Germany. The administrative structure consists of five counties and one metropolitan area, comprising 52 communities. In 2010, the population of Saarland was 1 million, and 18% of the population was younger than 20 years (Table A.6). The economically active population (47.8% of the total) is employed in production industries (29%), distribution, transportation and communications (25%), and other sectors (46%).

Cancer treatment is conducted by both state hospitals and physicians in private practice. In 2009, there were 21 hospitals with a capacity of 6689 beds, including one university hospital in Homburg. Regional hospitals dedicate considerable personnel and funds to cancer treatment. A small number of private oncology practices provide diagnostic and aftercare facilities. There are a total of 201 hospital beds for paediatric care. The university hospital provides facilities for paediatric oncology and haematology. In addition, there are four radiotherapy units and eight pathology departments, one of which specializes in neuropathology. Recently, several specialized units for cancer care have opened.

The Saarland Cancer Registry started in 1968 (Table A.10) and covers the population of the federal state of Saarland. All invasive malignant and in situ cancers and neoplasms of uncertain or unknown behaviour are registered. Cancer reporting by all physicians is mandated by state law. Data sources are pathology laboratories, hospitals, radiotherapy departments, outpatient clinics, and general practitioners. The completeness of case ascertainment is regularly estimated to be at least 95%. Other data sources are death certificates from local health authorities and the state statistical office. Trace-back activities are conducted for cases first notified from death certificates. The IACR/IARC rules for multiple primary tumours are used. The registry also uses data from the centralized population registry for follow up of cancer cases. The registry conducts descriptive and analytical epidemiological studies, independently and in national and international collaborative projects.

POPULATION AT RISK

Data were provided by sex and 5-year age groups for each calendar year. The estimates, which are based on the census and annual information on births, deaths, and migration, are provided by the State Statistical Office. The data for the missing year–age–sex categories were estimated at IARC using the methods described in Chapter 2. See also Germany, above.

EDITORS' COMMENTS

Although the registry provided data for 1990–2012, the first 4 years were not included because they had a high proportion of NOS and MV cases, which suggested underreporting and suboptimal accuracy. For the included period, day of incidence was considered imprecise in 21% of the cases (Table A.8). In the age group 15–19 years, 40% more cancers were reported for males than for females. Historically, non-malignant CNS tumours were not routinely registered, although some were reported and are included in the database (Table A.9). Pilocytic astrocytoma was coded with malignant behaviour until 2002 and with uncertain behaviour thereafter, according to the ICD-O edition in use (Table A.10). Skin carcinomas are registered, but they were not included in the submitted data. Laterality was complete for 39% of the cases of interest. See also Germany, above.

Schleswig-Holstein Cancer Registry, 2000–2012

Alexander Katalinic, Miriam Holzmann

Schleswig-Holstein is the northernmost federal state of Germany; it is bordered by the North Sea, the Baltic Sea, and Denmark to the north. It covers an area of 15 799 km^2 (4.4% of the whole country). Schleswig-Holstein has a temperate, seasonal maritime climate in which humid westerly winds predominate. It is located in the North German lowlands. The population is almost 2.8 million (3.5% of the national population), and 19% of the population is younger than 20 years (Table A.6). The predominant ethnic group is White. The population density is 179 per km^2, which is less than the national average. About 35% of the population lives in rural areas. Tourism and agriculture are the main sectors of the economy.

Medical care is provided by a tertiary health-care system (private practice, regional and statewide hospitals) embedded in a statutory health insurance system. About 3000 physicians, 280 hospital departments, and 15 pathologists are involved in cancer care. About 90% of citizens have national health insurance, and 10% have private health insurance. Children with cancer are treated mainly in two university hospitals, located in Kiel and Lübeck. Some children receive treatment at the University Hospital of Hamburg.

Cancer registration started in 1997 and is regulated by a federal law that requires mandatory notification by all physicians. The registry is funded by the state government. The registry has access to all death certificates in electronic format. Registration and quality control are performed according to IACR/ENCR guidelines.

Tumours are coded according to ICD-O-3 and ICD-10 (Table A.10). Completeness is more than 90%, as estimated by the National Centre for Cancer Registry Data located at the Robert Koch Institute. Patients are followed up by record linkage to death certificates from the health offices. Currently, other clinical data (relapse, progression) are not followed up. The data are used for health reporting, health monitoring, and health-care research. Reports, results, data, and an interactive cancer atlas are available online (https://www.krebsregister-sh.de/).

POPULATION AT RISK

The data are population projections provided by the Federal Statistical Office based on the census conducted in 1987. See also Germany, above.

EDITORS' COMMENTS

Although the registry started in 1998 (Table A.10), data for 1998 and 1999 were excluded at the suggestion of the registry because of low incidence rates and a high DCO%. Day of incidence is not collected (Table A.8) because of the data protection law, and the unknown month of incidence is coded to July. Age was calculated as the difference between date of diagnosis and date of birth, with day of diagnosis coded to 15; this may have affected the reported age-specific incidence rates.

The registry was unable to supply information on basis of diagnosis for 2.2% of cases (Table A.9), because most of these cases were notified from other German cancer registries and their original records were unavailable. Non-malignant CNS tumours have been systematically registered since 2006, and some earlier cases were registered retrospectively. Therefore, reported incidence rates are likely to be underestimated for diagnostic categories III and Xa and the total. Pilocytic astrocytoma was originally coded with malignant behaviour. In 2004, pilocytic astrocytoma was recoded with uncertain behaviour in accordance with the implementation of ICD-O-3. Laterality was complete only for testicular tumours; all were unilateral. Malignant carcinoid tumours of the appendix constituted 1.3% of the total dataset (Table A.11). See also Germany, above.

GERMANY, 5 Western registries (1994-2012)

	Age group (years)	Males	Females
Person-years	0	1 461 834	1 386 271
	1-4	6 160 257	5 842 178
	5-9	8 501 326	8 072 856
	10-14	9 295 544	8 818 752
	15-19	9 586 973	9 103 531
	0-14	25 418 961	24 120 057
	0-19	35 005 934	33 223 588

Please consult the quality indicators for this pool and its constituent registries

GERMANY, 5 Western registries (1994-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	**LEUKAEMIA**	122	1033	684	589	553	**2428**	**2981**	32.5	100.0	26.0	100.0	42.8	86.1	41.3	32.5	29.6	**52.9**	**47.6**	758	906	91.8	2.5
	a. Lymphoid	49	873	562	382	291	**1866**	**2157**	25.0	76.9	18.8	72.4	17.2	72.7	33.9	21.1	15.6	**41.1**	**35.4**	585	663	92.2	1.6
	b. Acute myeloid	47	107	69	99	132	**322**	**454**	4.3	13.3	4.0	15.2	16.5	8.9	4.2	5.5	7.1	**6.9**	**7.0**	100	135	92.1	3.3
	c. CMD	2	3	11	23	66	**39**	**105**	0.5	1.6	0.9	3.5	0.7	0.2	0.7	1.3	3.5	**0.7**	**1.3**	11	29	93.3	3.8
	d. MDS & other	18	40	32	70	47	**160**	**207**	2.1	6.6	1.8	6.9	6.3	3.3	1.9	3.9	2.5	**3.3**	**3.1**	49	61	94.7	1.9
	e. Unspecified	6	10	10	15	17	**41**	**58**	0.5	1.7	0.5	1.9	2.1	0.8	0.6	0.8	0.9	**0.9**	**0.9**	13	17	65.5	27.6
II	**LYMPHOMA & RELATED**	16	102	298	496	942	**912**	**1854**	12.2	100.0	16.1	100.0	5.6	8.5	18.0	27.4	50.4	**16.8**	**24.4**	267	519	97.1	0.9
	a. Hodgkin	0	14	82	270	645	**366**	**1011**	4.9	40.1	8.8	54.5	-	1.2	4.9	14.9	34.5	**6.3**	**12.6**	104	277	98.7	0.0
	b. Non-Hodgkin except BL	4	48	127	141	228	**320**	**548**	4.3	35.1	4.8	29.6	1.4	4.0	7.7	7.8	12.2	**6.1**	**7.5**	95	156	95.4	2.4
	c. Burkitt (BL)	1	23	71	61	42	**156**	**198**	2.1	17.1	1.7	10.7	0.4	1.9	4.3	3.4	2.2	**3.0**	**2.8**	46	58	96.5	0.5
	d. Lymphoreticular	10	16	15	16	17	**57**	**74**	0.8	6.3	0.6	4.0	3.5	1.3	0.9	0.9	0.9	**1.2**	**1.2**	18	22	95.9	0.0
	e. Unspecified	1	1	3	8	10	**13**	**23**	0.2	1.4	0.2	1.2	0.4	0.1	0.2	0.4	0.5	**0.2**	**0.3**	4	6	73.9	8.7
III	**CNS NEOPLASMS** †	102	473	495	483	421	**1553**	**1974**	20.8	100.0	17.2	100.0	35.8	39.4	29.9	26.7	22.5	**32.4**	**30.1**	476	589	83.7	3.1
	a. Ependymoma	18	88	39	35	27	**180**	**207**	2.4	11.6	1.8	10.5	6.3	7.3	2.4	1.9	1.4	**4.1**	**3.5**	57	64	98.1	0.0
	b. Astrocytoma	20	178	195	252	213	**645**	**858**	8.6	41.5	7.5	43.5	7.0	14.8	11.8	13.9	11.4	**13.0**	**12.6**	195	252	89.0	1.7
	c. CNS embryonal	35	112	126	60	40	**333**	**373**	4.5	21.4	3.2	18.9	12.3	9.3	7.6	3.3	2.1	**7.2**	**6.1**	104	115	95.4	0.8
	d. Other gliomas	11	37	73	49	32	**170**	**202**	2.3	10.9	1.8	10.2	3.9	3.1	4.4	2.7	1.7	**3.5**	**3.1**	52	60	56.9	1.0
	e. Other specified	5	34	37	58	87	**134**	**221**	1.8	8.6	1.9	11.2	1.8	2.8	2.2	3.2	4.7	**2.7**	**3.1**	40	64	89.6	0.0
	f. Unspecified CNS	13	24	25	29	22	**91**	**113**	1.2	5.9	1.0	5.7	4.6	2.0	1.5	1.6	1.2	**1.9**	**1.7**	28	34	14.2	36.3
IV	**NEUROBLASTOMA**	213	213	50	22	14	**498**	**512**	6.7	100.0	4.5	100.0	74.8	17.7	3.0	1.2	0.7	**12.4**	**9.8**	165	168	88.7	1.8
	a. (Ganglio)neuroblastoma	213	209	48	18	3	**488**	**491**	6.5	98.0	4.3	95.9	74.8	17.4	2.9	1.0	0.2	**12.2**	**9.5**	162	162	88.4	1.8
	b. Peripheral nervous	0	4	2	4	11	**10**	**21**	0.1	2.0	0.2	4.1	-	0.3	0.1	0.2	0.6	**0.2**	**0.3**	3	6	95.2	0.0
V	**RETINOBLASTOMA**	54	83	9	1	0	**147**	**147**	2.0	100.0	1.3	100.0	19.0	6.9	0.5	0.1	-	**3.8**	**2.9**	49	49	63.9	0.0
VI	**RENAL TUMOURS**	59	219	80	22	17	**380**	**397**	5.1	100.0	3.5	100.0	20.7	18.2	4.8	1.2	0.9	**9.2**	**7.3**	124	128	79.6	1.3
	a. Nephroblastoma	58	216	75	15	3	**364**	**367**	4.9	95.8	3.2	92.4	20.4	18.0	4.5	0.8	0.2	**8.8**	**6.9**	119	120	79.0	1.1
	b. Renal carcinoma	0	1	4	7	14	**12**	**26**	0.2	3.2	0.2	6.5	-	0.1	0.2	0.4	0.7	**0.2**	**0.3**	3	7	100.0	0.0
	c. Unspecified	1	2	1	0	0	**4**	**4**	0.1	1.1	0.0	1.0	0.4	0.2	0.1	-	-	**0.1**	**0.1**	1	1	0.0	25.0
VII	**HEPATIC TUMOURS**	26	49	8	16	17	**99**	**116**	1.3	100.0	1.0	100.0	9.1	4.1	0.5	0.9	0.9	**2.4**	**2.0**	32	37	90.5	0.9
	a. Hepatoblastoma	26	46	3	7	2	**82**	**84**	1.1	82.8	0.7	72.4	9.1	3.8	0.2	0.4	0.1	**2.0**	**1.6**	27	28	90.5	0.0
	b. Hepatic carcinoma	0	3	5	9	15	**17**	**32**	0.2	17.2	0.3	27.6	-	0.2	0.3	0.5	0.8	**0.3**	**0.4**	5	9	90.6	3.1
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VIII	**BONE TUMOURS**	0	28	87	266	292	**381**	**673**	5.1	100.0	5.9	100.0	-	2.3	5.2	14.7	15.6	**6.7**	**8.7**	109	187	95.8	0.9
	a. Osteosarcoma	0	6	37	138	151	**181**	**332**	2.4	47.5	2.9	49.3	-	0.5	2.2	7.6	8.1	**3.1**	**4.2**	51	92	97.9	0.0
	b. Chondrosarcoma	0	1	0	7	17	**8**	**25**	0.1	2.1	0.2	3.7	-	0.1	-	0.4	0.9	**0.1**	**0.3**	2	7	100.0	0.0
	c. Ewing & related	0	21	46	104	110	**171**	**281**	2.3	44.9	2.4	41.8	-	1.7	2.8	5.7	5.9	**3.1**	**3.7**	50	79	96.1	0.4
	d. Other specified	0	0	4	9	8	**13**	**21**	0.2	3.4	0.2	3.1	-	-	0.2	0.5	0.4	**0.2**	**0.3**	4	6	100.0	0.0
	e. Unspecified	0	0	0	8	6	**8**	**14**	0.1	2.1	0.1	2.1	-	-	-	0.4	0.3	**0.1**	**0.2**	2	4	28.6	35.7
IX	**SOFT TISSUE SARCOMA**	43	130	128	150	230	**451**	**681**	6.0	100.0	5.9	100.0	15.1	10.8	7.7	8.3	12.3	**9.4**	**10.1**	138	200	94.7	1.3
	a. Rhabdomyosarcoma	16	100	79	55	59	**250**	**309**	3.3	55.4	2.7	45.4	5.6	8.3	4.8	3.0	3.2	**5.4**	**4.9**	78	94	95.1	1.3
	b. Fibrosarcoma	13	6	12	16	34	**47**	**81**	0.6	10.4	0.7	11.9	4.6	0.5	0.7	0.9	1.8	**1.0**	**1.2**	14	24	97.5	1.2
	c. Kaposi sarcoma	0	0	0	0	1	**0**	**1**	-	-	0.0	0.1	-	-	-	-	0.1	**-**	**0.0**	-	0	0.0	0.0
	d. Other specified	5	12	27	61	104	**105**	**209**	1.4	23.3	1.8	30.7	1.8	1.0	1.6	3.4	5.6	**1.9**	**2.8**	31	59	96.7	0.0
	e. Unspecified	9	12	10	18	32	**49**	**81**	0.7	10.9	0.7	11.9	3.2	1.0	0.6	1.0	1.7	**1.0**	**1.2**	15	24	86.4	4.9
X	**GERM CELL TUMOURS**	43	40	38	106	567	**227**	**794**	3.0	100.0	6.9	100.0	15.1	3.3	2.3	5.9	30.3	**4.6**	**10.4**	69	220	95.1	0.6
	a. CNS germ cell ‡	2	0	10	38	35	**50**	**85**	0.7	22.0	0.7	10.7	0.7	-	0.6	2.1	1.9	**0.9**	**1.1**	14	24	87.1	3.5
	b. Other extragonadal	27	17	3	6	7	**53**	**60**	0.7	23.3	0.5	7.6	9.5	1.4	0.2	0.3	0.4	**1.3**	**1.1**	17	19	93.3	1.7
	c. Gonadal germ cell	13	23	24	54	462	**114**	**576**	1.5	50.2	5.0	72.5	4.6	1.9	1.4	3.0	24.7	**2.3**	**7.3**	34	158	99.1	0.0
	d. Gonadal carcinoma	0	0	0	4	41	**4**	**45**	0.1	1.8	0.4	5.7	-	-	-	0.2	2.2	**0.1**	**0.5**	1	12	95.6	0.0
	e. Unspecified gonadal	1	0	1	4	22	**6**	**28**	0.1	2.6	0.2	3.5	0.4	-	0.1	0.2	1.2	**0.1**	**0.3**	2	8	39.3	3.6
XI	**CARCINOMA & MELANOMA**	6	20	61	264	936	**351**	**1287**	4.7	100.0	11.2	100.0	2.1	1.7	3.7	14.6	50.1	**6.1**	**16.0**	100	350	97.4	0.3
	a. Adrenocortical	0	4	3	1	5	**8**	**13**	0.1	2.3	0.1	1.0	-	0.3	0.2	0.1	0.3	**0.2**	**0.2**	3	4	84.6	0.0
	b. Thyroid	0	1	19	84	263	**104**	**367**	1.4	29.6	3.2	28.5	-	0.1	1.1	4.6	14.1	**1.7**	**4.5**	29	100	97.0	0.3
	c. Nasopharyngeal	0	0	1	3	12	**4**	**16**	0.1	1.1	0.1	1.2	-	-	0.1	0.2	0.6	**0.1**	**0.2**	1	4	87.5	0.0
	d. Melanoma	3	11	23	76	340	**113**	**453**	1.5	32.2	3.9	35.2	1.1	0.9	1.4	4.2	18.2	**2.0**	**5.7**	33	124	99.1	0.0
	e. Skin carcinoma	2	3	5	24	90	**34**	**124**	0.5	9.7	1.1	9.6	0.7	0.2	0.3	1.3	4.8	**0.6**	**1.6**	10	34	93.5	0.0
	f. Other & unspecified	1	1	10	76	226	**88**	**314**	1.2	25.1	2.7	24.4	0.4	0.1	0.6	4.2	12.1	**1.5**	**3.9**	25	85	97.8	1.0
XII	**OTHER & UNSPECIFIED**	11	14	8	11	20	**44**	**64**	0.6	100.0	0.6	100.0	3.9	1.2	0.5	0.6	1.1	**1.0**	**1.0**	14	19	45.3	26.6
	a. Other specified	2	5	3	1	7	**11**	**18**	0.1	25.0	0.2	28.1	0.7	0.4	0.2	0.1	0.4	**0.3**	**0.3**	4	5	100.0	0.0
	b. Other unspecified	9	9	5	10	13	**33**	**46**	0.4	75.0	0.4	71.9	3.2	0.7	0.3	0.6	0.7	**0.7**	**0.7**	10	14	23.9	37.0
	TOTAL §	695	2404	1946	2426	4009	**7471**	**11480**	100.0	100.0	100.0	100.0	244.0	200.3	117.4	133.9	214.5	**157.5**	**170.4**	2300	3373	91.3	1.8

† includes 587 non-malignant ‡ includes 1 non-malignant
§ includes 3 with sex unknown

Please consult the quality indicators for this pool and its constituent registries

Greece

Greek Nationwide Registry of Childhood Hematological Malignancies and Solid Tumors, 1996–2014

E. Petridou, E. Ntzani, M. Kantzanou, N. Dessypris, P. Bouka, E. Bouka, M. Baka, M. Moschovi, S. Polychronopoulou, E. Hatzipantelis, M. Kourti, E. Stiakaki, S. Sgouros, K. Stefanaki, M. Themistokleous

Greece is located on the Balkan Peninsula in southern Europe and is bordered by Albania, North Macedonia, Bulgaria, and Turkey. The country is surrounded by the Aegean Sea, Ionian Sea, Cretan Sea, and Mediterranean Sea. Greece is a high-income country with a very high HDI. In 2010, the estimated population was 11.2 million, and 15% of the population was younger than 15 years (Table A.6, Table A.7).

Health care is provided through universal national health insurance and private health care. Children with cancer are treated in seven paediatric haematology and oncology departments across the country.

The population-based Nationwide Registry for Childhood Hematological Malignancies was established in 1996; in 2010, it was expanded to include CNS tumours. Since 2017, cases of neuroblastoma and nephroblastoma are also registered, and the registry is called the Nationwide Registry of Childhood Hematological Malignancies and Solid Tumors (NARECHEM-ST). Only the data on haematological malignancies and CNS tumours are included in IICC-3. NARECHEM-ST is located in the Medical School of the National and Kapodistrian University of Athens (NKUA), which also funds the part-time work of a tenured professor and a statistician. The registrar position depends on fundraising. Collaborating clinicians contribute their time for data recording and diagnosis confirmation, and facilitate access to medical records for information on follow-up. Doctoral students contribute their time for data collection and cleaning.

Data are collected in collaboration with all six public and one private paediatric haematology and oncology units in Greece, and the respective paediatric pathology and radiology units. Only patients of Greek nationality and immigrants who have resided in the country for more than 2 years are eligible for registration. The same criteria are applied to define the population at risk.

Sociodemographic, disease-related, and clinical variables for about 2600 incident cases of childhood leukaemia and lymphoma had been recorded until December 2014. Biological samples, including DNA, are also available, and collection of parental DNA was initiated in 2016. For every case, one control (matched on age and sex) is identified among children hospitalized for minor ailments. All information is maintained electronically in a FileMaker database. The study protocol was approved by the NKUA Bioethics Committee.

Quality control is ensured by performing annual checks of types of diagnoses and of numbers of cases provided by treating physicians, and by assessing medical records. Multiple automated checks in the database are planned according to the routine quality control procedures recommended for cancer registries.

Linkage with national death registration data is not possible in Greece. Therefore, active follow-up by the treating physician to whom the family reports is used to determine survival estimates. Comparisons with tabulated death data by age group, sex, and cancer type, which are confidentially provided by the Hellenic Statistical Authority (ELSTAT) to NARECHEM-ST for the respective time periods, show almost identical figures.

Aggregate figures based on the raw data from NARECHEM-ST are uploaded annually to the registry website. NARECHEM-ST has also initiated collaborations with 13 other registries in southern and eastern Europe. Case–control studies were conducted partly in collaboration with researchers in Sweden and with the Childhood Cancer and Leukemia International Consortium.

PUBLICATIONS

Papathoma P, Thomopoulos TP, Karalexi MA, Ryzhov A, Zborovskaya A, Dimitrova N, et al. (2015). Childhood central nervous system tumours: incidence and time trends in 13 Southern and Eastern European cancer registries. Eur J Cancer. 51(11):1444–55. https://doi.org/10.1016/j.ejca.2015.04.014 PMID:25971531

Petridou ET, Pourtsidis A, Dessypris N, Katsiardanis K, Baka M, Moschovi M, et al. (2008). Childhood leukaemias and lymphomas in Greece (1996–2006): a nationwide registration study. Arch Dis Child. 93(12):1027–32. https://doi.org/10.1136/adc.2007.133249 PMID:18676433

POPULATION AT RISK

Population data were provided by ELSTAT (https://www.statistics.gr/) and are based on censuses conducted in 1991, 2001, and 2011 (Table A.7). Data were provided in the requested detail for the age range 0–14 years.

EDITORS' COMMENTS

In this paediatric cancer registry, registration focused on the age range 0–14 years during the reporting period. Therefore, data for the age groups 15–19 years and 0–19 years are not shown in the tables. The incidence rate and the proportion of infants among children highlighted in Table A.9 appear to be low; however, these values are not unexpected, because only selected tumour types were included in this dataset. The registry does not have access to information on cause of death, but according to the registry, the comparison of incidence data produced by the registry with tabulated mortality data indicates little or no potential effect of DCO cases on incidence rates, assuming a high quality of death certification. The MV% is very high for the types of neoplasms included (Table A.9); this suggests that cases diagnosed clinically

may be missed by the registry, which may, in turn, affect the resulting incidence rates. Non-malignant CNS tumours were included, and pilocytic astrocytoma was coded with uncertain behaviour. The data provided by this specialized registry are included only in the relevant tumour-specific comparative tables relating to haematopoietic malignancies and CNS tumours for the respective reporting periods over which they were complete.

GREECE, paediatric specialized

	Age group (years)	Males	Females
	(1996-2014)		
Person-years	0	1 026 336	978 475
	1-4	4 165 736	3 981 512
	5-9	5 368 060	5 127 187
	10-14	5 701 014	5 418 124
	0-14	16 261 146	15 505 298
Average annual population	0-14	855 850	816 068
	(2010-2014)		
Person-years	0	269 478	255 878
	1-4	1 133 685	1 083 233
	5-9	1 373 057	1 311 328
	10-14	1 372 814	1 315 807
	0-14	4 149 034	3 966 246
Average annual population	0-14	829 807	793 249

Please consult the quality indicators for this registry

GREECE, paediatric, haematological neoplasms (1996-2014) and CNS tumours (2010-2014)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	67	798	435	309	**1609**	66.9	100.0	33.4	97.9	41.4	27.8	**54.4**	772	100.0	0.0
	a. Lymphoid	38	728	378	245	**1389**	57.8	86.3	19.0	89.4	36.0	22.0	**47.2**	668	100.0	0.0
	b. Acute myeloid	25	61	44	52	**182**	7.6	11.3	12.5	7.5	4.2	4.7	**6.0**	87	100.0	0.0
	c. CMD	0	3	8	6	**17**	0.7	1.1	-	0.4	0.8	0.5	**0.5**	8	100.0	0.0
	d. MDS & other	2	2	0	0	**4**	0.2	0.2	1.0	0.2	-	-	**0.2**	2	100.0	0.0
	e. Unspecified	2	4	5	6	**17**	0.7	1.1	1.0	0.5	0.5	0.5	**0.5**	8	100.0	0.0
II	LYMPHOMA & RELATED	0	83	181	268	**532**	22.1	100.0	-	10.2	17.2	24.1	**15.7**	248	100.0	0.0
	a. Hodgkin	0	14	57	147	**218**	9.1	41.0	-	1.7	5.4	13.2	**6.1**	100	100.0	0.0
	b. Non-Hodgkin except BL	0	20	75	80	**175**	7.3	32.9	-	2.5	7.1	7.2	**5.2**	82	100.0	0.0
	c. Burkitt (BL)	0	49	49	41	**139**	5.8	26.1	-	6.0	4.7	3.7	**4.4**	66	100.0	0.0
	d. Lymphoreticular	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	e. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
III	CNS NEOPLASMS †	12	103	89	47	**251**	10.4	100.0	22.8	46.5	33.2	17.5	**32.0**	463	88.0	0.0
	a. Ependymoma	2	17	3	3	**25**	1.0	10.0	3.8	7.7	1.1	1.1	**3.4**	46	100.0	0.0
	b. Astrocytoma	2	31	31	18	**82**	3.4	32.7	3.8	14.0	11.5	6.7	**10.3**	151	89.0	0.0
	c. CNS embryonal	7	39	26	13	**85**	3.5	33.9	13.3	17.6	9.7	4.8	**11.0**	156	100.0	0.0
	d. Other gliomas	1	4	14	6	**25**	1.0	10.0	1.9	1.8	5.2	2.2	**3.0**	46	28.0	0.0
	e. Other specified	0	12	13	6	**31**	1.3	12.4	-	5.4	4.8	2.2	**3.9**	57	100.0	0.0
	f. Unspecified CNS	0	0	2	1	**3**	0.1	1.2	-	-	0.7	0.4	**0.3**	6	0.0	0.0
IV	NEUROBLASTOMA	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	a. (Ganglio)neuroblastoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	b. Peripheral nervous	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
V	RETINOBLASTOMA	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
VI	RENAL TUMOURS	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	a. Nephroblastoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	b. Renal carcinoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	c. Unspecified	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
VII	HEPATIC TUMOURS	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	a. Hepatoblastoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	b. Hepatic carcinoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	c. Unspecified	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
VIII	BONE TUMOURS	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	a. Osteosarcoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	b. Chondrosarcoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	c. Ewing & related	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	d. Other specified	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	e. Unspecified	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
IX	SOFT TISSUE SARCOMA	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	a. Rhabdomyosarcoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	b. Fibrosarcoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	c. Kaposi sarcoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	d. Other specified	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	e. Unspecified	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
X	GERM CELL TUMOURS	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	a. CNS germ cell ‡	2	1	2	8	**13**	0.5	100.0	3.8	0.5	0.7	3.0	**1.5**	24	46.2	0.0
	b. Other extragonadal	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	c. Gonadal germ cell	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	d. Gonadal carcinoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	e. Unspecified gonadal	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
XI	CARCINOMA & MELANOMA	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	a. Adrenocortical	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	b. Thyroid	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	c. Nasopharyngeal	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	d. Melanoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	e. Skin carcinoma	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	f. Other & unspecified	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
XII	OTHER & UNSPECIFIED	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	a. Other specified	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	b. Other unspecified	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-
	TOTAL	-	-	-	-	**-**	-	-	-	-	-	-	**-**	-	-	-

† includes 77 non-malignant ‡ includes 1 non-malignant

Please consult the quality indicators for this registry

Hungary

Hungarian Childhood Cancer Registry, 1991–2014

Zsuzsanna Jakab, Dezső Schuler, Miklós Garami

Hungary is a democratic parliamentary republic located in central Europe. It is bordered by Slovakia to the north, Ukraine to the north-east, Romania to the east, Serbia to the south, Croatia to the south-west, Slovenia to the west, and Austria to the north-west. It covers an area of 93 030 km^2 and has a continental climate with hot summers and cold, snowy winters. Hungary has a high-income market economy and a very high standard of living, with a social security system, universal health-care coverage, and tuition-free university education. Major industries include food processing, pharmaceuticals, motor vehicle manufacturing, information technology, chemicals, metallurgy, machinery, electrical goods, and tourism. In 2010, the population was 10.0 million (Table A.7); the population size is decreasing, and 15% of the population is younger than 15 years (Table A.6). The population is mostly urban (70%), and more than 25% of people live in the Budapest metropolitan area.

Children with cancer are treated in 10 specialized paediatric haematology and oncology departments. The Hungarian Childhood Leukaemia Study Group was established in 1971, with the goal of standardizing diagnostic and therapeutic practices and improving survival of children with leukaemia. In 1973, centralization of treatment was extended to children with solid tumours.

The Hungarian Childhood Cancer Registry (HCCR) was established in 1971 (Table A.10) by the Hungarian Paediatric Haemato-Oncology Network (HPON). HCCR is a national, population-based childhood cancer registry with complete coverage of the population younger than 15 years. Details collected on new cancer diagnoses, specific treatments, and long-term follow-up are defined in cooperation with HPON, and HCCR provides administrative support and serves as a source of data for clinical studies. The goal of the registry is to contribute to understanding the causes of childhood cancer and help to continuously improve treatments while minimizing early and late toxicities. HCCR is located at the 2nd Department of Paediatrics of Semmelweis University in Budapest.

All hospitals in Hungary notify the registry of newly diagnosed cancer cases and send annual updates on follow-up thereafter. HCCR performs active case finding for retinoblastoma and CNS tumours, including non-malignant cases, by regularly matching against the National Institute of Clinical Neurosciences and ophthalmology departments, which has resulted in nearly complete registration for CNS tumours since 1984. Vital status after childhood is collected by regularly matching the files against the National Population Registry. Death certificates were not available for ascertainment of cancer cases, because it is the policy of the Central Statistics Agency not to release death certificates, which are destroyed soon after the basic statistics are produced.

The registry data are almost complete for leukaemia from 1973 and for solid tumours from 1978. Data are coded according to ENCR recommendations. Validity is checked by the Child-Check Program and international comparisons.

In 1999, cancer registration was mandated by law; this has facilitated access to data sources. HCCR was audited by an ENCR committee in 2002. Since 2011, cases are registered electronically. Since 2012, HPON has been financially supported by the Ministry of Human Capacities. HCCR is a member of IACR and ENCR, and has participated in several international studies investigating epidemiological, prognostic, and etiological factors of childhood cancer (e.g. IICC, European Childhood Leukaemia–Lymphoma Incidence Study [ECLIS], Automated Childhood Cancer Information System [ACCIS], European Cancer Registry-Based Study on Survival and Care of Cancer Patients [EUROCARE], PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies [PanCareSurFup]).

POPULATION AT RISK

The source of the data is the Hungarian Central Statistical Office (https://www.ksh.hu). The national census was conducted in 1990, 2001, and 2011 (Table A.7). Data were provided by sex and age groups (0, 1–4, 5–9, 10–14, 15–19 years) for each calendar year of the reporting period. The data for the missing year–age–sex categories were estimated at IARC using the methods described in Chapter 2.

EDITORS' COMMENTS

The registry contributed to all three IICC volumes (Table A.1). In this paediatric cancer registry, registration focused on the age range 0–14 years during the reporting period. Therefore, data for the age groups 15–19 years and 0–19 years are not shown in the tables. Lack of access to death certificates may result in a small number of missed cases. Information was provided on non-malignant CNS tumours, skin carcinomas, and laterality. Pilocytic astrocytoma was originally coded with malignant behaviour and was recoded with uncertain behaviour for submission to IICC-3.

HUNGARY, paediatric (1991-2014)

	Age group (years)	Males	Females
Person-years	0	1 246 538	1 181 390
	1-4	5 143 039	4 887 224
	5-9	6 773 879	6 451 044
	10-14	7 414 792	7 074 793
	0-14	20 578 248	19 594 451
Average annual population	0-14	857 427	816 435

Please consult the quality indicators for this registry

HUNGARY, paediatric (1991-2014)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	69	734	492	330	**1625**	28.5	100.0	28.4	73.2	37.2	22.8	**43.6**	622	100.0	0.0
	a. Lymphoid	41	641	422	220	**1324**	23.2	81.5	16.9	63.9	31.9	15.2	**35.9**	509	100.0	0.0
	b. Acute myeloid	17	77	55	76	**225**	3.9	13.8	7.0	7.7	4.2	5.2	**5.8**	85	100.0	0.0
	c. CMD	4	6	8	21	**39**	0.7	2.4	1.6	0.6	0.6	1.4	**0.9**	14	100.0	0.0
	d. MDS & other	7	8	7	13	**35**	0.6	2.2	2.9	0.8	0.5	0.9	**0.9**	13	100.0	0.0
	e. Unspecified	0	2	0	0	**2**	0.0	0.1	-	0.2	-	-	**0.1**	1	100.0	0.0
II	LYMPHOMA & RELATED	3	97	209	339	**648**	11.4	100.0	1.2	9.7	15.8	23.4	**15.0**	236	100.0	0.0
	a. Hodgkin	0	23	85	183	**291**	5.1	44.9	-	2.3	6.4	12.6	**6.5**	105	100.0	0.0
	b. Non-Hodgkin except BL	3	46	67	120	**236**	4.1	36.4	1.2	4.6	5.1	8.3	**5.6**	86	100.0	0.0
	c. Burkitt (BL)	0	24	53	32	**109**	1.9	16.8	-	2.4	4.0	2.2	**2.7**	41	100.0	0.0
	d. Lymphoreticular	0	2	2	3	**7**	0.1	1.1	-	0.2	0.2	0.2	**0.2**	3	100.0	0.0
	e. Unspecified	0	2	2	1	**5**	0.1	0.8	-	0.2	0.2	0.1	**0.1**	2	100.0	0.0
III	CNS NEOPLASMS †	101	424	481	454	**1460**	25.6	100.0	41.6	42.3	36.4	31.3	**37.1**	549	91.8	0.0
	a. Ependymoma	26	66	32	32	**156**	2.7	10.7	10.7	6.6	2.4	2.2	**4.3**	60	100.0	0.0
	b. Astrocytoma	24	170	208	212	**614**	10.8	42.1	9.9	16.9	15.7	14.6	**15.3**	230	98.2	0.0
	c. CNS embryonal	30	115	124	83	**352**	6.2	24.1	12.4	11.5	9.4	5.7	**9.2**	134	99.7	0.0
	d. Other gliomas	14	33	71	63	**181**	3.2	12.4	5.8	3.3	5.4	4.3	**4.5**	67	45.3	0.0
	e. Other specified	7	40	45	63	**155**	2.7	10.6	2.9	4.0	3.4	4.3	**3.8**	58	94.8	0.0
	f. Unspecified CNS	0	0	1	1	**2**	0.0	0.1	-	-	0.1	0.1	**0.0**	1	100.0	0.0
IV	NEUROBLASTOMA	238	260	52	20	**570**	10.0	100.0	98.0	25.9	3.9	1.4	**17.1**	226	98.4	0.0
	a. (Ganglio)neuroblastoma	238	258	50	17	**563**	9.9	98.8	98.0	25.7	3.8	1.2	**17.0**	224	98.4	0.0
	b. Peripheral nervous	0	2	2	3	**7**	0.1	1.2	-	0.2	0.2	0.2	**0.2**	3	100.0	0.0
V	RETINOBLASTOMA	53	69	7	0	**129**	2.3	100.0	21.8	6.9	0.5	-	**4.0**	52	82.9	0.0
VI	RENAL TUMOURS	48	179	59	16	**302**	5.3	100.0	19.8	17.8	4.5	1.1	**8.8**	119	99.7	0.0
	a. Nephroblastoma	48	179	56	9	**292**	5.1	96.7	19.8	17.8	4.2	0.6	**8.6**	115	99.7	0.0
	b. Renal carcinoma	0	0	3	7	**10**	0.2	3.3	-	-	0.2	0.5	**0.2**	4	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VII	HEPATIC TUMOURS	32	37	8	7	**84**	1.5	100.0	13.2	3.7	0.6	0.5	**2.5**	33	100.0	0.0
	a. Hepatoblastoma	31	36	6	3	**76**	1.3	90.5	12.8	3.6	0.5	0.2	**2.3**	30	100.0	0.0
	b. Hepatic carcinoma	1	1	2	4	**8**	0.1	9.5	0.4	0.1	0.2	0.3	**0.2**	3	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VIII	BONE TUMOURS	1	20	91	176	**288**	5.0	100.0	0.4	2.0	6.9	12.1	**6.4**	104	100.0	0.0
	a. Osteosarcoma	0	0	38	96	**134**	2.3	46.5	-	-	2.9	6.6	**2.9**	47	100.0	0.0
	b. Chondrosarcoma	0	0	1	6	**7**	0.1	2.4	-	-	0.1	0.4	**0.1**	2	100.0	0.0
	c. Ewing & related	1	18	47	68	**134**	2.3	46.5	0.4	1.8	3.6	4.7	**3.1**	49	100.0	0.0
	d. Other specified	0	2	5	5	**12**	0.2	4.2	-	0.2	0.4	0.3	**0.3**	4	100.0	0.0
	e. Unspecified	0	0	0	1	**1**	0.0	0.3	-	-	-	0.1	**0.0**	0	100.0	0.0
IX	SOFT TISSUE SARCOMA	38	109	77	91	**315**	5.5	100.0	15.7	10.9	5.8	6.3	**8.3**	120	100.0	0.0
	a. Rhabdomyosarcoma	11	68	46	28	**153**	2.7	48.6	4.5	6.8	3.5	1.9	**4.1**	59	100.0	0.0
	b. Fibrosarcoma	14	12	5	13	**44**	0.8	14.0	5.8	1.2	0.4	0.9	**1.2**	17	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	d. Other specified	12	23	22	44	**101**	1.8	32.1	4.9	2.3	1.7	3.0	**2.5**	38	100.0	0.0
	e. Unspecified	1	6	4	6	**17**	0.3	5.4	0.4	0.6	0.3	0.4	**0.4**	6	100.0	0.0
X	GERM CELL TUMOURS	24	33	22	60	**139**	2.4	100.0	9.9	3.3	1.7	4.1	**3.5**	52	99.3	0.0
	a. CNS germ cell ‡	4	1	10	15	**30**	0.5	21.6	1.6	0.1	0.8	1.0	**0.7**	11	96.7	0.0
	b. Other extragonadal	17	20	1	6	**44**	0.8	31.7	7.0	2.0	0.1	0.4	**1.3**	17	100.0	0.0
	c. Gonadal germ cell	2	12	9	35	**58**	1.0	41.7	0.8	1.2	0.7	2.4	**1.4**	21	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	e. Unspecified gonadal	1	0	2	4	**7**	0.1	5.0	0.4	-	0.2	0.3	**0.2**	3	100.0	0.0
XI	CARCINOMA & MELANOMA	9	10	28	87	**134**	2.3	100.0	3.7	1.0	2.1	6.0	**3.0**	48	100.0	0.0
	a. Adrenocortical	6	1	0	1	**8**	0.1	6.0	2.5	0.1	-	0.1	**0.2**	3	100.0	0.0
	b. Thyroid	0	1	10	37	**48**	0.8	35.8	-	0.1	0.8	2.6	**1.0**	17	100.0	0.0
	c. Nasopharyngeal	0	0	0	8	**8**	0.1	6.0	-	-	-	0.6	**0.2**	3	100.0	0.0
	d. Melanoma	2	3	7	16	**28**	0.5	20.9	0.8	0.3	0.5	1.1	**0.6**	10	100.0	0.0
	e. Skin carcinoma	1	0	3	6	**10**	0.2	7.5	0.4	-	0.2	0.4	**0.2**	4	100.0	0.0
	f. Other & unspecified	0	5	8	19	**32**	0.6	23.9	-	0.5	0.6	1.3	**0.7**	12	100.0	0.0
XII	OTHER & UNSPECIFIED	1	4	0	6	**11**	0.2	100.0	0.4	0.4	-	0.4	**0.3**	4	100.0	0.0
	a. Other specified	1	4	0	5	**10**	0.2	90.9	0.4	0.4	-	0.3	**0.3**	4	100.0	0.0
	b. Other unspecified	0	0	0	1	**1**	0.0	9.1	-	-	-	0.1	**0.0**	0	100.0	0.0
	TOTAL §	617	1976	1526	1586	**5705**	100.0	100.0	254.1	197.0	115.4	109.5	**149.6**	2165	97.3	0.0

† includes 467 non-malignant ‡ includes 5 non-malignant
§ includes 2 with sex unknown

Please consult the quality indicators for this registry

Iceland

Icelandic Cancer Registry, 1990–2014

Laufey Tryggvadóttir, Helgi Birgisson

Iceland is an island country located in the North Atlantic Ocean. It covers an area of 103 000 km^2. The island is geologically active, with a temperate subarctic climate on the coasts and a tundra climate in the inland areas. This democratic republic has a market economy and universal health care, and it ranks ninth worldwide in the HDI (2016). About 75% of the population of 0.3 million lives in the capital city of Reykjavik and the surrounding area. About 28% of the population is younger than 20 years (Table A.6). Most of the population is Christian (Protestant) and of northern European descent.

Patients in Iceland have easy and equal access to the health-care system. Cancer surgery is mainly limited to two hospitals, and specialized cancer treatment is provided at Landspítali University Hospital in Reykjavik, which is equipped with highly sophisticated imaging facilities.

The Icelandic Cancer Registry was established in 1954 and contains information on all cancers and their precursors in Iceland from 1955 (Table A.10). The registry was legally mandated in 2007 according to a new Directorate of Health Act. The Icelandic Cancer Society has run the cancer registry since it was established and continues to do so under a contract with the Directorate of Health; half of the registry's funding is provided by the Ministry of Welfare. Registration is compulsory, and informed consent is not required.

The core staff consists of a medical director, a managing director, two registrars, a data manager, and a statistician. There are also student and part-time researcher positions.

All three pathology laboratories in Iceland constitute the principal data sources, from which the registry receives data on all malignant and selected non-malignant neoplasms; the MV% is 95%. Other data sources are haematology laboratories, hospital departments, health-care facilities, consultants in private practice, and death certificates from Statistics Iceland in which malignant diseases are mentioned. Additional information is requested from the abovementioned sources if needed. The registration principles are defined according to European guidelines, and data are checked using the IARC/IACR CHECK Program.

Figures on incidence, prevalence, and survival are published electronically each year on the Icelandic Cancer Registry homepage and on the NORDCAN website. The registry conducts epidemiological research and provides data for such research. The registry also provides information for the planning of cancer prevention and treatment strategies.

PUBLICATIONS

Engholm G, Ferlay J, Christensen N, Bray F, Gjerstorff ML, Klint A, et al. (2010). NORDCAN – a Nordic tool for cancer information, planning, quality control and research. Acta Oncol. 49(5):725–36. https://doi.org/10.3109/02841861003782017 PMID:20491528

POPULATION AT RISK

The data were provided by the Icelandic National Roster, which has been in operation since 1952 and is regularly updated with information on births, deaths, and migration. Data were provided in the requested detail. The decimal portions of the estimated counts provided for some sex and age categories were rounded to the nearest integer at IARC (Table A.8).

EDITORS' COMMENTS

The registry also contributed to IICC-2 (Table A.1). Exact dates are recorded and are used to calculate age; however, day of birth and day of incidence were not provided because of data protection rules (Table A.8). The large proportion of cases aged 19 years in the age group 15–19 years results from a high incidence in diagnostic groups XI, II, and X. The reported proportion of non-malignant CNS tumours is high (Table A.9) because of strong links with neurology clinics throughout the country and systematic registration of all types of CNS tumours. Pilocytic astrocytoma was coded with uncertain behaviour. Information on skin carcinomas and laterality is complete.

ICELAND (1990-2014)

	Age group (years)	Males	Females
Person-years	0	56 793	54 420
	1-4	226 870	216 596
	5-9	276 566	265 021
	10-14	277 101	265 481
	15-19	279 822	267 589
	0-14	837 330	801 518
	0-19	1 117 152	1 069 107
Average annual population	0-14	33 493	32 061
	0-19	44 686	42 764

Please consult the quality indicators for this registry

ICELAND (1990-2014)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	**LEUKAEMIA**	6	33	15	12	14	**66**	**80**	28.9	100.0	21.3	100.0	54.0	74.4	27.7	22.1	25.6	**42.6**	**38.7**	601	728	100.0	0.0
	a. Lymphoid	3	28	14	7	3	**52**	**55**	22.8	78.8	14.6	68.8	27.0	63.1	25.8	12.9	5.5	**33.7**	**27.4**	473	501	100.0	0.0
	b. Acute myeloid	1	3	1	2	6	**7**	**13**	3.1	10.6	3.5	16.3	9.0	6.8	1.8	3.7	11.0	**4.5**	**5.9**	64	119	100.0	0.0
	c. CMD	0	1	0	2	4	**3**	**7**	1.3	4.5	1.9	8.8	-	2.3	-	3.7	7.3	**1.8**	**3.0**	27	64	100.0	0.0
	d. MDS & other	1	1	0	1	1	**3**	**4**	1.3	4.5	1.1	5.0	9.0	2.3	-	1.8	1.8	**1.9**	**1.9**	27	36	100.0	0.0
	e. Unspecified	1	0	0	0	0	**1**	**1**	0.4	1.5	0.3	1.3	9.0	-	-	-	-	**0.7**	**0.5**	9	9	100.0	0.0
II	**LYMPHOMA & RELATED**	0	4	10	7	37	**21**	**58**	9.2	100.0	15.4	100.0	-	9.0	18.5	12.9	67.6	**12.5**	**24.9**	193	531	100.0	0.0
	a. Hodgkin	0	0	5	3	28	**8**	**36**	3.5	38.1	9.6	62.1	-	-	9.2	5.5	51.1	**4.6**	**15.1**	74	330	100.0	0.0
	b. Non-Hodgkin except BL	0	2	0	3	8	**5**	**13**	2.2	23.8	3.5	22.4	-	4.5	-	5.5	14.6	**3.0**	**5.6**	46	119	100.0	0.0
	c. Burkitt (BL)	0	2	5	1	1	**8**	**9**	3.5	38.1	2.4	15.5	-	4.5	9.2	1.8	1.8	**4.9**	**4.2**	73	83	100.0	0.0
	d. Lymphoreticular	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	e. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
III	**CNS NEOPLASMS** †	3	19	19	29	18	**70**	**88**	30.7	100.0	23.4	100.0	27.0	42.8	35.1	53.4	32.9	**42.2**	**40.1**	641	805	83.0	0.0
	a. Ependymoma	0	0	1	2	1	**3**	**4**	1.3	4.3	1.1	4.5	-	-	1.8	3.7	1.8	**1.7**	**1.7**	28	37	100.0	0.0
	b. Astrocytoma	2	12	11	9	12	**34**	**46**	14.9	48.6	12.2	52.3	18.0	27.1	20.3	16.6	21.9	**21.1**	**21.3**	311	420	97.8	0.0
	c. CNS embryonal	1	2	3	3	0	**9**	**9**	3.9	12.9	2.4	10.2	9.0	4.5	5.5	5.5	-	**5.5**	**4.3**	82	82	100.0	0.0
	d. Other gliomas	0	2	0	2	0	**4**	**4**	1.8	5.7	1.1	4.5	-	4.5	-	3.7	-	**2.5**	**1.9**	36	36	75.0	0.0
	e. Other specified	0	0	1	7	3	**8**	**11**	3.5	11.4	2.9	12.5	-	-	1.8	12.9	5.5	**4.3**	**4.6**	74	101	100.0	0.0
	f. Unspecified CNS	0	3	3	6	2	**12**	**14**	5.3	17.1	3.7	15.9	-	6.8	5.5	11.1	3.7	**7.1**	**6.3**	110	128	7.1	0.0
IV	**NEUROBLASTOMA**	3	5	1	0	0	**9**	**9**	3.9	100.0	2.4	100.0	27.0	11.3	1.8	-	-	**6.2**	**4.8**	81	81	100.0	0.0
	a. (Ganglio)neuroblastoma	3	5	1	0	0	**9**	**9**	3.9	100.0	2.4	100.0	27.0	11.3	1.8	-	-	**6.2**	**4.8**	81	81	100.0	0.0
	b. Peripheral nervous	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
V	**RETINOBLASTOMA**	1	3	0	0	0	**4**	**4**	1.8	100.0	1.1	100.0	9.0	6.8	-	-	-	**2.8**	**2.2**	36	36	100.0	0.0
VI	**RENAL TUMOURS**	2	6	1	0	0	**9**	**9**	3.9	100.0	2.4	100.0	18.0	13.5	1.8	-	-	**6.2**	**4.8**	81	81	100.0	0.0
	a. Nephroblastoma	2	6	1	0	0	**9**	**9**	3.9	100.0	2.4	100.0	18.0	13.5	1.8	-	-	**6.2**	**4.8**	81	81	100.0	0.0
	b. Renal carcinoma	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VII	**HEPATIC TUMOURS**	0	1	0	2	1	**3**	**4**	1.3	100.0	1.1	100.0	-	2.3	-	3.7	1.8	**1.8**	**1.8**	27	37	100.0	0.0
	a. Hepatoblastoma	0	1	0	0	0	**1**	**1**	0.4	33.3	0.3	25.0	-	2.3	-	-	-	**0.7**	**0.5**	9	9	100.0	0.0
	b. Hepatic carcinoma	0	0	0	2	1	**2**	**3**	0.9	66.7	0.8	75.0	-	-	-	3.7	1.8	**1.1**	**1.2**	18	28	100.0	0.0
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VIII	**BONE TUMOURS**	0	0	3	6	15	**9**	**24**	3.9	100.0	6.4	100.0	-	-	5.5	11.1	27.4	**5.0**	**10.0**	83	220	100.0	0.0
	a. Osteosarcoma	0	0	3	5	10	**8**	**18**	3.5	88.9	4.8	75.0	-	-	5.5	9.2	18.3	**4.5**	**7.6**	74	165	100.0	0.0
	b. Chondrosarcoma	0	0	0	0	1	**0**	**1**	-	-	0.3	4.2	-	-	-	-	1.8	**-**	**0.4**	-	9	100.0	0.0
	c. Ewing & related	0	0	0	1	3	**1**	**4**	0.4	11.1	1.1	16.7	-	-	-	1.8	5.5	**0.5**	**1.6**	9	37	100.0	0.0
	d. Other specified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	e. Unspecified	0	0	0	0	1	**0**	**1**	-	-	0.3	4.2	-	-	-	-	1.8	**-**	**0.4**	-	9	100.0	0.0
IX	**SOFT TISSUE SARCOMA**	2	4	2	7	7	**15**	**22**	6.6	100.0	5.9	100.0	18.0	9.0	3.7	12.9	12.8	**9.1**	**9.9**	137	201	100.0	0.0
	a. Rhabdomyosarcoma	1	4	0	2	1	**7**	**8**	3.1	46.7	2.1	36.4	9.0	9.0	-	3.7	1.8	**4.6**	**3.9**	64	73	100.0	0.0
	b. Fibrosarcoma	1	0	1	1	2	**3**	**5**	1.3	20.0	1.3	22.7	9.0	-	1.8	1.8	3.7	**1.8**	**2.2**	27	46	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	d. Other specified	0	0	0	3	4	**3**	**7**	1.3	20.0	1.9	31.8	-	-	-	5.5	7.3	**1.6**	**2.9**	28	64	100.0	0.0
	e. Unspecified	0	0	1	1	0	**2**	**2**	0.9	13.3	0.5	9.1	-	-	1.8	1.8	-	**1.1**	**0.9**	18	18	100.0	0.0
X	**GERM CELL TUMOURS**	2	1	2	1	16	**6**	**22**	2.6	100.0	5.9	100.0	18.0	2.3	3.7	1.8	29.2	**3.8**	**9.5**	55	201	100.0	0.0
	a. CNS germ cell ‡	0	0	2	0	1	**2**	**3**	0.9	33.3	0.8	13.6	-	-	3.7	-	1.8	**1.2**	**1.3**	18	28	100.0	0.0
	b. Other extragonadal	1	0	0	0	0	**1**	**1**	0.4	16.7	0.3	4.5	9.0	-	-	-	-	**0.7**	**0.5**	9	9	100.0	0.0
	c. Gonadal germ cell	1	1	0	1	14	**3**	**17**	1.3	50.0	4.5	77.3	9.0	2.3	-	1.8	25.6	**1.9**	**7.3**	27	155	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	1	**0**	**1**	-	-	0.3	4.5	-	-	-	-	1.8	**-**	**0.4**	-	9	100.0	0.0
	e. Unspecified gonadal	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
XI	**CARCINOMA & MELANOMA**	1	2	2	11	40	**16**	**56**	7.0	100.0	14.9	100.0	9.0	4.5	3.7	20.3	73.1	**9.2**	**23.5**	147	512	100.0	0.0
	a. Adrenocortical	1	1	0	1	0	**3**	**3**	1.3	18.8	0.8	5.4	9.0	2.3	-	1.8	-	**1.9**	**1.5**	27	27	100.0	0.0
	b. Thyroid	0	0	0	1	11	**1**	**12**	0.4	6.3	3.2	21.4	-	-	-	1.8	20.1	**0.5**	**4.9**	9	110	100.0	0.0
	c. Nasopharyngeal	0	0	1	1	3	**2**	**5**	0.9	12.5	1.3	8.9	-	-	1.8	1.8	5.5	**1.1**	**2.1**	18	46	100.0	0.0
	d. Melanoma	0	1	0	4	20	**5**	**25**	2.2	31.3	6.6	44.6	-	2.3	-	7.4	36.5	**2.8**	**10.4**	46	229	100.0	0.0
	e. Skin carcinoma	0	0	0	2	0	**2**	**2**	0.9	12.5	0.5	3.6	-	-	-	3.7	-	**1.1**	**0.8**	18	18	100.0	0.0
	f. Other & unspecified	0	0	1	2	6	**3**	**9**	1.3	18.8	2.4	16.1	-	-	1.8	3.7	11.0	**1.7**	**3.8**	28	82	100.0	0.0
XII	**OTHER & UNSPECIFIED**	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	a. Other specified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	b. Other unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	TOTAL	20	78	55	75	148	**228**	**376**	100.0	100.0	100.0	100.0	179.8	175.9	101.6	138.2	270.4	**141.3**	**170.3**	2082	3434	96.0	0.0

† includes 36 non-malignant ‡ includes 1 non-malignant

Please consult the quality indicators for this registry

Ireland

National Cancer Registry Ireland, 1994–2012

Harry Comber, Fiona Dwane, Tracy Kelleher

Ireland is an island off the west coast of Europe. The Republic of Ireland covers an area of 70 273 km^2, 83% of the area of the island. The climate is temperate and moist. In 2013, the GDP was €41 billion. About 40% of the population has private health insurance. All public costs of health care are funded by general taxation. At the most recent census (2011), the population was 4.6 million, and 27% of the population was younger than 20 years (Table A.6).

Access to primary care and medication is free for 25% of the population (those in the lowest income quartile). All residents have access to free hospital care in public hospitals. There are about 11 000 public beds in public hospitals, 2500 private beds in public hospitals, and 2000 beds in private hospitals. There is a charge for outpatient and inpatient care in public hospitals (capped at €750 in a year); those with free general practitioner care do not have to pay. Those with private health insurance have access to private beds and private practice; this often reduces waiting times. In 2006–2010, 40 hospitals treated at least one child with cancer. A large proportion (56%) of solid tumours and 99% of haematological cancers in children were treated in the national paediatric oncology centre. CNS cancers were treated in two paediatric hospitals (including the national centre) and the two national neuro-oncology centres.

The registry is fully funded by the Irish Department of Health. It is not attached to a hospital or university. The entire resident population is covered by the registry. There are no significant ethnic or regional differences in the country. The coverage area has been the same since 1994.

Cancer notification is not mandatory in Ireland; most information is obtained from hospital medical records, through active case finding and data abstraction. The primary source is histopathology reports (85%), with about 5% from other hospital sources, mainly electronic discharge summaries from public hospitals. The registry has access to death certificates for all deaths in the country.

The registry staff includes 20 hospital-based members; they collect copies of histopathology reports and electronic discharge summaries and create a new case, and then provide this record to the main registry offices. This information is accessible to all registry staff, who over time can add information from the medical record, such as stage and treatment.

The ICD-O-3 coding system is used for site and morphology; TNM-5 is used for staging. Completeness of registration at 1 year is 96% and at 5 years is 99% (flow method). Follow-up is passive through linkage of registrations with death certificates; this is done quarterly. There is no system of active follow-up. Completeness of follow-up is high for the reporting period.

The registry data are used to produce annual reports, peer-reviewed articles, fact sheets available online (https://www.ncri.ie/publications), submissions to international collaborations (European Cancer Organisation [ECO], CI5, EUROCARE, CONCORD, ACCIS), and responses to queries from researchers and the public. Reports for the Department of Health and the National Cancer Control Programme are used in the planning and evaluation of health services. Registry data are also used in many research studies.

POPULATION AT RISK

Intercensal estimates are provided each year by the Central Statistics Office (https://www.cso.ie/en/census). The estimates are based on projections from the most recent census, allowing for gross migration flows reported by the Quarterly National Survey. The national census was conducted in 1991, 1996, 2002, 2006, and 2011 (Table A.7). Data were provided in the requested detail.

EDITORS' COMMENTS

Age is calculated at the registry using complete dates; however, day of birth was not provided with the data (Table A.8), as per the registry's policy. Non-malignant CNS tumours are included. Pilocytic astrocytoma was coded according to the ICD-O edition in use at the time of incidence (Table A.10) and recoded with uncertain behaviour for all calendar years in the dataset submitted to IICC-3. All skin carcinomas are recorded. Information on laterality is almost complete.

IRELAND (1994-2012)

	Age group (years)	Males	Females
Person-years	0	586 238	555 538
	1-4	2 249 233	2 138 278
	5-9	2 798 411	2 662 606
	10-14	2 904 306	2 755 180
	15-19	3 035 097	2 899 888
	0-14	8 538 188	8 111 602
	0-19	11 573 285	11 011 490
Average annual population	0-14	449 378	426 926
	0-19	609 120	579 552

Please consult the quality indicators for this registry

IRELAND (1994-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	**LEUKAEMIA**	44	359	198	159	157	**760**	**917**	30.7	100.0	24.3	100.0	38.5	81.8	36.3	28.1	26.5	**48.1**	**43.2**	686	818	99.3	0.2
	a. Lymphoid	23	300	161	112	77	**596**	**673**	24.1	78.4	17.8	73.4	20.1	68.4	29.5	19.8	13.0	**37.9**	**32.3**	538	603	99.9	0.0
	b. Acute myeloid	16	45	31	30	45	**122**	**167**	4.9	16.1	4.4	18.2	14.0	10.3	5.7	5.3	7.6	**7.6**	**7.6**	110	148	100.0	0.0
	c. CMD	0	6	2	6	20	**14**	**34**	0.6	1.8	0.9	3.7	-	1.4	0.4	1.1	3.4	**0.8**	**1.4**	13	29	100.0	0.0
	d. MDS & other	2	3	1	5	8	**11**	**19**	0.4	1.4	0.5	2.1	1.8	0.7	0.2	0.9	1.3	**0.7**	**0.8**	10	17	89.5	0.0
	e. Unspecified	3	5	3	6	7	**17**	**24**	0.7	2.2	0.6	2.6	2.6	1.1	0.5	1.1	1.2	**1.0**	**1.1**	15	21	87.5	8.3
II	**LYMPHOMA & RELATED**	6	37	73	143	316	**259**	**575**	10.5	100.0	15.2	100.0	5.3	8.4	13.4	25.3	53.2	**14.7**	**23.3**	232	498	99.3	0.2
	a. Hodgkin	0	3	25	82	220	**110**	**330**	4.4	42.5	8.7	57.4	-	0.7	4.6	14.5	37.1	**5.9**	**12.9**	98	283	99.7	0.0
	b. Non-Hodgkin except BL	2	18	30	43	75	**93**	**168**	3.8	35.9	4.4	29.2	1.8	4.1	5.5	7.6	12.6	**5.4**	**7.0**	84	147	98.8	0.6
	c. Burkitt (BL)	0	5	10	6	7	**21**	**28**	0.8	8.1	0.7	4.9	-	1.1	1.8	1.1	1.2	**1.2**	**1.2**	19	25	100.0	0.0
	d. Lymphoreticular	3	5	3	3	3	**14**	**17**	0.6	5.4	0.4	3.0	2.6	1.1	0.5	0.5	0.5	**0.9**	**0.8**	13	15	94.1	0.0
	e. Unspecified	1	6	5	9	11	**21**	**32**	0.8	8.1	0.8	5.6	0.9	1.4	0.9	1.6	1.9	**1.2**	**1.4**	19	28	100.0	0.0
III	**CNS NEOPLASMS** †	54	180	209	200	232	**643**	**875**	26.0	100.0	23.1	100.0	47.3	41.0	38.3	35.3	39.1	**39.0**	**39.0**	580	775	82.6	0.1
	a. Ependymoma	7	19	12	11	14	**49**	**63**	2.0	7.6	1.7	7.2	6.1	4.3	2.2	1.9	2.4	**3.1**	**2.9**	44	56	98.4	0.0
	b. Astrocytoma	23	89	94	101	106	**307**	**413**	12.4	47.7	10.9	47.2	20.1	20.3	17.2	17.8	17.9	**18.6**	**18.4**	277	366	89.1	0.0
	c. CNS embryonal	14	43	47	19	21	**123**	**144**	5.0	19.1	3.8	16.5	12.3	9.8	8.6	3.4	3.5	**7.7**	**6.8**	111	129	97.9	0.0
	d. Other gliomas	3	10	26	27	22	**66**	**88**	2.7	10.3	2.3	10.1	2.6	2.3	4.8	4.8	3.7	**3.8**	**3.8**	59	78	51.1	0.0
	e. Other specified	2	12	24	33	51	**71**	**122**	2.9	11.0	3.2	13.9	1.8	2.7	4.4	5.8	8.6	**4.1**	**5.1**	64	107	86.1	0.0
	f. Unspecified CNS	5	7	6	9	18	**27**	**45**	1.1	4.2	1.2	5.1	4.4	1.6	1.1	1.6	3.0	**1.7**	**2.0**	24	39	4.4	2.2
IV	**NEUROBLASTOMA**	53	85	21	5	6	**164**	**170**	6.6	100.0	4.5	100.0	46.4	19.4	3.8	0.9	1.0	**11.2**	**8.9**	148	153	92.9	0.0
	a. (Ganglio)neuroblastoma	53	84	20	2	2	**159**	**161**	6.4	97.0	4.3	94.7	46.4	19.1	3.7	0.4	0.3	**10.9**	**8.5**	144	146	92.5	0.0
	b. Peripheral nervous	0	1	1	3	4	**5**	**9**	0.2	3.0	0.2	5.3	-	0.2	0.2	0.5	0.7	**0.3**	**0.4**	4	8	100.0	0.0
V	**RETINOBLASTOMA**	15	48	1	0	0	**64**	**64**	2.6	100.0	1.7	100.0	13.1	10.9	0.2	-	-	**4.5**	**3.5**	58	58	81.3	0.0
VI	**RENAL TUMOURS**	17	83	26	4	3	**130**	**133**	5.3	100.0	3.5	100.0	14.9	18.9	4.8	0.7	0.5	**8.7**	**6.9**	118	120	98.5	0.0
	a. Nephroblastoma	17	79	25	3	0	**124**	**124**	5.0	95.4	3.3	93.2	14.9	18.0	4.6	0.5	-	**8.4**	**6.5**	112	112	98.4	0.0
	b. Renal carcinoma	0	4	1	1	3	**6**	**9**	0.2	4.6	0.2	6.8	-	0.9	0.2	0.2	0.5	**0.4**	**0.4**	5	8	100.0	0.0
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VII	**HEPATIC TUMOURS**	9	17	3	2	8	**31**	**39**	1.3	100.0	1.0	100.0	7.9	3.9	0.5	0.4	1.3	**2.1**	**1.9**	28	35	94.9	2.6
	a. Hepatoblastoma	8	17	3	0	0	**28**	**28**	1.1	90.3	0.7	71.8	7.0	3.9	0.5	-	-	**1.9**	**1.5**	25	25	96.4	0.0
	b. Hepatic carcinoma	0	0	0	2	8	**2**	**10**	0.1	6.5	0.3	25.6	-	-	-	0.4	1.3	**0.1**	**0.4**	2	9	100.0	0.0
	c. Unspecified	1	0	0	0	0	**1**	**1**	0.0	3.2	0.0	2.6	0.9	-	-	-	-	**0.1**	**0.1**	1	1	0.0	100.0
VIII	**BONE TUMOURS**	0	7	28	69	82	**104**	**186**	4.2	100.0	4.9	100.0	-	1.6	5.1	12.2	13.8	**5.7**	**7.5**	93	162	97.8	0.5
	a. Osteosarcoma	0	0	11	39	45	**50**	**95**	2.0	48.1	2.5	51.1	-	-	2.0	6.9	7.6	**2.7**	**3.8**	45	82	100.0	0.0
	b. Chondrosarcoma	0	0	0	1	4	**1**	**5**	0.0	1.0	0.1	2.7	-	-	-	0.2	0.7	**0.1**	**0.2**	1	4	100.0	0.0
	c. Ewing & related	0	5	17	26	27	**48**	**75**	1.9	46.2	2.0	40.3	-	1.1	3.1	4.6	4.5	**2.7**	**3.1**	43	66	98.7	0.0
	d. Other specified	0	1	0	1	4	**2**	**6**	0.1	1.9	0.2	3.2	-	0.2	-	0.2	0.7	**0.1**	**0.2**	2	5	100.0	0.0
	e. Unspecified	0	1	0	2	2	**3**	**5**	0.1	2.9	0.1	2.7	-	0.2	-	0.4	0.3	**0.2**	**0.2**	3	4	40.0	20.0
IX	**SOFT TISSUE SARCOMA**	14	51	46	47	74	**158**	**232**	6.4	100.0	6.1	100.0	12.3	11.6	8.4	8.3	12.5	**9.7**	**10.3**	142	205	99.1	0.0
	a. Rhabdomyosarcoma	3	44	29	19	15	**95**	**110**	3.8	60.1	2.9	47.4	2.6	10.0	5.3	3.4	2.5	**6.0**	**5.2**	86	98	98.2	0.0
	b. Fibrosarcoma	6	1	5	6	8	**18**	**26**	0.7	11.4	0.7	11.2	5.3	0.2	0.9	1.1	1.3	**1.1**	**1.2**	16	23	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	d. Other specified	3	6	9	18	45	**36**	**81**	1.5	22.8	2.1	34.9	2.6	1.4	1.6	3.2	7.6	**2.1**	**3.3**	32	70	100.0	0.0
	e. Unspecified	2	0	3	4	6	**9**	**15**	0.4	5.7	0.4	6.5	1.8	-	0.5	0.7	1.0	**0.5**	**0.6**	8	13	100.0	0.0
X	**GERM CELL TUMOURS**	21	12	14	28	145	**75**	**220**	3.0	100.0	5.8	100.0	18.4	2.7	2.6	4.9	24.4	**4.6**	**9.0**	67	190	98.2	0.0
	a. CNS germ cell ‡	2	1	5	12	9	**20**	**29**	0.8	26.7	0.8	13.2	1.8	0.2	0.9	2.1	1.5	**1.1**	**1.2**	18	25	96.6	0.0
	b. Other extragonadal	14	4	2	1	5	**21**	**26**	0.8	28.0	0.7	11.8	12.3	0.9	0.4	0.2	0.8	**1.4**	**1.3**	19	23	96.2	0.0
	c. Gonadal germ cell	5	7	6	14	122	**32**	**154**	1.3	42.7	4.1	70.0	4.4	1.6	1.1	2.5	20.6	**1.9**	**6.1**	29	131	100.0	0.0
	d. Gonadal carcinoma	0	0	0	1	7	**1**	**8**	0.0	1.3	0.2	3.6	-	-	-	0.2	1.2	**0.1**	**0.3**	1	7	100.0	0.0
	e. Unspecified gonadal	0	0	1	0	2	**1**	**3**	0.0	1.3	0.1	1.4	-	-	0.2	-	0.3	**0.1**	**0.1**	1	3	33.3	0.0
XI	**CARCINOMA & MELANOMA**	1	2	10	52	281	**65**	**346**	2.6	100.0	9.2	100.0	0.9	0.5	1.8	9.2	47.3	**3.5**	**13.3**	58	295	98.8	0.0
	a. Adrenocortical	0	1	1	2	1	**4**	**5**	0.2	6.2	0.1	1.4	-	0.2	0.2	0.4	0.2	**0.2**	**0.2**	4	4	80.0	0.0
	b. Thyroid	0	0	1	9	52	**10**	**62**	0.4	15.4	1.6	17.9	-	-	0.2	1.6	8.8	**0.5**	**2.4**	9	53	100.0	0.0
	c. Nasopharyngeal	0	0	0	6	12	**6**	**18**	0.2	9.2	0.5	5.2	-	-	-	1.1	2.0	**0.3**	**0.7**	5	15	100.0	0.0
	d. Melanoma	0	1	4	10	99	**15**	**114**	0.6	23.1	3.0	32.9	-	0.2	0.7	1.8	16.7	**0.8**	**4.4**	13	97	99.1	0.0
	e. Skin carcinoma	0	0	1	6	55	**7**	**62**	0.3	10.8	1.6	17.9	-	-	0.2	1.1	9.3	**0.4**	**2.4**	6	53	98.4	0.0
	f. Other & unspecified	1	0	3	19	62	**23**	**85**	0.9	35.4	2.2	24.6	0.9	-	0.5	3.4	10.4	**1.2**	**3.3**	20	73	98.8	0.0
XII	**OTHER & UNSPECIFIED**	3	8	3	6	4	**20**	**24**	0.8	100.0	0.6	100.0	2.6	1.8	0.5	1.1	0.7	**1.3**	**1.1**	18	21	70.8	0.0
	a. Other specified	1	5	2	0	2	**8**	**10**	0.3	40.0	0.3	41.7	0.9	1.1	0.4	-	0.3	**0.5**	**0.5**	7	9	100.0	0.0
	b. Other unspecified	2	3	1	6	2	**12**	**14**	0.5	60.0	0.4	58.3	1.8	0.7	0.2	1.1	0.3	**0.7**	**0.6**	11	12	50.0	0.0
	TOTAL	237	889	632	715	1308	**2473**	**3781**	100.0	100.0	100.0	100.0	207.6	202.6	115.7	126.3	220.4	**152.8**	**168.0**	2229	3330	94.4	0.2

† includes 341 non-malignant ‡ includes 3 non-malignant

Please consult the quality indicators for this registry

Italy

Italy is located in southern Europe. It covers an area of 301 340 km^2, which includes the large islands of Sardinia and Sicily and many smaller islands. The mainland is bordered to the north by, from west to east, France, Switzerland, Austria, and Slovenia; the remainder of the country has a long Mediterranean coastline. The terrain is mostly mountainous, and the north includes part of the Southern Alps. The climate ranges from humid subtropical to humid, continental, and oceanic.

Italy is an industrialized, high-income country with a very high HDI and high quality of life. The economy is driven by creative and innovative businesses, a large and competitive agricultural sector, and influential automobile, machinery, food, design, and fashion industries. The tertiary sector is the largest (65%), followed by industry (16%), construction (9%), and agriculture (3%).

Administratively, Italy is divided into 20 regions, which are further subdivided into 14 metropolitan cities and 96 provinces. In 2010, the estimated total population was 59.6 million (Table A.7), and 19% of the population was younger than 20 years (Table A.6). The average population density is 200 per km^2. The past 15 years have been characterized by the ageing of the Italian population and an influx of immigrants, who make up almost 10% of the total population. Large numbers of immigrants come from Romania, Albania, Morocco, and other countries in Europe, northern Asia, and Latin America. Immigrants settle mostly in the most economically developed areas of the northern and central parts of the country and contribute one third of new births. The life expectancy is 80 years for males and 85 years for females. About 10% of adults have obesity.

Since 1978, Italy has had a publicly financed health-care system that ensures equal access to health care, which is provided free of charge to all citizens and legally registered foreign residents. Medical care is organized at the regional level and provided by a system of public and private services. High-quality cancer care may be distributed unequally across the country. The Italian Association of Pediatric Hematology and Oncology (Associazione Italiana di Ematologia e Oncologia Pediatrica; AIEOP) (http://www.aieop.org/web) coordinates national and international clinical trials throughout the country. Cancer notification is not mandatory, and cancer registration is delegated to subnational government structures. Therefore, cancer registration is voluntary and is based on active case finding.

The Italian contributors to IICC-3 are all members of the Italian Association of Cancer Registries (AIRTUM) and contribute anonymized data to the AIRTUM database. National guidelines, which are available online (https://www.registri-tumori.it/cms/pagine/i-manuali-airtum), help standardize registration procedures. Several cancer registries have implemented an automated cancer registration system, called Open Registry, using EpiLink software, developed by the National Cancer Institute of Milan and based on the Linux operating system and Oracle Database. The registries have access to death certificates of residents at the regional level. Data are pooled to provide national estimates of cancer incidence, mortality, survival, and prevalence, for inclusion in collaborative publications, and for submission to international studies. AIRTUM has published analyses of cancer in children and adolescents, using the combined data from all registries.

PUBLICATIONS

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POPULATION AT RISK

The source of the data for all registries except the Reggio Emilia Cancer Registry and the Romagna Cancer Registry is the Italian National Institute of Statistics (ISTAT; https://www.istat.it/). The data are based on national censuses conducted in 1991, 2001, and 2011 (Table A.7). The census data are updated annually using information collected from the Population Register Offices. Unless otherwise specified for individual registries, population data were provided by AIRTUM. Data were provided in the requested detail for all participating registries.

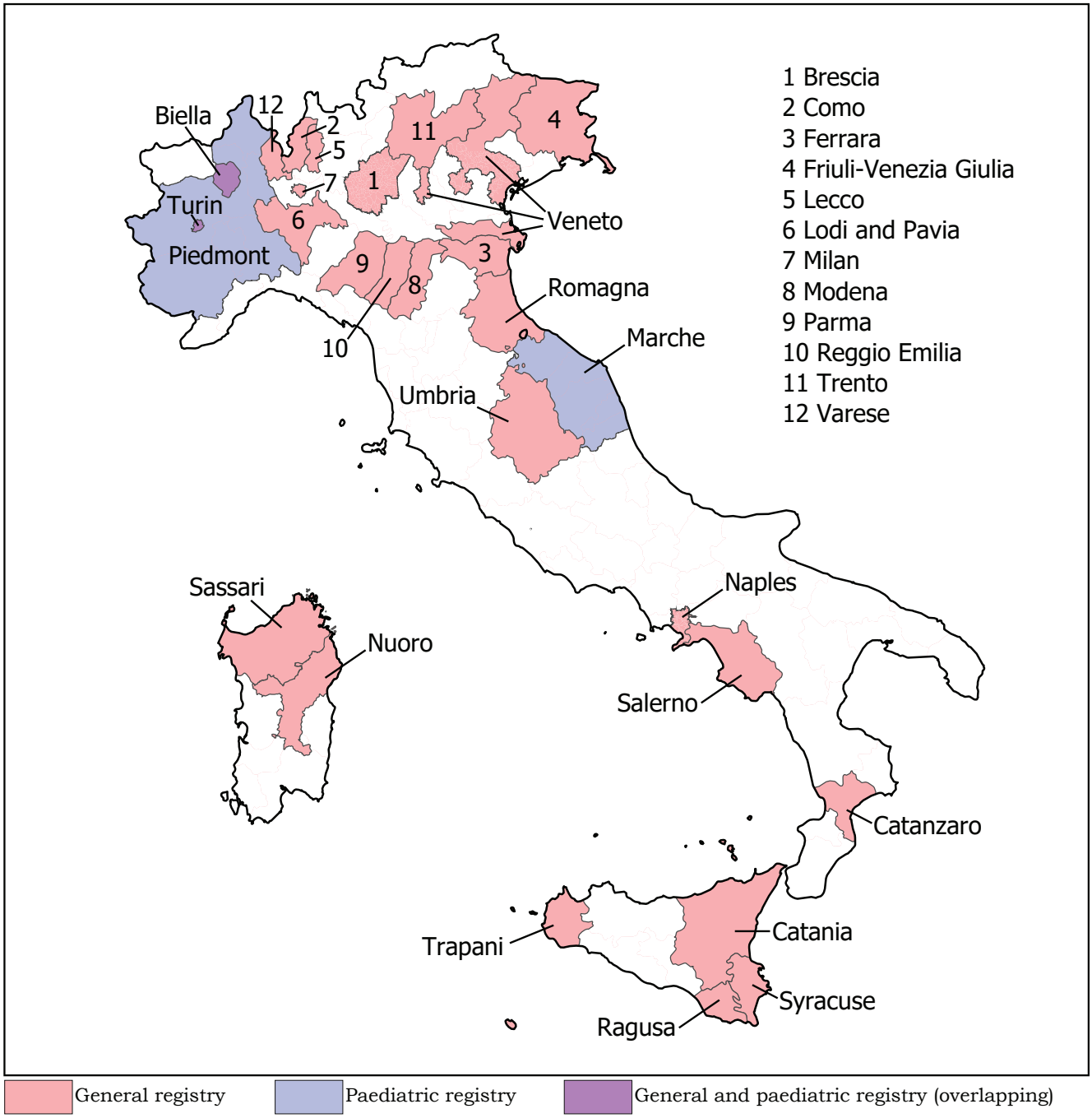
EDITORS' COMMENTS

AIRTUM provided a combined dataset and participated in coordination of the Italian contribution to IICC-3. The included data are presented in the IICC-3 book in the three tables (Table A.12): a combined dataset from two paediatric registries for the Marche and Piedmont regions, which include the age group 0–19 years for 1998–2011; the data from the Childhood Cancer Registry of Piedmont (CCRP) for the age group 0–14 years for 1990–2011; and the data pooled from 26 subnational areas covered by general cancer registries. In addition, the full incidence

tables are available online for 16 individual general cancer registries, and abbreviated tables are available for five smaller registries: Como, Ferrara, Lodi and Pavia, Trento, and Syracuse (Table A.12). The participating registries cover about 44% of the total target population younger than 20 years. Four of these registries contributed to IICC-2 (Parma, Ragusa, Varese, and Veneto), and CCRP participated in all three IICC volumes (Table A.1).

The paediatric population covered by the registries of Biella and the Piedmont Cancer Registry located in Turin is also covered by CCRP.

Despite efforts to standardize practices at the national level, considerable variation exists in registration practices and data quality. The registries (with the exception of Marche) have access to regional databases of death certificates. Not all registries record non-malignant CNS tumours; however, the 16 registries that systematically record them provided the relevant data to IICC-3. Reporting of non-melanoma skin cancer also varies. It is complete in some registries, whereas other registries include only some types of skin carcinoma, and still other registries do not record skin carcinoma. These variations in registration practices contribute to differences in incidence between the registries. Most of the included registries report very high incidence rates for children and adolescents compared with other European countries (Table A.9). The MV% varies between 80.3% and 96.8%. Nine registries have a high proportion of tumours with unspecified morphology (Table A.9). Information on laterality is complete in only two registries (CCRP and Biella). Laterality is also complete for one or two diagnoses of interest in four registries, is incomplete in 15 registries, and is not provided by seven registries.



Childhood Cancer Registry of the Marche Region, 1998–2007

Cristiana Pascucci, Mario Cocchioni

The registry covers the Marche Region, an area of 9694 km^2 in central Italy bordered by the Adriatic Sea to the east and the Apennine Mountains to the west. The region is divided into five provinces. The climate is Mediterranean along the coastal zone and oceanic in the mountainous zone. In 2010, the total population was 1.5 million, and 18% of the population was younger than 20 years (Table A.6). The economy is based on thriving small and medium-sized, highly specialized industries, which are located throughout the country but are concentrated mostly in the coastal areas. Regional manufacturers produce footwear, furniture, household equipment, and paper products.

The Marche Region has only one paediatric hospital, in the city of Ancona, which provides paediatric oncology services in a specialized unit. The neurosurgery units of the regional hospitals treat both children and adolescents with cancer.

The registry has collected data on children (aged 0–14 years) since 1990 (Table A.10) and on adolescents (aged 15–19 years) since 1998. All malignant tumours and all intracranial tumours (malignant, benign, and uncertain behaviour) are included, as defined in ICCC. Data for 1990–1995 were collected retrospectively; since 1996, active prospective collection has been accompanied by periodic follow-up of registered patients through official municipal population registries. The data are used for surveillance of cancer incidence in children and adolescents, including time trends and geographical variation, and to study survival and occurrence of second primary tumours.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The registry does not have access to identified death certificates; thus, a proportion of new cases may have been missed. The incidence rates are high (Table A.9). Non-malignant CNS tumours (except pituitary adenomas) were registered. Pilocytic astrocytoma was coded with malignant behaviour. Skin carcinomas were registered. Laterality was complete for 69% of the cases of interest. See also Italy, above.

Childhood Cancer Registry of Piedmont, 1990–2011

Daniela Alessi, Vanda Macerata, Corrado Magnani, Milena Maule, Franco Merletti, Maria Luisa Mosso, Carlotta Sacerdote, Benedetto Terracini

The region of Piedmont is located in north-western Italy and is bordered by the Italian regions of Liguria, Lombardy, Emilia-Romagna, and Aosta Valley, and by France and Switzerland. It covers an area of 25 402 km^2 and has a population of 4.4 million; 13% of the population is younger than 15 years, and 17% is younger than 20 years (Table A.6). The regional capital is Turin.

A regional network for childhood cancer care includes a regional referral centre and eight satellite units. Most care for children with cancer is supplied by either the regional referral centre or the satellite units; the satellite units provide low-complexity care in strict collaboration with the regional referral centre. General oncology centres within the covered area provide cancer care for some adolescent patients.

The Childhood Cancer Registry of Piedmont (CCRP) was established in 1965 (Table A.10) and has provided incidence data since 1967 for children diagnosed with cancer who reside in the Piedmont Region. The registry has recorded demographic and clinical data on children (aged 0–14 years) since 1965 and on adolescents (aged 15–19 years) since 2000.

Until 2008, cases were actively collected by trained personnel at 2–3-year intervals from hospital records and other relevant files. Cases were ascertained from records of all paediatric wards of the hospitals in the region and of other wards to which Piedmont residents may have been referred for diagnosis or treatment. This active case finding was supplemented from pathology reports, hospital admissions records, reimbursement records (for patients treated in other countries), mortality records, and the AIEOP database.

Since 2008, CCRP ascertains cases mainly from electronic archives of Italian hospital discharge records, electronic archives of pathology laboratories, archives of radiotherapy departments, and archives of hospital-based cancer registries, even if these do not cover the entire target population. For all identified cases, CCRP attempts to obtain all available clinical documentation.

The registry collects information on all newly diagnosed malignant and in situ neoplasms and non-malignant CNS tumours other than teratomas and neurofibromas. All cases in the registry are verified using IARCcrgTools checks.

Cases are actively followed up at regular intervals to ascertain vital status and cause of death. For each child, the current vital status is checked at the municipality where they were last known to have lived. For the deceased cases, the death certificate is obtained from the hospital or municipality where they last lived or where they died. Follow-up for multiple primary tumours is conducted routinely.

Data collected from CCRP have been used to describe incidence and survival for childhood cancer in the Piedmont Region and to investigate late effects in survivors. CCRP contributes data to AIRTUM and to international studies, such as EUROCARE and PanCareSurFup (https://www.pancaresurfup.eu/).

PUBLICATIONS

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POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

Two overlapping datasets are tabulated in IICC-3. The first covers the full period 1990–2011 for ages 0–14 years. The second covers 2000–2011 for ages 0–19 years. The overall incidence rates are high in both datasets (Table A.9). Data were provided on non-malignant CNS tumours (except teratomas) as defined in ICCC-3. The behaviour of pilocytic astrocytoma was originally coded according to the ICD-O edition in use (Table A.10), and all cases were later recoded with the conversion to ICD-O-3. Information on laterality was complete. See also Italy, above.

ITALY, 2 paediatric registries (1998-2011)

	Age group (years)	Males	Females
Person-years	0	294 278	277 470
	1-4	1 168 436	1 103 695
	5-9	1 436 321	1 356 645
	10-14	1 436 739	1 357 047
	15-19	1 481 311	1 396 614
	0-14	4 335 774	4 094 857
	0-19	5 817 085	5 491 471

Please consult the quality indicators for this pool and its constituent registries

ITALY, Piedmont, paediatric (1990-2011)

	Age group (years)	Males	Females
Person-years	0	399 924	377 602
	1-4	1 598 098	1 509 640
	5-9	1 986 757	1 877 661
	10-14	2 060 943	1 949 677
	0-14	6 045 722	5 714 580
Average annual population	0-14	274 806	259 754

Please consult the quality indicators for this registry

ITALY, 2 paediatric registries (1998-2011)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	15	232	125	104	102	**476**	**578**	29.6	100.0	23.9	100.0	26.2	102.1	44.8	37.2	35.4	**58.9**	**53.6**	844	1021	99.8	0.0
	a. Lymphoid	10	209	105	64	57	**388**	**445**	24.1	81.5	18.4	77.0	17.5	92.0	37.6	22.9	19.8	**48.6**	**42.1**	688	787	99.8	0.0
	b. Acute myeloid	2	16	13	26	32	**57**	**89**	3.5	12.0	3.7	15.4	3.5	7.0	4.7	9.3	11.1	**6.7**	**7.7**	101	157	100.0	0.0
	c. CMD	0	2	4	11	9	**17**	**26**	1.1	3.6	1.1	4.5	-	0.9	1.4	3.9	3.1	**1.9**	**2.2**	30	46	100.0	0.0
	d. MDS & other	3	5	2	3	3	**13**	**16**	0.8	2.7	0.7	2.8	5.2	2.2	0.7	1.1	1.0	**1.6**	**1.5**	23	28	100.0	0.0
	e. Unspecified	0	0	1	0	1	**1**	**2**	0.1	0.2	0.1	0.3	-	-	0.4	-	0.3	**0.1**	**0.2**	2	4	100.0	0.0
II	LYMPHOMA & RELATED	1	27	52	117	263	**197**	**460**	12.2	100.0	19.1	100.0	1.7	11.9	18.6	41.9	91.4	**22.0**	**37.6**	352	809	99.8	0.0
	a. Hodgkin	0	5	21	67	202	**93**	**295**	5.8	47.2	12.2	64.1	-	2.2	7.5	24.0	70.2	**10.1**	**23.6**	166	517	99.7	0.0
	b. Non-Hodgkin except BL	0	13	14	27	48	**54**	**102**	3.4	27.4	4.2	22.2	-	5.7	5.0	9.7	16.7	**6.2**	**8.6**	96	180	100.0	0.0
	c. Burkitt (BL)	0	8	17	22	11	**47**	**58**	2.9	23.9	2.4	12.6	-	3.5	6.1	7.9	3.8	**5.3**	**5.0**	84	103	100.0	0.0
	d. Lymphoreticular	1	1	0	1	2	**3**	**5**	0.2	1.5	0.2	1.1	1.7	0.4	-	0.4	0.7	**0.4**	**0.4**	5	9	100.0	0.0
	e. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
III	CNS NEOPLASMS †	30	135	121	123	100	**409**	**509**	25.4	100.0	21.1	100.0	52.5	59.4	43.3	44.0	34.7	**49.2**	**46.0**	727	901	86.2	0.0
	a. Ependymoma	5	27	9	9	11	**50**	**61**	3.1	12.2	2.5	12.0	8.7	11.9	3.2	3.2	3.8	**6.3**	**5.8**	88	108	96.7	0.0
	b. Astrocytoma	12	47	54	49	35	**162**	**197**	10.1	39.6	8.2	38.7	21.0	20.7	19.3	17.5	12.2	**19.4**	**17.7**	288	349	92.9	0.0
	c. CNS embryonal	8	25	23	14	12	**70**	**82**	4.3	17.1	3.4	16.1	14.0	11.0	8.2	5.0	4.2	**8.6**	**7.6**	124	145	100.0	0.0
	d. Other gliomas	1	5	8	7	11	**21**	**32**	1.3	5.1	1.3	6.3	1.7	2.2	2.9	2.5	3.8	**2.5**	**2.8**	37	57	62.5	0.0
	e. Other specified	3	28	18	36	30	**85**	**115**	5.3	20.8	4.8	22.6	5.2	12.3	6.4	12.9	10.4	**10.0**	**10.1**	151	203	81.7	0.0
	f. Unspecified CNS	1	3	9	8	1	**21**	**22**	1.3	5.1	0.9	4.3	1.7	1.3	3.2	2.9	0.3	**2.4**	**2.0**	37	39	4.5	0.0
IV	NEUROBLASTOMA	65	58	18	2	6	**143**	**149**	8.9	100.0	6.2	100.0	113.7	25.5	6.4	0.7	2.1	**19.0**	**15.2**	252	262	99.3	0.0
	a. (Ganglio)neuroblastoma	65	58	18	1	4	**142**	**146**	8.8	99.3	6.0	98.0	113.7	25.5	6.4	0.4	1.4	**18.9**	**15.0**	250	257	99.3	0.0
	b. Peripheral nervous	0	0	0	1	2	**1**	**3**	0.1	0.7	0.1	2.0	-	-	-	0.4	0.7	**0.1**	**0.2**	2	5	100.0	0.0
V	RETINOBLASTOMA	13	21	0	0	0	**34**	**34**	2.1	100.0	1.4	100.0	22.7	9.2	-	-	-	**4.6**	**3.6**	60	60	70.6	0.0
VI	RENAL TUMOURS	12	48	11	2	3	**73**	**76**	4.5	100.0	3.1	100.0	21.0	21.1	3.9	0.7	1.0	**9.6**	**7.7**	129	134	100.0	0.0
	a. Nephroblastoma	12	48	10	1	0	**71**	**71**	4.4	97.3	2.9	93.4	21.0	21.1	3.6	0.4	-	**9.4**	**7.3**	125	125	100.0	0.0
	b. Renal carcinoma	0	0	1	1	3	**2**	**5**	0.1	2.7	0.2	6.6	-	-	0.4	0.4	1.0	**0.2**	**0.4**	4	9	100.0	0.0
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VII	HEPATIC TUMOURS	8	7	4	5	2	**24**	**26**	1.5	100.0	1.1	100.0	14.0	3.1	1.4	1.8	0.7	**3.0**	**2.5**	42	46	100.0	0.0
	a. Hepatoblastoma	8	7	2	1	0	**18**	**18**	1.1	75.0	0.7	69.2	14.0	3.1	0.7	0.4	-	**2.4**	**1.8**	32	32	100.0	0.0
	b. Hepatic carcinoma	0	0	2	4	2	**6**	**8**	0.4	25.0	0.3	30.8	-	-	0.7	1.4	0.7	**0.6**	**0.7**	11	14	100.0	0.0
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VIII	BONE TUMOURS	0	2	14	48	46	**64**	**110**	4.0	100.0	4.6	100.0	-	0.9	5.0	17.2	16.0	**6.9**	**8.9**	114	194	100.0	0.0
	a. Osteosarcoma	0	0	9	33	29	**42**	**71**	2.6	65.6	2.9	64.5	-	-	3.2	11.8	10.1	**4.5**	**5.7**	75	126	100.0	0.0
	b. Chondrosarcoma	0	0	0	0	3	**0**	**3**	-	-	0.1	2.7	-	-	-	-	1.0	**-**	**0.2**	-	5	100.0	0.0
	c. Ewing & related	0	2	5	15	14	**22**	**36**	1.4	34.4	1.5	32.7	-	0.9	1.8	5.4	4.9	**2.4**	**3.0**	39	64	100.0	0.0
	d. Other specified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	e. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
IX	SOFT TISSUE SARCOMA	7	24	18	29	51	**78**	**129**	4.8	100.0	5.3	100.0	12.2	10.6	6.4	10.4	17.7	**9.3**	**11.2**	139	227	100.0	0.0
	a. Rhabdomyosarcoma	2	22	9	6	14	**39**	**53**	2.4	50.0	2.2	41.1	3.5	9.7	3.2	2.1	4.9	**4.9**	**4.9**	69	93	100.0	0.0
	b. Fibrosarcoma	4	1	1	6	9	**12**	**21**	0.7	15.4	0.9	16.3	7.0	0.4	0.4	2.1	3.1	**1.4**	**1.8**	21	37	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	d. Other specified	0	1	8	14	23	**23**	**46**	1.4	29.5	1.9	35.7	-	0.4	2.9	5.0	8.0	**2.5**	**3.7**	41	81	100.0	0.0
	e. Unspecified	1	0	0	3	5	**4**	**9**	0.2	5.1	0.4	7.0	1.7	-	-	1.1	1.7	**0.4**	**0.7**	7	16	100.0	0.0
X	GERM CELL TUMOURS	14	13	6	17	77	**50**	**127**	3.1	100.0	5.3	100.0	24.5	5.7	2.1	6.1	26.8	**6.1**	**10.8**	89	222	95.3	0.0
	a. CNS germ cell ‡	6	1	4	10	2	**21**	**23**	1.3	42.0	1.0	18.1	10.5	0.4	1.4	3.6	0.7	**2.5**	**2.1**	37	41	73.9	0.0
	b. Other extragonadal	4	8	0	0	2	**12**	**14**	0.7	24.0	0.6	11.0	7.0	3.5	-	-	0.7	**1.6**	**1.4**	21	25	100.0	0.0
	c. Gonadal germ cell	4	4	2	7	65	**17**	**82**	1.1	34.0	3.4	64.6	7.0	1.8	0.7	2.5	22.6	**2.0**	**6.7**	30	143	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	7	**0**	**7**	-	-	0.3	5.5	-	-	-	-	2.4	**-**	**0.5**	-	12	100.0	0.0
	e. Unspecified gonadal	0	0	0	0	1	**0**	**1**	-	-	0.0	0.8	-	-	-	-	0.3	**-**	**0.1**	-	2	100.0	0.0
XI	CARCINOMA & MELANOMA	0	3	10	47	151	**60**	**211**	3.7	100.0	8.7	100.0	-	1.3	3.6	16.8	52.5	**6.4**	**16.8**	107	370	99.5	0.0
	a. Adrenocortical	0	0	2	1	0	**3**	**3**	0.2	5.0	0.1	1.4	-	-	0.7	0.4	-	**0.3**	**0.3**	5	5	100.0	0.0
	b. Thyroid	0	1	4	19	69	**24**	**93**	1.5	40.0	3.9	44.1	-	0.4	1.4	6.8	24.0	**2.6**	**7.4**	43	163	100.0	0.0
	c. Nasopharyngeal	0	0	0	2	4	**2**	**6**	0.1	3.3	0.2	2.8	-	-	-	0.7	1.4	**0.2**	**0.5**	4	11	100.0	0.0
	d. Melanoma	0	2	1	10	43	**13**	**56**	0.8	21.7	2.3	26.5	-	0.9	0.4	3.6	14.9	**1.4**	**4.5**	23	98	98.2	0.0
	e. Skin carcinoma	0	0	2	1	6	**3**	**9**	0.2	5.0	0.4	4.3	-	-	0.7	0.4	2.1	**0.3**	**0.7**	5	16	100.0	0.0
	f. Other & unspecified	0	0	1	14	29	**15**	**44**	0.9	25.0	1.8	20.9	-	-	0.4	5.0	10.1	**1.6**	**3.5**	27	77	100.0	0.0
XII	OTHER & UNSPECIFIED	0	2	0	0	3	**2**	**5**	0.1	100.0	0.2	100.0	-	0.9	-	-	1.0	**0.3**	**0.4**	4	9	100.0	0.0
	a. Other specified	0	2	0	0	2	**2**	**4**	0.1	100.0	0.2	80.0	-	0.9	-	-	0.7	**0.3**	**0.4**	4	7	100.0	0.0
	b. Other unspecified	0	0	0	0	1	**0**	**1**	-	-	0.0	20.0	-	-	-	-	0.3	**-**	**0.1**	-	2	100.0	0.0
	TOTAL	165	572	379	494	804	**1610**	**2414**	100.0	100.0	100.0	100.0	288.6	251.7	135.7	176.8	279.4	**195.4**	**214.3**	2858	4255	96.3	0.0

† includes 236 non-malignant ‡ includes 2 non-malignant

Please consult the quality indicators for this pool and its constituent registries

ITALY, Piedmont, paediatric (1990-2011)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	22	324	186	151	**683**	31.4	100.0	28.3	104.3	48.1	37.7	**60.9**	874	100.0	0.0
	a. Lymphoid	10	293	153	90	**546**	25.1	79.9	12.9	94.3	39.6	22.4	**49.5**	700	100.0	0.0
	b. Acute myeloid	9	23	20	46	**98**	4.5	14.3	11.6	7.4	5.2	11.5	**8.2**	124	100.0	0.0
	c. CMD	0	2	7	11	**20**	0.9	2.9	-	0.6	1.8	2.7	**1.6**	25	100.0	0.0
	d. MDS & other	2	4	3	2	**11**	0.5	1.6	2.6	1.3	0.8	0.5	**1.0**	14	100.0	0.0
	e. Unspecified	1	2	3	2	**8**	0.4	1.2	1.3	0.6	0.8	0.5	**0.7**	10	100.0	0.0
II	LYMPHOMA & RELATED	1	40	67	155	**263**	12.1	100.0	1.3	12.9	17.3	38.6	**20.9**	333	99.6	0.0
	a. Hodgkin	0	6	27	78	**111**	5.1	42.2	-	1.9	7.0	19.4	**8.5**	140	100.0	0.0
	b. Non-Hodgkin except BL	0	15	20	42	**77**	3.5	29.3	-	4.8	5.2	10.5	**6.2**	98	100.0	0.0
	c. Burkitt (BL)	0	17	19	34	**70**	3.2	26.6	-	5.5	4.9	8.5	**5.7**	89	100.0	0.0
	d. Lymphoreticular	1	2	0	1	**4**	0.2	1.5	1.3	0.6	-	0.2	**0.4**	5	100.0	0.0
	e. Unspecified	0	0	1	0	**1**	0.0	0.4	-	-	0.3	-	**0.1**	1	0.0	0.0
III	CNS NEOPLASMS †	29	164	180	170	**543**	24.9	100.0	37.3	52.8	46.6	42.4	**46.6**	693	87.1	0.0
	a. Ependymoma	4	38	19	13	**74**	3.4	13.6	5.1	12.2	4.9	3.2	**6.7**	95	98.6	0.0
	b. Astrocytoma	12	58	71	75	**216**	9.9	39.8	15.4	18.7	18.4	18.7	**18.3**	275	95.8	0.0
	c. CNS embryonal	7	30	37	22	**96**	4.4	17.7	9.0	9.7	9.6	5.5	**8.4**	123	99.0	0.0
	d. Other gliomas	0	5	10	6	**21**	1.0	3.9	-	1.6	2.6	1.5	**1.8**	27	47.6	0.0
	e. Other specified	5	22	27	42	**96**	4.4	17.7	6.4	7.1	7.0	10.5	**8.0**	122	89.6	0.0
	f. Unspecified CNS	1	11	16	12	**40**	1.8	7.4	1.3	3.5	4.1	3.0	**3.4**	51	5.0	0.0
IV	NEUROBLASTOMA	78	74	21	6	**179**	8.2	100.0	100.3	23.8	5.4	1.5	**17.3**	230	99.4	0.0
	a. (Ganglio)neuroblastoma	78	74	21	2	**175**	8.0	97.8	100.3	23.8	5.4	0.5	**17.0**	225	99.4	0.0
	b. Peripheral nervous	0	0	0	4	**4**	0.2	2.2	-	-	-	1.0	**0.3**	5	100.0	0.0
V	RETINOBLASTOMA	25	28	1	0	**54**	2.5	100.0	32.2	9.0	0.3	-	**5.4**	70	79.6	0.0
VI	RENAL TUMOURS	14	58	19	5	**96**	4.4	100.0	18.0	18.7	4.9	1.2	**9.1**	123	100.0	0.0
	a. Nephroblastoma	14	58	19	4	**95**	4.4	99.0	18.0	18.7	4.9	1.0	**9.0**	122	100.0	0.0
	b. Renal carcinoma	0	0	0	1	**1**	0.0	1.0	-	-	-	0.2	**0.1**	1	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VII	HEPATIC TUMOURS	11	10	2	4	**27**	1.2	100.0	14.1	3.2	0.5	1.0	**2.5**	35	100.0	0.0
	a. Hepatoblastoma	11	9	0	1	**21**	1.0	77.8	14.1	2.9	-	0.2	**2.1**	27	100.0	0.0
	b. Hepatic carcinoma	0	1	2	3	**6**	0.3	22.2	-	0.3	0.5	0.7	**0.5**	8	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VIII	BONE TUMOURS	0	4	21	66	**91**	4.2	100.0	-	1.3	5.4	16.5	**6.9**	115	100.0	0.0
	a. Osteosarcoma	0	0	10	39	**49**	2.2	53.8	-	-	2.6	9.7	**3.7**	62	100.0	0.0
	b. Chondrosarcoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	c. Ewing & related	0	4	11	25	**40**	1.8	44.0	-	1.3	2.8	6.2	**3.1**	51	100.0	0.0
	d. Other specified	0	0	0	2	**2**	0.1	2.2	-	-	-	0.5	**0.1**	2	100.0	0.0
	e. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
IX	SOFT TISSUE SARCOMA	10	40	24	43	**117**	5.4	100.0	12.9	12.9	6.2	10.7	**10.1**	149	100.0	0.0
	a. Rhabdomyosarcoma	5	32	12	10	**59**	2.7	50.4	6.4	10.3	3.1	2.5	**5.4**	76	100.0	0.0
	b. Fibrosarcoma	5	2	3	6	**16**	0.7	13.7	6.4	0.6	0.8	1.5	**1.4**	20	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	d. Other specified	0	6	9	20	**35**	1.6	29.9	-	1.9	2.3	5.0	**2.8**	44	100.0	0.0
	e. Unspecified	0	0	0	7	**7**	0.3	6.0	-	-	-	1.7	**0.5**	9	100.0	0.0
X	GERM CELL TUMOURS	16	16	7	23	**62**	2.8	100.0	20.6	5.1	1.8	5.7	**5.4**	79	93.5	1.6
	a. CNS germ cell	4	0	5	9	**18**	0.8	29.0	5.1	-	1.3	2.2	**1.5**	23	83.3	0.0
	b. Other extragonadal	6	11	0	0	**17**	0.8	27.4	7.7	3.5	-	-	**1.7**	22	94.1	5.9
	c. Gonadal germ cell	6	5	2	13	**26**	1.2	41.9	7.7	1.6	0.5	3.2	**2.2**	33	100.0	0.0
	d. Gonadal carcinoma	0	0	0	1	**1**	0.0	1.6	-	-	-	0.2	**0.1**	1	100.0	0.0
	e. Unspecified gonadal	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
XI	CARCINOMA & MELANOMA	1	1	11	48	**61**	2.8	100.0	1.3	0.3	2.8	12.0	**4.6**	77	100.0	0.0
	a. Adrenocortical	1	0	2	0	**3**	0.1	4.9	1.3	-	0.5	-	**0.3**	4	100.0	0.0
	b. Thyroid	0	1	5	22	**28**	1.3	45.9	-	0.3	1.3	5.5	**2.1**	35	100.0	0.0
	c. Nasopharyngeal	0	0	0	4	**4**	0.2	6.6	-	-	-	1.0	**0.3**	5	100.0	0.0
	d. Melanoma	0	0	1	8	**9**	0.4	14.8	-	-	0.3	2.0	**0.7**	11	100.0	0.0
	e. Skin carcinoma	0	0	2	1	**3**	0.1	4.9	-	-	0.5	0.2	**0.2**	4	100.0	0.0
	f. Other & unspecified	0	0	1	13	**14**	0.6	23.0	-	-	0.3	3.2	**1.0**	18	100.0	0.0
XII	OTHER & UNSPECIFIED	0	2	0	0	**2**	0.1	100.0	-	0.6	-	-	**0.2**	3	100.0	0.0
	a. Other specified	0	2	0	0	**2**	0.1	100.0	-	0.6	-	-	**0.2**	3	100.0	0.0
	b. Other unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	TOTAL	207	761	539	671	**2178**	100.0	100.0	266.2	244.9	139.5	167.3	**190.0**	2780	96.0	0.0

† includes 266 non-malignant

Please consult the quality indicators for this registry

ITALY, 26 registries (1992-2013)

Registry	Period	Cases	%	Person-years	%
Biella	1995-2010	137	1.2	588 324	1.0
Brescia	1999-2012	559	4.8	2 923 390	5.2
Catania, Messina and Enna	2003-2013	1044	9.0	4 530 969	8.1
Catanzaro	2003-2009	85	0.7	459 923	0.8
Como	2003-2011	229	2.0	952 520	1.7
Ferrara	1992-2011	227	1.9	974 075	1.7
Friuli Venezia Giulia	1995-2010	620	5.3	3 040 691	5.4
Lecco	2003-2010	92	0.8	493 225	0.9
Lodi and Pavia	2003-2009	187	1.6	871 351	1.6
Milan	1999-2007	356	3.1	1 686 328	3.0
Modena	1992-2012	465	4.0	2 351 139	4.2
Naples South	1996-2012	727	6.2	3 233 449	5.8
Nuoro	2003-2012	99	0.8	417 795	0.7
Parma	1992-2013	325	2.8	1 452 583	2.6
Ragusa and Caltanissetta	1992-2012	364	3.1	1 844 943	3.3
Reggio Emilia	1996-2012	313	2.7	1 514 558	2.7
Romagna	1992-2011	782	6.7	3 726 779	6.6
Salerno	1997-2009	698	6.0	3 265 591	5.8
Sassari	1992-2011	381	3.3	1 879 736	3.3
Syracuse	1999-2012	213	1.8	1 210 439	2.2
Trapani	2002-2009	137	1.2	743 243	1.3
Trento	2001-2010	172	1.5	996 225	1.8
Turin	1992-2012	540	4.6	2 970 190	5.3
Umbria	1994-2011	610	5.2	2 608 763	4.6
Varese	1992-2012	672	5.8	3 245 012	5.8
Veneto	1992-2009	1629	14.0	8 190 092	14.6
ITALY	**1992-2013**	**11663**	**100.0**	**56 171 333**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

Biella, Piedmont Cancer Registry, 1995–2010

Adriano Giacomin, Simona Andreone, Piercarlo Vercellino

The Province of Biella, which was created in 1992, is located in the northern part of the Piedmont Region. It covers an area of 913 km^2 and has a total population of 0.2 million; most of the population lives in urban areas. In 2007, the registration area was extended to include the Province of Vercelli, which covers an area of 2081 km^2. This approximately doubled the population at risk. In 2010, the total population was 0.4 million, and 16% of the population was younger than 20 years (Table A.6). The population of the two provinces includes migrants who arrived from north-east Italy in the 1950s and 1960s, from southern Italy in the 1970s, and from other countries (Albania, Romania, and Morocco) more recently. The birth rate is low, and the proportion of elderly people (65 years and older) in the population is high.

The textile industry has long been the main activity in Biella, but it has declined recently. Vercelli Province is known for the cultivation of rice. No unusual environmental or occupational exposures were observed in the area, but the prevalence of smoking, alcohol consumption, and drug use is high.

There is one hospital with 450 beds that provides standard surgical specialized services, and there are two private clinics. Patients must travel to the larger medical centres of Milan, Turin, Novara, and Pavia for thoracic surgery, neurosurgery, paediatric oncology, and haematology services.

The registry has collected data on cancer cases since 1995 (Table A.10). It is funded and equipped by the Local Health Authority with the support of the Tempia Foundation. The registry works in collaboration with the Piedmont Reference Center for Epidemiology and Cancer Prevention (CPO) in Turin. The staff consists of one full-time medical officer, one nurse registrar, and one part-time medical officer. The registry uses a custom database structure, complete with clinical and pathological variables, and the coding system is based on search strings. The registry includes benign intracranial and intraspinal tumours and all tumours with malignant, in situ, or uncertain behaviour, except basal and squamous cell skin carcinomas. Non-melanoma skin cancers are included only if the diagnosed case is of specific clinical interest, for example presenting local invasivity as ulcus terebrans, intracranial invasivity, metastatic lesions, or atypical age of incidence.

Data are actively collected using hospital discharge records, pathology reports, and clinical reports, and from imaging archives, laboratory test results, and records from oncological, haematological, and palliative care, radiotherapy, and screening. Once a year the registry verifies all mortality data in the population registry of the province to identify DCO cases and to verify vital status and current place of residence of registered patients. Data are also validated using the IARCcrgTools and CheckAIRTUM rules. Completeness and accuracy are evaluated regularly. The registry reports incidence, mortality, trends, and changes in hospital admissions and survival to local authorities and contributes to evaluation of health services and development of guidelines. The registry is involved in experimental and epidemiological research.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The number of incident cases during the reporting period was not sufficiently large for presentation of the data in a table, but the registry contributed to the national pool (Table A.12). The childhood population covered by this registry is also covered by CCRP. Non-malignant CNS tumours were registered, and pilocytic astrocytoma was coded with uncertain behaviour. Non-melanoma skin cancers are included selectively, as specified above. Laterality is complete. See also Italy, above.

Brescia Cancer Registry, 1999–2012

Michele Magoni, Cinzia Gasparotti, Claudio Sileo

The Province of Brescia is located in the east part of the Lombardy region in northern Italy, and its capital is the city of Brescia. It is bordered by the provinces of Sondrio, Bergamo, Cremona, Mantua, Verona (Veneto Region), and Trentino. The province is known for its three lakes, three rivers, and three valleys. The terrain varies, with mountains in the north, hills in the central region, and a wide plain in the south. Brescia is highly industrialized and has intensive agriculture.

The Brescia Cancer Registry covers a part of the province of 3465 km^2, which corresponds to the Brescia Local Health Authority (ASL Brescia). In 2010, the covered population was 1.1 million, and 20% of the population was younger than 20 years (Table A.6).

The registry is part of the Brescia Local Health Authority, which has access to all the databases of health services provided by the regional health-care system, as part of the national system. This includes civil registry, mortality by cause, hospitalization, drug, diagnostic, and specialist services. Good collaboration with local hospitals and a strict respect for national privacy legislation facilitate access by registry staff members to histology reports and medical files.

POPULATION AT RISK

Population data were provided in the requested detail. See also Italy, above.

EDITORS' COMMENTS

The MV% is rather low (80%), and the proportion of cases based on clinical findings is correspondingly low; however, cases are recorded as MV only if the pathology reports are available for review by a registry staff member. The proportion of cases with unspecified morphology is high (17.5%) (Table A.9), because of difficulties with obtaining pathology reports from data providers in the past. Thus,

the resulting rates may be lower for specific and higher for unspecified cancer types. Non-malignant CNS tumours were not systematically registered; thus, they are not provided. Pilocytic astrocytoma has been coded with malignant behaviour since 2010 and is included. Therefore, the reported incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. Non-melanoma skin cancers are not systematically collected by the registry. Laterality was not provided. See also Italy, above.

Catania, Messina, and Enna, Catania-Messina-Syracuse-Enna Integrated Cancer Registry, 2003–2013

Andrea Benedetto, Marine Castaing, Andrea Di Cataldo, Alessia Anna Di Prima, Paolo Fidelbo, Antonella Ippolito, Eleonora Irato, Anna Leone, Paola Nunzia Rita Pesce, Alessandra Savasta, Carlo Sciacchitano, Antonietta Torrisi, Antonina Torrisi, Massimo Varvarà, Carmelo Viscosi

Catania, Messina, and Enna are provinces on the eastern and northern coasts of Sicily that are next to the Ionian Sea and experience mild winters and long, dry, hot summers. Rolling green hills dotted with olive groves and wineries dominate the more rural landscape, and in the cities ancient structures are juxtaposed with more modern buildings. A prominent landmark is Mount Etna, which at a height of 3320 m above sea level is the highest active volcano in Europe. Mount Etna plagues the Catania area with black ash with its frequent eruptions. The cities of Catania and Messina are the second and third largest economic and industrial hubs of Sicily, after Palermo. The main economic resources of this area are related to the ports, agriculture, tourism, and several electronic, chemical, and pharmaceutical businesses. The three provinces have a population of about 1.9 million, and 21% of the population is younger than 20 years (Table A.6). Because specialized paediatric health care is lacking in the area, the patients migrate for treatment, mostly to the north of the mainland.

The cancer registry of Catania and Messina was established in 2000, after the establishment in 1999 of the cancer registry of Syracuse, with which it was combined in 2005. Population data are available from 2003 (Table A.10). Data for Syracuse (described below) are provided separately because of the separate initial development of the Sicilian registries and their different registration periods. In 2009, the province of Enna was annexed to the Catania-Messina-Syracuse registry, based on a regional decree. The resulting registry was then called the Catania-Messina-Syracuse-Enna Integrated Cancer Registry (https://registrotumori-ct-me-en.it/).

The registry ensures a strong collaboration with the Sicilian Epidemiological Observatory and the other registries in the region, in an effort to achieve a regional surveillance network. In addition, a specific collaboration has been established with the local unit of the AIEOP network to ensure complete registration of childhood cancers. The primary sources of case finding are Italian hospital discharge records, histopathology reports, and death certificates. The registry's archives are digital but mostly not coded; thus, automatic processing of information on cancer cases is not feasible. Therefore, cases are abstracted semi-automatically and completed manually.

The procedures for data processing, coding, and staging were prepared in accordance with IARC, ENCR, and AIRTUM rules. Since it was established, the registry has stimulated the improvement of the quality of local cancer data, such as the coding of histopathology reports.

PUBLICATIONS

Torrisi A, Castaing M, Giurato E, Pesce P, Sciacchitano C, Calabretta L, et al. (2011). Preliminary data on the incidence of paediatric and adolescent tumours in the provinces of Catania and Messina. [in Italian] AIRTUM Conference, Palermo.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The overall incidence rates are high. The proportion of cases with unspecified morphology is rather high, including among the MV cases (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. The proportion of cases aged 19 years in the age group 15–19 years was slightly lower than expected (Table A.9). Sex was unknown for one case (Table A.8). Age did not correspond with dates of birth and incidence in 4% of cases (Table A.8). Non-malignant CNS tumours were registered, and pilocytic astrocytoma was coded with uncertain behaviour. Information on laterality was incomplete, and there were no cases of bilateral tumours in the dataset. See also Italy, above.

Catanzaro Cancer Registry, 2003–2009

Antonella Sutera Sardo, Adriana Mazzei, Maria Antonia Sia, Emilia Caligiuri, Rocco Micò, Santo Scalzi, Stefania Del Duca, Raimondo De Nardo, Filomena Mancusi

The province of Catanzaro is one of the five provinces in the Calabria region, which is located in southern Italy. The province covers an area of 5200 km^2, located on both sides of the Calabrian Apennines. The capital city of Catanzaro is located in the centre of the province, on the narrowest part of Italy, where only 30 km separate the Ionian Sea from the Tyrrhenian Sea. Other parts of the province are mostly mountainous, with steep-sided valleys formed by short rivers. The eastern part of the province forms part of the high plateau of La Sila, about 1200 m above sea level. The climate is typically Mediterranean. The economy relies heavily on maritime tourism; the major tertiary economic activities are trade in Lamezia Terme and tourism in Soverato.

Health insurance coverage is guaranteed by the national health system, which also provides facilities for paediatric oncology. In 2010, the population was 0.4 million, and 21% of the population was younger than 20 years (Table A.6). There are 80 municipalities in the province of Catanzaro. Since the Catanzaro Cancer Registry started, the coverage has expanded from 58 to all 80 municipalities in the province.

The registry collects key information from hospital discharge records, pathology reports, and the ISTAT death certificates. Other data sources include medical records, radiotherapy records, records of disability or other health exemptions, and radiology archives. Data completeness is verified using the CheckAIRTUM program, which comprises several indicators (including the mortality-to-incidence ratio), by comparison with the records of the neighbouring areas and with previous years.

Vital status of registered patients is verified through linkage of registry information with mortality registries, consultation of archives of hospital discharge records, the municipality's records of the assisted people, and other means, including active verification of vital status by direct contact with the patients. The data are provided to the public and to clinicians by request through a dedicated website (www.registrotumoricatanzaro.it).

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The number of incident cases during the reporting period was not sufficiently large for presentation of the data in a table, but the registry contributed to the national pool (Table A.12). From 2005 to 2006, the covered population increased by about 55% because of the expansion of the registration area. Non-malignant CNS tumours are registered, and pilocytic astrocytoma is coded with uncertain behaviour. Laterality was not provided. See also Italy, above.

Cancer Registry of Como Province, 2003–2011

Gemma Gola, Mariangela Corti, Mariacarmela Caparelli, Luigi Grandi

The province of Como covers an area of 1198 km^2 and is located in the Lombardy Region in northern Italy. The area extends around Lake Como. About 67% of the province is mountainous, and 26% is hilly. Its shared border with Switzerland gives the province an international character. The province is divided into 160 municipalities.

Economic activity is dominated by small and medium-sized businesses, many of an artisanal nature. Also prominent are manufacturing, particularly of textiles and clothing, and metalworking and woodworking (including furniture making). Much of the working population lives in the southern part of the province; the average age is higher in the northern part of the province. The population has increased considerably since the 1960s, mainly because of immigration from eastern and southern Italy. About 19% of the population is younger than 20 years (Table A.6).

The province of Como is served by eight general hospitals, which offer all major specialties of medical and surgical care, including paediatrics, oncology, and radiotherapy; there are three pathology departments. Children with haematological or rare cancer types also receive care in specialized hospitals located in large towns and cities (Monza, Milan, and Pavia) in nearby provinces.

The population-based Cancer Registry of Como Province was established in 2008. The registry is supported by the Lombardy Regional Health Authority and is run by the Cancer Registry and Oncological Screening Unit. Professional registry staff consist of one epidemiologist (who is also the director of the registry), two case ascertainers, and one computer programmer, who specializes in record linkage and data checking. The registry uses the Open Registry system. All cases diagnosed before age 20 years are also scrutinized manually.

The main electronic information sources for cancer registration are the hospital discharge records routinely generated by all hospitals in Italy, pathology reports from pathology units within the province (and also from some units outside the province), and mortality data. The accuracy of the automated system was tested by comparison with manual registration, and the site code concordance between the two systems (automated and manual) was 98.4%. The completeness of registration is monitored annually using capture–recapture methods. Clinical consistency is also checked routinely. Death certificates and the municipal register are used to update the vital status.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The overall incidence rates were high, and the proportion of children younger than 15 years in the dataset was slightly lower than expected (Table A.9). Non-malignant CNS tumours were registered, and pilocytic astrocytoma was coded with uncertain behaviour. Laterality was not provided. See also Italy, above.

Ferrara Province Cancer Registry, 1991–2011

Stefano Ferretti, Laura Marzola, Elena Migliari, Nada Carletti, Chiara Petrucci, Patrizia Biavati

The province of Ferrara is located in the north-eastern part of the Emilia-Romagna region, close to the Adriatic Sea. It is also bordered by the Po River to the north, the provinces of Bologna and Ravenna to the south, and the provinces of Modena and Mantova to the west. The average temperature is 14.4 °C, and the average rainfall is 706 mm per year. In 2010, the population was 0.5 million, with a slightly increasing trend after the decrease in the previous decades because of changes in birth rates and migration. About 14% of the population is younger than 20 years (Table A.6). Employed people (44% of the total population) work in industry (28%), agriculture (6%), and trade and services (66%). For several decades, mechanical and chemical industries have been the main sources of air and water pollution.

Foreign residents made up 7.6% of the overall population in 2011, compared with 3.2% in 2005. Most of the immigrants were from Ukraine (16%), Morocco, Albania, Pakistan, and Romania.

Health care is delivered through three care districts, which manage a network of four general hospitals equipped with haematology, pathology, radiotherapy, and paediatric oncology units.

The Ferrara Province Cancer Registry has covered the entire province since 1991 and is managed by the provincial health service. Data are collected actively and passively. The main data sources are the discharge records from all public hospitals, pathology laboratories, and mortality and clinical archives (radiology, laboratory services). The registry follows IARC and ENCR standards. Completeness of registration is more than 95%, based on evaluation of mortality-to-incidence ratio, DCO%, and comparisons with other registries and over time. In addition to descriptive epidemiology, the registry is involved in evaluating the impact of cancer environmental risks and in prevention programmes (screening) and clinical research.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The overall incidence rates are very high. Cases are recorded as MV only if the pathology reports are available for review by a registry staff member, and access is sometimes denied for reasons of privacy. This may explain the high proportion of cases with unspecified morphology (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. Non-malignant CNS tumours are registered and are likely to be complete because of close collaboration with a pathologist. Pilocytic astrocytoma is coded with uncertain behaviour. All skin carcinomas are registered and are believed to be complete. Laterality was complete for retinoblastoma. See also Italy, above.

Friuli-Venezia Giulia Cancer Registry, 1995–2010

Diego Serraino, Loris Zanier, Tiziana Angelin, Ettore Bidoli, Luigino Dal Maso, Emilia De Santis, Ornella Forgiarini, Federica Toffolutti, Stefania Del Zotto

Friuli-Venezia Giulia is the easternmost region in northern Italy. The regional capital city is Trieste. (The city of Venice is not included in this region.) The region covers an area of 7924 km^2 and has a population of about 1.2 million; 17% of the population is younger than 20 years (Table A.6). The economy is based on small and medium-sized businesses, which focus on specialized farming and high-quality tourism. The port of Trieste has a strategic role in trade with northern and eastern Europe.

The Friuli-Venezia Giulia Cancer Registry covers the whole population of the region. The registry has collected population-based data since 1998, with retrospective data collection since 1995.

The registry conducts epidemiological studies on the main local risk factors for cancer and helps to identify prevention opportunities and to guide preventive actions. In addition, the registry has promoted the EUROMED collaboration among some Mediterranean cancer registries, particularly with the Sétif Cancer Registry in Algeria.

PUBLICATIONS

Birri S, Brunetti D, Bidoli E, Serraino D (2013). Cancer in children and adolescents in Friuli Venezia Giulia 1995–2007. [in Italian] Associazione Genitori Malati Emopatici Neoplastici Friuli Venezia Giulia.

Zucchetto A, Serraino D, Dal Maso L, Birri S, Francisci S, Zigon G, et al. (2013). Cancer estimates up to 2015 in Friuli Venezia Giulia. Tumori. 99(3):318–26. https://doi.org/10.1177/030089161309900306 PMID:24158060

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The overall incidence rates were high in the age group 0–19 years, and the proportion of cases aged 19 years in the age group 15–19 years was high (Table A.9), because of a gradual increase in incidence rates with age. Non-malignant CNS tumours were not registered during the

reporting period. Pilocytic astrocytoma was coded with uncertain behaviour, but there were no cases in the dataset. Therefore, the reported incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. Laterality was not provided. See also Italy, above.

Lecco, Brianza Cancer Registry, 2003–2010

Luca Cavalieri d'Oro, Magda Rognoni, Leonardo Le Rose, Elisabetta Merlo, Lina Negrino, Lucia Pezzuto, Franco Tortorella, Silvana Mileto, Antonella Bracchi, Giovanna Tagliabue, Paolo Contiero

The province of Lecco is located in the northern part of the Lombardy region. The province covers an area of 814 km^2, more than 70% of which consists of lakes (e.g. Como, Annone) and pre-Alpine mountains (Valsassina). The remaining southern area has a high population density, with a prevalence of manufacturing activity in small and medium-sized industries (of which 26% are metalworking) and heavy traffic in the Brianza area. The city of Lecco is the capital of the province.

The population is 0.3 million, and 19% of the population is younger than 20 years (Table A.6). The population is mostly White, and 5.7% of residents are foreign-born.

The public health service department provides general paediatric health care through the Maternal and Child Department of the Hospital of Lecco Province, which is organized in two public hospitals and a network of primary health centres. An integrated home-care system was established in 1992. Local health services provide care to about 20% of paediatric cancer cases that require hospitalization. Most children with cancer are treated in the major national paediatric oncology referral centres in the relatively nearby cities of Milan, Monza, and Pavia, the specialized centres of the Lombardy Oncology Network.

The Lecco Cancer Registry is located within the Lecco Local Health Authority (ASL Lecco), in the Preventive and Community Medicine Department and the Research and Health Development Service. The registry is staffed by two part-time physicians (hygiene specialists) and a full-time nurse. Since its founding in 2008, the registry has received continuous technical and scientific support from the National Institute for Treatment of Tumours in Milan (Istituto Nazionale per la Cura dei Tumori di Milano). Cancer data are available from 2003 (Table A.10).

The registry uses the Open Registry system. It collects data on the residents of the province from hospital discharge records throughout Italy. Cancer cases are identified through record linkage to other available sources and types of data, including autopsy reports, histology of primary tumour, histology of metastases, cytology, medical records, diagnostic imaging, laboratory analyses, therapy, hospital discharge records, and death records.

Registry data are used to analyse cancer incidence and survival and to evaluate and propose health services in consideration of needs, such as palliative care, migration of patients, and cancer screening programmes.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The number of incident cases during the reporting period was not sufficiently large for presentation of the data in a table, but the registry contributed to the national pool (Table A.12). Non-malignant CNS tumours were not registered, except for pilocytic astrocytoma, which was coded with uncertain behaviour. Therefore, the incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. All skin carcinomas are registered and are believed to be complete. Laterality was complete for retinoblastoma and gonadal tumours. See also Italy, above.

Lodi and Pavia, South Lombardy Cancer Registry, 2003–2009

Giovanni Marazza, Cesare Fratti, Lorenza Boschetti, Annalisa Lanino, Isabella Martinelli, Sonia Brè, Ilaria Marzani, Anna Merli, Simona Migliazza, Elena Reggiani, Loredana Sgariboldi, Margherita Tisacchi, Maria Teresa Vighi

The provinces of Lodi and Pavia are located in the southern part of the Lombardy region of northern Italy and together cover an area of 3747 km^2. Most of the area is the flat Po Plain, but 20% is hilly or mountainous. Unlike the rest of Lombardy, the two provinces are mainly agricultural, similar to the neighbouring regions of Piedmont and Emilia-Romagna. The total population is 0.8 million (235 000 in Lodi and 548 000 in Pavia), and 17% of the population is younger than 20 years (Table A.6). The mean population density is 209 per km^2 (280 per km^2 in Lodi and 174 per km^2 in Pavia). Immigrants make up 10% of the population. Most residents (87.3%) live in communities with a population of less than 5000. The elderly index (the ratio of the population 65 years and older to the population younger than 15 years, multiplied by 100) is high: 133 in Lodi and 189 in Pavia.

The registration area has 23 hospitals: 4 in Lodi and 19 in Pavia. There are 33 paediatricians in Lodi and 59 in Pavia, and there are 152 general practitioners in Lodi and 407 in Pavia.

The South Lombardy Cancer Registry covers the provinces of Lodi and Pavia. The registry staff consists of three physicians, four other health professionals, an information technologist, and a statistician, all employed part-time. The registry also receives support from the Varese province branch of the Lombardy Cancer Registry. The registry uses the Open Registry system. The main electronic information sources are hospital discharge

reports (routinely generated by all Italian hospitals), pathology reports from all laboratories within the two provinces and the major laboratories outside the provinces that often examine specimens from residents of Lodi and Pavia, and mortality data from local health authorities.

The registry reports incidence, mortality, and survival statistics. Registry data are also used for planning and evaluation of health services.

POPULATION AT RISK

Population data were provided in the requested detail. See also Italy, above.

EDITORS' COMMENTS

The overall incidence rates are high (Table A.9), but they are comparable to those of some other Italian registries. The proportion of cases with unspecified morphology is rather high (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. The MV% decreased after 2007. The registry attributes both these observations to difficulty obtaining information from some hospitals. Non-malignant CNS tumours were not registered, except for pilocytic astrocytoma, which was coded with uncertain behaviour. Therefore, the reported incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. The records of skin carcinomas are believed to be complete, because they are based on pathology records. Information on laterality was complete for the registered cases of retinoblastoma, although their number may have been underestimated because some patients may have sought treatment abroad. See also Italy, above.

Milan Cancer Registry, 1999–2007

Antonio Giampiero Russo, Anita Andreano, Simona Ghilardi, Rosalba Distefano, Maria Quattrocchi, Mariateresa Vighi

Milan is the capital city of the Lombardy region. It is located in northern Italy. The climate is hot in summer and moderately cold and wet in winter. The city of Milan covers an area of 182 km^2 and has a population of 1.3 million. The population density is 7000 per km^2. The province of Milan covers an area of 1575 km^2 and has an average population density of 2000 per km^2. The wider Milan metropolitan area includes central Lombardy and eastern Piedmont, with a population of about 7.5 million. Milan is a leading centre in the fields of art, commerce, design, education, entertainment, fashion, finance, health care, media, services, research, and tourism.

The Milan Cancer Registry was established in May 2002 in agreement with the Regional Health Plan. It is funded by the regional health system and started registering cancers in 1999. During the reporting period, the registry covered the city of Milan; in 2010, the total population was 1.2 million, and 17% of the population was younger than 20 years (Table A.6). In 2007, the registry began collecting data for the entire province. In January 2016, in accordance with the new regional health law, the registries of the city of Milan and the provinces of Milan and Lodi were merged to form the Cancer Registry of the Agency for Health Protection of Milan (ATS Milano – Città Metropolitana).

The registry is semi-automated and uses a custom database and management software. The registry is based on the registered resident population of the regional health system, death certificates, hospital discharge records, records of outpatient visits and examinations, oncology drug prescriptions, and pathology records archives, which are linked using a unique key with deterministic record linkage and subjected to a pre-defined selection algorithm. Records are then reviewed and completed by the registrars. Full hospital records are obtained from the hospitals if needed. Most paediatric cases are verified in this way, because of the relatively small numbers and the need for additional information. Registered patients are followed up for vital status through record linkage between the cancer registry database and the regional health system database of the registered resident population.

Registry data are used by health policy-makers to evaluate health-care and treatment policies and to plan prevention activities. Currently, the registry is working to implement a specific registration procedure for paediatric tumours, with the goal of integrating clinical data with population registry data. This is facilitated by the presence of paediatric national cancer centres within the registration area (National Cancer Institute of Milan) and nearby (San Gerardo Hospital, Monza), and by the links with the Medical School of the University of Bicocca. The links between population-based and clinical registries enable follow-up status to be updated, particularly for off-therapy patients.

PUBLICATIONS

Russo AG, Bisanti L (2007). Rapporto sui tumori a Milano [Milan cancer report].

Autelitano M, Bisanti L (2013). Secondo Rapporto sui tumori a Milano [Second report on cancer in Milan].

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The incidence rates are very high, similar to those of some other Italian cancer registries. There is also an unexpected predominance of cases in boys in the age group 0–14 years (Table A.9); this is most marked in the diagnostic group II (lymphomas). Non-malignant CNS tumours were not recorded systematically until 2007, which may explain the relatively low proportion of these tumours (Table A.9). Pilocytic astrocytoma was coded with uncertain behaviour. Information on laterality was provided for 54% of the cases of interest. See also Italy, above.

Modena Cancer Registry, 1990–2012

Claudia Cirilli, Katia Valla, Vincenzo Amendola

The province of Modena is one of the nine provinces of the Emilia-Romagna region, located in northern Italy. It is bordered by the provinces of Bologna to the east, Reggio Emilia to the west, Lucca and Pistoia to the south, and Mantova to the north.

The population of the province is 0.7 million; 12% of the population are immigrants, and 19% of the population is younger than 20 years (Table A.6). The province is divided into 47 municipalities. The city of Modena, the capital of the province, is the only large city. Modena is an ancient town and is also known for its automotive industry. The province is served by nine public hospitals, one cancer centre, and five private clinics.

The Modena Cancer Registry covers the population of the entire province. It was established in 1988 and is located in the Local Health Authority of Modena. The registry staff comprises a medical director and coordinator, a research manager, and two registrars.

The principal data sources are reports from three pathology laboratories, hospital discharge records, and death certificates. These files are submitted to the registry periodically and are processed using specialized software. All cases are identified and pre-coded by the computer system and validated by trained registry staff. The registry uses IARC rules for classifying multiple primary tumours and complies with the procedures of the IARCcrgTools software.

Vital status of registered patients is verified by matching registrations against death notifications and public health database records. The proportion of records that could not be matched is less than 1%.

The registry produces annual reports of cancer incidence, mortality, and survival.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The proportion of cases aged 19 years in the age group 15–19 years was 29.2% (Table A.9); the largest excess of patients aged 19 years was seen in the diagnostic groups II (lymphomas) and XI (epithelial neoplasms). Non-malignant CNS tumours were registered, and pilocytic astrocytoma was coded with uncertain behaviour. Skin carcinomas were not provided. Information on laterality was known for 60% of the cases of interest. See also Italy, above.

Naples South, Campania Region Cancer Registry, 1996–2012

Mario Fusco, Maria Francesca Vitale, Caterina Bellatalla, Maria Fusco, Carmela Perrotta, Margherita Panico, Valerio Ciullo

Campania is a populous region in southern Italy with almost 6 million people; it covers an area of 13 590 km^2. The region is located on the Italian Peninsula, with the Mediterranean Sea to the west, and includes the small Phlegraean Islands and Capri. The cultural and historical heritage of the region makes it a tourist destination. The region is divided administratively into four provinces and the Metropolitan City of Naples, which is the capital of Campania. In 2010, the population of the city was about 0.9 million, and the population of the province of Naples was 3 million. The area is economically depressed and is characterized by high rates of unemployment and temporary employment. The territory has clearly delimited regions: a highly urbanized and industrialized area around Naples, a rural area, and a coastal region.

There are eight public general hospitals, three pathology laboratories, and two private radiotherapy centres operating within the framework of the national health service. About 70% of the resident patients with cancer receive care from the National Cancer Institute, the two University Faculties of Medicine, or the oncology departments of other hospitals in Naples, and 10% of patients travel to hospitals in central and northern Italy for treatment. Most children with cancer are treated in the Campania Region Children's Hospital and in the paediatric clinics of the two university hospitals in Naples; about 30% travel to hospitals in northern and central Italy for treatment.

The Campania Region Cancer Registry is located in ASL Napoli 3 Sud and was established in January 1996. Until December 2007, the registration area included 35 municipalities covering an area of 499 km^2 in the north-eastern part of the province of Naples. In January 2008, the registration area increased to 770 km^2, and it now covers 59 municipalities. The covered population doubled between 2007 and 2008; in 2010, the covered population was 1.2 million.

The registry actively collects data from all hospital discharge records of patients residing in the region, including from hospitals outside the region, through record linkage with the Regional Health Agency. The registry performs active case finding annually, using the records of municipal registers, regional pathology and haematology laboratories, and regional radiotherapy departments. The regional mortality registry is checked for DCO cases and for follow-up for vital status. DCO cases are traced back to general practitioners and paediatricians. Incomplete medical records are also traced back.

All registered cases are followed up for vital status at 3-year intervals using the municipal population registries and the regional mortality registry.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The overall incidence rates are very high (Table A.9), although they are comparable to those of some other Italian registries. Non-malignant CNS tumours are registered, and pilocytic astrocytoma is coded with uncertain behaviour. Skin carcinomas are registered. Laterality was complete for nephroblastoma. See also Italy, above.

Nuoro Cancer Registry, 2003–2012

Mario Usala, Filomena Pala, Giovanna Maria Sini, Nicolina Pintori, Luisa Canu, Giuliana Demurtas, Nina Doa

The province of Nuoro is located in the east-central part of the autonomous region of Sardinia in Italy. The economy of the province is based on farming, trade, the construction industry, and tourism.

Cancer care is provided by five hospitals (including the Hospital of Nuoro), with about 500 beds. All of the main surgical and medical specialties are available, including haematology and oncology and radiotherapy services. Many clinics are located throughout the districts of the province. Cancer service providers are part of the regional cancer network.

The Nuoro Cancer Registry covers the population of 0.2 million of the province of Nuoro from 2003 (Table A.10). The registry is funded by the Nuoro Local Health Authority (ASL Nuoro), and it also has a partnership with the Local Health Authority of Lanusei, another town in the province of Nuoro.

The registry has full access to all hospital records of patients residing in the province and to hospitals' pathology reports. It also receives records from the local mortality registry. Each registry case file is completed manually if needed. All data are stored digitally in compliance with Italian privacy law. Data are checked for duplicate records and for quality. Completeness and accuracy are evaluated periodically.

The registry publishes reports on incidence, mortality, and survival, and it participates in clinical and analytical epidemiological studies.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The number of incident cases during the reporting period was not sufficiently large for presentation of the data in a table, but the registry contributed to the national pool (Table A.12). Non-malignant CNS tumours were registered, and pilocytic astrocytoma was coded with uncertain behaviour. Skin carcinomas are recorded. Laterality is not recorded. See also Italy, above.

Parma Cancer Registry, 1992–2013

Maria Michiara, Francesco Bozzani, Paolo Sgargi

The province of Parma is located in the north-western part of the Emilia-Romagna region in northern Italy. The province covers an area of 34 449 km^2, and it is divided into 47 municipalities. The city of Parma is the largest municipality and the provincial capital.

In 2010, the population of the province was 0.4 million, and 17% of the population was younger than 20 years (Table A.6). The population has grown mainly by immigration from Albania, the Republic of Moldova, Romania, Morocco, Tunisia, and other countries. The provincial employment rate is 69%. Of employed residents, about 63% work in the service sector, 33% in the industrial sector, and 4% in agriculture.

The province has one large general university hospital, two small public hospitals, and three private hospitals. The university hospital has oncology, radiotherapy, haematology, paediatric oncology, and pathology departments.

The Parma Cancer Registry was founded in 1976; in 1978, it started registering cancers (Table A.10) of all residents of the province. It is located within the medical oncology division of the general university hospital of the province. The staff consists of an oncologist (the registry director), a statistician, and a full-time biologist. The registry has direct access to public pathology records, and private hospitals submit electronic data annually. For hospital discharges that occur outside the province, diagnostic data are obtained through an official request to the director of the relevant department. The registered patients are followed up for vital status through direct access to the electronic database of the local health authority. Data are collected actively and passively. Identifiable information is protected in compliance with Italian law.

After the data were provided to IICC-3, ISTAT revised its estimates of the population of Parma province for 2002–2010 downwards, by 3–4%. Using the revised population data would have resulted in slightly higher reported incidence rates.

The registry collaborates with AIRTUM and local health authorities on various research projects and epidemiological studies.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

Incidence is high, similarly to some other Italian registries. The proportion of cases aged 19 years in the age group 15–19 years was high. Non-malignant CNS tumours were registered (Table A.9), and pilocytic astrocytoma was coded with uncertain behaviour. Laterality was complete for nephroblastoma. See also Italy, above.

Ragusa and Caltanissetta, Ragusa Cancer Registry extended to Caltanissetta province, 1992–2012

Rosario Tumino, Giuseppe Cascone, Graziella Frasca, Maria Concetta Giurdanella, Caterina Martorana, Gabriele Morana, Carmela Nicita, Concetta Patrizia Rollo, Maria Grazia Ruggeri, Eugenia Spata, Stefania Vacirca

Ragusa and Caltanissetta are two neighbouring provinces in southern Sicily. The area is characterized by the typical Mediterranean climate and lifestyle. Ragusa province is a small, rural, unpolluted area, whereas the province of Caltanissetta hosts a contaminated site related to the large Mediterranean refinery at Gela, which was linked to a high number of congenital malformations in this municipality. Agriculture and related activities are the main occupations for the local population in both of the covered provinces.

The two provinces cover a total area of 3738 km^2. In 2010, the population was 0.6 million, and 22% of the total population was younger than 20 years (Table A.6). Almost all of them were White and Christian (Catholic).

Oncology facilities are available in five district general hospitals. These facilities consist of one oncology department, two clinical oncology units, one haematology department, three public surgical pathology laboratories, two public radiotherapy units, six public computed tomography units, one public magnetic resonance imaging unit, and five surgical departments. There are also three private hospitals. Because there are no facilities for specialized treatment of children and adolescents with cancer, many of these patients are diagnosed and treated in university hospitals in other provinces of Sicily or in paediatric centres in northern Italy.

The Ragusa Cancer Registry was established in 1981 (Table A.10) in the surgical pathology unit of Ragusa Hospital; in 2010, it became part of the Department of Preventive Medicine of the Ragusa Local Health Authority (Azienda Sanitaria Provinciale Ragusa). The registry initially covered the 12 municipalities of Ragusa province in central south-eastern Sicily. In 2007, the registration area was expanded to include the 22 municipalities of the neighbouring Caltanissetta province, thereby doubling the covered population. The registry is funded by the Government of Sicily and the non-profit organization of social utility Association for Epidemiological Research of Ragusa Ibla (Associazione Iblea Per La Ricerca Epidemiologica – Organizzazione Non Lucrativa Di Utilità Sociale).

Data are collected actively from surgical pathology laboratories, public health insurance offices, radiotherapy units, and oncology departments and units. In addition, AIEOP annually provides data on patients younger than 20 years who have been diagnosed or treated in any of the Italian paediatric referral centres. The registry makes efforts to obtain information on these cases using capture–recapture procedures and verifies the completeness of registration. Copies of death certificates for all residents of the region whose death certificates mention cancer are routinely received from local vital statistics offices. The registry also receives hospital discharge files from the regional government for residents treated outside the registration area. The registry follows ENCR recommendations. Registered patients are actively followed up for vital status through the official municipal registers. Data from the registry have been included in a monograph of Italian cancer registries.

PUBLICATIONS

Bianchi F, Bianca S, Dardanoni G, Linzalone N, Pierini A (2006). Congenital malformations in newborns residing in the municipality of Gela (Sicily, Italy). [in Italian] Epidemiol Prev. 30(1):19–26. PMID:16826695

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The overall incidence rate was high in children (ages 0–14 years). The proportion of cases with unspecified morphology is rather high (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. Non-malignant CNS tumours were included. The behaviour of pilocytic astrocytoma was originally coded according to the ICD-O edition in use (Table A.10) and was recoded with uncertain behaviour with the implementation of ICD-O-3. Information on laterality was provided for 65% of the cases of interest. See also Italy, above.

Reggio Emilia Cancer Registry, 1996–2012

Lucia Mangone, Enza Di Felice, Massimo Vicentini, Annamaria Pezzarossi, Francesca Ferrari, Francesca Roncaglia, Paolo Giorgi Rossi

The province of Reggio Emilia is one of the nine provinces in the Emilia-Romagna region. It covers an area of 2292 km^2 and has a population of 0.5 million; 20% of the population is younger than 20 years (Table A.6). There is an influx of foreign citizens, especially among children and adolescents; this might have contributed to the increase of the population by 42% between the minimum in 1996 and the maximum in 2012. The province of Reggio Emilia is divided into 45 municipalities, and the capital city is Reggio Emilia.

The province has an efficient and active regional system of health policies. The regional health service includes 109 oncology centres, 50 haematology centres, 10 radiotherapy centres, and six specialized paediatric oncology centres.

The Reggio Emilia Cancer Registry was established in 2001 and was accredited by AIRTUM in 2004, with retrospective data collection for 1996–2000. The main data sources are pathology reports, hospital discharge records, and mortality records. Other sources include records from pharmacists, outpatient specialists, forensic medical practitioners, and general practitioners, and prescription

charge exemptions. The registered cases are followed up for vital status every 6 months. Data are validated using IARCcrgTools and CheckAIRTUM.

The data are published annually and made available to physicians, citizens, and health policy-makers. The registry is involved in many national and international studies of clinical and environmental epidemiology and in studies evaluating the impact of screening programmes. The registry benefits from a strong network of collaborators, high-quality digitized data and data exchange, and a qualified and competent staff. There is a very low percentage of hospitalizations outside the province and outside the region. The staff continuously strive to improve cancer registry operations, data quality, and expertise in registration of paediatric cancer.

PUBLICATIONS

Mangone L, Vicentini M, Piana S, Caroli S, Cassetti T, Di Felice E, et al. (2014). Tumours in the province of Reggio Emilia – years 2009–2010. [in Italian] AUSL Reggio Emilia.

Mangone L, Rashid I, Vicentini M, Bonelli LA, Borciani E, Casella C, et al. (2015). Evaluation of the cancer co-pay fee exemption data source (048 code) to estimate cancer incidence. [in Italian] Epidemiol Prev. 39(4):226–33. PMID:26499235

POPULATION AT RISK

The data on the resident population have been provided annually since 1987 by the Emilia-Romagna Regional Statistical Service (https://statistica.regione.emilia-romagna.it/), in collaboration with the statistical offices of the provinces. The population data are based on data collected by the municipal population registries. The reference date for population data is 31 December of each year, which for statistical purposes coincides with 1 January of the following year. See also Italy, above.

EDITORS' COMMENTS

The overall incidence rates were high in children and adolescents (Table A.9). Non-malignant CNS tumours were registered (Table A.9), and pilocytic astrocytoma was coded with uncertain behaviour. Information on laterality was complete for 82% of the cases of interest. See also Italy, above.

Romagna Cancer Registry, 1990–2012

Fabio Falcini, Lauro Bucchi, Americo Colamartini, Orietta Giuliani, Stefania Giorgetti, Monica Palumbo, Rosa Vattiato, Alessandra Ravaioli, Silvia Mancini, Chiara Balducci, Benedetta Vitali, Carlo Cordaro, Licia Caprara, Mila Ravegnani, Chiara Tonelli

Romagna is a historical region corresponding with a south-eastern portion of the Emilia-Romagna region in northern Italy. The major cities are Cesena, Faenza, Forlì, Imola, Ravenna, and Rimini. The covered area of 4769 km^2 has a temperate and continental climate with harsh, foggy winters and warm, sultry summers. The southern part (48% of the total area) is hilly and sparsely populated.

The region is wealthy and socioeconomically homogeneous, with high consumption of goods and services per inhabitant. The economy is based mainly on an efficient agricultural system and numerous small, family-owned industrial firms.

There are 15 public hospitals and 12 certified private hospitals in the registration area. Cancer care is provided by three medical oncology departments, seven day hospitals, one oncology and haematology department of the national health service, and the Romagna Cancer Institute (IRCCS Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori) (IRST) at Meldola in Forlì. The public hospitals have seven general paediatrics departments and no specialist paediatric oncology services. Typically, children with cancer travel to the neighbouring city of Bologna to receive care at the department of paediatric oncology and haematology in the university hospital there.

When it was established in 1985, the Romagna Cancer Registry covered about half the area that it covered in 2012. The coverage was expanded gradually in 1989, 1991, and 1993. The registry was further expanded in 2003 to include the neighbouring district of Imola and in 2010 to include some small municipalities in the Marecchia valley. The resulting registration area has a population of 1.3 million, and 17% of the population is younger than 20 years (Table A.6).

In 2007, the Romagna Cancer Registry became a department of IRST. The main information sources are pathology reports, hospital discharge records, records from private clinics, and death certificates accessed in public health departments and local health authorities. The registry's information system is entirely web-based. The data are processed using an automated matching procedure. Registered cases are followed up for vital status based on computerized linkage with death certificate registries and with regional and municipal population registries.

The registry contributes to the planning and evaluation of cancer control programmes at the local and national levels. It also contributes to national and international statistical publications, research studies, and AIRTUM epidemiological projects.

POPULATION AT RISK

The population data are provided by the Emilia-Romagna Regional Statistical Service (https://statistica.regione.emilia-romagna.it). The population estimates are based on the data collected by the population registries of the 348 municipalities of the region and are updated every year. See also Italy, above.

EDITORS' COMMENTS

The overall incidence rates and the proportion of cases with unspecified morphology are high (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. The proportion of cases aged 19 years in the age group 15–19 years was slightly higher than expected (Table A.9). Non-malignant CNS tumours were registered (Table A.9), and pilocytic astrocytoma was coded with uncertain behaviour. The high proportion of non-malignant CNS tumours may be explained by efficient linkage with an electronic database of hospital discharge records since 2001. Skin carcinomas are registered and are believed to be complete. Information on laterality was provided for 85% of the cases of interest. Malignant carcinoid tumours of the appendix constituted 1.1% of the total dataset (Table A.11). See also Italy, above.

Salerno Cancer Registry, 1997–2009

Anna Luisa Caiazzo, Rossella Cavallo

The province of Salerno is one of the five administrative units of the Campania region, located in the south-western part of the Italian peninsula. The economy is based mainly on services, tourism, pottery, and agriculture. The city of Salerno, the capital of the province, has an active port.

The Salerno Cancer Registry was established in 1996. It covers the whole province of Salerno. The population is about 1.1 million, and 21% of the population is younger than 20 years (Table A.6).

The main data sources are hospital registries, outpatient clinics, pathology laboratories, haematology laboratories, regional population and mortality registries, and death certificates. The registered cases are followed up for vital status using death certificates, national population and mortality registries, and relevant records from hospital registries.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The overall incidence rates and the proportion of cases with unspecified morphology are high (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. CNS tumours of uncertain behaviour were registered, but benign CNS tumours were not registered. Pilocytic astrocytoma was coded with uncertain behaviour. Registration of skin carcinomas is believed to be complete. Information on laterality was not provided. See also Italy, above.

Sassari, North Sardinia Tumour Registry, 1992–2011

Rosaria Cesaraccio, Daniela Pirino, Giannalisa Carmela Pitzus, Ornelia Sechi, Antonio Cossu, Giuseppe Palmieri, Francesco Tanda

The province of Sassari is located in the northern part of the autonomous region of Sardinia. The province covers an area of 7520 km^2 and has a population density of 65 per km^2. In 2010, the population was 0.5 million, and 17% of the population was younger than 20 years (Table A.6). The population is homogeneous ethnically and culturally. It is not evenly distributed geographically; 51% live in urban areas. The main economic activities are agriculture and tourism. The province has two ports and two airports. A petrochemical industry has ceased operations. The capital of the province is the city of Sassari.

The national health service provides general health care through one regional and four district hospitals and primary health centres. The oncology department is located in the regional hospital in Sassari, and it provides diagnostic, surgical oncology, chemotherapy, and radiotherapy services. Most children receive care from paediatricians in the private sector.

The North Sardinia Tumour Registry (formerly the Sassari Cancer Registry) has covered the population of Sassari province since 1992 (Table A.10). All malignant tumours with ICD-O-3 codes are registered, as are all non-malignant intracranial and spinal neoplasms. In situ carcinomas are also recorded, but typically they are excluded from incidence, except for urinary bladder carcinoma. Cases with insufficient detail are registered only when the evidence is clear or when a cancer diagnosis is found on the death certificate.

The registry staff reviews hospital discharge records, biopsy reports, and death certificates. The staff registrars also review the medical records of outpatient departments involved in the diagnosis and treatment of cancer. The number and distribution of hospitals and diagnostic facilities in the area are adequate, so that missed cases are unlikely.

The registry prepares annual reports of cancer incidence and survival, highlighting changes and noteworthy patterns. Registry data have also been used by the regional government in the development of cancer control plans.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The proportion of cases with unspecified morphology is rather high (16%) (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. Pathology reports are not obtained for patients treated outside the registration area. The proportion of cases aged 0–14 years in the total dataset is low (Table A.9), which may be explained by a low proportion of residents younger than 15 years in the general population (Table A.6). Non-malignant CNS tumours were registered, and pilocytic astrocytoma was coded with uncertain behaviour. Information on laterality was provided for 82% of the cases of interest. See also Italy, above.

Syracuse Cancer Registry, 1999–2012

Anselmo Madeddu, Francesca Bella, Ylenia Dinaro, Antonino Colanino Ziino, Rossitto Luisella, Muni Angela, Francesco Tisano

The province of Syracuse is located in the south-eastern part of the autonomous island region of Sicily in the south of Italy. Geographically, the area consists of a western highland region, with altitudes ranging from 450 m to 865 m above sea level, and an eastern coastal plain facing the Mediterranean Sea. The province of Syracuse extends from the borders of the province of Catania in the north to the borders of the province of Ragusa in the south. The population density is 193 per km^2. The principal town is Syracuse. The population of the province is 0.4 million, and 21% of the population is younger than 20 years (Table A.6).

The main sources of water and air pollution in the province are chemical industries and agricultural chemical treatments. The area is socioeconomically heterogeneous; the economy is based mainly on industry in the cities of Augusta, Priolo Gargallo, and Melilli and on agriculture in the north (District of Lentini) and the south (District of Noto). Most of the population is employed in services and industry, especially tourism. The population is relatively homogeneous ethnically and culturally.

The Syracuse Cancer Registry (SCR) covers all 21 municipalities of the province. The registry is located within the Health Care District of Syracuse. The registry was established in 1997 by the Government of Sicily in partnership with the Department of Hygiene of the University of Catania; it is funded by the Local Health Authority of Syracuse. In 2005, the SCR joined the new Integrated Cancer Registry of the provinces of Catania, Messina, and Syracuse, to which the province of Enna was added in 2009, so that the SCR is now a part of the Catania-Messina-Syracuse-Enna Integrated Cancer Registry. The data from the SCR are presented separately because they are available for a longer registration period.

The registry is staffed by two full-time epidemiologists, one part-time epidemiologist, two full-time health nurses, and one full-time registrar (a health worker). A variable number of physicians and undergraduates (epidemiologists and pathologists) from the University of Catania are also involved in the activities of the SCR.

The SCR began collecting data on 1 January 1999 (Table A.10), after a pilot phase in which the feasibility of registration was evaluated. The registry has collected information on malignant cancers for all topographic sites, on in situ bladder tumours since 1999, and on tumours of the cervix uteri, breast, and colorectum since 2007. Since 2012, the SCR has also registered other non-malignant tumours of the bladder, CNS, pituitary gland, craniopharyngeal duct, pineal gland, and carotid body.

The main information sources are histology and cytology laboratories, regional hospitals' discharge records and clinical records, private clinics, local health-care districts (health insurance, compensation funds, or exemptions from payment), and death certificates from the department of public health. The registry has access to municipal rosters to check personal data and to update the vital status of registered patients.

PUBLICATIONS

Madeddu A, Contrino L, Tisano F, Sciacca S (2007). I tumori in provincia di Siracusa dal 1999 al 2002. Università degli Studi di Catania, Dipartimento di Igiene e Registro Tumori Integrato Me-Ct-Sr.

Madeddu A, Contrino L, Tisano F, Sciacca S (2009). I tumori in provincia di Siracusa dal 2002 al 2005: incidenza, mortalità, sopravvivenza, trend. Università degli Studi di Catania, Dipartimento di Igiene e Registro Tumori Integrato Me-Ct-Sr.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The proportion of cases aged 19 years in the age group 15–19 years was almost one third (Table A.9), probably because of random variation, which is typical for datasets with small numbers of cases. The sex ratio was low in the age group 0–14 years (Table A.9), possibly because of the small number of cases in the dataset. Non-malignant CNS tumours were not registered routinely until 2012; none were included in the dataset. There were no cases of pilocytic astrocytoma in the dataset. Therefore, the reported incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. Information on laterality was not provided. See also Italy, above.

Trapani Cancer Registry, 2002–2009

Giuseppa Candela, Tiziana Scuderi, Antonio Fazzino

Trapani province is located on the western tip of the autonomous island region of Sicily. The Egadi Islands and the volcanic Pantelleria Island are also included in the province, which covers an area of 2470 km^2. The topography is half hilly and half plain, which is conducive to viticulture. The province is one of the most urbanized of Sicily, with a population density of 167 per km^2. The province has a total population of 0.4 million; 21% of the total population is younger than 20 years (Table A.6), and 19% is aged 65 years and older. The province is divided into 24 municipalities, and Trapani is the capital city.

Because there are no specialist facilities for paediatric and adolescent oncology, pathology, or neuro-oncology in the province, patients must travel elsewhere to receive treatment. About 60% of all paediatric hospital admissions in the registration area take place in the city of Palermo. Rapid access to Palermo via a good road network limits the discomfort of travel for treatment. Among the remaining paediatric hospital admissions, 35% are outside Sicily, with 15% in Liguria, where the leading Gaslini Institute is located.

The Trapani Cancer Registry was established in February 2003, with retrospective data collection since

2002 (Table A.10). The registry covers the population of the entire province. By law, the registration area will be expanded to cover the province of Agrigento, which will double the covered population.

Although the registration area is mainly rural, it has a few industrial sites, which are known for their high environmental risk. The registry applies georeferencing to study the distribution of tumours in the population.

PUBLICATIONS

Candela P, Scuderi T, Putaggio A (2013). Incidenza, mortalità, sopravvivenza e prevalenza dei tumori in provincia di Trapani nel periodo 2002–2006. Trapani, Italy: Registro Tumori di Trapani.

Candela P, Putaggio A, Scuderi T, Pirrello S (2013). Tecniche di georeferenziazione ed analisi spaziale dei tumori in Provincia di Trapani (2002–2006). Trapani, Italy: Registro Tumori di Trapani.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The number of incident cases during the reporting period was not sufficiently large for presentation of the data in a table, but the registry contributed to the national pool (Table A.12). Non-malignant CNS tumours are registered, although no benign CNS tumours were recorded during the reporting period. Pilocytic astrocytoma is coded with uncertain behaviour or malignant behaviour. Laterality is known in two thirds of the cases of interest. See also Italy, above.

Trento Cancer Registry, 2001–2010

Silvano Piffer, Roberto Rizzello, Lucia Bombarda, Mariangela Pedron, Maria Gentilini

The autonomous province of Trento is located in northern Italy, between Bolzano province and the Veneto and Lombardy regions. The province covers an area of 6207 km^2 and is almost entirely mountainous; 70% of the area is more than 1000 m above sea level. Half the area is covered by forests. The province is in a transition zone between continental and alpine climates.

In 2010, employment by sector was as follows: agriculture, 4%; industry, 27%; trade, 13%; and services, 56%. Summer and winter tourism is an important income source. In 2010, the unemployment rate was 4.3%, compared with the Italian average of 8.4%.

Foreign-born residents make up 9% of the resident population; most of them (40%) come from central and eastern Europe. About 2% of the population speaks minority languages, particularly Ladin and German.

In 2010, the population was 0.5 million, and 21% of the population was younger than 20 years (Table A.6). Among foreign residents, 27.6% are younger than 20 years.

Paediatric care is provided by a network of community paediatricians and the paediatrics department of a hospital. Cancer care is provided by a medical oncology department and a radiation oncology department. A department of neurosurgery was established in mid-2006. About 30% of children with cancer receive their first diagnostic assessment or treatment at clinical centres of excellence outside the province of Trento.

The Trento Cancer Registry is located in the epidemiological unit of the local health authority and covers the entire province from 1999 (Table A.10). Cases are found in electronic databases of pathology departments, hospital discharge records, and mortality records, linked together.

The registration procedures ensure almost complete coverage. All cases are systematically followed up for vital status through linkage between the registry database and the provincial mortality database. Data quality is checked and validated using IARCcrgTools and CheckAIRTUM.

PUBLICATIONS

Piffer S, Gentilini M, Rizzello R, Mazzoleni G, Bellù F, Rossi S (2013). Estimates of cancer burden in Trentino-Alto Adige. Tumori. 99(3):296–307. https://doi.org/10.1177/030089161309900304 PMID:24158058

Piffer S, Gentilini M, De Nisi M, Rizzello R, Bombarda L, Pancheri S, et al. (2018). L'incidenza dei tumori in provincia di Trento. Anni 2011–2012. Trento, Italy: Azienda Provinciale per i Servizi Sanitari.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The number of incident cases during the reporting period was not sufficiently large for presentation of the data in a table, but the registry contributed to the national pool (Table A.12). Registration of non-malignant CNS tumours may be incomplete before 2009, but they are included in the dataset. The behaviour of pilocytic astrocytoma was originally coded according to the ICD-O in use (Table A.10) and was recoded with uncertain behaviour in 2009, when ICD-O-3 was implemented. Laterality was provided for 62% of the cases of interest. See also Italy, above.

Turin, Piedmont Cancer Registry, 1992–2012

Roberto Zanetti, Stefano Rosso, Silvia Patriarca, Irene Sobrato, Paola Busso, Rossana Prandi, Franca Gilardi, Lidia Sacchetto

The city of Turin is an important business and cultural centre in north-western Italy. It is the capital city of the Metropolitan City of Turin and of the Piedmont Region. The city is located mainly on the western bank of the Po River, in the Susa Valley, and is surrounded by the western Alpine arch and the Superga hill.

The demographics of the population of 0.9 million (17% younger than 20 years) (Table A.6) have been influenced by important migrations from other regions in Italy, especially during the 1960s. More recently, 13% of residents (mainly young adults) migrated from other countries, particularly from Romania and countries in northern Africa.

Turin has 14 public hospitals and 12 private clinics that offer cancer treatment. A paediatric teaching hospital provides all required care to children with cancer from the entire population of the Piedmont region and provides specialized care to patients from regions outside Piedmont.

The Piedmont Cancer Registry began collecting information on new cancer cases resident in the city of Turin in 1985 (Table A.10). The registry is part of the Piedmont Reference Center for Epidemiology and Cancer Prevention (CPO). It is staffed by a director, two epidemiologists, four registrars, and a research assistant.

The principal sources of information are records from hospitals, pathology laboratories, radiotherapy services, and death certificates. Registration is almost completely active and is largely electronic. Follow-up procedures to update vital status of registered patients include periodic record linkages with the mortality registry and active follow-up in municipal rosters. The registry collaborates with the specialized CCRP, which also records clinical information on cancers treated in the AIEOP network.

In Turin, leukaemia and CNS neoplasms are the most common malignancies in the age group 0–19 years, but lymphomas are the most common in adolescent boys and girls.

The registry periodically publishes and updates reports online (https://www.cpo.it/). The data are used by the local health authority to plan regional cancer services. The registry collaborates with several national and international scientific consortia and databases.

PUBLICATIONS

Alessi D, Pastore G, Bagnati R, Baussano I, Dalmasso P, Dama E, et al. (2006). Frequenza e prognosi dei tumori infantili in Piemonte. Il Registro dei Tumori Infantili del Piemonte 1967–2004.

Maule MM, Dama E, Mosso ML, Magnani C, Pastore G, Merletti F; Childhood Cancer Registry of Piedmont (2008). High incidence of acute promyelocytic leukemia in children in northwest Italy, 1980–2003: a report from the Childhood Cancer Registry of Piedmont. Leukemia. 22(2):439–41. https://doi.org/10.1038/sj.leu.2404916 PMID:17851559

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The childhood population covered by this registry is also covered by CCRP. The high sex ratio in the age group 15–19 years (Table A.9) is mainly the result of germ cell tumours occurring predominantly in males. Because the rules for registration of non-malignant CNS tumours, including pilocytic astrocytoma, changed during the reporting period, data on these tumours were not provided by the registry. Thus, the reported incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. Skin carcinomas have not been registered since 2002. Information on laterality was not provided. See also Italy, above.

Umbria Cancer Registry, 1994–2011

Giuseppe Masanotti, Fortunato Bianconi, Fabrizio Stracci

The Umbria region is located in central Italy. It is characterized by hills, mountains, valleys, and historical towns. The region covers an area of 8456 km^2 and has a population of 0.9 million; 7% of the population is younger than 20 years (Table A.6). The population density is 107 per km^2. The region is divided into two provinces; 74% of the population resides in the province of Perugia and 26% in the province of Terni. The two main eponymous cities are home to 30.7% of the population. The city of Perugia is the regional capital. The 7.1% increase in the population since 2001 is due exclusively to immigration. The largest groups of foreign-born residents come from Romania (25%), Albania (17.2%), and Morocco (10.6%). Between 2001 and 2011, the population of Italian-born residents decreased by 0.3%, whereas the population of foreign-born residents increased by 222%.

Regional health care is provided mostly in public hospitals and health districts of the two local health agencies (one in each province). There are two large hospitals and 18 smaller public hospitals (with a total of 3603 beds) and five private clinics. Two specialized oncology centres are located in the two main cities in the departments of clinical oncology, surgical oncology, paediatric oncology, radiotherapy, and haematology.

The Umbria Cancer Registry covers the population of the whole region. The registry is managed by the Department of Experimental Medicine in the Section of Public Health of the University of Perugia and is funded by the regional health authority. The registry uses the Web 2.0 management system S.G.RTUP based on AMPAX technology and object-oriented programming. The ISO/IEC 27001:2005 standard is followed to ensure data security. The S.G.RTUP system is linked to the oncology

network. Cases are identified from medical records of public and private clinics and hospitals, pathology reports, radiotherapy records, and death certificates. Other data sources are regional cytology centres, personal case histories and independent studies, reimbursement requests (for patients treated outside the region), and other cancer registries. Trace-back is performed for cases of unspecified behaviour, cases of unknown primary site, cases with outpatient records as the only source, or DCO cases, and these procedures include contacting the family physician. IACR rules are used to define multiple primary tumours. Data integrity and consistency are checked using IARCcrgTools and specific checks established for studies that require data beyond the basic set of variables.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

Of all the Italian cancer registries, the Umbria Cancer Registry recorded the highest overall incidence rates for children and adolescents (Table A.9). Non-malignant CNS tumours were recorded, and pilocytic astrocytoma was coded with uncertain behaviour. Information on laterality was provided for 75% of the cases of interest. See also Italy, above.

Varese, Lombardy Cancer Registry, 1992–2012

Giovanna Tagliabue, Paolo Contiero, Andrea Tittarelli, Sabrina Fabiano, Anna Maghini, Tiziana Codazzi, Giulio Barigelletti, Anna D'Agostino, Alessandro Borgini, Carlo Modonesi, Franco Berrino

The province of Varese is one of 12 administrative units of the Lombardy region, located in northern Italy. The Varese province is located in the western part of the region and is bordered by Switzerland to the north, the region of Piedmont to the west, and two other provinces of the Lombardy region to the south and east. The northern part of the province is mountainous, and the southern part encompasses part of the Lombardy plain and is flat. The province covers an area of 1198 km^2.

The population increased by 50% between 1961 and 2016 due to migration of large numbers of people from eastern and southern Italy. Those who settled tended to retain the distinctive dietary and cultural habits of their origins, which differ considerably from those of the native population. These differences have made it possible to conduct descriptive studies on differences in cancer risk by place of birth and to conduct studies on diet and cancer.

The population density is 742.9 per km^2; 18% of the total population of 0.9 million is younger than 20 years (Table A.6). About 40% of the working population is employed in industry – a considerable decrease compared with 1971 – and less than 2% is employed in agriculture. It is not possible to partition the province into urban and rural areas.

The province has 11 general hospitals, including one university hospital with modern diagnostic and treatment facilities for cancer care. There are also five private clinics. About 70% of all paediatric hospital discharges are for patients from outside the province of Varese.

The Lombardy Cancer Registry, which covers the province of Varese, was established in 1974 and has provided population-based data since 1976 (Table A.10). The registry is supported by the Lombardy Regional Health Authority and is run by the Cancer Registry and Environmental Epidemiology Unit of the National Cancer Institute of Milan.

The Lombardy Cancer Registry uses the Open Registry system. The main electronic information sources are hospital discharge records, surgical pathology reports from pathology units in the province and, since 1998, from major pathology units outside the province (which often examine specimens from residents in the province), and mortality data from local health units. Use of the Open Registry software and translation tables enables automatic application of coding systems and correct identification and automatic acceptance of 60% of cases. The clinical records of the remaining cases are checked manually. Comparison of the automated system with manual registration showed a site code concordance between the two systems (automated and manual) of 98.4%. The completeness of registration is monitored annually using capture–recapture methods. Clinical consistency is also checked routinely by re-abstraction and manual recoding of a random sample of cases.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

The overall incidence rates were high, as for some other Italian registries. The large proportion of cases aged 19 years in the age group 15–19 years probably reflects a natural increase in incidence rates with age. Non-malignant CNS tumours were not registered, except pilocytic astrocytoma, which was coded with uncertain behaviour. Therefore, the reported incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. Skin carcinomas were registered and are believed to be complete. Information on laterality was provided for 87% of the cases of interest. See also Italy, above.

Veneto Tumour Registry, 1992–2009

Massimo Rugge, Maddalena Baracco, Susanna Baracco, Emanuela Bovo, Antonella Dal Cin, Anna Rita Fiore, Alessandra Greco, Stefano Guzzinati, Daniele Monetti, Silvia Rizzato, Alberto Rosano, Carmen Fiorella Stocco, Manuel Zorzi

The Veneto Region is located in north-eastern Italy and is bordered by the regions of Friuli-Venezia Giulia, Emilia-Romagna, Lombardy, and Trentino-Alto Adige/Südtirol. It is bordered by Austria at its northernmost corner and by the Adriatic Sea to the east. The region is one of the richest in Italy and is home to many of the nation's leading economic districts. The unemployment rate in 2006 was 4.0%, compared with a national average of 6.8%. The region's capital and most populous city is Venice.

The Veneto Region has long been a land of mass emigration. Recently, the region has received large numbers of immigrants, mostly from Romania (25.2%), Morocco, China, the Republic of Moldova, and Albania. Almost 10% of the population of 5 million is foreign-born.

Health care is provided by 21 local health units, two autonomous hospitals, and an oncology centre. Most of the local health units provide comprehensive services for cancer diagnosis, surgery, and chemotherapy. Radiotherapy and a few expensive diagnostic tools are available at the national level. There are five paediatric oncology centres, affiliated with AIEOP. Most children with cancer are treated in the two major hospitals of Padua and Verona.

The Veneto Tumour Registry covers about half of the population of the Veneto Region, including all the major urban centres and almost all of the mountainous part of the region. Until 1997, the registry covered 11 of 21 local health units, and since 1998, it has covered 12 local health units. The registration area has a total covered population of 2.6 million, and 18% of the population is younger than 20 years (Table A.6). The registry is funded by the regional government. The staff consists of two physicians (a director and an epidemiologist), three operators, four statisticians, a data manager, three programmers, and one clerk.

The registry electronically collects data annually from hospital discharge records from all hospitals in the region, death certificates for Veneto residents, and pathology records from the region's 15 pathology laboratories. All of the region's local health units submit a copy of the population files, which are used as a reference in linking source records. All cases are evaluated using a case-resolution programme and checked manually.

There are no differences in incidence between Veneto and the pooled dataset of Italian cancer registries. There are no temporal trends in incidence. The registry staff is not aware of any unusual environmental or occupational exposures that could affect cancer incidence. Incidence, survival, and prevalence data are reported online (https://www.registrotumoriveneto.it/it). The registry collaborates with other Italian registries on research projects and is involved in international epidemiological studies.

POPULATION AT RISK

See Italy, above.

EDITORS' COMMENTS

Non-malignant CNS tumours were registered (Table A.9). Pilocytic astrocytoma was originally coded according to the ICD-O edition in use (Table A.10) and recoded with uncertain behaviour in the IICC-3 dataset. Information on laterality was provided for 71% of the cases of interest, and there were no cases of bilateral retinoblastoma in the dataset. See also Italy, above.

ITALY, 26 registries (1992-2013)

	Age group (years)	Males	Females
Person-years	0	1 413 907	1 335 690
	1-4	5 634 445	5 322 443
	5-9	6 960 781	6 581 229
	10-14	7 124 998	6 743 765
	15-19	7 731 970	7 322 105
	0-14	21 134 131	19 983 127
	0-19	28 866 101	27 305 232

Please consult the quality indicators for this pool and its constituent registries

ITALY, 26 registries (1992-2013)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	**LEUKAEMIA**	103	1012	686	503	499	**2304**	**2803**	30.7	100.0	24.0	100.0	37.5	92.4	50.7	36.3	33.1	**58.4**	**52.7**	841	1007	97.9	0.3
	a. Lymphoid	48	883	571	343	252	**1845**	**2097**	24.5	80.1	18.0	74.8	17.5	80.6	42.2	24.7	16.7	**47.1**	**40.2**	674	758	98.6	0.1
	b. Acute myeloid	30	85	85	115	136	**315**	**451**	4.2	13.7	3.9	16.1	10.9	7.8	6.3	8.3	9.0	**7.7**	**8.0**	115	160	98.0	0.4
	c. CMD	9	13	14	33	75	**69**	**144**	0.9	3.0	1.2	5.1	3.3	1.2	1.0	2.4	5.0	**1.6**	**2.4**	25	50	99.3	0.0
	d. MDS & other	7	13	4	4	9	**28**	**37**	0.4	1.2	0.3	1.3	2.5	1.2	0.3	0.3	0.6	**0.7**	**0.7**	10	13	97.3	0.0
	e. Unspecified	9	18	12	8	27	**47**	**74**	0.6	2.0	0.6	2.6	3.3	1.6	0.9	0.6	1.8	**1.2**	**1.3**	17	26	74.3	6.8
II	**LYMPHOMA & RELATED**	28	151	315	629	1223	**1123**	**2346**	14.9	100.0	20.1	100.0	10.2	13.8	23.3	45.4	81.2	**25.7**	**38.2**	408	815	98.7	0.1
	a. Hodgkin	0	20	84	371	888	**475**	**1363**	6.3	42.3	11.7	58.1	-	1.8	6.2	26.8	59.0	**10.3**	**21.3**	172	467	99.6	0.0
	b. Non-Hodgkin except BL	6	46	111	157	272	**320**	**592**	4.3	28.5	5.1	25.2	2.2	4.2	8.2	11.3	18.1	**7.4**	**9.8**	117	207	99.5	0.2
	c. Burkitt (BL)	1	39	87	69	28	**196**	**224**	2.6	17.5	1.9	9.5	0.4	3.6	6.4	5.0	1.9	**4.6**	**4.0**	72	81	100.0	0.0
	d. Lymphoreticular	21	38	26	14	9	**99**	**108**	1.3	8.8	0.9	4.6	7.6	3.5	1.9	1.0	0.6	**2.6**	**2.1**	36	39	97.2	0.0
	e. Unspecified	0	8	7	18	26	**33**	**59**	0.4	2.9	0.5	2.5	-	0.7	0.5	1.3	1.7	**0.8**	**1.0**	12	21	67.8	3.4
III	**CNS NEOPLASMS** †	87	491	525	451	488	**1554**	**2042**	20.7	100.0	17.5	100.0	31.6	44.8	38.8	32.5	32.4	**38.3**	**37.0**	567	729	73.3	0.5
	a. Ependymoma	15	68	40	33	29	**156**	**185**	2.1	10.0	1.6	9.1	5.5	6.2	3.0	2.4	1.9	**4.0**	**3.5**	57	67	97.3	0.0
	b. Astrocytoma	23	165	193	149	135	**530**	**665**	7.1	34.1	5.7	32.6	8.4	15.1	14.3	10.7	9.0	**13.0**	**12.1**	194	238	97.1	0.0
	c. CNS embryonal	15	92	103	55	47	**265**	**312**	3.5	17.1	2.7	15.3	5.5	8.4	7.6	4.0	3.1	**6.6**	**5.8**	97	113	99.0	0.0
	d. Other gliomas	4	45	31	50	40	**130**	**170**	1.7	8.4	1.5	8.3	1.5	4.1	2.3	3.6	2.7	**3.2**	**3.1**	47	61	68.8	0.0
	e. Other specified	7	33	39	56	90	**135**	**225**	1.8	8.7	1.9	11.0	2.5	3.0	2.9	4.0	6.0	**3.2**	**3.8**	49	79	83.6	0.0
	f. Unspecified CNS	23	88	119	108	147	**338**	**485**	4.5	21.8	4.2	23.8	8.4	8.0	8.8	7.8	9.8	**8.2**	**8.6**	123	172	11.8	2.3
IV	**NEUROBLASTOMA**	200	248	76	21	11	**545**	**556**	7.3	100.0	4.8	100.0	72.7	22.6	5.6	1.5	0.7	**14.9**	**11.7**	199	203	96.8	0.0
	a. (Ganglio)neuroblastoma	198	242	70	13	4	**523**	**527**	7.0	96.0	4.5	94.8	72.0	22.1	5.2	0.9	0.3	**14.4**	**11.2**	191	192	96.8	0.0
	b. Peripheral nervous	2	6	6	8	7	**22**	**29**	0.3	4.0	0.2	5.2	0.7	0.5	0.4	0.6	0.5	**0.5**	**0.5**	8	10	96.6	0.0
V	**RETINOBLASTOMA**	75	78	2	1	1	**156**	**157**	2.1	100.0	1.3	100.0	27.3	7.1	0.1	0.1	0.1	**4.4**	**3.4**	57	57	73.2	0.0
VI	**RENAL TUMOURS**	51	188	80	18	15	**337**	**352**	4.5	100.0	3.0	100.0	18.5	17.2	5.9	1.3	1.0	**9.0**	**7.2**	123	128	93.8	0.0
	a. Nephroblastoma	48	180	67	8	1	**303**	**304**	4.0	89.9	2.6	86.4	17.5	16.4	4.9	0.6	0.1	**8.2**	**6.4**	111	111	98.0	0.0
	b. Renal carcinoma	0	3	7	9	12	**19**	**31**	0.3	5.6	0.3	8.8	-	0.3	0.5	0.6	0.8	**0.4**	**0.5**	7	11	100.0	0.0
	c. Unspecified	3	5	6	1	2	**15**	**17**	0.2	4.5	0.1	4.8	1.1	0.5	0.4	0.1	0.1	**0.4**	**0.3**	5	6	5.9	0.0
VII	**HEPATIC TUMOURS**	29	36	9	8	13	**82**	**95**	1.1	100.0	0.8	100.0	10.5	3.3	0.7	0.6	0.9	**2.2**	**1.9**	30	34	90.5	1.1
	a. Hepatoblastoma	25	29	6	3	1	**63**	**64**	0.8	76.8	0.5	67.4	9.1	2.6	0.4	0.2	0.1	**1.7**	**1.4**	23	23	100.0	0.0
	b. Hepatic carcinoma	1	3	3	4	12	**11**	**23**	0.1	13.4	0.2	24.2	0.4	0.3	0.2	0.3	0.8	**0.3**	**0.4**	4	8	87.0	0.0
	c. Unspecified	3	4	0	1	0	**8**	**8**	0.1	9.8	0.1	8.4	1.1	0.4	-	0.1	-	**0.2**	**0.2**	3	3	25.0	12.5
VIII	**BONE TUMOURS**	4	25	94	230	215	**353**	**568**	4.7	100.0	4.9	100.0	1.5	2.3	6.9	16.6	14.3	**7.9**	**9.3**	128	200	94.4	0.2
	a. Osteosarcoma	1	4	33	100	100	**138**	**238**	1.8	39.1	2.0	41.9	0.4	0.4	2.4	7.2	6.6	**3.0**	**3.8**	50	83	99.6	0.0
	b. Chondrosarcoma	0	0	2	7	11	**9**	**20**	0.1	2.5	0.2	3.5	-	-	0.1	0.5	0.7	**0.2**	**0.3**	3	7	100.0	0.0
	c. Ewing & related	1	18	48	99	78	**166**	**244**	2.2	47.0	2.1	43.0	0.4	1.6	3.5	7.1	5.2	**3.8**	**4.1**	60	86	98.4	0.0
	d. Other specified	0	1	4	4	9	**9**	**18**	0.1	2.5	0.2	3.2	-	0.1	0.3	0.3	0.6	**0.2**	**0.3**	3	6	100.0	0.0
	e. Unspecified	2	2	7	20	17	**31**	**48**	0.4	8.8	0.4	8.5	0.7	0.2	0.5	1.4	1.1	**0.7**	**0.8**	11	17	43.8	2.1
IX	**SOFT TISSUE SARCOMA**	49	105	110	138	224	**402**	**626**	5.3	100.0	5.4	100.0	17.8	9.6	8.1	10.0	14.9	**9.9**	**11.0**	147	221	99.5	0.0
	a. Rhabdomyosarcoma	19	69	56	51	57	**195**	**252**	2.6	48.5	2.2	40.3	6.9	6.3	4.1	3.7	3.8	**4.9**	**4.6**	71	90	100.0	0.0
	b. Fibrosarcoma	10	5	11	17	22	**43**	**65**	0.6	10.7	0.6	10.4	3.6	0.5	0.8	1.2	1.5	**1.0**	**1.1**	16	23	100.0	0.0
	c. Kaposi sarcoma	0	1	0	0	2	**1**	**3**	0.0	0.2	0.0	0.5	-	0.1	-	-	0.1	**0.0**	**0.1**	0	1	100.0	0.0
	d. Other specified	13	20	29	51	124	**113**	**237**	1.5	28.1	2.0	37.9	4.7	1.8	2.1	3.7	8.2	**2.7**	**3.9**	41	82	99.2	0.0
	e. Unspecified	7	10	14	19	19	**50**	**69**	0.7	12.4	0.6	11.0	2.5	0.9	1.0	1.4	1.3	**1.2**	**1.2**	18	25	98.6	0.0
X	**GERM CELL TUMOURS**	33	46	28	90	422	**197**	**619**	2.6	100.0	5.3	100.0	12.0	4.2	2.1	6.5	28.0	**4.8**	**10.0**	72	212	97.1	0.0
	a. CNS germ cell ‡	6	8	12	30	22	**56**	**78**	0.7	28.4	0.7	12.6	2.2	0.7	0.9	2.2	1.5	**1.3**	**1.3**	20	28	93.6	0.0
	b. Other extragonadal	19	24	1	3	11	**47**	**58**	0.6	23.9	0.5	9.4	6.9	2.2	0.1	0.2	0.7	**1.3**	**1.2**	17	21	98.3	0.0
	c. Gonadal germ cell	7	14	12	48	350	**81**	**431**	1.1	41.1	3.7	69.6	2.5	1.3	0.9	3.5	23.2	**1.9**	**6.7**	29	146	100.0	0.0
	d. Gonadal carcinoma	0	0	0	2	22	**2**	**24**	0.0	1.0	0.2	3.9	-	-	-	0.1	1.5	**0.0**	**0.4**	1	8	100.0	0.0
	e. Unspecified gonadal	1	0	3	7	17	**11**	**28**	0.1	5.6	0.2	4.5	0.4	-	0.2	0.5	1.1	**0.2**	**0.4**	4	10	57.1	0.0
XI	**CARCINOMA & MELANOMA**	7	16	65	240	949	**328**	**1277**	4.4	100.0	10.9	100.0	2.5	1.5	4.8	17.3	63.0	**7.2**	**19.8**	119	434	99.5	0.0
	a. Adrenocortical	5	3	0	1	7	**9**	**16**	0.1	2.7	0.1	1.3	1.8	0.3	-	0.1	0.5	**0.2**	**0.3**	3	6	100.0	0.0
	b. Thyroid	0	3	22	92	420	**117**	**537**	1.6	35.7	4.6	42.1	-	0.3	1.6	6.6	27.9	**2.5**	**8.2**	42	182	99.4	0.0
	c. Nasopharyngeal	0	0	1	9	25	**10**	**35**	0.1	3.0	0.3	2.7	-	-	0.1	0.6	1.7	**0.2**	**0.5**	4	12	100.0	0.0
	d. Melanoma	0	4	14	57	220	**75**	**295**	1.0	22.9	2.5	23.1	-	0.4	1.0	4.1	14.6	**1.6**	**4.6**	27	100	98.6	0.0
	e. Skin carcinoma	1	4	16	32	114	**53**	**167**	0.7	16.2	1.4	13.1	0.4	0.4	1.2	2.3	7.6	**1.2**	**2.6**	19	57	100.0	0.0
	f. Other & unspecified	1	2	12	49	163	**64**	**227**	0.9	19.5	1.9	17.8	0.4	0.2	0.9	3.5	10.8	**1.4**	**3.5**	23	77	100.0	0.0
XII	**OTHER & UNSPECIFIED**	33	39	25	39	86	**136**	**222**	1.8	100.0	1.9	100.0	12.0	3.6	1.8	2.8	5.7	**3.4**	**4.0**	50	78	29.3	1.8
	a. Other specified	3	12	0	1	12	**16**	**28**	0.2	11.8	0.2	12.6	1.1	1.1	-	0.1	0.8	**0.4**	**0.5**	6	10	100.0	0.0
	b. Other unspecified	30	27	25	38	74	**120**	**194**	1.6	88.2	1.7	87.4	10.9	2.5	1.8	2.7	4.9	**3.0**	**3.4**	44	68	19.1	2.1
	TOTAL §	699	2435	2015	2368	4146	**7517**	**11663**	100.0	100.0	100.0	100.0	254.2	222.2	148.8	170.7	275.4	**186.1**	**206.2**	2741	4118	91.9	0.2

† includes 772 non-malignant ‡ includes 6 non-malignant
§ includes 1 with sex unknown

Please consult the quality indicators for this pool and its constituent registries

Lithuania

Lithuanian Cancer Registry, 2000–2012

Nadezda Lipunova, Giedre Smailyte, Ieva Vincerzevskiene, Auguste Kaceniene, Jevgenij Obzigailov

Lithuania is located along the south-eastern shore of the Baltic Sea, to the east of Sweden and Denmark. It is bordered by Latvia to the north, Belarus to the east and south, Poland to the south, and the Kaliningrad region of the Russian Federation to the south-west. The climate varies between maritime and continental. The country has a fast-growing economy and a very high HDI. In 2010, the estimated population was 3.1 million (Table A.7), and 22% of the population was younger than 20 years (Table A.6). Vilnius is the capital and the most populous city.

Paediatric oncology services are provided in the Children's Oncohaematology Department of the Vilnius University Children's Hospital and in the Paediatric Oncology and Haematology Division of the Hospital of Lithuanian University of Health Sciences Kaunas Clinics.

The Lithuanian Cancer Registry is a population-based registry. Cancer registration started in 1957 (Table A.10). Population-based data are available from 1964 and were included in international studies as from 1988. The Epidemiology Department of the Institute of Oncology was responsible for the collection and analysis of cancer incidence data until 1984, when the Lithuanian Cancer Registry was founded as a separate body. The registry became a member of IACR in 1993.

The main sources of information on cancer cases are primary, secondary, and tertiary health-care institutions. All physicians must complete a notification form when a new case of cancer is diagnosed, and the registry staff conduct extensive quality control and data analysis. The standard notification form includes personal identification number, names, sex, date of birth, place of residence, date of diagnosis, cancer site according to ICD-10 (since 1998), and topography and morphology codes according to ICD-O-2 (1998–2002) or ICD-O-3 (since 2003) (Table A.10). The notifications are supplemented by information from death certificates from the Causes of Death Registry, and the data are entered into an electronic database suitable for research purposes.

The registry routinely publishes data. One example, the most recent publication, is available at https://www.nvi.lt/uploads/pdf/Vezio%20registras/Vezys_lietuvoje_2012.pdf.

POPULATION AT RISK

The source of the population data is Statistics Lithuania (https://osp.stat.gov.lt); the data are based on the 2001 and 2011 censuses (Table A.7). Data were provided in the requested detail.

EDITORS' COMMENTS

The proportion of non-malignant CNS tumours is low (Table A.9). The registry could not rule out some level of underreporting of the overall incidence; however, this was thought unlikely to be different between cancer types (malignant or non-malignant). Pilocytic astrocytoma was coded with uncertain behaviour. Skin carcinomas are reportable. Laterality was not reported.

LITHUANIA (2000-2012)

	Age group (years)	Males	Females
Person-years	0	203 806	193 427
	1-4	831 328	788 422
	5-9	1 171 227	1 111 370
	10-14	1 446 889	1 380 556
	15-19	1 617 345	1 555 673
	0-14	3 653 250	3 473 775
	0-19	5 270 595	5 029 448
Average annual population	0-14	281 019	267 213
	0-19	405 430	386 881

Please consult the quality indicators for this registry

LITHUANIA (2000-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	16	145	98	63	88	322	410	36.6	100.0	29.3	100.0	40.3	89.5	42.9	22.3	27.7	51.2	45.9	725	864	99.3	0.0
	a. Lymphoid	5	124	85	42	44	256	300	29.1	79.5	21.4	73.2	12.6	76.6	37.2	14.9	13.9	41.1	35.0	580	650	100.0	0.0
	b. Acute myeloid	6	17	10	15	24	48	72	5.5	14.9	5.1	17.6	15.1	10.5	4.4	5.3	7.6	7.4	7.4	105	143	100.0	0.0
	c. CMD	0	0	3	3	15	6	21	0.7	1.9	1.5	5.1	-	-	1.3	1.1	4.7	0.7	1.6	12	36	100.0	0.0
	d. MDS & other	3	2	0	3	2	8	10	0.9	2.5	0.7	2.4	7.6	1.2	-	1.1	0.6	1.3	1.1	18	21	100.0	0.0
	e. Unspecified	2	2	0	0	3	4	7	0.5	1.2	0.5	1.7	5.0	1.2	-	-	0.9	0.8	0.8	10	15	57.1	0.0
II	LYMPHOMA & RELATED	1	22	23	63	141	109	250	12.4	100.0	17.9	100.0	2.5	13.6	10.1	22.3	44.4	14.1	21.0	219	441	99.6	0.0
	a. Hodgkin	0	8	10	28	99	46	145	5.2	42.2	10.4	58.0	-	4.9	4.4	9.9	31.2	5.8	11.5	91	247	99.3	0.0
	b. Non-Hodgkin except BL	1	6	6	22	31	35	66	4.0	32.1	4.7	26.4	2.5	3.7	2.6	7.8	9.8	4.5	5.6	69	118	100.0	0.0
	c. Burkitt (BL)	0	7	4	12	8	23	31	2.6	21.1	2.2	12.4	-	4.3	1.8	4.2	2.5	3.1	3.0	47	60	100.0	0.0
	d. Lymphoreticular	0	1	2	1	2	4	6	0.5	3.7	0.4	2.4	-	0.6	0.9	0.4	0.6	0.6	0.6	9	12	100.0	0.0
	e. Unspecified	0	0	1	0	1	1	2	0.1	0.9	0.1	0.8	-	-	0.4	-	0.3	0.1	0.2	2	4	100.0	0.0
III	CNS NEOPLASMS †	12	43	43	53	68	151	219	17.2	100.0	15.6	100.0	30.2	26.5	18.8	18.7	21.4	22.1	21.9	324	431	76.7	4.6
	a. Ependymoma	0	3	7	4	5	14	19	1.6	9.3	1.4	8.7	-	1.9	3.1	1.4	1.6	2.0	1.9	30	38	100.0	0.0
	b. Astrocytoma	5	14	14	19	29	52	81	5.9	34.4	5.8	37.0	12.6	8.6	6.1	6.7	9.1	7.6	7.9	111	157	100.0	0.0
	c. CNS embryonal	1	10	10	11	9	32	41	3.6	21.2	2.9	18.7	2.5	6.2	4.4	3.9	2.8	4.7	4.2	69	83	100.0	0.0
	d. Other gliomas	0	3	3	6	6	12	18	1.4	7.9	1.3	8.2	-	1.9	1.3	2.1	1.9	1.6	1.7	25	34	100.0	0.0
	e. Other specified	2	0	2	2	2	6	8	0.7	4.0	0.6	3.7	5.0	-	0.9	0.7	0.6	0.9	0.8	13	16	100.0	0.0
	f. Unspecified CNS	4	13	7	11	17	35	52	4.0	23.2	3.7	23.7	10.1	8.0	3.1	3.9	5.4	5.4	5.4	77	104	1.9	19.2
IV	NEUROBLASTOMA	19	24	7	6	3	56	59	6.4	100.0	4.2	100.0	47.8	14.8	3.1	2.1	0.9	9.9	7.9	133	137	100.0	0.0
	a. (Ganglio)neuroblastoma	19	24	7	5	1	55	56	6.3	98.2	4.0	94.9	47.8	14.8	3.1	1.8	0.3	9.8	7.6	131	132	100.0	0.0
	b. Peripheral nervous	0	0	0	1	2	1	3	0.1	1.8	0.2	5.1	-	-	-	0.4	0.6	0.1	0.2	2	5	100.0	0.0
V	RETINOBLASTOMA	5	7	1	0	0	13	13	1.5	100.0	0.9	100.0	12.6	4.3	0.4	-	-	2.4	1.9	32	32	100.0	0.0
VI	RENAL TUMOURS	8	36	10	6	10	60	70	6.8	100.0	5.0	100.0	20.1	22.2	4.4	2.1	3.2	10.5	8.8	142	157	91.4	1.4
	a. Nephroblastoma	7	34	10	3	3	54	57	6.1	90.0	4.1	81.4	17.6	21.0	4.4	1.1	0.9	9.6	7.6	129	134	94.7	0.0
	b. Renal carcinoma	0	0	0	3	7	3	10	0.3	5.0	0.7	14.3	-	-	-	1.1	2.2	0.3	0.7	5	16	100.0	0.0
	c. Unspecified	1	2	0	0	0	3	3	0.3	5.0	0.2	4.3	2.5	1.2	-	-	-	0.6	0.4	7	7	0.0	33.3
VII	HEPATIC TUMOURS	2	1	1	5	2	9	11	1.0	100.0	0.8	100.0	5.0	0.6	0.4	1.8	0.6	1.2	1.1	18	22	90.9	9.1
	a. Hepatoblastoma	2	1	1	0	0	4	4	0.5	44.4	0.3	36.4	5.0	0.6	0.4	-	-	0.7	0.6	10	10	100.0	0.0
	b. Hepatic carcinoma	0	0	0	5	1	5	6	0.6	55.6	0.4	54.5	-	-	-	1.8	0.3	0.5	0.5	9	10	100.0	0.0
	c. Unspecified	0	0	0	0	1	0	1	-	-	0.1	9.1	-	-	-	-	0.3	-	0.1	-	2	0.0	100.0
VIII	BONE TUMOURS	1	3	9	31	44	44	88	5.0	100.0	6.3	100.0	2.5	1.9	3.9	11.0	13.9	5.2	7.2	84	154	97.7	0.0
	a. Osteosarcoma	0	0	1	15	21	16	37	1.8	36.4	2.6	42.0	-	-	0.4	5.3	6.6	1.7	2.8	29	62	100.0	0.0
	b. Chondrosarcoma	0	0	1	2	5	3	8	0.3	6.8	0.6	9.1	-	-	0.4	0.7	1.6	0.3	0.6	6	14	100.0	0.0
	c. Ewing & related	1	3	6	12	14	22	36	2.5	50.0	2.6	40.9	2.5	1.9	2.6	4.2	4.4	2.8	3.2	44	66	100.0	0.0
	d. Other specified	0	0	0	1	0	1	1	0.1	2.3	0.1	1.1	-	-	-	0.4	-	0.1	0.1	2	2	100.0	0.0
	e. Unspecified	0	0	1	1	4	2	6	0.2	4.5	0.4	6.8	-	-	0.4	0.4	1.3	0.2	0.5	4	10	66.7	0.0
IX	SOFT TISSUE SARCOMA	8	20	8	19	29	55	84	6.3	100.0	6.0	100.0	20.1	12.3	3.5	6.7	9.1	8.5	8.6	121	166	100.0	0.0
	a. Rhabdomyosarcoma	4	13	3	12	7	32	39	3.6	58.2	2.8	46.4	10.1	8.0	1.3	4.2	2.2	4.9	4.3	70	81	100.0	0.0
	b. Fibrosarcoma	1	0	3	1	5	5	10	0.6	9.1	0.7	11.9	2.5	-	1.3	0.4	1.6	0.7	0.9	11	19	100.0	0.0
	c. Kaposi sarcoma	0	1	0	0	0	1	1	0.1	1.8	0.1	1.2	-	0.6	-	-	-	0.2	0.1	2	2	100.0	0.0
	d. Other specified	3	6	2	6	13	17	30	1.9	30.9	2.1	35.7	7.6	3.7	0.9	2.1	4.1	2.6	3.0	37	58	100.0	0.0
	e. Unspecified	0	0	0	0	4	0	4	-	-	0.3	4.8	-	-	-	-	1.3	-	0.3	-	6	100.0	0.0
X	GERM CELL TUMOURS	5	6	4	11	41	26	67	3.0	100.0	4.8	100.0	12.6	3.7	1.8	3.9	12.9	3.8	5.9	55	120	97.0	0.0
	a. CNS germ cell	0	0	1	5	2	6	8	0.7	23.1	0.6	11.9	-	-	0.4	1.8	0.6	0.7	0.6	11	14	100.0	0.0
	b. Other extragonadal	3	5	0	0	4	8	12	0.9	30.8	0.9	17.9	7.6	3.1	-	-	1.3	1.5	1.5	20	26	100.0	0.0
	c. Gonadal germ cell	1	1	3	5	26	10	36	1.1	38.5	2.6	53.7	2.5	0.6	1.3	1.8	8.2	1.3	2.9	20	61	100.0	0.0
	d. Gonadal carcinoma	0	0	0	1	4	1	5	0.1	3.8	0.4	7.5	-	-	-	0.4	1.3	0.1	0.4	2	8	100.0	0.0
	e. Unspecified gonadal	1	0	0	0	5	1	6	0.1	3.8	0.4	9.0	2.5	-	-	-	1.6	0.2	0.5	2	10	66.7	0.0
XI	CARCINOMA & MELANOMA	1	1	3	20	87	25	112	2.8	100.0	8.0	100.0	2.5	0.6	1.3	7.1	27.4	2.9	8.4	47	184	99.1	0.0
	a. Adrenocortical	1	0	1	1	2	3	5	0.3	12.0	0.4	4.5	2.5	-	0.4	0.4	0.6	0.4	0.5	6	10	80.0	0.0
	b. Thyroid	0	0	1	9	44	10	54	1.1	40.0	3.9	48.2	-	-	0.4	3.2	13.9	1.1	3.9	18	87	100.0	0.0
	c. Nasopharyngeal	0	0	0	0	4	0	4	-	-	0.3	3.6	-	-	-	-	1.3	-	0.3	-	6	100.0	0.0
	d. Melanoma	0	0	0	1	11	1	12	0.1	4.0	0.9	10.7	-	-	-	0.4	3.5	0.1	0.9	2	19	100.0	0.0
	e. Skin carcinoma	0	0	1	6	10	7	17	0.8	28.0	1.2	15.2	-	-	0.4	2.1	3.2	0.8	1.3	13	29	100.0	0.0
	f. Other & unspecified	0	1	0	3	16	4	20	0.5	16.0	1.4	17.9	-	0.6	-	1.1	5.0	0.5	1.5	8	33	100.0	0.0
XII	OTHER & UNSPECIFIED	3	4	2	1	7	10	17	1.1	100.0	1.2	100.0	7.6	2.5	0.9	0.4	2.2	1.7	1.8	24	35	11.8	35.3
	a. Other specified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Other unspecified	3	4	2	1	7	10	17	1.1	100.0	1.2	100.0	7.6	2.5	0.9	0.4	2.2	1.7	1.8	24	35	11.8	35.3
	TOTAL	81	312	209	278	520	880	1400	100.0	100.0	100.0	100.0	203.9	192.6	91.6	98.3	163.9	133.5	140.3	1924	2743	94.1	1.3

† includes 15 non-malignant

Please consult the quality indicators for this registry

Malta

Malta National Cancer Registry, 1994–2013

Dominic Agius

The Malta National Cancer Registry covers the population of the Maltese Islands, a small archipelago (316 km^2) in the Mediterranean Sea. The total resident population is 0.4 million, and 23% of the population is younger than 20 years (Table A.6). No clear distinction exists between urban and rural populations. Most of the population is Roman Catholic. There are no distinct ethnic minority groups. The number of foreign nationals has increased over the years, and they make up about 5% of the total population.

The Malta National Health Service provides free care for all at the point of delivery, funded by federal taxes. All residents have access to preventive, diagnostic, therapeutic, and rehabilitative services in government hospitals and health centres. There is an acute care hospital in Msida, which is in the centre of the largest island, and a smaller general hospital on the island of Gozo. Less than 20% of residents are covered by private health insurance. There is one private hospital. Cancer surgery is provided in all Maltese hospitals, along with paediatric and adolescent oncology, pathology, and other services. Radiotherapy and chemotherapy services are provided at the new, state-of-the-art Sir Anthony Mamo Oncology Centre.

The registry is part of the Department of Health Information and Research and is fully funded by the Government of Malta. It is staffed by a full-time medical officer and two registrars.

Data are collected mainly through active extraction from pathology laboratories' databases, hospital records, and the National Mortality Registry. The National Mortality Registry is also part of the Department of Health Information and Research, and linkage between the cancer registry and mortality databases is performed regularly. The mortality registry is the national source of death statistics.

Almost all cancers diagnosed in Maltese residents are registered. The registered patients are followed up using death certificates, and the date last known alive is extracted from hospital admissions and consultation records as possible.

Some Maltese residents receive treatment abroad, especially in the United Kingdom and Italy. These patients are first assessed and diagnosed locally, and specialized treatment is sought abroad if it is not available in Malta. The records of such patients are centrally accessible to the registry and are handled similarly to the records of patients who are treated locally.

The Malta National Cancer Registry collaborates with other cancer registries in the Southern and Eastern European Group of Cancer Registries. To date, case records have not been exchanged, but registry data and staff expertise are shared when writing research articles.

Registry data were included in CI5 Volumes VII–XI and in the EUROCARE and CONCORD studies. The registry is the recognized national source of information on cancer incidence. It responds to requests for information from both local and international sources.

POPULATION AT RISK

Population data are provided by the National Statistics Office (https://nso.gov.mt/en/Pages/NSO-Home.aspx) and are based on the 1985, 1995, 2005, and 2011 censuses (Table A.7). Data were provided in the requested detail.

EDITORS' COMMENTS

Pilocytic astrocytoma was coded with malignant behaviour in 1994–2003 and with non-malignant behaviour in 2004–2013, which might have contributed to the relatively low proportion of non-malignant CNS tumours in the dataset (Table A.9). Other non-malignant CNS tumours were registered throughout the reporting period. Skin carcinomas are registered. Laterality is complete.

MALTA (1994-2013)

	Age group (years)	Males	Females
Person-years	0	43 639	41 177
	1-4	180 727	171 200
	5-9	244 863	232 347
	10-14	269 567	255 126
	15-19	289 092	272 451
	0-14	738 796	699 850
	0-19	1 027 888	972 301
Average annual population	0-14	36 940	34 993
	0-19	51 394	48 615

Please consult the quality indicators for this registry

MALTA (1994-2013)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	2	32	28	21	18	83	101	33.6	100.0	28.7	100.0	23.6	90.9	58.7	40.0	32.1	60.7	54.2	883	1043	100.0	0.0
	a. Lymphoid	0	28	20	14	8	62	70	25.1	74.7	19.9	69.3	-	79.6	41.9	26.7	14.2	46.1	38.9	664	735	100.0	0.0
	b. Acute myeloid	1	1	6	3	8	11	19	4.5	13.3	5.4	18.8	11.8	2.8	12.6	5.7	14.2	7.5	9.0	114	186	100.0	0.0
	c. CMD	1	2	0	2	1	5	6	2.0	6.0	1.7	5.9	11.8	5.7	-	3.8	1.8	3.8	3.3	53	62	100.0	0.0
	d. MDS & other	0	1	1	2	1	4	5	1.6	4.8	1.4	5.0	-	2.8	2.1	3.8	1.8	2.7	2.5	41	50	100.0	0.0
	e. Unspecified	0	0	1	0	0	1	1	0.4	1.2	0.3	1.0	-	-	2.1	-	-	0.7	0.5	10	10	100.0	0.0
II	LYMPHOMA & RELATED	2	8	6	16	31	32	63	13.0	100.0	17.9	100.0	23.6	22.7	12.6	30.5	55.2	21.8	29.3	330	606	100.0	0.0
	a. Hodgkin	0	2	0	9	19	11	30	4.5	34.4	8.5	47.6	-	5.7	-	17.2	33.8	6.8	12.8	109	278	100.0	0.0
	b. Non-Hodgkin except BL	0	2	3	4	11	9	20	3.6	28.1	5.7	31.7	-	5.7	6.3	7.6	19.6	6.0	9.1	92	190	100.0	0.0
	c. Burkitt (BL)	0	1	2	3	0	6	6	2.4	18.8	1.7	9.5	-	2.8	4.2	5.7	-	3.9	3.0	61	61	100.0	0.0
	d. Lymphoreticular	2	3	1	0	1	6	7	2.4	18.8	2.0	11.1	23.6	8.5	2.1	-	1.8	5.1	4.4	68	77	100.0	0.0
	e. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
III	CNS NEOPLASMS †	1	13	15	16	8	45	53	18.2	100.0	15.1	100.0	11.8	36.9	31.4	30.5	14.2	31.4	27.5	470	541	88.7	0.0
	a. Ependymoma	1	1	0	0	0	2	2	0.8	4.4	0.6	3.8	11.8	2.8	-	-	-	1.8	1.4	23	23	100.0	0.0
	b. Astrocytoma	0	8	4	11	4	23	27	9.3	51.1	7.7	50.9	-	22.7	8.4	21.0	7.1	15.9	13.9	238	274	96.3	0.0
	c. CNS embryonal	0	3	6	2	3	11	14	4.5	24.4	4.0	26.4	-	8.5	12.6	3.8	5.3	7.8	7.3	116	143	100.0	0.0
	d. Other gliomas	0	0	1	2	1	3	4	1.2	6.7	1.1	7.5	-	-	2.1	3.8	1.8	1.8	1.8	30	38	25.0	0.0
	e. Other specified	0	0	3	1	0	4	4	1.6	8.9	1.1	7.5	-	-	6.3	1.9	-	2.6	2.0	41	41	100.0	0.0
	f. Unspecified CNS	0	1	1	0	0	2	2	0.8	4.4	0.6	3.8	-	2.8	2.1	-	-	1.6	1.2	22	22	0.0	0.0
IV	NEUROBLASTOMA	7	6	4	0	0	17	17	6.9	100.0	4.8	100.0	82.5	17.0	8.4	-	-	14.2	11.0	191	191	100.0	0.0
	a. (Ganglio)neuroblastoma	7	6	4	0	0	17	17	6.9	100.0	4.8	100.0	82.5	17.0	8.4	-	-	14.2	11.0	191	191	100.0	0.0
	b. Peripheral nervous	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
V	RETINOBLASTOMA	3	4	1	0	0	8	8	3.2	100.0	2.3	100.0	35.4	11.4	2.1	-	-	6.9	5.3	91	91	75.0	0.0
VI	RENAL TUMOURS	0	12	4	2	1	18	19	7.3	100.0	5.4	100.0	-	34.1	8.4	3.8	1.8	14.4	11.6	198	207	100.0	0.0
	a. Nephroblastoma	0	12	4	1	0	17	17	6.9	94.4	4.8	89.5	-	34.1	8.4	1.9	-	13.9	10.8	189	189	100.0	0.0
	b. Renal carcinoma	0	0	0	1	1	1	2	0.4	5.6	0.6	10.5	-	-	-	1.9	1.8	0.6	0.8	10	18	100.0	0.0
	c. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VII	HEPATIC TUMOURS	0	3	0	0	0	3	3	1.2	100.0	0.9	100.0	-	8.5	-	-	-	2.7	2.1	34	34	66.7	0.0
	a. Hepatoblastoma	0	2	0	0	0	2	2	0.8	66.7	0.6	66.7	-	5.7	-	-	-	1.8	1.4	23	23	100.0	0.0
	b. Hepatic carcinoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	c. Unspecified	0	1	0	0	0	1	1	0.4	33.3	0.3	33.3	-	2.8	-	-	-	0.9	0.7	11	11	0.0	0.0
VIII	BONE TUMOURS	0	0	6	6	8	12	20	4.9	100.0	5.7	100.0	-	-	12.6	11.4	14.2	7.4	8.9	120	191	100.0	0.0
	a. Osteosarcoma	0	0	2	2	3	4	7	1.6	33.3	2.0	35.0	-	-	4.2	3.8	5.3	2.5	3.1	40	67	100.0	0.0
	b. Chondrosarcoma	0	0	0	1	2	1	3	0.4	8.3	0.9	15.0	-	-	-	1.9	3.6	0.6	1.2	10	27	100.0	0.0
	c. Ewing & related	0	0	4	2	3	6	9	2.4	50.0	2.6	45.0	-	-	8.4	3.8	5.3	3.8	4.2	61	88	100.0	0.0
	d. Other specified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	e. Unspecified	0	0	0	1	0	1	1	0.4	8.3	0.3	5.0	-	-	-	1.9	-	0.6	0.4	10	10	100.0	0.0
IX	SOFT TISSUE SARCOMA	0	3	4	5	12	12	24	4.9	100.0	6.8	100.0	-	8.5	8.4	9.5	21.4	8.1	11.1	124	231	100.0	0.0
	a. Rhabdomyosarcoma	0	3	2	2	6	7	13	2.8	58.3	3.7	54.2	-	8.5	4.2	3.8	10.7	5.1	6.4	74	128	100.0	0.0
	b. Fibrosarcoma	0	0	0	0	2	0	2	-	-	0.6	8.3	-	-	-	-	3.6	-	0.8	-	18	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Other specified	0	0	2	3	4	5	9	2.0	41.7	2.6	37.5	-	-	4.2	5.7	7.1	3.0	3.9	50	85	100.0	0.0
	e. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
X	GERM CELL TUMOURS	1	0	1	2	7	4	11	1.6	100.0	3.1	100.0	11.8	-	2.1	3.8	12.5	2.7	4.9	41	103	100.0	0.0
	a. CNS germ cell	0	0	0	0	1	0	1	-	-	0.3	9.1	-	-	-	-	1.8	-	0.4	-	9	100.0	0.0
	b. Other extragonadal	1	0	0	0	0	1	1	0.4	25.0	0.3	9.1	11.8	-	-	-	-	0.9	0.7	11	11	100.0	0.0
	c. Gonadal germ cell	0	0	1	2	6	3	9	1.2	75.0	2.6	81.8	-	-	2.1	3.8	10.7	1.8	3.8	30	83	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	e. Unspecified gonadal	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
XI	CARCINOMA & MELANOMA	0	0	2	10	20	12	32	4.9	100.0	9.1	100.0	-	-	4.2	19.1	35.6	6.9	13.3	116	294	100.0	0.0
	a. Adrenocortical	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	b. Thyroid	0	0	0	3	7	3	10	1.2	25.0	2.8	31.3	-	-	-	5.7	12.5	1.7	4.1	29	91	100.0	0.0
	c. Nasopharyngeal	0	0	0	0	1	0	1	-	-	0.3	3.1	-	-	-	-	1.8	-	0.4	-	9	100.0	0.0
	d. Melanoma	0	0	2	5	9	7	16	2.8	58.3	4.5	50.0	-	-	4.2	9.5	16.0	4.1	6.8	69	149	100.0	0.0
	e. Skin carcinoma	0	0	0	0	1	0	1	-	-	0.3	3.1	-	-	-	-	1.8	-	0.4	-	9	100.0	0.0
	f. Other & unspecified	0	0	0	2	2	2	4	0.8	16.7	1.1	12.5	-	-	-	3.8	3.6	1.1	1.7	19	37	100.0	0.0
XII	OTHER & UNSPECIFIED	0	0	0	1	0	1	1	0.4	100.0	0.3	100.0	-	-	-	1.9	-	0.6	0.4	10	10	100.0	0.0
	a. Other specified	0	0	0	1	0	1	1	0.4	100.0	0.3	100.0	-	-	-	1.9	-	0.6	0.4	10	10	100.0	0.0
	b. Other unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	TOTAL	16	81	71	79	105	247	352	100.0	100.0	100.0	100.0	188.6	230.2	148.8	150.6	187.0	177.7	179.8	2607	3542	97.4	0.0

† includes 7 non-malignant

Please consult the quality indicators for this registry

The Netherlands

Netherlands Cancer Registry, 1993–2013

Otto Visser, Henrike Karim-Kos, Brendy Wauben-Spaetgens, Karin Timmermans

The Netherlands is located in western Europe. It is bordered by Germany to the east, Belgium to the south, and the North Sea to the north-west. Half of the mainland area is 1 m above sea level or lower. The mild climate is favourable to highly developed intensive agriculture. The standard of living is high, with universal health care, public education, and a wide range of social benefits. The country is very densely populated, with a population of 16.6 million in an area of 41 543 km^2. About 23% of the population is younger than 20 years (Table A.6).

Cancer care is provided by all hospitals in the Netherlands (eight university hospitals, one specialized cancer hospital, and more than 70 general hospitals). However, cancer care is increasingly centralized in a limited number of institutions. Because of these mergers, the number of general hospitals has decreased in recent decades. On average, 1000–1500 new cancer cases per year are diagnosed in each general hospital (up to 2500 in the largest hospitals), compared with fewer than 500 new cases per year in each general hospital 25 years ago. Radiotherapy is available in all university hospitals and several general hospitals. The Netherlands Comprehensive Cancer Organisation (IKNL) is a partnership between health-care professionals and cancer and palliative care institutions. IKNL facilitates access to comprehensive, high-quality cancer care (e.g. by coordinating specialist consultation and support networks and by assembling tumour-specific working groups to develop, implement, and evaluate cancer guidelines); it is funded by the Ministry of Health, Welfare, and Sport.

The Netherlands Cancer Registry covers all 17 million residents. It is maintained by IKNL. The main source of information is the national pathology archive, which sends weekly notifications of all cancer cases. Once a year, the registry is linked with the national hospital discharge register (which provides 5–10% of the registry's registered cases). Hospital records are reviewed by specially trained registration clerks for additional cases. Death certificates are not available, because of privacy regulations. The registry has been population-based since 1989 (Table A.10), and the data are more than 95% complete. However, cases diagnosed only at the time of death are missed, as are cases with no associated pathology records.

The registry publishes national and regional data on annual cancer incidence, prevalence, and survival online (https://iknl.nl/). It also receives more than 400 requests per year for more detailed information. Registry data are used to support numerous projects in collaboration with hospitals and universities, such as evaluations of guidelines and the national cancer control plan.

POPULATION AT RISK

The source of the population data is Statistics Netherlands (https://opendata.cbs.nl/statline/#/CBS/en). The census in the Netherlands has been register-based since 1971 and was complemented by a survey in 2011 (Table A.7). Data were provided in the requested detail.

EDITORS' COMMENTS

The registry participated in IICC-2 (Table A.1). Although non-malignant CNS tumours were included only from 1999 onwards, they made up 42.5% of the CNS tumours (Table A.9). The absence of DCO cases may indicate that a small proportion of new cases are missed by the registry. Pilocytic astrocytoma was coded with uncertain behaviour. Because of privacy regulations the registry could not provide day of birth or day of incidence (Table A.8). The first occurrence of squamous skin carcinoma, melanoma, and other skin carcinoma in a patient is registered. Laterality data are complete. Carcinoid tumours of the appendix were coded with malignant behaviour and made up 2.5% of all cases (Table A.11).

THE NETHERLANDS (1993-2013)

	Age group (years)	Males	Females
Person-years	0	2 057 545	1 960 207
	1-4	8 365 968	7 985 734
	5-9	10 535 909	10 065 512
	10-14	10 413 205	9 950 681
	15-19	10 364 100	9 897 131
	0-14	31 372 627	29 962 134
	0-19	41 736 727	39 859 265
Average annual population	0-14	1 493 935	1 426 768
	0-19	1 987 463	1 898 060

Please consult the quality indicators for this registry

THE NETHERLANDS (1993-2013)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	167	1334	772	574	508	**2847**	**3355**	30.9	100.0	24.3	100.0	41.6	81.6	37.5	28.2	25.1	**48.8**	**43.5**	697	822	100.0	0.0
	a. Lymphoid	77	1109	650	393	283	**2229**	**2512**	24.2	78.3	18.2	74.9	19.2	67.8	31.6	19.3	14.0	**38.3**	**32.8**	545	615	100.0	0.0
	b. Acute myeloid	62	180	80	130	148	**452**	**600**	4.9	15.9	4.3	17.9	15.4	11.0	3.9	6.4	7.3	**7.7**	**7.6**	111	147	100.0	0.0
	c. CMD	3	4	17	19	46	**43**	**89**	0.5	1.5	0.6	2.7	0.7	0.2	0.8	0.9	2.3	**0.7**	**1.0**	11	22	100.0	0.0
	d. MDS & other	24	38	23	26	27	**111**	**138**	1.2	3.9	1.0	4.1	6.0	2.3	1.1	1.3	1.3	**1.9**	**1.8**	27	34	100.0	0.0
	e. Unspecified	1	3	2	6	4	**12**	**16**	0.1	0.4	0.1	0.5	0.2	0.2	0.1	0.3	0.2	**0.2**	**0.2**	3	4	100.0	0.0
II	LYMPHOMA & RELATED	33	191	326	519	1098	**1069**	**2167**	11.6	100.0	15.7	100.0	8.2	11.7	15.8	25.5	54.2	**16.8**	**25.2**	262	532	100.0	0.0
	a. Hodgkin	0	16	77	268	761	**361**	**1122**	3.9	33.8	8.1	51.8	-	1.0	3.7	13.2	37.6	**5.3**	**12.6**	88	276	100.0	0.0
	b. Non-Hodgkin except BL	9	75	124	162	283	**370**	**653**	4.0	34.6	4.7	30.1	2.2	4.6	6.0	8.0	14.0	**5.8**	**7.7**	90	160	100.0	0.0
	c. Burkitt (BL)	1	64	114	82	43	**261**	**304**	2.8	24.4	2.2	14.0	0.2	3.9	5.5	4.0	2.1	**4.2**	**3.7**	64	74	100.0	0.0
	d. Lymphoreticular	23	36	10	6	8	**75**	**83**	0.8	7.0	0.6	3.8	5.7	2.2	0.5	0.3	0.4	**1.4**	**1.1**	18	20	100.0	0.0
	e. Unspecified	0	0	1	1	3	**2**	**5**	0.0	0.2	0.0	0.2	-	-	0.0	0.0	0.1	**0.0**	**0.1**	0	1	100.0	0.0
III	CNS NEOPLASMS †	124	624	706	609	618	**2063**	**2681**	22.4	100.0	19.4	100.0	30.9	38.2	34.3	29.9	30.5	**34.0**	**33.2**	504	657	82.7	0.0
	a. Ependymoma	23	106	53	52	51	**234**	**285**	2.5	11.3	2.1	10.6	5.7	6.5	2.6	2.6	2.5	**4.0**	**3.7**	57	70	99.6	0.0
	b. Astrocytoma	42	215	287	241	227	**785**	**1012**	8.5	38.1	7.3	37.7	10.5	13.1	13.9	11.8	11.2	**12.8**	**12.5**	192	248	90.2	0.0
	c. CNS embryonal	32	164	153	81	43	**430**	**473**	4.7	20.8	3.4	17.6	8.0	10.0	7.4	4.0	2.1	**7.3**	**6.1**	105	116	100.0	0.0
	d. Other gliomas	6	52	86	61	40	**205**	**245**	2.2	9.9	1.8	9.1	1.5	3.2	4.2	3.0	2.0	**3.3**	**3.0**	50	60	51.4	0.0
	e. Other specified	13	56	88	139	228	**296**	**524**	3.2	14.3	3.8	19.5	3.2	3.4	4.3	6.8	11.3	**4.7**	**6.2**	72	129	80.3	0.0
	f. Unspecified CNS	8	31	39	35	29	**113**	**142**	1.2	5.5	1.0	5.3	2.0	1.9	1.9	1.7	1.4	**1.9**	**1.8**	28	35	0.7	0.0
IV	NEUROBLASTOMA	167	224	40	14	9	**445**	**454**	4.8	100.0	3.3	100.0	41.6	13.7	1.9	0.7	0.4	**8.3**	**6.5**	109	111	98.5	0.0
	a. (Ganglio)neuroblastoma	167	222	36	10	4	**435**	**439**	4.7	97.8	3.2	96.7	41.6	13.6	1.7	0.5	0.2	**8.1**	**6.3**	107	108	98.4	0.0
	b. Peripheral nervous	0	2	4	4	5	**10**	**15**	0.1	2.2	0.1	3.3	-	0.1	0.2	0.2	0.2	**0.2**	**0.2**	2	4	100.0	0.0
V	RETINOBLASTOMA	109	133	18	1	0	**261**	**261**	2.8	100.0	1.9	100.0	27.1	8.1	0.9	0.0	-	**4.9**	**3.8**	64	64	80.8	0.0
VI	RENAL TUMOURS	69	347	109	19	20	**544**	**564**	5.9	100.0	4.1	100.0	17.2	21.2	5.3	0.9	1.0	**9.9**	**7.9**	133	138	96.5	0.0
	a. Nephroblastoma	69	346	104	16	6	**535**	**541**	5.8	98.3	3.9	95.9	17.2	21.2	5.0	0.8	0.3	**9.7**	**7.6**	131	133	96.3	0.0
	b. Renal carcinoma	0	1	5	3	14	**9**	**23**	0.1	1.7	0.2	4.1	-	0.1	0.2	0.1	0.7	**0.1**	**0.3**	2	6	100.0	0.0
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VII	HEPATIC TUMOURS	39	56	26	13	22	**134**	**156**	1.5	100.0	1.1	100.0	9.7	3.4	1.3	0.6	1.1	**2.4**	**2.1**	33	38	98.7	0.0
	a. Hepatoblastoma	38	53	19	3	2	**113**	**115**	1.2	84.3	0.8	73.7	9.5	3.2	0.9	0.1	0.1	**2.1**	**1.6**	28	28	98.3	0.0
	b. Hepatic carcinoma	1	3	7	10	20	**21**	**41**	0.2	15.7	0.3	26.3	0.2	0.2	0.3	0.5	1.0	**0.3**	**0.5**	5	10	100.0	0.0
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VIII	BONE TUMOURS	3	33	144	292	340	**472**	**812**	5.1	100.0	5.9	100.0	0.7	2.0	7.0	14.3	16.8	**7.1**	**9.3**	115	199	100.0	0.0
	a. Osteosarcoma	0	3	59	153	191	**215**	**406**	2.3	45.6	2.9	50.0	-	0.2	2.9	7.5	9.4	**3.2**	**4.6**	53	100	100.0	0.0
	b. Chondrosarcoma	0	0	1	4	21	**5**	**26**	0.1	1.1	0.2	3.2	-	-	0.0	0.2	1.0	**0.1**	**0.3**	1	6	100.0	0.0
	c. Ewing & related	3	26	66	101	100	**196**	**296**	2.1	41.5	2.1	36.5	0.7	1.6	3.2	5.0	4.9	**3.0**	**3.5**	48	73	100.0	0.0
	d. Other specified	0	4	17	31	26	**52**	**78**	0.6	11.0	0.6	9.6	-	0.2	0.8	1.5	1.3	**0.8**	**0.9**	13	19	100.0	0.0
	e. Unspecified	0	0	1	3	2	**4**	**6**	0.0	0.8	0.0	0.7	-	-	0.0	0.1	0.1	**0.1**	**0.1**	1	1	100.0	0.0
IX	SOFT TISSUE SARCOMA	51	190	154	154	315	**549**	**864**	5.9	100.0	6.3	100.0	12.7	11.6	7.5	7.6	15.5	**9.2**	**10.6**	134	212	100.0	0.0
	a. Rhabdomyosarcoma	22	151	102	55	69	**330**	**399**	3.6	60.1	2.9	46.2	5.5	9.2	5.0	2.7	3.4	**5.7**	**5.2**	81	98	100.0	0.0
	b. Fibrosarcoma	10	3	3	12	11	**28**	**39**	0.3	5.1	0.3	4.5	2.5	0.2	0.1	0.6	0.5	**0.5**	**0.5**	7	10	100.0	0.0
	c. Kaposi sarcoma	0	0	1	0	5	**1**	**6**	0.0	0.2	0.0	0.7	-	-	0.0	-	0.2	**0.0**	**0.1**	0	1	100.0	0.0
	d. Other specified	14	28	42	75	203	**159**	**362**	1.7	29.0	2.6	41.9	3.5	1.7	2.0	3.7	10.0	**2.5**	**4.2**	39	89	100.0	0.0
	e. Unspecified	5	8	6	12	27	**31**	**58**	0.3	5.6	0.4	6.7	1.2	0.5	0.3	0.6	1.3	**0.5**	**0.7**	8	14	100.0	0.0
X	GERM CELL TUMOURS	80	58	45	130	630	**313**	**943**	3.4	100.0	6.8	100.0	19.9	3.5	2.2	6.4	31.1	**5.2**	**11.0**	77	232	98.6	0.0
	a. CNS germ cell ‡	14	7	25	43	47	**89**	**136**	1.0	28.4	1.0	14.4	3.5	0.4	1.2	2.1	2.3	**1.4**	**1.6**	22	33	95.6	0.0
	b. Other extragonadal	50	34	0	4	21	**88**	**109**	1.0	28.1	0.8	11.6	12.4	2.1	-	0.2	1.0	**1.7**	**1.5**	22	27	100.0	0.0
	c. Gonadal germ cell	16	16	18	79	537	**129**	**666**	1.4	41.2	4.8	70.6	4.0	1.0	0.9	3.9	26.5	**2.0**	**7.5**	32	164	99.4	0.0
	d. Gonadal carcinoma	0	0	0	4	18	**4**	**22**	0.0	1.3	0.2	2.3	-	-	-	0.2	0.9	**0.1**	**0.2**	1	5	100.0	0.0
	e. Unspecified gonadal	0	1	2	0	7	**3**	**10**	0.0	1.0	0.1	1.1	-	0.1	0.1	-	0.3	**0.1**	**0.1**	1	2	70.0	0.0
XI	CARCINOMA & MELANOMA	8	50	97	353	1013	**508**	**1521**	5.5	100.0	11.0	100.0	2.0	3.1	4.7	17.3	50.0	**7.7**	**17.2**	124	374	99.8	0.0
	a. Adrenocortical	0	8	1	1	4	**10**	**14**	0.1	2.0	0.1	0.9	-	0.5	0.0	0.0	0.2	**0.2**	**0.2**	2	3	100.0	0.0
	b. Thyroid	1	14	32	58	182	**105**	**287**	1.1	20.7	2.1	18.9	0.2	0.9	1.6	2.8	9.0	**1.6**	**3.3**	26	71	100.0	0.0
	c. Nasopharyngeal	0	0	4	16	22	**20**	**42**	0.2	3.9	0.3	2.8	-	-	0.2	0.8	1.1	**0.3**	**0.5**	5	10	100.0	0.0
	d. Melanoma	5	23	36	91	407	**155**	**562**	1.7	30.5	4.1	36.9	1.2	1.4	1.7	4.5	20.1	**2.4**	**6.4**	38	138	99.5	0.0
	e. Skin carcinoma	1	1	5	11	17	**18**	**35**	0.2	3.5	0.3	2.3	0.2	0.1	0.2	0.5	0.8	**0.3**	**0.4**	4	9	100.0	0.0
	f. Other & unspecified	1	4	19	176	381	**200**	**581**	2.2	39.4	4.2	38.2	0.2	0.2	0.9	8.6	18.8	**2.9**	**6.5**	49	143	100.0	0.0
XII	OTHER & UNSPECIFIED	5	11	3	3	16	**22**	**38**	0.2	100.0	0.3	100.0	1.2	0.7	0.1	0.1	0.8	**0.4**	**0.5**	5	9	63.2	0.0
	a. Other specified	2	7	2	3	9	**14**	**23**	0.2	63.6	0.2	60.5	0.5	0.4	0.1	0.1	0.4	**0.2**	**0.3**	3	6	100.0	0.0
	b. Other unspecified	3	4	1	0	7	**8**	**15**	0.1	36.4	0.1	39.5	0.7	0.2	0.0	-	0.3	**0.1**	**0.2**	2	4	6.7	0.0
	TOTAL	855	3251	2440	2681	4589	**9227**	**13816**	100.0	100.0	100.0	100.0	212.8	198.8	118.4	131.7	226.5	**154.5**	**170.7**	2258	3391	95.9	0.0

† includes 1177 non-malignant ‡ includes 17 non-malignant

Please consult the quality indicators for this registry

Norway

Cancer Registry of Norway, 1990–2013

Inger Kristin Larsen, Tom Børge Johannesen, Giske Ursin, Aina Helen Dahlen

Norway covers an area of 324 000 km² and is one of the northernmost countries in the world. Large areas are dominated by the Scandinavian Mountains. The average elevation is 460 m, and 32% of the mainland is located above the tree line. The climate is relatively temperate, mainly because the North Atlantic Current increases the air temperature.

In 2010, the total population was 4.9 million (Table A.7), and about 25% of the population was younger than 20 years (Table A.6). Most of the population is White. First-generation immigrants make up 13.7% of the population (6.5% from industrialized countries and 7.3% from other countries). Norway has a developed mixed economy with heavy state-ownership. The economic growth has been fuelled by an abundance of natural resources, including petroleum exploration and production, hydroelectric power, and fisheries. The country has a very high standard of living compared with other European countries and has a strongly integrated welfare system.

The financing and provision of hospital services is mainly the responsibility of the national government. Norway has a national health service, financed by income and wealth taxation. Out-of-pocket payment is required only for outpatient hospital services and for medication costs above €240 per year. Inpatient hospital services are provided free of charge. Norway has an excellent standard of state-funded health care. Medical personnel are extremely well trained, and health care is available to all citizens and registered long-term residents. Private health care is also available, but its use is limited. The National Insurance Administration is responsible for the state insurance scheme, which guarantees a basic level of welfare for all.

Four regional health authorities in Norway are responsible for specialist health care. Surgical treatment of cancer is provided in both general hospitals and oncology centres, and radiotherapy is available in 10 separate departments. In 2014, there were about 3.8 hospital beds and 4.4 physicians per 1000 inhabitants.

All hospitals, laboratories, and general practitioners are required to report new cases of cancer. The Ministry of Health and Social Affairs is financially responsible for the Cancer Registry of Norway. The registry has about 150 employees, organized into four departments and three screening units. The staff consists of physicians, researchers, statisticians, research assistants, information and technology staff, and administrative personnel.

The registry receives about 300 000 notifications per year, all of which are coded and registered manually by staff members. The registry also records additional information on all patients treated for cancer, obtained from the Norwegian Patient Register. These data are a key source in ascertaining unreported cases. The estimated completeness for all cases combined is 98.8%, and the MV% is about 95%.

The *Cancer in Norway* report is published annually, with updated numbers on incidence, mortality, survival, and prevalence. The registry receives about 250 requests per year for cancer data for inclusion in cancer research projects. The registry provides updated data to the authorities for use in cancer prevention, cancer care planning, and evaluation of health services.

PUBLICATIONS

Larsen IK, Småstuen M, Johannesen TB, Langmark F, Parkin DM, Bray F, et al. (2009). Data quality at the Cancer Registry of Norway: an overview of comparability, completeness, validity and timeliness. Eur J Cancer. 45(7):1218–31. https://doi.org/10.1016/j.ejca.2008.10.037 PMID:19091545

Cancer Registry of Norway (2016). Cancer in Norway 2015 – cancer incidence, mortality, survival and prevalence in Norway. Oslo, Norway: Cancer Registry of Norway.

POPULATION AT RISK

Population data are provided by Statistics Norway (https://www.ssb.no/en). The data are based on the 1990, 2001, and 2011 censuses (Table A.7). Data were provided in the requested detail.

EDITORS' COMMENTS

The registry participated in both previous IICC volumes (Table A.1). Day of birth and day of incidence were not provided (Table A.8). The reported proportion of non-malignant CNS tumours is high (Table A.9), although all of these were tumours with uncertain behaviour, because there were no benign cases in the dataset and the overall incidence in the diagnostic group III was high. Pilocytic astrocytoma was coded with malignant behaviour until 1992 and with uncertain behaviour thereafter. Although the registry records all malignant cases, only seven skin carcinomas were present in the dataset. Information on laterality was not provided.

NORWAY (1990-2013)

	Age group (years)	Males	Females
Person-years	0	730 442	692 187
	1-4	2 944 874	2 799 643
	5-9	3 623 807	3 446 252
	10-14	3 581 233	3 399 809
	15-19	3 597 362	3 417 583
	0-14	10 880 356	10 337 891
	0-19	14 477 718	13 755 474
Average annual population	0-14	453 348	430 745
	0-19	603 238	573 145

Please consult the quality indicators for this registry

NORWAY (1990-2013)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	**LEUKAEMIA**	65	511	256	192	176	**1024**	**1200**	30.0	100.0	23.6	100.0	45.7	89.0	36.2	27.5	25.1	**50.8**	**45.0**	720	846	99.8	0.1
	a. Lymphoid	33	417	218	139	110	**807**	**917**	23.7	78.8	18.0	76.4	23.2	72.6	30.8	19.9	15.7	**40.0**	**34.6**	568	646	99.9	0.0
	b. Acute myeloid	26	71	34	34	37	**165**	**202**	4.8	16.1	4.0	16.8	18.3	12.4	4.8	4.9	5.3	**8.2**	**7.5**	116	142	99.5	0.5
	c. CMD	0	6	1	8	22	**15**	**37**	0.4	1.5	0.7	3.1	-	1.0	0.1	1.1	3.1	**0.7**	**1.2**	11	26	100.0	0.0
	d. MDS & other	6	10	2	8	6	**26**	**32**	0.8	2.5	0.6	2.7	4.2	1.7	0.3	1.1	0.9	**1.3**	**1.2**	18	23	100.0	0.0
	e. Unspecified	0	7	1	3	1	**11**	**12**	0.3	1.1	0.2	1.0	-	1.2	0.1	0.4	0.1	**0.5**	**0.5**	8	8	100.0	0.0
II	**LYMPHOMA & RELATED**	17	66	97	168	345	**348**	**693**	10.2	100.0	13.6	100.0	11.9	11.5	13.7	24.1	49.2	**15.9**	**23.4**	247	493	99.6	0.0
	a. Hodgkin	2	5	28	83	226	**118**	**344**	3.5	33.9	6.8	49.6	1.4	0.9	4.0	11.9	32.2	**5.1**	**11.2**	84	245	99.7	0.0
	b. Non-Hodgkin except BL	2	27	37	57	83	**123**	**206**	3.6	35.3	4.0	29.7	1.4	4.7	5.2	8.2	11.8	**5.6**	**7.0**	87	146	99.0	0.0
	c. Burkitt (BL)	0	12	21	23	22	**56**	**78**	1.6	16.1	1.5	11.3	-	2.1	3.0	3.3	3.1	**2.6**	**2.7**	40	55	100.0	0.0
	d. Lymphoreticular	13	21	8	5	9	**47**	**56**	1.4	13.5	1.1	8.1	9.1	3.7	1.1	0.7	1.3	**2.4**	**2.2**	33	39	100.0	0.0
	e. Unspecified	0	1	3	0	5	**4**	**9**	0.1	1.1	0.2	1.3	-	0.2	0.4	-	0.7	**0.2**	**0.3**	3	6	100.0	0.0
III	**CNS NEOPLASMS** †	113	293	319	291	358	**1016**	**1374**	29.8	100.0	27.0	100.0	79.4	51.0	45.1	41.7	51.0	**48.6**	**49.1**	717	972	82.5	0.2
	a. Ependymoma	20	35	16	13	17	**84**	**101**	2.5	8.3	2.0	7.4	14.1	6.1	2.3	1.9	2.4	**4.2**	**3.8**	59	71	97.0	0.0
	b. Astrocytoma	29	116	105	104	103	**354**	**457**	10.4	34.8	9.0	33.3	20.4	20.2	14.9	14.9	14.7	**16.9**	**16.4**	250	323	93.4	0.0
	c. CNS embryonal	24	50	73	32	34	**179**	**213**	5.2	17.6	4.2	15.5	16.9	8.7	10.3	4.6	4.8	**8.7**	**7.8**	126	150	99.5	0.0
	d. Other gliomas	2	17	36	26	44	**81**	**125**	2.4	8.0	2.5	9.1	1.4	3.0	5.1	3.7	6.3	**3.8**	**4.3**	57	89	71.2	0.0
	e. Other specified	5	21	36	64	72	**126**	**198**	3.7	12.4	3.9	14.4	3.5	3.7	5.1	9.2	10.3	**5.7**	**6.7**	89	141	88.4	0.0
	f. Unspecified CNS	33	54	53	52	88	**192**	**280**	5.6	18.9	5.5	20.4	23.2	9.4	7.5	7.4	12.5	**9.3**	**10.0**	135	198	47.5	1.1
IV	**NEUROBLASTOMA**	65	91	15	4	7	**175**	**182**	5.1	100.0	3.6	100.0	45.7	15.8	2.1	0.6	1.0	**9.3**	**7.4**	122	127	99.5	0.0
	a. (Ganglio)neuroblastoma	65	90	14	4	5	**173**	**178**	5.1	98.9	3.5	97.8	45.7	15.7	2.0	0.6	0.7	**9.2**	**7.3**	121	124	99.4	0.0
	b. Peripheral nervous	0	1	1	0	2	**2**	**4**	0.1	1.1	0.1	2.2	-	0.2	0.1	-	0.3	**0.1**	**0.1**	1	3	100.0	0.0
V	**RETINOBLASTOMA**	34	48	3	0	0	**85**	**85**	2.5	100.0	1.7	100.0	23.9	8.4	0.4	-	-	**4.6**	**3.5**	59	59	67.1	0.0
VI	**RENAL TUMOURS**	20	92	36	12	6	**160**	**166**	4.7	100.0	3.3	100.0	14.1	16.0	5.1	1.7	0.9	**8.2**	**6.5**	112	116	99.4	0.0
	a. Nephroblastoma	20	90	34	8	0	**152**	**152**	4.5	95.0	3.0	91.6	14.1	15.7	4.8	1.1	-	**7.8**	**6.1**	107	107	100.0	0.0
	b. Renal carcinoma	0	0	0	2	6	**2**	**8**	0.1	1.3	0.2	4.8	-	-	-	0.3	0.9	**0.1**	**0.3**	1	6	100.0	0.0
	c. Unspecified	0	2	2	2	0	**6**	**6**	0.2	3.8	0.1	3.6	-	0.3	0.3	0.3	-	**0.3**	**0.2**	4	4	83.3	0.0
VII	**HEPATIC TUMOURS**	15	30	4	7	11	**56**	**67**	1.6	100.0	1.3	100.0	10.5	5.2	0.6	1.0	1.6	**2.9**	**2.6**	39	47	98.5	0.0
	a. Hepatoblastoma	13	27	0	0	1	**40**	**41**	1.2	71.4	0.8	61.2	9.1	4.7	-	-	0.1	**2.2**	**1.7**	28	29	97.6	0.0
	b. Hepatic carcinoma	2	3	4	7	10	**16**	**26**	0.5	28.6	0.5	38.8	1.4	0.5	0.6	1.0	1.4	**0.7**	**0.9**	11	18	100.0	0.0
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VIII	**BONE TUMOURS**	1	6	36	97	104	**140**	**244**	4.1	100.0	4.8	100.0	0.7	1.0	5.1	13.9	14.8	**6.1**	**8.0**	100	174	97.5	0.0
	a. Osteosarcoma	0	1	17	55	60	**73**	**133**	2.1	52.1	2.6	54.5	-	0.2	2.4	7.9	8.6	**3.1**	**4.3**	52	95	98.5	0.0
	b. Chondrosarcoma	0	0	0	2	10	**2**	**12**	0.1	1.4	0.2	4.9	-	-	-	0.3	1.4	**0.1**	**0.4**	1	9	100.0	0.0
	c. Ewing & related	0	3	14	32	22	**49**	**71**	1.4	35.0	1.4	29.1	-	0.5	2.0	4.6	3.1	**2.1**	**2.4**	35	51	98.6	0.0
	d. Other specified	0	2	4	7	7	**13**	**20**	0.4	9.3	0.4	8.2	-	0.3	0.6	1.0	1.0	**0.6**	**0.7**	9	14	95.0	0.0
	e. Unspecified	1	0	1	1	5	**3**	**8**	0.1	2.1	0.2	3.3	0.7	-	0.1	0.1	0.7	**0.1**	**0.3**	2	6	75.0	0.0
IX	**SOFT TISSUE SARCOMA**	24	57	40	66	101	**187**	**288**	5.5	100.0	5.7	100.0	16.9	9.9	5.7	9.5	14.4	**8.9**	**10.2**	132	204	100.0	0.0
	a. Rhabdomyosarcoma	13	44	20	18	17	**95**	**112**	2.8	50.8	2.2	38.9	9.1	7.7	2.8	2.6	2.4	**4.7**	**4.2**	67	79	100.0	0.0
	b. Fibrosarcoma	4	3	4	11	17	**22**	**39**	0.6	11.8	0.8	13.5	2.8	0.5	0.6	1.6	2.4	**1.0**	**1.3**	16	28	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	d. Other specified	3	7	13	30	54	**53**	**107**	1.6	28.3	2.1	37.2	2.1	1.2	1.8	4.3	7.7	**2.4**	**3.6**	38	76	100.0	0.0
	e. Unspecified	4	3	3	7	13	**17**	**30**	0.5	9.1	0.6	10.4	2.8	0.5	0.4	1.0	1.9	**0.8**	**1.0**	12	21	100.0	0.0
X	**GERM CELL TUMOURS**	17	26	15	55	260	**113**	**373**	3.3	100.0	7.3	100.0	11.9	4.5	2.1	7.9	37.1	**5.3**	**12.4**	80	265	98.9	0.0
	a. CNS germ cell ‡	1	3	8	16	17	**28**	**45**	0.8	24.8	0.9	12.1	0.7	0.5	1.1	2.3	2.4	**1.2**	**1.5**	20	32	97.8	0.0
	b. Other extragonadal	8	9	1	1	3	**19**	**22**	0.6	16.8	0.4	5.9	5.6	1.6	0.1	0.1	0.4	**1.0**	**0.9**	13	15	90.9	0.0
	c. Gonadal germ cell	8	13	5	30	220	**56**	**276**	1.6	49.6	5.4	74.0	5.6	2.3	0.7	4.3	31.4	**2.6**	**9.1**	40	196	100.0	0.0
	d. Gonadal carcinoma	0	0	0	6	11	**6**	**17**	0.2	5.3	0.3	4.6	-	-	-	0.9	1.6	**0.2**	**0.5**	4	12	100.0	0.0
	e. Unspecified gonadal	0	1	1	2	9	**4**	**13**	0.1	3.5	0.3	3.5	-	0.2	0.1	0.3	1.3	**0.2**	**0.4**	3	9	92.3	0.0
XI	**CARCINOMA & MELANOMA**	0	7	15	69	301	**91**	**392**	2.7	100.0	7.7	100.0	-	1.2	2.1	9.9	42.9	**3.9**	**12.7**	65	279	99.0	0.0
	a. Adrenocortical	0	2	1	1	1	**4**	**5**	0.1	4.4	0.1	1.3	-	0.3	0.1	0.1	0.1	**0.2**	**0.2**	3	4	100.0	0.0
	b. Thyroid	0	0	4	17	69	**21**	**90**	0.6	23.1	1.8	23.0	-	-	0.6	2.4	9.8	**0.9**	**2.9**	15	64	98.9	0.0
	c. Nasopharyngeal	0	0	1	0	4	**1**	**5**	0.0	1.1	0.1	1.3	-	-	0.1	-	0.6	**0.0**	**0.2**	1	4	100.0	0.0
	d. Melanoma	0	2	5	15	125	**22**	**147**	0.6	24.2	2.9	37.5	-	0.3	0.7	2.1	17.8	**1.0**	**4.8**	16	105	98.6	0.0
	e. Skin carcinoma	0	0	0	0	7	**0**	**7**	-	-	0.1	1.8	-	-	-	-	1.0	**-**	**0.2**	-	5	100.0	0.0
	f. Other & unspecified	0	3	4	36	95	**43**	**138**	1.3	47.3	2.7	35.2	-	0.5	0.6	5.2	13.5	**1.8**	**4.5**	31	98	99.3	0.0
XII	**OTHER & UNSPECIFIED**	5	4	4	2	11	**15**	**26**	0.4	100.0	0.5	100.0	3.5	0.7	0.6	0.3	1.6	**0.8**	**0.9**	11	18	65.4	0.0
	a. Other specified	1	1	0	0	3	**2**	**5**	0.1	13.3	0.1	19.2	0.7	0.2	-	-	0.4	**0.1**	**0.2**	1	4	100.0	0.0
	b. Other unspecified	4	3	4	2	8	**13**	**21**	0.4	86.7	0.4	80.8	2.8	0.5	0.6	0.3	1.1	**0.6**	**0.8**	9	15	57.1	0.0
	TOTAL	376	1231	840	963	1680	**3410**	**5090**	100.0	100.0	100.0	100.0	264.3	214.3	118.8	137.9	239.5	**165.2**	**181.9**	2405	3602	94.1	0.1

† includes 709 non-malignant ‡ includes 1 non-malignant

Please consult the quality indicators for this registry

Poland

Poland covers an area of 312 680 km^2 in central Europe. It is bounded by the Baltic Sea to the north and shares borders with the Russian Federation, Lithuania, Belarus, Ukraine, Slovakia, the Czech Republic, and Germany. Poland has a continental climate, affected by westerly winds.

Poland is a developed and democratic country with a high-income economy and very high standards of living, safety, education, and economic freedom. Exports include machinery, furniture, food products, clothing, shoes, and cosmetics. A large number of private farms produce food for the European Union market. Poland's environmental situation has improved since the ouster of the communist regime in 1989, because the emphasis on heavy industry decreased and government awareness of environmental issues increased.

Poland has a state-funded social security system and a universal health-care system for all citizens. The health-care system is based on an all-inclusive insurance system. State-subsidized health care is available to all Polish citizens and includes specialized paediatric and oncological care. Insurance coverage is compulsory for children.

In 2010, the population was 38.6 million (Table A.7), and 21% of the population was younger than 20 years (Table A.6). About 60% of the population lives in urban areas, and the average population density is 122 per km^2. The population is predominantly White Slavonic. In recent years, an increase in emigration and a decrease in the birth rate has produced stagnant population growth. In 2013, the total fertility rate was estimated to be 1.33 children per woman. Polish society is homogeneous; there are no large groups of ethnic minorities. The country is divided into 16 regions (voivodeships); the capital city of Warsaw is located in Masovian Voivodeship.

Cancer registration in Poland has national coverage and includes all age groups. Notification of all cancer cases became mandatory in 1962. A law on public statistics that went into effect on 29 June 1995 and the Personal Data Control Act of 29 August 1997 require all health-care institutions and physicians to report all cancer cases at diagnosis or at follow-up visits using a standard cancer notification form. The form can be completed either on paper or electronically through a personal account in the registry system. Cancer cases are also ascertained from death certificates. All 16 voivodeships have a population-based cancer registry.

All malignancies defined by ICD-10 codes C00–C97 and all in situ neoplasms D00–D09 were always reportable. From 2013, neoplasms of uncertain or unknown behaviour (D37–D48) are also registered. The collected data were coded using ICD-10 on the notification forms and then recoded to ICD-O-3 in the registries (Table A.10). Since 2013, ICD-O-3 is also used as a standard coding system.

In 2010–2013, the Polish National Cancer Registry developed a web-based platform for the exchange of knowledge on the cancer burden. The project was supported by the European Regional Development Fund, and the principal goal was to improve the quality of epidemiological data on malignant tumours and facilitate the conduct of modern epidemiological studies using information technologies. An electronic system was developed through which all 16 regional registries provide data to the central database at the Polish National Cancer Registry in Warsaw (http://onkologia.org.pl), and the regional registries also cooperate among themselves.

POPULATION AT RISK

The source of population data for all registries is the Central Statistical Office of Poland (https://stat.gov.pl/en/topics/population/population). Population estimates are based on national censuses conducted in 1988, 1995 (survey), 2002, and 2011 (Table A.7). All censuses except the 2011 census were based on the traditional method in which census enumerators visit all inhabited units in person. In the 2011 census, a mixed method was used in which data from records and information systems were combined with data obtained through direct statistical surveys. Population data are produced annually as at 31 December. All registries provided data in the requested detail by sex and single year of age for each calendar year of the reporting period.

EDITORS' COMMENTS

Although Poland is included in all three IICC volumes, none of the earlier participating registries provided data to IICC-3 (Table A.1). In IICC-3, datasets from five Polish registries are included. The national dataset is presented in the IICC-3 book, and the standard tables for the regional registries of Greater Poland, Kielce, Lower Silesia, and Lublin are available online (Table A.12).

Date of incidence was incomplete in all Polish datasets (Table A.8). The incomplete dates may have affected the age-specific rates. Non-malignant CNS tumours other than pilocytic astrocytoma were not registered during the reporting period (Table A.9), and the registries used different rules for coding the behaviour of pilocytic astrocytoma. Laterality was recorded, but it was incomplete in all contributing registries. Skin carcinomas were reportable in all of the Polish cancer registries.

Polish National Cancer Registry, 2001–2013

Urszula Wojciechowska, Joanna Didkowska

The Polish National Cancer Registry began registering cancer data in 1956 (Table A.10). In 2013, the structure of the registry was changed by the ordinance of the Minister of Health, making it a unit of the Cancer Centre and Institute of Oncology in Warsaw, which is responsible for the registry. Data on cancer incidence are received electronically via an online connection with the registration offices of the 16 voivodeships and recorded in the central database.

The coding system used on the registration forms is ICD-10; the cancers are recoded to ICD-O-3 in the Polish National Cancer Registry according to conversion tables. The completeness of registration in voivodeships varies between 80% and 96%. The lower rate of completeness is caused by lack of access to data sources (pathology laboratories), lack of cooperation with the childhood cancer centres, and organizational and financial problems related to the cancer registration system. Registered cases are followed up for vital status using data obtained from death certificates collected by the Central Statistical Office. The Polish National Cancer Registry publishes annual reports on cancer statistics (http://onkologia.org.pl, http://onkologia.org.pl/publikacje).

POPULATION AT RISK
See Poland, above.

EDITORS' COMMENTS
Day of incidence was not available for 14% of cases (Table A.8). The proportion of cases with unspecified morphology was relatively high (Table A.9) because of inadequate cooperation between the regional cancer registries and cancer centres. Non-malignant CNS tumours made up 7% of the dataset (Table A.9); they were all cases of pilocytic astrocytoma, which were coded with uncertain behaviour. Laterality information was available for 58% of the cases of interest. See also Poland, above.

POLAND (2001-2013)

	Age group (years)	Males	Females
Person-years	0	2 533 456	2 396 363
	1-4	10 227 312	9 696 809
	5-9	13 208 126	12 564 747
	10-14	15 334 746	14 618 102
	15-19	18 319 818	17 524 738
	0-14	41 303 640	39 276 021
	0-19	59 623 458	56 800 759
Average annual population	0-14	3 177 203	3 021 232
	0-19	4 586 420	4 369 289

Please consult the quality indicators for this registry

Greater Poland Cancer Registry, 1999–2013

Maciej Trojanowski, Anna Kubiak, Wiesława Olenderczyk, Agata Plucińska, Beata Szczęch, Łukasz Taraszkiewicz, Teresa Wosicka

Greater Poland Voivodeship is located in west-central Poland and is the second largest voivodeship, covering an area of 29 825 km^2. Agricultural land accounts for 60% of the area, and 26% of the province is covered by forests. The voivodeship has about 800 lakes and one main river, the Warta River. The climate is mild as a result of the influence of oceanic air masses. The voivodeship has two national parks and 12 landscape parks, which are protected areas. Greater Poland is one of the most developed regions in the country. In 2010, the population was 3.4 million, and 23% of the population was younger than 20 years (Table A.6). Although more than half of the population lives in cities, this percentage is slowly decreasing in favour of rural areas.

Most children with cancer are treated in the Oncology, Haematology and Paediatric Transplant Clinic at the University Hospital of the University of Medical Sciences in Poznań. Radiotherapy services are provided at the Greater Poland Cancer Centre in Poznań.

The Greater Poland Cancer Registry is located in the Greater Poland Cancer Centre and cooperates closely with both units that treat children with cancer. The completeness of cancer registration based on the incidence-to-mortality ratio was 100% in 2013. Follow-up of the patients is based on data from cancer notification forms, hospital admissions records, patient records, and mortality data from the Central Statistical Office of Poland. Data collected by the registry are published annually as the bulletin *Cancer in the Region of Greater Poland*. Registry data are also used in many epidemiological studies at the local and international levels: ENCR, CONCORD, European Registration of Cancer Care (EURECCA) Breast Study Group, European study on breast and colorectal cancer, IICC-3, the Southern and Eastern European Group of Cancer Registries exploring childhood cancers, and others.

PUBLICATIONS
Doganis D, Panagopoulou P, Tragiannidis A, Vichos T, Moschovi M, Polychronopoulou S, et al. (2018). Survival and mortality rates of Wilms tumour in Southern and Eastern European countries: socioeconomic differentials compared with the United States of America. Eur J Cancer. 101:38–46. https://doi.org/10.1016/j.ejca.2018.06.012 PMID:30014973

Georgakis MK, Dessypris N, Baka M, Moschovi M, Papadakis V, Polychronopoulou S, et al. (2018). Neuroblastoma among children in Southern and Eastern European cancer registries: variations in incidence and temporal trends compared to US. Int J Cancer. 142(10):1977–85. https://doi.org/10.1002/ijc.31222 PMID:29250786

POPULATION AT RISK
See Poland, above.

EDITORS' COMMENTS
Day of incidence was not available for more than 50% of cases, and the age calculated at IARC was used in all analyses (Table A.8). Non-malignant CNS tumours were recorded and consisted of a few cases of pilocytic astrocytoma coded with uncertain behaviour and one benign case. Laterality was available for 80% of the cases of interest. See also Poland, above.

Kielce, Holy Cross Cancer Registry, 1990–2013

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Holy Cross Voivodeship covers an area of 11 691 km^2 and is located in south-central Poland. The region comprises the Holy Cross Mountains in the north and agricultural land in the south. The Vistula River forms the south-eastern border of the voivodeship. The annual average temperature is 6.9 °C, although the temperature may vary between −30 °C and 30 °C. The average annual rainfall is about 565 mm. The total population is 1.3 million, and 21% of the population is younger than 20 years (Table A.6). More than half the population (55%) lives in rural areas.

The Holy Cross Cancer Centre is located in Kielce, which is the capital city of Holy Cross Voivodeship. This

POLAND (2001-2013)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	144	1453	845	676	743	**3118**	**3861**	30.6	100.0	23.9	100.0	29.2	72.9	32.8	22.6	20.7	**42.0**	**37.2**	598	702	99.6	0.0
	a. Lymphoid	85	1225	716	458	433	**2484**	**2917**	24.3	79.7	18.1	75.6	17.2	61.5	27.8	15.3	12.1	**33.8**	**28.9**	479	539	99.7	0.0
	b. Acute myeloid	45	180	95	152	237	**472**	**709**	4.6	15.1	4.4	18.4	9.1	9.0	3.7	5.1	6.6	**6.2**	**6.3**	89	122	99.6	0.0
	c. CMD	1	8	15	36	46	**60**	**106**	0.6	1.9	0.7	2.7	0.2	0.4	0.6	1.2	1.3	**0.7**	**0.8**	11	17	99.1	0.0
	d. MDS & other	2	4	0	1	0	**7**	**7**	0.1	0.2	0.0	0.2	0.4	0.2	-	0.0	-	**0.1**	**0.1**	1	1	100.0	0.0
	e. Unspecified	11	36	19	29	27	**95**	**122**	0.9	3.0	0.8	3.2	2.2	1.8	0.7	1.0	0.8	**1.3**	**1.1**	18	22	97.5	0.0
II	LYMPHOMA & RELATED	27	192	392	671	1445	**1282**	**2727**	12.6	100.0	16.9	100.0	5.5	9.6	15.2	22.4	40.3	**14.8**	**20.6**	232	434	99.5	0.0
	a. Hodgkin	0	45	120	386	1042	**551**	**1593**	5.4	43.0	9.9	58.4	-	2.3	4.7	12.9	29.1	**5.9**	**11.1**	97	242	99.4	0.0
	b. Non-Hodgkin except BL	6	66	144	171	271	**387**	**658**	3.8	30.2	4.1	24.1	1.2	3.3	5.6	5.7	7.6	**4.6**	**5.3**	71	109	99.7	0.0
	c. Burkitt (BL)	0	32	87	62	49	**181**	**230**	1.8	14.1	1.4	8.4	-	1.6	3.4	2.1	1.4	**2.2**	**2.0**	34	41	100.0	0.0
	d. Lymphoreticular	21	44	25	21	15	**111**	**126**	1.1	8.7	0.8	4.6	4.3	2.2	1.0	0.7	0.4	**1.5**	**1.3**	21	24	100.0	0.0
	e. Unspecified	0	5	16	31	68	**52**	**120**	0.5	4.1	0.7	4.4	-	0.3	0.6	1.0	1.9	**0.6**	**0.9**	9	19	99.2	0.0
III	CNS NEOPLASMS †	133	577	651	623	757	**1984**	**2741**	19.4	100.0	17.0	100.0	27.0	29.0	25.3	20.8	21.1	**25.2**	**24.3**	373	479	77.7	1.1
	a. Ependymoma	24	93	53	56	74	**226**	**300**	2.2	11.4	1.9	10.9	4.9	4.7	2.1	1.9	2.1	**3.0**	**2.8**	43	53	100.0	0.0
	b. Astrocytoma	31	152	187	196	282	**566**	**848**	5.5	28.5	5.2	30.9	6.3	7.6	7.3	6.5	7.9	**7.1**	**7.3**	106	145	100.0	0.0
	c. CNS embryonal	35	166	207	176	98	**584**	**682**	5.7	29.4	4.2	24.9	7.1	8.3	8.0	5.9	2.7	**7.4**	**6.4**	110	124	99.9	0.1
	d. Other gliomas	5	41	35	42	73	**123**	**196**	1.2	6.2	1.2	7.2	1.0	2.1	1.4	1.4	2.0	**1.6**	**1.7**	23	33	100.0	0.0
	e. Other specified	3	8	15	21	38	**47**	**85**	0.5	2.4	0.5	3.1	0.6	0.4	0.6	0.7	1.1	**0.6**	**0.7**	9	14	80.0	0.0
	f. Unspecified CNS	35	117	154	132	192	**438**	**630**	4.3	22.1	3.9	23.0	7.1	5.9	6.0	4.4	5.4	**5.6**	**5.5**	82	109	6.0	4.8
IV	NEUROBLASTOMA	252	299	94	45	25	**690**	**715**	6.8	100.0	4.4	100.0	51.1	15.0	3.6	1.5	0.7	**10.2**	**8.1**	137	140	99.9	0.0
	a. (Ganglio)neuroblastoma	248	295	90	36	16	**669**	**685**	6.6	97.0	4.2	95.8	50.3	14.8	3.5	1.2	0.4	**9.9**	**7.8**	133	135	99.9	0.0
	b. Peripheral nervous	4	4	4	9	9	**21**	**30**	0.2	3.0	0.2	4.2	0.8	0.2	0.2	0.3	0.3	**0.3**	**0.3**	4	5	100.0	0.0
V	RETINOBLASTOMA	90	124	24	1	0	**239**	**239**	2.3	100.0	1.5	100.0	18.3	6.2	0.9	0.0	-	**3.6**	**2.8**	48	48	100.0	0.0
VI	RENAL TUMOURS	96	407	142	42	60	**687**	**747**	6.7	100.0	4.6	100.0	19.5	20.4	5.5	1.4	1.7	**10.0**	**8.1**	136	144	92.0	0.5
	a. Nephroblastoma	85	374	131	34	19	**624**	**643**	6.1	90.8	4.0	86.1	17.2	18.8	5.1	1.1	0.5	**9.1**	**7.2**	123	126	99.8	0.2
	b. Renal carcinoma	3	0	6	4	27	**13**	**40**	0.1	1.9	0.2	5.4	0.6	-	0.2	0.1	0.8	**0.2**	**0.3**	2	6	100.0	0.0
	c. Unspecified	8	33	5	4	14	**50**	**64**	0.5	7.3	0.4	8.6	1.6	1.7	0.2	0.1	0.4	**0.7**	**0.7**	10	12	7.8	4.7
VII	HEPATIC TUMOURS	54	58	16	24	43	**152**	**195**	1.5	100.0	1.2	100.0	11.0	2.9	0.6	0.8	1.2	**2.2**	**2.0**	30	36	92.3	0.5
	a. Hepatoblastoma	45	57	16	8	3	**126**	**129**	1.2	82.9	0.8	66.2	9.1	2.9	0.6	0.3	0.1	**1.9**	**1.5**	25	25	99.2	0.8
	b. Hepatic carcinoma	0	0	0	15	32	**15**	**47**	0.1	9.9	0.3	24.1	-	-	-	0.5	0.9	**0.1**	**0.3**	3	7	100.0	0.0
	c. Unspecified	9	1	0	1	8	**11**	**19**	0.1	7.2	0.1	9.7	1.8	0.1	-	0.0	0.2	**0.2**	**0.2**	2	3	26.3	0.0
VIII	BONE TUMOURS	9	45	120	359	459	**533**	**992**	5.2	100.0	6.1	100.0	1.8	2.3	4.7	12.0	12.8	**5.8**	**7.4**	94	158	91.9	0.6
	a. Osteosarcoma	0	6	45	160	208	**211**	**419**	2.1	39.6	2.6	42.2	-	0.3	1.7	5.3	5.8	**2.2**	**3.0**	37	66	100.0	0.0
	b. Chondrosarcoma	1	1	8	24	53	**34**	**87**	0.3	6.4	0.5	8.8	0.2	0.1	0.3	0.8	1.5	**0.4**	**0.6**	6	13	100.0	0.0
	c. Ewing & related	3	23	50	135	123	**211**	**334**	2.1	39.6	2.1	33.7	0.6	1.2	1.9	4.5	3.4	**2.3**	**2.6**	37	55	100.0	0.0
	d. Other specified	1	4	7	11	29	**23**	**52**	0.2	4.3	0.3	5.2	0.2	0.2	0.3	0.4	0.8	**0.3**	**0.4**	4	8	100.0	0.0
	e. Unspecified	4	11	10	29	46	**54**	**100**	0.5	10.1	0.6	10.1	0.8	0.6	0.4	1.0	1.3	**0.6**	**0.8**	10	16	20.0	6.0
IX	SOFT TISSUE SARCOMA	63	212	161	202	323	**638**	**961**	6.3	100.0	5.9	100.0	12.8	10.6	6.2	6.7	9.0	**8.3**	**8.4**	120	165	99.9	0.1
	a. Rhabdomyosarcoma	26	144	100	82	82	**352**	**434**	3.4	55.2	2.7	45.2	5.3	7.2	3.9	2.7	2.3	**4.7**	**4.2**	67	79	99.8	0.2
	b. Fibrosarcoma	18	21	18	38	49	**95**	**144**	0.9	14.9	0.9	15.0	3.7	1.1	0.7	1.3	1.4	**1.2**	**1.2**	18	25	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	d. Other specified	13	41	38	64	148	**156**	**304**	1.5	24.5	1.9	31.6	2.6	2.1	1.5	2.1	4.1	**1.9**	**2.4**	29	50	100.0	0.0
	e. Unspecified	6	6	5	18	44	**35**	**79**	0.3	5.5	0.5	8.2	1.2	0.3	0.2	0.6	1.2	**0.4**	**0.6**	6	13	100.0	0.0
X	GERM CELL TUMOURS	67	70	45	132	971	**314**	**1285**	3.1	100.0	8.0	100.0	13.6	3.5	1.7	4.4	27.1	**4.0**	**9.2**	58	194	93.5	0.2
	a. CNS germ cell	7	4	15	41	44	**67**	**111**	0.7	21.3	0.7	8.6	1.4	0.2	0.6	1.4	1.2	**0.8**	**0.9**	12	18	100.0	0.0
	b. Other extragonadal	30	19	4	0	15	**53**	**68**	0.5	16.9	0.4	5.3	6.1	1.0	0.2	-	0.4	**0.8**	**0.7**	11	13	100.0	0.0
	c. Gonadal germ cell	25	43	19	71	781	**158**	**939**	1.5	50.3	5.8	73.1	5.1	2.2	0.7	2.4	21.8	**2.0**	**6.4**	29	138	100.0	0.0
	d. Gonadal carcinoma	0	0	0	2	46	**2**	**48**	0.0	0.6	0.3	3.7	-	-	-	0.1	1.3	**0.0**	**0.3**	0	7	100.0	0.0
	e. Unspecified gonadal	5	4	7	18	85	**34**	**119**	0.3	10.8	0.7	9.3	1.0	0.2	0.3	0.6	2.4	**0.4**	**0.8**	6	18	29.4	2.5
XI	CARCINOMA & MELANOMA	2	30	51	247	934	**330**	**1264**	3.2	100.0	7.8	100.0	0.4	1.5	2.0	8.2	26.1	**3.5**	**8.6**	58	188	97.0	0.1
	a. Adrenocortical	0	6	3	2	4	**11**	**15**	0.1	3.3	0.1	1.2	-	0.3	0.1	0.1	0.1	**0.2**	**0.1**	2	3	100.0	0.0
	b. Thyroid	0	10	23	134	452	**167**	**619**	1.6	50.6	3.8	49.0	-	0.5	0.9	4.5	12.6	**1.7**	**4.2**	29	92	100.0	0.0
	c. Nasopharyngeal	0	0	0	10	35	**10**	**45**	0.1	3.0	0.3	3.6	-	-	-	0.3	1.0	**0.1**	**0.3**	2	7	100.0	0.0
	d. Melanoma	1	3	10	24	154	**38**	**192**	0.4	11.5	1.2	15.2	0.2	0.2	0.4	0.8	4.3	**0.4**	**1.3**	7	28	99.0	0.0
	e. Skin carcinoma	1	2	3	19	68	**25**	**93**	0.2	7.6	0.6	7.4	0.2	0.1	0.1	0.6	1.9	**0.3**	**0.6**	4	14	74.2	0.0
	f. Other & unspecified	0	9	12	58	221	**79**	**300**	0.8	23.9	1.9	23.7	-	0.5	0.5	1.9	6.2	**0.9**	**2.0**	14	45	96.0	0.3
XII	OTHER & UNSPECIFIED	45	67	46	80	190	**238**	**428**	2.3	100.0	2.6	100.0	9.1	3.4	1.8	2.7	5.3	**3.1**	**3.6**	45	71	25.7	2.6
	a. Other specified	1	8	0	10	26	**19**	**45**	0.2	8.0	0.3	10.5	0.2	0.4	-	0.3	0.7	**0.2**	**0.3**	3	7	100.0	0.0
	b. Other unspecified	44	59	46	70	164	**219**	**383**	2.1	92.0	2.4	89.5	8.9	3.0	1.8	2.3	4.6	**2.9**	**3.2**	41	64	17.0	2.9
	TOTAL	982	3534	2587	3102	5950	**10205**	**16155**	100.0	100.0	100.0	100.0	199.2	177.4	100.4	103.6	166.0	**132.8**	**140.3**	1928	2758	92.3	0.4

† includes 207 non-malignant

Please consult the quality indicators for this registry

cancer centre provides diagnostic and treatment services for adults. The Children's Hospital of Kielce provides care for children and adolescents with cancer.

The Holy Cross Cancer Registry constitutes a department of the Holy Cross Cancer Centre. The registry was established in 1988 (Table A.10) and at that time covered an area of 9200 km^2, with a population of 1.1 million. In 1999, the registration area and the covered population were enlarged, as a result of changes to administrative divisions in Poland. The registry is managed by a physician oncologist, one full-time biologist, and four full-time registrars. The Holy Cross Cancer Centre collects data on all cancer cases in the region. Although cancer reporting is mandatory, it is often neglected; therefore, all received records are completed by the registry staff and checked against data from the Statistical Office in Kielce, local civil departments, and hospitals. In 2002, registration completeness was 100%.

The registry prepares annual reports on cancer incidence and mortality for the local government and sends the incidence data to the Polish National Cancer Registry, which compiles national statistics. The data are published and used in many research projects and international collaborative projects. Policy-makers use the registry data for health services planning and evaluation. Reports are presented at national and international conferences.

The registry is a voting member of ENCR and IACR and participated in international projects such as CI5, Europe against Cancer: Optimisation of the Use of Registries for Scientific Excellence in Research (EUROCOURSE), ACCIS, European Cancer Health Indicator Project (EUROCHIP), Surveillance of Rare Cancers in Europe (RARECANCER), and CONCORD.

POPULATION AT RISK

See Poland, above.

EDITORS' COMMENTS

The registry could not ascertain new cancer cases from death certificates (Table A.9); thus, the reported rates may be slightly underestimated. The proportion of unspecified cases is rather high (Table A.9), probably because of the incomplete records received by the registry. Day of incidence was not available for half of the cases, and month of incidence was missing for 10% of cases (Table A.8); this may have had an impact on the age-specific rates. The age used in the analyses was calculated at IARC from the provided dates (Table A.8). The few tumours coded with uncertain behaviour were all cases of pilocytic astrocytoma, which was the only non-malignant CNS tumour type recorded in the dataset. Laterality was available for 77% of the cases of interest. See also Poland, above.

Lower Silesian Cancer Registry, 2000–2013

Jerzy Błaszczyk, Kamila Kępska, Elżbieta Chwieralska, Elżbieta Lipska, Małgorzata Modrzejewska

The region of Lower Silesia is located in south-western Poland. It is bordered by Germany to the west, the Czech Republic to the south, and two regions of Poland: Upper Silesia to the east and Greater Poland Voivodeship to the north. It covers an area of 19 947 km^2 and covers a plain that extends to the foot of the Karkonosze Mountains, which create the southern border of the region. Lower Silesia is an intensely urbanized region and has many industries. The region has four large cities with populations of more than 100 000, including Wrocław, the capital of the region.

In 2010, the population of Lower Silesia was 2.9 million, and 20% of the population was younger than 20 years (Table A.6). Most of the population (70%) lives in cities, and about 15% are employed in industry.

The Lower Silesian Oncology Centre in Wrocław is a referral hospital with 355 beds. More than 100 oncologists provide surgical oncology, chemotherapy, radiotherapy, brachytherapy, and outpatient palliative care. Radiotherapy services are also provided by Euromedic Onkoterapia in the city of Wałbrzych.

The Lower Silesian Cancer Registry was established in 1962, when cancer reporting was introduced in Poland. It is part of the Cancer Epidemiology Department of the Lower Silesian Oncology Centre in Wrocław. The registry covers the whole region of Lower Silesia and employs six medical administrative staff members who ensure data quality and completeness; the registry also employs a physician, a mathematician, and a computer programmer. Population-based data are available from 1988 (Table A.10).

Data have been registered electronically since 1984. Automatic checks are applied to eliminate duplicate registrations, identify multiple primary tumours, and correct errors of topography and morphology. The completeness of registration is 98%.

After a 2-year period of verification, the collected information is analysed to provide estimates of cancer incidence by site, age-standardized to the world standard population. The registry also analyses the distribution of new cases by age and place and time trends. Mapping is used extensively to visualize the data.

Registry data are published annually in the bulletin *Cancer Cases in the Region of Lower Silesia Poland*.

The registry is a voting member of ENCR and IACR and participates in international projects such as ACCIS, CI5, CONCORD, EUROCARE, EUROCHIP, and RARECANCER.

POPULATION AT RISK

See Poland, above.

EDITORS' COMMENTS

Most children with cancer are treated outside the region; this may result in underascertainment of certain childhood cancers and may explain a slightly lower than expected proportion of cancers diagnosed before age 15 years (Table A.9), whereas patients aged 15–19 years may have been treated in a large comprehensive cancer centre for adult patients located within the region. One quarter of cases had incomplete date of incidence (Table A.8). Non-malignant CNS tumours were not registered. Pilocytic astrocytoma was coded with malignant behaviour. Laterality was available for 90% of the cases of interest, and it was almost complete for nephroblastoma. See also Poland, above.

Lublin Cancer Registry, 1999–2013

Beata Koscianska, Justyna Nieweglowska, Tadeusz Rogalewski, Monika Malec, Dorota Janczarek

Lublin Voivodeship is located in south-eastern Poland, partly on Lublin Highland, and covers an area of 25 155 km^2. It is an agricultural region with a few centres of food production and chemical industry located around major cities and a coal mining centre in the area of Łęczna. The capital city is Lublin.

In 2010, the population of Lublin Voivodeship was 2.2 million (5.7% of the national population), and 22% of the population was younger than 20 years (Table A.6). An average population density of 86 per km^2 is considered low compared with the national average of 122 per km^2; 53.4% of the population lives in rural areas. Specialized paediatric and cancer care is provided by University Children's Hospital, which has a paediatric oncology and haematology unit. The Saint John of Dukla Centre of Oncology of Lublin Region, located in Lublin, provides cancer care for the entire region. It offers a wide range of cancer treatments, including surgery, chemotherapy, radiotherapy, brachytherapy, and diagnostics, supported by radiology, microbiology, and genetics services.

The Lublin Cancer Registry covers the whole voivodeship. It is part of the Saint John of Dukla Centre of Oncology of Lublin Region and has collected data on cancer incidence and mortality since 1974 (Table A.8). It is funded by the Ministry of Health. The staff consists of three full-time employees, who are managed by a physician who is employed part-time.

The data are extracted from cancer notification forms and death registrations. The completeness of registration was estimated to be about 92% in 2004, 100% in 2007, and 100% in 2010, based on the incidence-to-mortality ratios of 1.38, 1.73, and 1.73, respectively. Vital status is followed up using the cancer notification forms. In addition, information on dates of death is provided annually by the Ministry of the Interior.

The registry analyses the data to describe incidence and mortality patterns and trends by sex, age groups, and cancer site. This information is published in annual reports and monographs. The registry data are also used in educational programmes for students, in postgraduate training, and for cancer prevention programmes.

POPULATION AT RISK

See Poland, above.

EDITORS' COMMENTS

The proportion of cases with unspecified morphology was high (Table A.9), because of inadequate access to pathology reports in the past. The proportion of cases aged 19 years in the age group 15–19 years was 25.8% (Table A.9); this may in part be the result of imprecise date of incidence for some cases (Table A.8). The incidence of leukaemia increased markedly during the reporting period. Pilocytic astrocytoma was registered with both uncertain behaviour and malignant behaviour throughout the reporting period. No other non-malignant CNS tumours were registered. The incidence of CNS tumours decreased over time, largely because of a steep decrease in the diagnostic subgroup IIIf, which may reflect an increasing tendency for unverified tumours to be defined as non-malignant and therefore excluded. Laterality was provided for 51% of the cases of interest. See also Poland, above.

Portugal

Portugal is located mostly on the Iberian Peninsula in south-western Europe. It is bordered by the Atlantic Ocean to the west and south and by Spain to the north and east. The climate is Mediterranean; the annual average temperature varies from 8–12 °C in the mountainous interior in the north to 16–18 °C in the south and in the Guadiana River Basin. The territory of Portugal also includes the Atlantic archipelagos of the Azores and Madeira, each an autonomous region with its own regional government.

Portugal is a developed country with a high-income, advanced economy, a developed market, and a high standard of living. The main sectors of the economy are agriculture, forestry, fishing, copper mining, industry, and tourism. Since the 1990s, the economy has increasingly focused on exports, private investment, and the development of the high-tech sector. Thus, business services have overtaken more traditional industries such as textiles, clothing, footwear, cork, wood products, and beverages.

The population is 10.6 million (Table A.7), and 20% of the population is younger than 20 years (Table A.6). The life expectancy is more than 80 years. The total fertility rate has been below the replacement rate of 2.1 since the 1980s. More than half of births are to unmarried women. A single religion (Roman Catholicism) and a single language have contributed to ethnic homogeneity over most of the country's history. Portuguese society is characterized by increasing socioeconomic inequality.

The Portuguese health-care system is composed of three coexisting systems: the National Health Service, special social health insurance schemes (health subsystems) for certain professions (e.g. police, military, and banking), and voluntary private health insurance. The National Health Service provides most of the universal coverage. In addition, about 25% of the population is covered by the health subsystems, 10% by private insurance schemes, and 7% by mutual funds. A national database of all the patients of the national health-care system (Registo Nacional de Utentes) enables the identification of patients with cancer and the verification of their data by authorized entities, including cancer registries.

In Portugal, population-based cancer registration started in 1976 with the establishment of the population-based cancer registry in Viana do Castelo in 1976, followed by the registry in Vila Nova de Gaia, established in 1980. On 16 January 1988, Law N 35/88 was adopted, which mandated cancer notification and the creation of the regional cancer registries. Four regional registries – Azores, Central Region, North Region, and South Region (the South Region includes the Madeira region) – cover the entire population of Portugal. They routinely exchange information on registered cases, thereby avoiding duplication and ensuring the completeness of registration.

PUBLICATIONS

Amado J, Matos E, Calheiros JM, Ramalho A, Ramalho C, Castro A, et al. (1992). Incidência e mortalidade por tumores malignos no Concelho de Vila Nova de Gala: 1981–1987. Acta Med Port. 5:373–8.

POPULATION AT RISK

The population data were provided by Statistics Portugal (https://www.ine.pt/); they are based on the 1991, 2001, and 2011 censuses (Table A.7), accounting for births, deaths, and migration. All registries provided population data in the required detail.

EDITORS' COMMENTS

Combined data for the four Portuguese registries are presented in the IICC-3 book (Table A.12). Although the registration areas of the mainland registries were redefined in 2010, there is no overlap in the data they provided. Data for the individual registries are available online in standard tables for the three mainland registries of Central Region, North Region, and South Region, and an abbreviated table is shown for the smaller Azores Cancer Registry (Table A.12). A combined dataset for the registries of Central Region, South Region, and Vila Nova de Gaia was also included in IICC-2 (Table A.1).

Date of incidence is incomplete in the Portuguese registries, except for South Region (Table A.8). Unlike the other three Portuguese registries, the Azores Cancer Registry has access to identified death certificates that mention cancer. In all registries, non-malignant CNS tumours were registered, and pilocytic astrocytoma was coded with uncertain behaviour. Skin carcinomas were reportable in all registries, although some cases may be missed.

PORTUGAL (1991-2012)

Registry	Period	Cases	%	Person-years	%
Azores	1997-2011	198	3.1	1 027 305	2.8
Centre	2000-2010	969	15.0	5 406 211	14.5
North	1991-2010	2575	39.9	16 009 471	42.9
South	1998-2012	2706	42.0	14 895 375	39.9
PORTUGAL	**1991-2012**	**6448**	**100.0**	**37 338 362**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

Azores Cancer Registry, 1997–2011

Gonçalo Forjaz, José Cabral, Jorge Câmara, Francisco Gomes, Anabela Faria, Marina Soares, Raul Rego, Vitor Rodrigues

The Azores archipelago is an autonomous Portuguese region made up of nine volcanic islands located in the North Atlantic Ocean. The islands are divided into three groups: the Western group (Flores and Corvo), the Central group (Terceira, Faial, Pico, São Jorge, and Graciosa), and the Eastern group (São Miguel and Santa Maria).

The population is 0.2 million, and 25% of the population is younger than 20 years; this proportion is larger than that of the mainland population (Table A.6).

The health-care system in the Azores is separate from that of the mainland and has its own organization, management, funding, and operation. It is nearly free for all residents. There are three important health institutions, located on the islands of São Miguel, Terceira, and Faial. There are also 16 health centres and one oncology centre. In addition to providing health care, the oncology centre is responsible for the Azores Cancer Registry and for organized cancer screening programmes (breast cancer, cervical cancer, and colorectal cancer).

Most cancer cases are diagnosed and treated locally. However, almost all Azorean children and adolescents with cancer are referred to mainland hospitals, mostly to the Portuguese Institute of Oncology. For such cases, comprehensive data collection for the registry is maintained through access to patients' transfer files and their respective clinical pathways. Each regional hospital has its own department of paediatrics, which follows up most paediatric cancer cases, usually under the supervision of the Portuguese Institute of Oncology.

The Azores Cancer Registry was created in 1993 and covers an area of 2346 km^2 (the whole area of the archipelago). Some data were collected retrospectively starting in June 2007; the data are considered complete as from 1997. Data are collected both passively and actively from the three regional public hospitals, several private pathology laboratories, and the three regional population-based cancer registries located on the mainland. Death certificates that specifically mention cancer are received by the registry from the civil register offices located in each of the Azorean cities. On the basis of the information from hospital information systems and death certificates, registry staff members perform active case finding in hospital records and health centre records. Tumours are coded according to ICD-O-3 (Table A.10), which is also used to count multiple primary tumours. CanReg5 software is used for data entry and analysis.

The Azores Cancer Registry is a member of ENCR, IACR, and the Global Initiative for Cancer Registry Development (GICR) and has participated in international studies, such as CI5 Volumes X and XI, ACCIS, EUROCARE-5, and CONCORD-2 and CONCORD-3.

POPULATION AT RISK

See Portugal, above.

EDITORS' COMMENTS

The increased proportion of unexpected frequencies of particular days of birth or days of incidence in the dataset (Table A.8) is probably a reflection of the small size of the dataset, which may also explain the slightly lower proportion of cases diagnosed before age 15 years in the dataset (Table A.9). The proportion of non-malignant CNS tumours is low (Table A.9); the registry believes that a moderate proportion of non-malignant cases may have been missed. This should be borne in mind when interpreting the incidence rates reported for diagnostic categories III and Xa and the total. Unlike the other three Portuguese registries, the Azores Cancer Registry has access to identified death certificates mentioning cancer; however, no DCO cases were identified. Laterality is complete for nephroblastoma and gonadal tumours. See also Portugal, above.

Portugal Central Region Cancer Registry, 2000–2010

Manuel António Silva, Branca Carrito, Cristina Anjinho, Eduarda Cavaleiro, Joana Bastos, José Chelinho, José Paulo Magalhães, Vítor Rodrigues

The Central Region Cancer Registry covers the Central Region of Portugal. Until 2009, the registry covered an area of about 27 000 km^2 and had a population of about 2.4 million (~23% of the national population). The registry covered the districts of Aveiro, Castelo Branco, Coimbra, Guarda, Leiria, and Viseu. About 19% of the covered population was younger than 20 years (Table A.6). In 2010, there were changes to the areas covered by the three regional cancer registries of mainland Portugal. The coverage area of the Central Region Cancer Registry changed to the administrative areas called *concelhos* (municipalities) belonging to the Central Health Administrative Region (ARS-Centro), which in 2011 had about 1.7 million inhabitants (17% of the national population).

Coimbra, the capital city of the Central Region, has three main public hospitals with two radiotherapy departments. The main sources of information for the Central Region Cancer Registry are these institutions, in addition to a network of five smaller hospitals and county health centres, and some private diagnostic facilities. Most children with cancer are treated at the paediatric hospital in Coimbra.

The Central Region Cancer Registry started in 1989 (Table A.10). Data on cancer cases are entered into the electronic registry database directly at the data source locations. This information is checked for consistency between variables (sex, codes, etc.) using IARCcrgTools routines and manual checks.

Vital status of children with cancer is verified either passively, using information recorded by the data sources, or by active consultation of the database of the National Registry of Deaths. This follow-up is considered complete for children with cancer.

Since 1989, the registry has published annual reports of cancer incidence (https://www.ipocoimbra.min-saude.pt/), and registry data are used in descriptive and analytical epidemiological studies.

POPULATION AT RISK
See Portugal, above.

EDITORS' COMMENTS
Day of incidence was imprecise in a proportion of cases (Table A.8). The registry computes age automatically and rounds it with respect to a calendar year, rather than with respect to a birth date. The registry does not have access to death certificates (Table A.9); thus, some new cases may be missed. A large number of thyroid carcinoma cases and Hodgkin lymphoma cases contributed to the high proportion of cases aged 19 years in the age group 15–19 years (Table A.9). Laterality is nearly complete. See also Portugal, above.

Portugal North Region Cancer Registry, 1991–2010

José Laranja Pontes, Maria José Bento, Clara Castro, Luís Antunes, Filipa Gonçalves, Anabela Sousa, Roxanne Garcia, Tatiana Domingues, Vânia Teixeira, Rui Henrique

The North Region Cancer Registry registers all new cancer cases in the North Region of Portugal. The region has five districts: Braga, Bragança, Porto, Viana do Castelo, and Vila Real. The northern and eastern parts of the region are bordered by the Spanish provinces of Galicia and Castilla y Léon, and the western part of the region is bordered by the Atlantic Ocean. The climate is temperate oceanic. In 2011, 62% of the active population worked in services, 35% worked in the secondary sector, and 3% worked in the primary sector.

In 2010, the population of the North Region was 3.3 million, and 21% of the population was younger than 20 years (Table A.6). Almost 60% of the population lived in the district of Porto.

The region has about 20 public general hospitals and one specialized cancer treatment centre. The main treatment centres are located in the district of Porto, but each district capital has at least one central hospital. Porto, Braga, and Vila Real have radiotherapy centres. Paediatric and adolescent cancer care is provided in only two centres, located in the city of Porto. The health-care system is composed of a network of primary health-care centres, which is supplemented by private clinics and laboratories.

The North Region Cancer Registry is located in Porto at the Portuguese Institute of Oncology. It collects data from hospitals, clinics, and pathology laboratories. Since 2014, the registry has been staffed by a medical epidemiologist, four registrars, one biologist, and two statisticians. One medical pathologist and one oncology surgeon serve as consultants.

The data are received mostly by passive notification in coded format. Since June 2005, all hospitals can submit the data using a common website. The vital status of registered patients is checked regularly using updates received from data sources and complemented by active searching performed by registry staff members.

The registry publishes an annual report of cancer incidence in the registration area. Survival data since 2000 are available (https://ipoporto.pt/roreno/). The registry develops research projects in collaboration with the University of Porto and the University of Minho and participates in international projects (e.g. EUROCARE and CONCORD-2) and other collaborative studies involving European cancer registries.

POPULATION AT RISK
See Portugal, above.

EDITORS' COMMENTS
Day of incidence is imprecise for more than half of the cases (Table A.8); this may affect the age-specific incidence rates. Until 2005, only month and year of diagnosis was registered, with day of diagnosis coded to 1 or 15. The registry does not have access to identified death certificates; thus, some new cases may be missed. Information on laterality was provided for 73% of the tumours of interest. See also Portugal, above.

Portugal South Region Cancer Registry, 1998–2012

Ana Da Costa Miranda, Alexandra Mayer-da-Silva, Gabriela Caldas, Luisa Gloria, Cláudia Brito

The South Region includes Lisbon (the national capital) and its metropolitan area, Vale do Tejo, the regions of Alentejo and Algarve, and the Autonomous Region of Madeira. These areas comprise about half of the country, in terms of both area (39 700 km^2) and population.

In 2010, the population was 4.7 million, and 21% of the population was younger than 20 years (Table A.6). Of the economically active population, about 75% are employed in the service sector, 20% in industry, and 6% in agriculture.

General health care is provided by 40 public general hospitals, one university hospital, a network of 147 primary health-care centres, and the cancer institute in Lisbon. There is one general practitioner per 2000 inhabitants. Almost all patients with cancer are diagnosed and treated by medical specialists who work in the hospitals.

The South Region Cancer Registry started in 1989 as part of a programme for nationwide cancer registration financed by public health funds. Since 2000, data have been collected in all hospitals and health centres, using electronic connections to the registry database. Registration forms are received from private hospitals and pathology laboratories. One clinician in each institution is responsible for registration. The registry network server is located in the cancer institute in Lisbon. Since 2007, the registry has integrated data from additional sources, such as pathology reports, surgical reports, hospital admissions records, and chemotherapy and radiotherapy records.

The permanent registry staff consists of two physicians specialized in epidemiology (one of whom leads the registry), two statisticians, and 10 tumour registrars. One pathologist, two oncologists, and one gastroenterologist serve as consultants.

Since 1988, reporting of all new cancer cases has been mandatory. The registration of a case usually starts with a pathology report, which is received from any public or private pathology laboratory. The required information is then retrieved from the medical records in each hospital or health centre by trained tumour registrars or local physicians and entered into the central server. In addition, hospital discharge records of cancer patients and records of hospital pharmacy and radiotherapy services are compared with the registry database and the additional cases are reviewed and entered.

The registry uses ICD-O-3 for coding of tumours and reporting of multiple primary tumours. The TNM classification system is used for staging.

Data are routinely checked for completeness, consistency, and duplicates using IARCcrgTools and additional registry-specific software, and by reviewing samples of cases (internal auditing). Data are exchanged with the other regional cancer registries to obtain information on residents who are diagnosed and treated outside the registration area.

Follow-up of registered patients for vital status is conducted annually by linkage of the South Region Cancer Registry database with the national population registry.

The main purpose of the registry is to estimate cancer incidence and survival in the region. The registry prepares an annual report on childhood cancer incidence and survival. Registry data are used in epidemiological studies at the regional, national, and international levels, including the EUROCARE studies.

POPULATION AT RISK

The decimal portions of the estimated counts provided for some sex and age categories were rounded to the nearest integer at IARC (Table A.8). See also Portugal, above.

EDITORS' COMMENTS

The registry does not have access to identified death certificates. Although some new cases may be missed as a result, registry staff believe that the number is very low because treatment of paediatric cancer is highly centralized. Non-malignant CNS tumours were systematically registered only for the age group 0–14 years; because the collection of these tumours started later in the age group 15–19 years, the rate in adolescents is probably underestimated. Laterality is nearly complete for retinoblastoma and nephroblastoma. Basal cell skin carcinomas were excluded from the data provided by the registry because of suspected incomplete ascertainment. See also Portugal, above.

PORTUGAL (1991-2012)

	Age group (years)	Males	Females
Person-years	0	900 046	849 006
	1-4	3 607 161	3 407 408
	5-9	4 593 972	4 350 762
	10-14	4 801 586	4 575 112
	15-19	5 227 977	5 025 332
	0-14	13 902 765	13 182 288
	0-19	19 130 742	18 207 620

Please consult the quality indicators for this pool and its constituent registries

PORTUGAL (1991-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	**LEUKAEMIA**	51	471	358	278	242	**1158**	**1400**	26.7	100.0	21.7	100.0	29.2	67.1	40.0	29.6	23.6	**44.6**	**39.9**	646	764	98.5	0.0
	a. Lymphoid	34	373	262	159	123	**828**	**951**	19.1	71.5	14.7	67.9	19.4	53.2	29.3	17.0	12.0	**32.3**	**27.8**	463	523	98.6	0.0
	b. Acute myeloid	7	70	59	86	76	**222**	**298**	5.1	19.2	4.6	21.3	4.0	10.0	6.6	9.2	7.4	**8.2**	**8.0**	123	160	98.7	0.0
	c. CMD	2	6	13	17	24	**38**	**62**	0.9	3.3	1.0	4.4	1.1	0.9	1.5	1.8	2.3	**1.3**	**1.6**	21	33	100.0	0.0
	d. MDS & other	4	10	15	11	7	**40**	**47**	0.9	3.5	0.7	3.4	2.3	1.4	1.7	1.2	0.7	**1.5**	**1.3**	22	26	95.7	0.0
	e. Unspecified	4	12	9	5	12	**30**	**42**	0.7	2.6	0.7	3.0	2.3	1.7	1.0	0.5	1.2	**1.2**	**1.2**	17	23	95.2	0.0
II	**LYMPHOMA & RELATED**	14	124	199	309	619	**646**	**1265**	14.9	100.0	19.6	100.0	8.0	17.7	22.2	33.0	60.4	**22.8**	**31.3**	355	657	99.6	0.0
	a. Hodgkin	0	12	68	184	445	**264**	**709**	6.1	40.9	11.0	56.0	-	1.7	7.6	19.6	43.4	**8.7**	**16.5**	143	360	99.7	0.0
	b. Non-Hodgkin except BL	3	46	61	77	124	**187**	**311**	4.3	28.9	4.8	24.6	1.7	6.6	6.8	8.2	12.1	**6.7**	**8.0**	103	164	100.0	0.0
	c. Burkitt (BL)	0	40	51	33	17	**124**	**141**	2.9	19.2	2.2	11.1	-	5.7	5.7	3.5	1.7	**4.6**	**4.0**	69	77	100.0	0.0
	d. Lymphoreticular	11	23	13	4	6	**51**	**57**	1.2	7.9	0.9	4.5	6.3	3.3	1.5	0.4	0.6	**2.1**	**1.8**	29	32	96.5	0.0
	e. Unspecified	0	3	6	11	27	**20**	**47**	0.5	3.1	0.7	3.7	-	0.4	0.7	1.2	2.6	**0.7**	**1.1**	11	24	97.9	0.0
III	**CNS NEOPLASMS** †	69	316	312	281	257	**978**	**1235**	22.5	100.0	19.2	100.0	39.4	45.0	34.9	30.0	25.1	**37.0**	**34.3**	544	669	90.0	0.0
	a. Ependymoma	21	53	19	25	18	**118**	**136**	2.7	12.1	2.1	11.0	12.0	7.6	2.1	2.7	1.8	**4.7**	**4.1**	66	75	100.0	0.0
	b. Astrocytoma	22	127	135	123	109	**407**	**516**	9.4	41.6	8.0	41.8	12.6	18.1	15.1	13.1	10.6	**15.3**	**14.2**	226	279	95.7	0.0
	c. CNS embryonal	15	71	61	55	33	**202**	**235**	4.7	20.7	3.6	19.0	8.6	10.1	6.8	5.9	3.2	**7.7**	**6.7**	112	129	99.6	0.0
	d. Other gliomas	4	30	48	30	40	**112**	**152**	2.6	11.5	2.4	12.3	2.3	4.3	5.4	3.2	3.9	**4.2**	**4.1**	62	82	73.0	0.0
	e. Other specified	4	18	36	33	37	**91**	**128**	2.1	9.3	2.0	10.4	2.3	2.6	4.0	3.5	3.6	**3.3**	**3.4**	50	68	97.7	0.0
	f. Unspecified CNS	3	17	13	15	20	**48**	**68**	1.1	4.9	1.1	5.5	1.7	2.4	1.5	1.6	2.0	**1.8**	**1.8**	27	36	16.2	0.0
IV	**NEUROBLASTOMA**	111	169	37	17	10	**334**	**344**	7.7	100.0	5.3	100.0	63.5	24.1	4.1	1.8	1.0	**14.2**	**11.2**	189	194	95.9	0.0
	a. (Ganglio)neuroblastoma	109	167	31	13	6	**320**	**326**	7.4	95.8	5.1	94.8	62.3	23.8	3.5	1.4	0.6	**13.7**	**10.8**	182	185	95.7	0.0
	b. Peripheral nervous	2	2	6	4	4	**14**	**18**	0.3	4.2	0.3	5.2	1.1	0.3	0.7	0.4	0.4	**0.5**	**0.5**	8	10	100.0	0.0
V	**RETINOBLASTOMA**	34	79	3	0	0	**116**	**116**	2.7	100.0	1.8	100.0	19.4	11.3	0.3	-	-	**5.1**	**4.0**	66	66	77.6	0.0
VI	**RENAL TUMOURS**	32	131	48	17	18	**228**	**246**	5.3	100.0	3.8	100.0	18.3	18.7	5.4	1.8	1.8	**9.5**	**7.7**	129	138	96.7	0.0
	a. Nephroblastoma	32	130	48	10	3	**220**	**223**	5.1	96.5	3.5	90.7	18.3	18.5	5.4	1.1	0.3	**9.2**	**7.2**	125	126	97.3	0.0
	b. Renal carcinoma	0	1	0	7	13	**8**	**21**	0.2	3.5	0.3	8.5	-	0.1	-	0.7	1.3	**0.3**	**0.5**	4	11	100.0	0.0
	c. Unspecified	0	0	0	0	2	**0**	**2**	-	-	0.0	0.8	-	-	-	-	0.2	**-**	**0.0**	-	1	0.0	0.0
VII	**HEPATIC TUMOURS**	14	19	9	6	6	**48**	**54**	1.1	100.0	0.8	100.0	8.0	2.7	1.0	0.6	0.6	**2.0**	**1.7**	27	30	92.6	0.0
	a. Hepatoblastoma	13	19	5	1	0	**38**	**38**	0.9	79.2	0.6	70.4	7.4	2.7	0.6	0.1	-	**1.6**	**1.3**	22	22	97.4	0.0
	b. Hepatic carcinoma	1	0	4	4	5	**9**	**14**	0.2	18.8	0.2	25.9	0.6	-	0.4	0.4	0.5	**0.3**	**0.4**	5	7	92.9	0.0
	c. Unspecified	0	0	0	1	1	**1**	**2**	0.0	2.1	0.0	3.7	-	-	-	0.1	0.1	**0.0**	**0.0**	1	1	0.0	0.0
VIII	**BONE TUMOURS**	2	13	52	122	164	**189**	**353**	4.4	100.0	5.5	100.0	1.1	1.9	5.8	13.0	16.0	**6.3**	**8.5**	103	183	98.0	0.0
	a. Osteosarcoma	0	2	18	67	90	**87**	**177**	2.0	46.0	2.7	50.1	-	0.3	2.0	7.1	8.8	**2.8**	**4.2**	47	91	99.4	0.0
	b. Chondrosarcoma	0	0	0	4	11	**4**	**15**	0.1	2.1	0.2	4.2	-	-	-	0.4	1.1	**0.1**	**0.3**	2	7	100.0	0.0
	c. Ewing & related	1	9	29	44	49	**83**	**132**	1.9	43.9	2.0	37.4	0.6	1.3	3.2	4.7	4.8	**2.8**	**3.3**	45	69	100.0	0.0
	d. Other specified	0	1	1	2	8	**4**	**12**	0.1	2.1	0.2	3.4	-	0.1	0.1	0.2	0.8	**0.1**	**0.3**	2	6	100.0	0.0
	e. Unspecified	1	1	4	5	6	**11**	**17**	0.3	5.8	0.3	4.8	0.6	0.1	0.4	0.5	0.6	**0.4**	**0.4**	6	9	64.7	0.0
IX	**SOFT TISSUE SARCOMA**	28	78	68	85	149	**259**	**408**	6.0	100.0	6.3	100.0	16.0	11.1	7.6	9.1	14.5	**9.8**	**10.8**	144	216	99.8	0.0
	a. Rhabdomyosarcoma	18	56	47	30	36	**151**	**187**	3.5	58.3	2.9	45.8	10.3	8.0	5.3	3.2	3.5	**5.9**	**5.4**	84	102	100.0	0.0
	b. Fibrosarcoma	3	1	1	3	12	**8**	**20**	0.2	3.1	0.3	4.9	1.7	0.1	0.1	0.3	1.2	**0.3**	**0.5**	4	10	100.0	0.0
	c. Kaposi sarcoma	0	0	0	3	4	**3**	**7**	0.1	1.2	0.1	1.7	-	-	-	0.3	0.4	**0.1**	**0.2**	2	4	100.0	0.0
	d. Other specified	4	10	11	39	80	**64**	**144**	1.5	24.7	2.2	35.3	2.3	1.4	1.2	4.2	7.8	**2.2**	**3.5**	35	74	99.3	0.0
	e. Unspecified	3	11	9	10	17	**33**	**50**	0.8	12.7	0.8	12.3	1.7	1.6	1.0	1.1	1.7	**1.3**	**1.3**	18	27	100.0	0.0
X	**GERM CELL TUMOURS**	17	38	24	61	184	**140**	**324**	3.2	100.0	5.0	100.0	9.7	5.4	2.7	6.5	17.9	**5.2**	**8.1**	77	167	97.8	0.0
	a. CNS germ cell	1	2	15	24	21	**42**	**63**	1.0	30.0	1.0	19.4	0.6	0.3	1.7	2.6	2.0	**1.4**	**1.6**	23	33	96.8	0.0
	b. Other extragonadal	8	13	1	6	11	**28**	**39**	0.6	20.0	0.6	12.0	4.6	1.9	0.1	0.6	1.1	**1.1**	**1.1**	16	21	97.4	0.0
	c. Gonadal germ cell	8	22	6	28	132	**64**	**196**	1.5	45.7	3.0	60.5	4.6	3.1	0.7	3.0	12.9	**2.4**	**4.8**	35	100	99.5	0.0
	d. Gonadal carcinoma	0	0	1	1	15	**2**	**17**	0.0	1.4	0.3	5.2	-	-	0.1	0.1	1.5	**0.1**	**0.4**	1	8	100.0	0.0
	e. Unspecified gonadal	0	1	1	2	5	**4**	**9**	0.1	2.9	0.1	2.8	-	0.1	0.1	0.2	0.5	**0.1**	**0.2**	2	5	66.7	0.0
XI	**CARCINOMA & MELANOMA**	6	11	53	150	438	**220**	**658**	5.1	100.0	10.2	100.0	3.4	1.6	5.9	16.0	42.7	**7.3**	**15.3**	119	333	99.5	0.0
	a. Adrenocortical	1	1	1	2	1	**5**	**6**	0.1	2.3	0.1	0.9	0.6	0.1	0.1	0.2	0.1	**0.2**	**0.2**	3	3	100.0	0.0
	b. Thyroid	0	3	13	59	188	**75**	**263**	1.7	34.1	4.1	40.0	-	0.4	1.5	6.3	18.3	**2.4**	**6.0**	40	132	99.6	0.0
	c. Nasopharyngeal	0	0	2	22	26	**24**	**50**	0.6	10.9	0.8	7.6	-	-	0.2	2.3	2.5	**0.8**	**1.2**	13	26	100.0	0.0
	d. Melanoma	0	4	19	27	70	**50**	**120**	1.2	22.7	1.9	18.2	-	0.6	2.1	2.9	6.8	**1.7**	**2.9**	27	61	99.2	0.0
	e. Skin carcinoma	2	2	4	7	23	**15**	**38**	0.3	6.8	0.6	5.8	1.1	0.3	0.4	0.7	2.2	**0.5**	**0.9**	8	19	97.4	0.0
	f. Other & unspecified	3	1	14	33	130	**51**	**181**	1.2	23.2	2.8	27.5	1.7	0.1	1.6	3.5	12.7	**1.7**	**4.2**	28	91	100.0	0.0
XII	**OTHER & UNSPECIFIED**	4	9	2	8	22	**23**	**45**	0.5	100.0	0.7	100.0	2.3	1.3	0.2	0.9	2.1	**0.9**	**1.2**	13	24	53.3	0.0
	a. Other specified	0	4	1	1	7	**6**	**13**	0.1	26.1	0.2	28.9	-	0.6	0.1	0.1	0.7	**0.2**	**0.3**	3	7	100.0	0.0
	b. Other unspecified	4	5	1	7	15	**17**	**32**	0.4	73.9	0.5	71.1	2.3	0.7	0.1	0.7	1.5	**0.7**	**0.8**	9	17	34.4	0.0
	TOTAL	382	1458	1165	1334	2109	**4339**	**6448**	100.0	100.0	100.0	100.0	218.4	207.9	130.2	142.3	205.7	**164.6**	**173.8**	2412	3441	96.3	0.0

† includes 433 non-malignant

Please consult the quality indicators for this pool and its constituent registries

Russian Federation

The Russian Federation is the largest country in the world, extending from eastern Europe to the most easterly point of Asia. The country covers an area of 17 098 246 km^2, of which 23% is in Europe and 77% is in Asia.

In 2010, the estimated total population was 143.2 million (Table A.7), and 21% of the population was younger than 20 years (Table A.6). In 2010, 78% of the population was ethnic Russian, 4% was Tatar, and the remainder consisted of more than 180 officially designated nationalities or ethnic groups, each accounting for less than 1.5% of the total. In 2010, the average population density was 8.4 per km^2, with marked variations across the country. The European part of the Russian Federation is much more densely populated than the Asian part, with 77% of the total population, and Moscow (the capital) and most other major cities are in the European part. Of the total workforce, 66% are employed in services, 27% in industry, and 7% in agriculture. The Russian Federation is an upper-middle-income country with a very high HDI.

Medical care is free of charge for the entire population and is covered by national medical insurance.

A unified registration procedure of patients with cancer was established in the former Soviet Union in 1953. The recording of all cancer cases is mandatory. For each case a registration card is generated and submitted to a regional cancer registry. The records of patients residing in other areas of the country are shared with the relevant registries.

POPULATION AT RISK

The most recent population census in the former Soviet Union was conducted in 1989 by the Central Statistical Committee and counted the resident population. After the dissolution of the Soviet Union in 1991, population censuses were conducted in 2002 and 2010 (Table A.7) by the Russian Federal State Statistics Service (https://rosstat.gov.ru/) and counted all permanent residents in the Russian Federation. Births, deaths, and migration are taken into account to estimate the annual population data. Data were provided in the requested detail by all registries.

EDITORS' COMMENTS

The cancer data for the Russian Federation are presented in the IICC-3 book in two tables: data collected by the Childhood Cancer Registry of Moscow Region, and data from the Chelyabinsk Cancer Registry combined with those from the Samara Cancer Registry. The separate tables of the two general cancer registries are available online (Table A.12). Compared with the general cancer registries, the paediatric registry systematically recorded non-malignant CNS tumours and had an acceptable MV% and proportion of clinically diagnosed cases. The incidence rates were somewhat higher in the general cancer registries, although the rates for individual diagnostic groups were comparable.

Childhood Cancer Registry of Moscow Region, 2000–2009

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The Moscow Region (*oblast*) is one of about 80 federal subjects and is the largest administrative division of the Russian Federation. It is located in the eastern portion of the European part of the Russian Federation and covers an area of 45 900 km^2. The city of Moscow is not a part of the Moscow Region. The climate is temperate continental, with warm summers and cold winters.

The Moscow Region is the second most populous federal subject. In 2010, the population was 7.1 million, and 12% of the population was younger than 15 years (4% of the national paediatric population) (Table A.6). The main industries are machinery and metalworking, and chemical and light industry. There is a substantial service sector. Agriculture has a relatively minor role in the economy.

The Moscow Region is divided into 72 municipal districts (*okrug*), which are clustered into 12 medical districts. The only department that provides specialized care for children and adolescents with cancer within the region is located in Moscow Regional Oncological Hospital, in Balashikha. Some patients undergo cancer treatment in the federal cancer centres in the city of Moscow.

The population-based childhood cancer registry was established in the Moscow Region in 2000 (Table A.10). It was founded by the Ministry of Healthcare and Social Development of the Moscow Region and the Dmitry Rogachev National Research Centre of Paediatric Haematology, Oncology and Immunology, in Moscow. The registry collects information on the burden of cancer in children aged 0–14 years.

Data are collected actively and passively. Multiple sources of information are used, including discharge letters from oncology hospitals, reports from pathology laboratories, and data from the general cancer registry of the Moscow Region. National law requires oncologists to complete a notification form for all newly diagnosed cancer cases. The registry has access to the database of the Ministry of Healthcare and Social Development of the Moscow Region, which has information on patients referred to federal cancer centres. The registry also collaborates closely with primary care paediatricians. A special notification form has been created and is completed for newly diagnosed patients and for patients who have completed cancer treatment. Regional law mandates inclusion of this form as part of the mandatory annual medical report prepared by paediatricians in municipal districts. Follow-up information is collected actively in hospital databases and from notification forms from primary care paediatricians. Special requests for information are sent to primary care paediatricians to trace back additional data on these patients. Identifiable death certificates are not available to the registry, but it does have access to the de-identified cancer mortality database of the Moscow Region.

All CNS tumours are registered. The completeness of registration is estimated to be more than 90%.

The registry prepares annual reports, which are used for planning specialized paediatric cancer care in the region.

POPULATION AT RISK

The annual population estimates in the Moscow Region are based on the Russian Federation population census conducted in 2002 and were provided by the Moscow Regional Committee of the Federal State Statistics Service (https://gks.ru/region/docl1146/Main.htm). See also Russian Federation, above.

EDITORS' COMMENTS

In this paediatric cancer registry, registration focused on the age group 0–14 years during the reporting period. Therefore, data for the age groups 15–19 years and 0–19 years are not shown in the tables. Dates of incidence were imprecise in a proportion of cases (Table A.8). Because the registry does not have access to identified death certificates, a proportion of new cases may be missed. This could also explain the slightly lower overall incidence rate compared with that of the general cancer registries, even though non-malignant CNS tumours were recorded throughout the reporting period (Table A.9). Pilocytic astrocytoma was coded with uncertain behaviour. Laterality was almost complete for the cases of interest and was included in the relevant tables. See also Russian Federation, above.

RUSSIAN FEDERATION, Moscow region, paediatric (2000-2009)

	Age group (years)	Males	Females
Person-years	0	292 679	274 519
	1-4	1 084 373	1 021 499
	5-9	1 339 401	1 268 926
	10-14	1 782 917	1 702 640
	0-14	4 499 370	4 267 584
Average annual population	0-14	449 937	426 758

Please consult the quality indicators for this registry

RUSSIAN FEDERATION, Moscow region, paediatric (2000-2009)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	13	183	82	75	**353**	30.0	100.0	22.9	86.9	31.4	21.5	**44.8**	631	100.0	0.0
	a. Lymphoid	7	158	65	51	**281**	23.9	79.6	12.3	75.0	24.9	14.6	**36.2**	506	100.0	0.0
	b. Acute myeloid	3	21	12	20	**56**	4.8	15.9	5.3	10.0	4.6	5.7	**6.6**	97	100.0	0.0
	c. CMD	0	1	2	2	**5**	0.4	1.4	-	0.5	0.8	0.6	**0.6**	9	100.0	0.0
	d. MDS & other	2	2	2	1	**7**	0.6	2.0	3.5	0.9	0.8	0.3	**0.9**	13	100.0	0.0
	e. Unspecified	1	1	1	1	**4**	0.3	1.1	1.8	0.5	0.4	0.3	**0.5**	7	100.0	0.0
II	LYMPHOMA & RELATED	0	14	34	99	**147**	12.5	100.0	-	6.6	13.0	28.4	**14.5**	233	98.6	0.0
	a. Hodgkin	0	5	9	64	**78**	6.6	53.1	-	2.4	3.5	18.4	**7.2**	118	100.0	0.0
	b. Non-Hodgkin except BL	0	4	15	26	**45**	3.8	30.6	-	1.9	5.8	7.5	**4.6**	74	100.0	0.0
	c. Burkitt (BL)	0	3	10	7	**20**	1.7	13.6	-	1.4	3.8	2.0	**2.3**	35	100.0	0.0
	d. Lymphoreticular	0	1	0	1	**2**	0.2	1.4	-	0.5	-	0.3	**0.2**	3	100.0	0.0
	e. Unspecified	0	1	0	1	**2**	0.2	1.4	-	0.5	-	0.3	**0.2**	3	0.0	0.0
III	CNS NEOPLASMS †	10	72	98	90	**270**	23.0	100.0	17.6	34.2	37.6	25.8	**31.5**	470	81.1	0.0
	a. Ependymoma	2	11	10	6	**29**	2.5	10.7	3.5	5.2	3.8	1.7	**3.6**	52	96.6	0.0
	b. Astrocytoma	4	31	39	43	**117**	9.9	43.3	7.1	14.7	15.0	12.3	**13.5**	202	94.0	0.0
	c. CNS embryonal	1	22	20	11	**54**	4.6	20.0	1.8	10.4	7.7	3.2	**6.7**	97	100.0	0.0
	d. Other gliomas	0	2	11	8	**21**	1.8	7.8	-	0.9	4.2	2.3	**2.3**	36	19.0	0.0
	e. Other specified	0	2	8	14	**24**	2.0	8.9	-	0.9	3.1	4.0	**2.4**	39	91.7	0.0
	f. Unspecified CNS	3	4	10	8	**25**	2.1	9.3	5.3	1.9	3.8	2.3	**2.9**	44	4.0	0.0
IV	NEUROBLASTOMA	14	36	18	4	**72**	6.1	100.0	24.7	17.1	6.9	1.1	**9.8**	134	95.8	0.0
	a. (Ganglio)neuroblastoma	14	36	18	4	**72**	6.1	100.0	24.7	17.1	6.9	1.1	**9.8**	134	95.8	0.0
	b. Peripheral nervous	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
V	RETINOBLASTOMA	6	20	3	0	**29**	2.5	100.0	10.6	9.5	1.2	-	**4.1**	54	75.9	0.0
VI	RENAL TUMOURS	13	38	14	5	**70**	6.0	100.0	22.9	18.0	5.4	1.4	**9.5**	129	98.6	0.0
	a. Nephroblastoma	13	37	13	3	**66**	5.6	94.3	22.9	17.6	5.0	0.9	**9.1**	123	98.5	0.0
	b. Renal carcinoma	0	1	1	2	**4**	0.3	5.7	-	0.5	0.4	0.6	**0.4**	7	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VII	HEPATIC TUMOURS	9	6	1	2	**18**	1.5	100.0	15.9	2.8	0.4	0.6	**2.5**	33	77.8	0.0
	a. Hepatoblastoma	9	6	1	0	**16**	1.4	88.9	15.9	2.8	0.4	-	**2.3**	30	75.0	0.0
	b. Hepatic carcinoma	0	0	0	2	**2**	0.2	11.1	-	-	-	0.6	**0.2**	3	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VIII	BONE TUMOURS	0	7	14	46	**67**	5.7	100.0	-	3.3	5.4	13.2	**6.6**	106	100.0	0.0
	a. Osteosarcoma	0	1	7	22	**30**	2.6	44.8	-	0.5	2.7	6.3	**2.8**	47	100.0	0.0
	b. Chondrosarcoma	0	0	2	0	**2**	0.2	3.0	-	-	0.8	-	**0.2**	4	100.0	0.0
	c. Ewing & related	0	6	5	23	**34**	2.9	50.7	-	2.8	1.9	6.6	**3.4**	54	100.0	0.0
	d. Other specified	0	0	0	1	**1**	0.1	1.5	-	-	-	0.3	**0.1**	1	100.0	0.0
	e. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
IX	SOFT TISSUE SARCOMA	10	20	15	22	**67**	5.7	100.0	17.6	9.5	5.8	6.3	**8.0**	116	100.0	0.0
	a. Rhabdomyosarcoma	7	16	8	5	**36**	3.1	53.7	12.3	7.6	3.1	1.4	**4.7**	66	100.0	0.0
	b. Fibrosarcoma	1	1	3	5	**10**	0.9	14.9	1.8	0.5	1.2	1.4	**1.1**	17	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	d. Other specified	1	3	4	12	**20**	1.7	29.9	1.8	1.4	1.5	3.4	**2.1**	32	100.0	0.0
	e. Unspecified	1	0	0	0	**1**	0.1	1.5	1.8	-	-	-	**0.1**	2	100.0	0.0
X	GERM CELL TUMOURS	10	8	4	25	**47**	4.0	100.0	17.6	3.8	1.5	7.2	**5.2**	77	91.5	0.0
	a. CNS germ cell ‡	1	1	2	8	**12**	1.0	25.5	1.8	0.5	0.8	2.3	**1.2**	19	83.3	0.0
	b. Other extragonadal	8	7	0	0	**15**	1.3	31.9	14.1	3.3	-	-	**2.2**	28	93.3	0.0
	c. Gonadal germ cell	1	0	2	15	**18**	1.5	38.3	1.8	-	0.8	4.3	**1.6**	27	94.4	0.0
	d. Gonadal carcinoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	e. Unspecified gonadal	0	0	0	2	**2**	0.2	4.3	-	-	-	0.6	**0.2**	3	100.0	0.0
XI	CARCINOMA & MELANOMA	1	1	6	28	**36**	3.1	100.0	1.8	0.5	2.3	8.0	**3.4**	55	100.0	0.0
	a. Adrenocortical	1	0	0	0	**1**	0.1	2.8	1.8	-	-	-	**0.1**	2	100.0	0.0
	b. Thyroid	0	0	3	11	**14**	1.2	38.9	-	-	1.2	3.2	**1.3**	22	100.0	0.0
	c. Nasopharyngeal	0	0	0	3	**3**	0.3	8.3	-	-	-	0.9	**0.2**	4	100.0	0.0
	d. Melanoma	0	1	2	4	**7**	0.6	19.4	-	0.5	0.8	1.1	**0.7**	11	100.0	0.0
	e. Skin carcinoma	0	0	0	3	**3**	0.3	8.3	-	-	-	0.9	**0.2**	4	100.0	0.0
	f. Other & unspecified	0	0	1	7	**8**	0.7	22.2	-	-	0.4	2.0	**0.7**	12	100.0	0.0
XII	OTHER & UNSPECIFIED	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	a. Other specified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	b. Other unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	TOTAL	86	405	289	396	**1176**	100.0	100.0	151.6	192.3	110.8	113.6	**139.8**	2040	93.9	0.0

† includes 100 non-malignant ‡ includes 1 non-malignant

Please consult the quality indicators for this registry

RUSSIAN FEDERATION, 2 registries (1998-2015)

Registry	Period	Cases	%	Person-years	%
Chelyabinsk	2008-2012	539	23.6	3 767 369	22.9
Samara	1998-2015	1746	76.4	12 719 183	77.1
RUSSIAN FEDERATION	**1998-2015**	**2285**	**100.0**	**16 486 552**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

Chelyabinsk Cancer Registry, 2008–2012

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The Chelyabinsk Region (*oblast*) is a federal subject located on the border of Europe and Asia, in the southern part of the Ural Mountains. The region covers an area of 88 529 km^2. The administrative centre is the city of Chelyabinsk, which was founded in 1736. The leading industries in this developed agro-industrial region are ferrous metallurgy, mechanical engineering, and nuclear processing. In 1957, part of the territory was subjected to radioactive contamination as a result of an accident at the Mayak nuclear fuel reprocessing plant, and the population in the East-Ural Radioactive Trace zone is still affected.

The population is 3.5 million, and 22% of the population is younger than 20 years (Table A.6). Chelyabinsk *oblast* has one medical university and many clinics and hospitals. Surgical and other treatment of malignant tumours in patients aged 0–17 years is performed in the Chelyabinsk Oblast Children's Teaching Hospital, which has 48 beds. Surgical treatment of brain tumours is provided by two neurosurgical departments, located in Chelyabinsk Regional Teaching Hospital and Regional Teaching Hospital No. 3. Surgical treatment of thyroid tumours is performed in Chelyabinsk City Hospital No. 1, where the surgical endocrinology centre is located. Radiation treatment is administered in radiotherapy departments, mostly in the region's principal oncology institutions – Chelyabinsk Regional Clinical Oncology Dispensary (682 beds), Magnitogorsk Regional Oncology Dispensary No. 2 (208 beds), and Kopeysk Regional Oncology Dispensary No. 3 (90 beds) – and in oncology departments of general hospitals in Chelyabinsk *oblast* (total of 562 beds).

The population-based cancer registry covers the entire territory of Chelyabinsk *oblast*. It is located in the Chelyabinsk Regional Clinical Oncology Centre. The registry collects and analyses information on cancer burden. Cases are followed up throughout their lifetime. Deaths are registered monthly in civil registration offices. The registry includes dates and causes of death in the registry database. Two state reports based on these data are submitted annually: (i) on the number of new cancer cases registered during the year, and (ii) on characteristics of the patients registered according to morphological verification, disease stage, treatment, and mortality rates in the first year of observation. The information is delivered to the Moscow P.A. Herzen Oncology Research Institute, where it is used by the Federal State Statistics Service to generate reports.

POPULATION AT RISK

See Russian Federation, above.

EDITORS' COMMENTS

All cases except DCO cases were coded as MV. The proportion of cases with unspecified morphology among MV cases is high (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. The proportion of cases aged 19 years in the age group 15–19 years was higher than expected (Table A.9); 30% of these cases were Hodgkin lymphoma. Non-malignant CNS tumours were not collected during the reporting period, except pilocytic astrocytoma, which was coded with uncertain behaviour. Laterality was complete for all of the cases of interest. See also Russian Federation, above.

Samara Cancer Registry, 1998–2015

A.G. Egorova, A.E. Orlov, A.S. Frolov, A.N. Somov, T.F. Popova, A.A. Ershov, A.V. Lutkovskiy

The Samara Region is located in the south-western part of the Russian Federation and covers an area of 53 600 km^2. The administrative centre is the city of Samara, which is located at the confluence of the Volga and Samara rivers. The region has deposits of oil, natural gas, oil shale, sulfur, gypsum, limestone, and dolomite tar. The climate is continental and dry. In 2010, the total population was 3.2 million, and 20% of the population was younger than 20 years (Table A.6). The population of the region is 83.4% Russian citizens, 3.6% Chuvash, 3.6% Tatars, 3.6% Mordvinians, and 3.5% Ukrainians; 80% of the population lives in urban areas. The Samara Region is a well-developed industrial region; the industries include mechanical engineering, oil and gas, oil refining, petrochemicals, chemicals, food, light industry, and production of building materials. Agricultural activities include growing wheat, millet, rye, barley, buckwheat, sunflowers, vegetables, and potatoes, breeding cattle and sheep, and fishing. The region has a well-developed transportation infrastructure (rail, road, air, river) and oil pipelines.

The health-care system in the region is financed through the territorial mandatory health insurance fund, supported by taxes paid by local enterprises, and regional and federal budgets. All residents are covered by the compulsory medical insurance system and are allocated to the clinic providing free health care. There are about 40 paediatric clinics, including Regional Hospital No. 1, which has a paediatric oncology department with 50 beds. The department provides surgery and chemotherapy services for children with solid tumours and haematological malignancies. Radiotherapy is performed in the Samara Regional Clinical Oncology Centre. Paediatric neuro-oncological care is provided in the children's neurosurgical department of Regional Hospital No. 1.

The Samara Cancer Registry is based in a division of the Samara Regional Clinical Oncology Centre, which is the main specialized oncological medical institution in the region. The registry is funded by the regional government.

Tumours were coded according to ICD-10 and ICD-O-2 (Table A.10), on the basis of the Russian Ministry of Health Order of 19 April 1999 No. 135 "On improving the state cancer registry system". Children with cancer make up about 1% of all registered cancer cases.

All physicians are required to fill in a notification form for each detected cancer and send it to the Samara Cancer Registry. After a course of treatment conducted by a specialist (surgery, chemotherapy, radiotherapy), patients with cancer are subject to dispensary observation; for children, this is performed by paediatricians. On a quarterly basis, the registry sends a list of patients with cancer (including children) who are subject to dispensary inspection to clinics, which are required to update patients' health status. Data on the returned forms are then entered into the registry. All medical organizations in the region are connected to a single mortality database with information on cause of death of all regional residents, which is updated in real time. Information from this database is sent to the Samara Cancer Registry monthly.

Registry data are regularly used by all medical institutions in the region to analyse the incidence, mortality, survival, and causes of late diagnosis of cancer. Data are used to conduct research and are disseminated through meetings, conferences, and awareness campaigns, and in journals and monographs, published in the Russian Federation and some other countries.

PUBLICATIONS

Egorova A, Orlov A (2014). [Evaluation of morbidity, mortality and survival rates observed in malignant tumours in the Samara region in the years 2003–2012]. Eurasian Union of Scientists. 9(4):30–2.

Orlov A, Egorova A, Starinskiy V (2014). [Analysis of cancer epidemiological trends in the regions of Russia – the basis of the successful implementation of regional programmes for the prevention of cancer]. Samara.

POPULATION AT RISK

The population is monitored annually by the Federal State Statistics Service for the Samara Region, and the results are published in demographic yearbooks and online (http://samarastat.ru/). See also Russian Federation, above.

EDITORS' COMMENTS

The registry provided data for 1990–2015; however, early years were not included in IICC-3, because of inferred underregistration. The MV% is very high (Table A.9). This suggests that some cases diagnosed clinically may be missed and may thus influence the resulting incidence rates overall or in some diagnostic categories. The registry justified the high MV% by the efficiency and completeness of the pathology services, including autopsies of children who died from cancer. Day of incidence is missing for 13% of cases (Table A.8), mostly for cases registered before 2007. The sex ratio was low for children aged 0–14 years (Table A.9). Non-malignant CNS tumours were not systematically registered; they accounted for only 1.5% of CNS tumours (Table A. 9). The one case of pilocytic astrocytoma was coded with uncertain behaviour. Laterality was provided for 78% of the cases of interest, and there were no recorded cases of bilateral tumours; therefore, the data could not be included in the laterality tables. See also Russian Federation, above.

RUSSIAN FEDERATION, 2 registries (1998-2015)

	Age group (years)	Males	Females
Person-years	0	409 062	386 047
	1-4	1 508 387	1 425 364
	5-9	1 837 951	1 744 030
	10-14	2 096 360	1 994 080
	15-19	2 579 398	2 505 873
	0-14	5 851 760	5 549 521
	0-19	8 431 158	8 055 394

Please consult the quality indicators for this pool and its constituent registries

RUSSIAN FEDERATION, 2 registries (1998-2015)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	30	218	144	99	95	**491**	**586**	31.8	100.0	25.6	100.0	37.7	74.3	40.2	24.2	18.7	**45.7**	**39.7**	655	748	98.6	1.4
	a. Lymphoid	17	188	128	68	49	**401**	**450**	26.0	81.7	19.7	76.8	21.4	64.1	35.7	16.6	9.6	**37.6**	**31.3**	537	585	98.9	1.1
	b. Acute myeloid	8	26	16	28	32	**78**	**110**	5.0	15.9	4.8	18.8	10.1	8.9	4.5	6.8	6.3	**7.0**	**6.8**	102	134	98.2	1.8
	c. CMD	1	0	0	2	7	**3**	**10**	0.2	0.6	0.4	1.7	1.3	-	-	0.5	1.4	**0.2**	**0.5**	4	11	100.0	0.0
	d. MDS & other	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	e. Unspecified	4	4	0	1	7	**9**	**16**	0.6	1.8	0.7	2.7	5.0	1.4	-	0.2	1.4	**0.9**	**1.0**	12	19	93.8	6.3
II	LYMPHOMA & RELATED	10	41	57	112	235	**220**	**455**	14.2	100.0	19.9	100.0	12.6	14.0	15.9	27.4	46.2	**18.4**	**24.6**	285	516	99.1	0.4
	a. Hodgkin	0	11	14	54	185	**79**	**264**	5.1	35.9	11.6	58.0	-	3.7	3.9	13.2	36.4	**6.2**	**13.0**	100	282	100.0	0.0
	b. Non-Hodgkin except BL	2	20	28	45	41	**95**	**136**	6.1	43.2	6.0	29.9	2.5	6.8	7.8	11.0	8.1	**8.0**	**8.0**	124	164	98.5	1.5
	c. Burkitt (BL)	0	0	3	0	0	**3**	**3**	0.2	1.4	0.1	0.7	-	-	0.8	-	-	**0.3**	**0.2**	4	4	100.0	0.0
	d. Lymphoreticular	8	7	9	12	6	**36**	**42**	2.3	16.4	1.8	9.2	10.1	2.4	2.5	2.9	1.2	**3.2**	**2.8**	47	53	95.2	0.0
	e. Unspecified	0	3	3	1	3	**7**	**10**	0.5	3.2	0.4	2.2	-	1.0	0.8	0.2	0.6	**0.7**	**0.6**	9	12	100.0	0.0
III	CNS NEOPLASMS †	24	102	91	77	58	**294**	**352**	19.0	100.0	15.4	100.0	30.2	34.8	25.4	18.8	11.4	**26.7**	**23.3**	390	447	96.6	2.6
	a. Ependymoma	3	16	7	3	5	**29**	**34**	1.9	9.9	1.5	9.7	3.8	5.5	2.0	0.7	1.0	**2.8**	**2.4**	39	44	100.0	0.0
	b. Astrocytoma	9	40	27	31	26	**107**	**133**	6.9	36.4	5.8	37.8	11.3	13.6	7.5	7.6	5.1	**9.7**	**8.7**	141	167	99.2	0.0
	c. CNS embryonal	6	26	32	19	14	**83**	**97**	5.4	28.2	4.2	27.6	7.5	8.9	8.9	4.6	2.8	**7.6**	**6.5**	111	125	99.0	1.0
	d. Other gliomas	3	13	11	10	7	**37**	**44**	2.4	12.6	1.9	12.5	3.8	4.4	3.1	2.4	1.4	**3.4**	**2.9**	49	56	88.6	9.1
	e. Other specified	2	1	5	2	0	**10**	**10**	0.6	3.4	0.4	2.8	2.5	0.3	1.4	0.5	-	**0.9**	**0.7**	13	13	90.0	10.0
	f. Unspecified CNS	1	6	9	12	6	**28**	**34**	1.8	9.5	1.5	9.7	1.3	2.0	2.5	2.9	1.2	**2.4**	**2.1**	37	43	88.2	8.8
IV	NEUROBLASTOMA	51	33	7	4	6	**95**	**101**	6.1	100.0	4.4	100.0	64.1	11.2	2.0	1.0	1.2	**9.6**	**7.7**	127	133	100.0	0.0
	a. (Ganglio)neuroblastoma	51	31	7	2	5	**91**	**96**	5.9	95.8	4.2	95.0	64.1	10.6	2.0	0.5	1.0	**9.3**	**7.4**	122	127	100.0	0.0
	b. Peripheral nervous	0	2	0	2	1	**4**	**5**	0.3	4.2	0.2	5.0	-	0.7	-	0.5	0.2	**0.3**	**0.3**	5	6	100.0	0.0
V	RETINOBLASTOMA	12	29	0	1	1	**42**	**43**	2.7	100.0	1.9	100.0	15.1	9.9	-	0.2	0.2	**4.3**	**3.4**	56	57	100.0	0.0
VI	RENAL TUMOURS	26	50	20	11	8	**107**	**115**	6.9	100.0	5.0	100.0	32.7	17.0	5.6	2.7	1.6	**10.5**	**8.5**	143	151	100.0	0.0
	a. Nephroblastoma	26	50	20	11	4	**107**	**111**	6.9	100.0	4.9	96.5	32.7	17.0	5.6	2.7	0.8	**10.5**	**8.3**	143	147	100.0	0.0
	b. Renal carcinoma	0	0	0	0	4	**0**	**4**	-	-	0.2	3.5	-	-	-	-	0.8	**-**	**0.2**	-	4	100.0	0.0
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VII	HEPATIC TUMOURS	6	10	2	0	4	**18**	**22**	1.2	100.0	1.0	100.0	7.5	3.4	0.6	-	0.8	**1.8**	**1.6**	24	28	100.0	0.0
	a. Hepatoblastoma	5	8	2	0	1	**15**	**16**	1.0	83.3	0.7	72.7	6.3	2.7	0.6	-	0.2	**1.5**	**1.2**	20	21	100.0	0.0
	b. Hepatic carcinoma	1	2	0	0	2	**3**	**5**	0.2	16.7	0.2	22.7	1.3	0.7	-	-	0.4	**0.3**	**0.3**	4	6	100.0	0.0
	c. Unspecified	0	0	0	0	1	**0**	**1**	-	-	0.0	4.5	-	-	-	-	0.2	**-**	**0.0**	-	1	100.0	0.0
VIII	BONE TUMOURS	2	2	13	45	53	**62**	**115**	4.0	100.0	5.0	100.0	2.5	0.7	3.6	11.0	10.4	**4.8**	**6.0**	79	131	100.0	0.0
	a. Osteosarcoma	1	2	7	20	26	**30**	**56**	1.9	48.4	2.5	48.7	1.3	0.7	2.0	4.9	5.1	**2.4**	**3.0**	38	64	100.0	0.0
	b. Chondrosarcoma	0	0	1	6	10	**7**	**17**	0.5	11.3	0.7	14.8	-	-	0.3	1.5	2.0	**0.5**	**0.8**	9	19	100.0	0.0
	c. Ewing & related	1	0	1	11	10	**13**	**23**	0.8	21.0	1.0	20.0	1.3	-	0.3	2.7	2.0	**1.0**	**1.2**	16	26	100.0	0.0
	d. Other specified	0	0	1	4	4	**5**	**9**	0.3	8.1	0.4	7.8	-	-	0.3	1.0	0.8	**0.4**	**0.5**	6	10	100.0	0.0
	e. Unspecified	0	0	3	4	3	**7**	**10**	0.5	11.3	0.4	8.7	-	-	0.8	1.0	0.6	**0.6**	**0.6**	9	12	100.0	0.0
IX	SOFT TISSUE SARCOMA	10	34	21	20	55	**85**	**140**	5.5	100.0	6.1	100.0	12.6	11.6	5.9	4.9	10.8	**7.9**	**8.5**	113	167	100.0	0.0
	a. Rhabdomyosarcoma	4	17	9	5	10	**35**	**45**	2.3	41.2	2.0	32.1	5.0	5.8	2.5	1.2	2.0	**3.3**	**3.0**	47	57	100.0	0.0
	b. Fibrosarcoma	2	7	7	4	10	**20**	**30**	1.3	23.5	1.3	21.4	2.5	2.4	2.0	1.0	2.0	**1.8**	**1.9**	27	37	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
	d. Other specified	2	3	2	7	25	**14**	**39**	0.9	16.5	1.7	27.9	2.5	1.0	0.6	1.7	4.9	**1.2**	**2.0**	18	43	100.0	0.0
	e. Unspecified	2	7	3	4	10	**16**	**26**	1.0	18.8	1.1	18.6	2.5	2.4	0.8	1.0	2.0	**1.5**	**1.6**	21	31	100.0	0.0
X	GERM CELL TUMOURS	6	10	9	19	61	**44**	**105**	2.8	100.0	4.6	100.0	7.5	3.4	2.5	4.6	12.0	**3.8**	**5.7**	57	117	100.0	0.0
	a. CNS germ cell	0	1	1	2	3	**4**	**7**	0.3	9.1	0.3	6.7	-	0.3	0.3	0.5	0.6	**0.3**	**0.4**	5	8	100.0	0.0
	b. Other extragonadal	3	5	2	1	1	**11**	**12**	0.7	25.0	0.5	11.4	3.8	1.7	0.6	0.2	0.2	**1.1**	**0.9**	15	16	100.0	0.0
	c. Gonadal germ cell	2	4	3	13	51	**22**	**73**	1.4	50.0	3.2	69.5	2.5	1.4	0.8	3.2	10.0	**1.8**	**3.7**	28	78	100.0	0.0
	d. Gonadal carcinoma	0	0	2	3	5	**5**	**10**	0.3	11.4	0.4	9.5	-	-	0.6	0.7	1.0	**0.4**	**0.5**	6	11	100.0	0.0
	e. Unspecified gonadal	1	0	1	0	1	**2**	**3**	0.1	4.5	0.1	2.9	1.3	-	0.3	-	0.2	**0.2**	**0.2**	3	4	100.0	0.0
XI	CARCINOMA & MELANOMA	12	13	12	39	161	**76**	**237**	4.9	100.0	10.4	100.0	15.1	4.4	3.4	9.5	31.7	**6.4**	**12.1**	98	256	99.2	0.8
	a. Adrenocortical	10	5	1	0	2	**16**	**18**	1.0	21.1	0.8	7.6	12.6	1.7	0.3	-	0.4	**1.6**	**1.4**	22	23	100.0	0.0
	b. Thyroid	1	0	2	16	47	**19**	**66**	1.2	25.0	2.9	27.8	1.3	-	0.6	3.9	9.2	**1.4**	**3.2**	24	70	100.0	0.0
	c. Nasopharyngeal	0	0	1	0	2	**1**	**3**	0.1	1.3	0.1	1.3	-	-	0.3	-	0.4	**0.1**	**0.2**	1	3	100.0	0.0
	d. Melanoma	1	4	1	5	28	**11**	**39**	0.7	14.5	1.7	16.5	1.3	1.4	0.3	1.2	5.5	**1.0**	**2.0**	14	42	97.4	2.6
	e. Skin carcinoma	0	0	2	2	28	**4**	**32**	0.3	5.3	1.4	13.5	-	-	0.6	0.5	5.5	**0.3**	**1.5**	5	33	100.0	0.0
	f. Other & unspecified	0	4	5	16	54	**25**	**79**	1.6	32.9	3.5	33.3	-	1.4	1.4	3.9	10.6	**2.0**	**3.9**	32	85	98.7	1.3
XII	OTHER & UNSPECIFIED	2	7	0	2	3	**11**	**14**	0.7	100.0	0.6	100.0	2.5	2.4	-	0.5	0.6	**1.1**	**1.0**	15	17	92.9	7.1
	a. Other specified	0	0	0	2	3	**2**	**5**	0.1	18.2	0.2	35.7	-	-	-	0.5	0.6	**0.1**	**0.2**	2	5	100.0	0.0
	b. Other unspecified	2	7	0	0	0	**9**	**9**	0.6	81.8	0.4	64.3	2.5	2.4	-	-	-	**0.9**	**0.7**	12	12	88.9	11.1
	TOTAL	191	549	376	429	740	**1545**	**2285**	100.0	100.0	100.0	100.0	240.2	187.1	105.0	104.9	145.5	**141.1**	**142.1**	2042	2769	98.8	1.0

† includes 9 non-malignant

Please consult the quality indicators for this pool and its constituent registries

Slovakia

Slovakia is located in central Europe and is bordered by Ukraine to the east, Hungary and Austria to the south, the Czech Republic to the west, and Poland to the north. The country covers an area of 49 035 km^2 and has a continental climate, which is strongly influenced by altitude and type of relief. Arable land suitable for agriculture comprises about 30% of the territory.

Slovakia became independent in 1993, after the peaceful dissolution of the Czech and Slovak Federative Republic. During the reporting period, the country experienced transformation from a one-party socialist state into a democracy with a very high standard of living and an advanced market economy driven by exports of automobiles and electronics. In 2010, the population of Slovakia was 5.4 million, and 22% of the population was younger than 20 years (Table A.6). During the reporting period, the proportion of people younger than 20 years decreased and that of people aged 60 years and older increased.

Health care in Slovakia is provided free of charge to patients with cancer, but all residents must pay for mandatory health insurance. The primary health units are the Community Medical Stations headed by a general practitioner and supported by paediatricians and gynaecologists; these units offer general outpatient diagnostic and treatment services. Transportation links and relatively short distances enable access to more specialized facilities. Offices of Public Health are responsible for prevention of diseases. Major political changes in 1990 led to the creation of the private health sector, and by 2005, nearly 55% of the 98 829 employees in health services worked in the private sector.

Peripheral care for patients with cancer is provided by outpatient oncology clinics, which are located in all counties. These clinics are run by oncologists and are responsible for active patient follow-up. The Slovak League Against Cancer supports cancer-related health education. Specialized diagnostic and treatment services for children with cancer were provided by three major departments that specialized in paediatric oncology and by some other paediatric departments. Since 1992, the care of patients younger than 20 years has been centralized in the three specialized cancer treatment centres, which are located in Bratislava, Banská Bystrica, and Košice. Some adolescents may be treated in general cancer units.

POPULATION AT RISK

The population data were provided by the Statistical Office of the Slovak Republic (https://slovak.statistics.sk) and are based on the 1991, 2001, and 2011 censuses (Table A.7). Data were provided in the requested detail for 1991–2011. For 1990, data were provided by sex and age groups (0, 1–4, 5,9, 10–14, 15–19 years), and the population counts for the missing age–sex categories were estimated at IARC using the methods described in Chapter 2.

EDITORS' COMMENTS

The two Slovak registries presented in full tables in the IICC-3 book (Table A.12) both cover the entire country, but they differ in their history, mission, target age range, data sources, registration practice, and reporting period. The two groups are working towards closer cooperation and data exchange, and they provide comparable data. Both registries register all non-malignant CNS tumours, although the coding of the behaviour of pilocytic astrocytoma differs between the two registries.

Slovak National Cancer Registry, 1990–2009

Chakameh Safaei Diba, Ivan Plesko

Notification of cancer cases and deaths has been mandatory in Slovakia since 1952. The Slovak National Cancer Registry was established in 1976 (Table A.10), with retrospective data collection since 1968. Data sources include notifications, death certificates, and autopsy, histology, cytology, and hospital discharge reports. The registry database is annually matched against the database of hospitalizations established by the Ministry of Health. Missing information is requested from providers. The ICD-O-1, ICD-9, and TNM classifications were used to code cases since 1968; they were replaced by ICD-O-2 and ICD-10 in 1994 and by ICD-O-3 in 2007 (Table A.10). The registry staff consists of one full-time physician specializing in epidemiology, two part-time physicians specializing in oncology and pathology, one statistician, and six registrars.

Data on the burden of childhood cancer are shared with paediatric oncologists. The registry data were presented in both previous IICC volumes and have been used in several international studies (e.g. European Cancer Incidence and Mortality [EUROCIM], ECLIS, EUROCARE, and ACCIS).

POPULATION AT RISK

See Slovakia, above.

EDITORS' COMMENTS

The registry participated in both previous IICC volumes (Table A.1). The provided dates and age were inconsistent in 7% of cases (Table A.8). Non-malignant CNS tumours and skin carcinomas are systematically recorded. Pilocytic astrocytoma was originally coded according to the ICD-O edition in use (Table A.10) and recoded with uncertain behaviour in the IICC-3 dataset, according to ICD-O-3. Laterality was almost complete. See also Slovakia, above.

SLOVAKIA (1990-2009)

	Age group (years)	Males	Females
Person-years	0	622 078	591 397
	1-4	2 604 995	2 481 153
	5-9	3 616 112	3 452 319
	10-14	4 109 902	3 934 735
	15-19	4 454 889	4 272 255
	0-14	10 953 087	10 459 604
	0-19	15 407 976	14 731 859
Average annual population	0-14	547 654	522 980
	0-19	770 399	736 593

Please consult the quality indicators for this registry

SLOVAKIA (1990-2009)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	32	352	226	190	194	800	994	27.1	100.0	21.7	100.0	26.4	69.2	32.0	23.6	22.2	40.8	36.6	583	694	99.9	0.1
	a. Lymphoid	17	298	176	129	93	620	713	21.0	77.5	15.6	71.7	14.0	58.6	24.9	16.0	10.7	32.0	27.2	455	508	100.0	0.0
	b. Acute myeloid	10	42	39	42	60	133	193	4.5	16.6	4.2	19.4	8.2	8.3	5.5	5.2	6.9	6.5	6.6	95	129	100.0	0.0
	c. CMD	1	6	6	12	25	25	50	0.8	3.1	1.1	5.0	0.8	1.2	0.8	1.5	2.9	1.1	1.5	17	32	100.0	0.0
	d. MDS & other	0	1	5	4	8	10	18	0.3	1.3	0.4	1.8	-	0.2	0.7	0.5	0.9	0.4	0.5	7	11	100.0	0.0
	e. Unspecified	4	5	0	3	8	12	20	0.4	1.5	0.4	2.0	3.3	1.0	-	0.4	0.9	0.7	0.7	9	14	95.0	5.0
II	LYMPHOMA & RELATED	17	68	147	181	358	413	771	14.0	100.0	16.9	100.0	14.0	13.4	20.8	22.5	41.0	18.5	23.5	284	489	99.6	0.3
	a. Hodgkin	0	17	51	114	263	182	445	6.2	44.1	9.7	57.7	-	3.3	7.2	14.2	30.1	7.5	12.6	120	271	100.0	0.0
	b. Non-Hodgkin except BL	5	24	68	45	79	142	221	4.8	34.4	4.8	28.7	4.1	4.7	9.6	5.6	9.1	6.5	7.1	99	144	100.0	0.0
	c. Burkitt (BL)	0	12	20	10	8	42	50	1.4	10.2	1.1	6.5	-	2.4	2.8	1.2	0.9	2.0	1.8	30	34	100.0	0.0
	d. Lymphoreticular	8	13	6	5	3	32	35	1.1	7.7	0.8	4.5	6.6	2.6	0.8	0.6	0.3	1.7	1.4	24	26	100.0	0.0
	e. Unspecified	4	2	2	7	5	15	20	0.5	3.6	0.4	2.6	3.3	0.4	0.3	0.9	0.6	0.7	0.7	11	13	85.0	10.0
III	CNS NEOPLASMS †	41	206	214	221	234	682	916	23.1	100.0	20.0	100.0	33.8	40.5	30.3	27.5	26.8	32.9	31.5	485	619	87.4	4.1
	a. Ependymoma	7	32	17	22	16	78	94	2.6	11.4	2.1	10.3	5.8	6.3	2.4	2.7	1.8	4.0	3.5	57	66	100.0	0.0
	b. Astrocytoma	9	76	91	105	112	281	393	9.5	41.2	8.6	42.9	7.4	14.9	12.9	13.1	12.8	13.2	13.1	197	261	100.0	0.0
	c. CNS embryonal	13	40	39	25	15	117	132	4.0	17.2	2.9	14.4	10.7	7.9	5.5	3.1	1.7	5.9	5.0	85	94	100.0	0.0
	d. Other gliomas	3	12	17	18	25	50	75	1.7	7.3	1.6	8.2	2.5	2.4	2.4	2.2	2.9	2.3	2.5	35	49	100.0	0.0
	e. Other specified	4	22	15	26	37	67	104	2.3	9.8	2.3	11.4	3.3	4.3	2.1	3.2	4.2	3.2	3.4	47	69	98.1	1.9
	f. Unspecified CNS	5	24	35	25	29	89	118	3.0	13.0	2.6	12.9	4.1	4.7	5.0	3.1	3.3	4.3	4.1	63	80	4.2	30.5
IV	NEUROBLASTOMA	72	94	22	13	9	201	210	6.8	100.0	4.6	100.0	59.3	18.5	3.1	1.6	1.0	11.7	9.3	155	161	99.0	1.0
	a. (Ganglio)neuroblastoma	72	93	20	11	7	196	203	6.6	97.5	4.4	96.7	59.3	18.3	2.8	1.4	0.8	11.4	9.1	152	156	99.0	1.0
	b. Peripheral nervous	0	1	2	2	2	5	7	0.2	2.5	0.2	3.3	-	0.2	0.3	0.2	0.2	0.2	0.2	3	5	100.0	0.0
V	RETINOBLASTOMA	22	32	4	0	0	58	58	2.0	100.0	1.3	100.0	18.1	6.3	0.6	-	-	3.5	2.7	46	46	98.3	1.7
VI	RENAL TUMOURS	28	85	44	5	13	162	175	5.5	100.0	3.8	100.0	23.1	16.7	6.2	0.6	1.5	9.1	7.4	124	131	98.3	0.6
	a. Nephroblastoma	26	84	44	4	3	158	161	5.3	97.5	3.5	92.0	21.4	16.5	6.2	0.5	0.3	8.9	7.0	121	123	100.0	0.0
	b. Renal carcinoma	0	0	0	0	9	0	9	-	-	0.2	5.1	-	-	-	-	1.0	-	0.2	-	5	100.0	0.0
	c. Unspecified	2	1	0	1	1	4	5	0.1	2.5	0.1	2.9	1.6	0.2	-	0.1	0.1	0.2	0.2	3	4	40.0	20.0
VII	HEPATIC TUMOURS	15	15	5	7	10	42	52	1.4	100.0	1.1	100.0	12.4	2.9	0.7	0.9	1.1	2.3	2.1	32	37	92.3	5.8
	a. Hepatoblastoma	12	14	4	4	2	34	36	1.2	81.0	0.8	69.2	9.9	2.8	0.6	0.5	0.2	1.9	1.5	26	27	100.0	0.0
	b. Hepatic carcinoma	0	0	1	3	8	4	12	0.1	9.5	0.3	23.1	-	-	0.1	0.4	0.9	0.2	0.3	3	7	100.0	0.0
	c. Unspecified	3	1	0	0	0	4	4	0.1	9.5	0.1	7.7	2.5	0.2	-	-	-	0.2	0.2	3	3	0.0	75.0
VIII	BONE TUMOURS	0	10	34	127	129	171	300	5.8	100.0	6.6	100.0	-	2.0	4.8	15.8	14.8	6.7	8.6	111	185	99.0	0.7
	a. Osteosarcoma	0	2	13	72	59	87	146	2.9	50.9	3.2	48.7	-	0.4	1.8	9.0	6.8	3.3	4.1	56	89	100.0	0.0
	b. Chondrosarcoma	0	0	0	10	11	10	21	0.3	5.8	0.5	7.0	-	-	-	1.2	1.3	0.4	0.6	6	13	100.0	0.0
	c. Ewing & related	0	7	19	39	49	65	114	2.2	38.0	2.5	38.0	-	1.4	2.7	4.8	5.6	2.7	3.4	43	71	100.0	0.0
	d. Other specified	0	1	1	4	7	6	13	0.2	3.5	0.3	4.3	-	0.2	0.1	0.5	0.8	0.3	0.4	4	8	100.0	0.0
	e. Unspecified	0	0	1	2	3	3	6	0.1	1.8	0.1	2.0	-	-	0.1	0.2	0.3	0.1	0.2	2	4	50.0	33.3
IX	SOFT TISSUE SARCOMA	28	51	51	59	83	189	272	6.4	100.0	5.9	100.0	23.1	10.0	7.2	7.3	9.5	9.3	9.4	135	183	97.8	2.2
	a. Rhabdomyosarcoma	11	35	34	22	16	102	118	3.5	54.0	2.6	43.4	9.1	6.9	4.8	2.7	1.8	5.2	4.4	74	83	100.0	0.0
	b. Fibrosarcoma	5	6	3	9	12	23	35	0.8	12.2	0.8	12.9	4.1	1.2	0.4	1.1	1.4	1.1	1.2	16	23	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Other specified	9	7	9	24	42	49	91	1.7	25.9	2.0	33.5	7.4	1.4	1.3	3.0	4.8	2.3	2.8	34	58	100.0	0.0
	e. Unspecified	3	3	5	4	13	15	28	0.5	7.9	0.6	10.3	2.5	0.6	0.7	0.5	1.5	0.7	0.9	11	18	78.6	21.4
X	GERM CELL TUMOURS	23	33	10	40	304	106	410	3.6	100.0	9.0	100.0	19.0	6.5	1.4	5.0	34.8	5.3	12.0	76	251	98.3	0.2
	a. CNS germ cell ‡	4	3	4	7	10	18	28	0.6	17.0	0.6	6.8	3.3	0.6	0.6	0.9	1.1	0.9	0.9	13	18	100.0	0.0
	b. Other extragonadal	8	11	0	0	14	19	33	0.6	17.9	0.7	8.0	6.6	2.2	-	-	1.6	1.2	1.3	15	23	100.0	0.0
	c. Gonadal germ cell	10	18	5	30	249	63	312	2.1	59.4	6.8	76.1	8.2	3.5	0.7	3.7	28.5	3.0	8.8	44	187	100.0	0.0
	d. Gonadal carcinoma	0	0	0	1	15	1	16	0.0	0.9	0.3	3.9	-	-	-	0.1	1.7	0.0	0.4	1	9	100.0	0.0
	e. Unspecified gonadal	1	1	1	2	16	5	21	0.2	4.7	0.5	5.1	0.8	0.2	0.1	0.2	1.8	0.2	0.6	4	13	66.7	4.8
XI	CARCINOMA & MELANOMA	2	10	22	74	275	108	383	3.7	100.0	8.4	100.0	1.6	2.0	3.1	9.2	31.5	4.4	10.5	71	229	100.0	0.0
	a. Adrenocortical	1	4	1	4	2	10	12	0.3	9.3	0.3	3.1	0.8	0.8	0.1	0.5	0.2	0.5	0.4	7	8	100.0	0.0
	b. Thyroid	0	1	7	23	91	31	122	1.0	28.7	2.7	31.9	-	0.2	1.0	2.9	10.4	1.2	3.3	20	72	100.0	0.0
	c. Nasopharyngeal	0	0	3	11	17	14	31	0.5	13.0	0.7	8.1	-	-	0.4	1.4	1.9	0.5	0.9	9	19	100.0	0.0
	d. Melanoma	0	3	3	14	53	20	73	0.7	18.5	1.6	19.1	-	0.6	0.4	1.7	6.1	0.8	2.0	13	44	100.0	0.0
	e. Skin carcinoma	0	1	1	5	38	7	45	0.2	6.5	1.0	11.7	-	0.2	0.1	0.6	4.4	0.3	1.2	5	26	100.0	0.0
	f. Other & unspecified	1	1	7	17	74	26	100	0.9	24.1	2.2	26.1	0.8	0.2	1.0	2.1	8.5	1.1	2.7	17	60	100.0	0.0
XII	OTHER & UNSPECIFIED	8	3	5	7	10	23	33	0.8	100.0	0.7	100.0	6.6	0.6	0.7	0.9	1.1	1.2	1.2	17	22	42.4	21.2
	a. Other specified	0	1	0	2	6	3	9	0.1	13.0	0.2	27.3	-	0.2	-	0.2	0.7	0.1	0.3	2	5	100.0	0.0
	b. Other unspecified	8	2	5	5	4	20	24	0.7	87.0	0.5	72.7	6.6	0.4	0.7	0.6	0.5	1.0	0.9	15	17	20.8	29.2
	TOTAL	288	959	784	924	1619	2955	4574	100.0	100.0	100.0	100.0	237.3	188.6	110.9	114.9	185.5	145.8	154.7	2119	3046	96.4	1.4

† includes 308 non-malignant ‡ includes 3 non-malignant

Please consult the quality indicators for this registry

Slovak Clinical Cancer Registry of Children and Adolescents, 2000–2012

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The Slovak Clinical Cancer Registry of Children and Adolescents, which covers the whole population of Slovakia, is the result of a close collaboration between the three specialized paediatric oncology treatment centres, which are located in Bratislava, Banská Bystrica, and Košice. These centres all use the same treatment strategies (protocols according to European and American treatment groups) and are involved in international clinical studies. On the initiative of the heads of these centres, a Section of Paediatric Haematology and Oncology was established within the Slovak Paediatric Society. This led to the creation of the Slovak childhood cancer database to centralize the collection of data on cancer in children and adolescents. In 2015, the database was renamed the Slovak Clinical Cancer Registry of Children and Adolescents. Registration of patients in this registry requires informed consent.

Until 2014, cancer diagnoses were coded according to ICD-10, and cancer cases were recorded in an electronic spreadsheet. In 2014, all cancer cases were converted to the ICD-O-3 classification after verification of the medical records, and the database was imported into the CanReg5 software provided by IARC. Information sources are the medical records of the three treatment centres and other specialized hospitals.

The registry includes all malignant tumours, including skin tumours and Langerhans cell histiocytosis, all unspecified and some benign tumours, and tumours of borderline malignancy. Data collection is mainly active. The database is updated annually, based on information provided by the treatment centres about new cases and the follow-up of registered patients. The goals of the registry are to monitor childhood cancer incidence and survival, provide an overview of cancer diagnosis and management, and evaluate outcomes with respect to diagnosis, treatment, and predisposing characteristics.

PUBLICATIONS

Makohusová M, Kaiserová E, Colombet M, Bubanská E, Oravkinová I, Stančoková T, et al. (2017). The Slovak Clinical Cancer Registry of Children and Adolescents: rationale, organization and incidence in years 2000–2012. Pediatr Blood Cancer. 64(Suppl 3):S415.

Kaiserová E, Bubánska E, Oravkinová I, Stančoková T, Šubová Z, Plank L (2006). [Incidence and curability of childhood tumours in the Slovak Republic]. Onkológia. 1(3):180–6.

POPULATION AT RISK

See Slovakia, above.

EDITORS' COMMENTS

In this paediatric cancer registry, registration focused on the age range 0–14 years during the reporting period. Therefore, data for the age groups 15–19 years and 0–19 years are not shown in the tables. All non-malignant CNS tumours are registered. Pilocytic astrocytoma was coded mostly with uncertain behaviour, but a few cases were coded with malignant behaviour. Skin carcinomas are reportable, but none were recorded, probably because the patients were treated outside the paediatric oncology network. Laterality was 90% complete, and the dataset was included in the laterality table for nephroblastoma. See also Slovakia, above.

SLOVAKIA, paediatric (2000-2012)

	Age group (years)	Males	Females
Person-years	0	365 121	349 379
	1-4	1 455 573	1 385 171
	5-9	1 939 425	1 845 460
	10-14	2 268 138	2 167 857
	0-14	6 028 257	5 747 867
Average annual population	0-14	463 712	442 144

Please consult the quality indicators for this registry

SLOVAKIA, paediatric (2000-2012)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	27	203	139	115	**484**	29.8	100.0	37.8	71.5	36.7	25.9	**44.4**	637	100.0	0.0
	a. Lymphoid	9	170	113	79	**371**	22.8	76.7	12.6	59.8	29.9	17.8	**34.3**	490	100.0	0.0
	b. Acute myeloid	9	23	21	24	**77**	4.7	15.9	12.6	8.1	5.5	5.4	**6.8**	100	100.0	0.0
	c. CMD	3	1	0	6	**10**	0.6	2.1	4.2	0.4	-	1.4	**0.8**	12	100.0	0.0
	d. MDS & other	1	5	1	1	**8**	0.5	1.7	1.4	1.8	0.3	0.2	**0.8**	11	100.0	0.0
	e. Unspecified	5	4	4	5	**18**	1.1	3.7	7.0	1.4	1.1	1.1	**1.6**	24	100.0	0.0
II	LYMPHOMA & RELATED	3	30	57	106	**196**	12.1	100.0	4.2	10.6	15.1	23.9	**15.4**	241	99.5	0.0
	a. Hodgkin	0	9	17	68	**94**	5.8	48.0	-	3.2	4.5	15.3	**6.9**	112	100.0	0.0
	b. Non-Hodgkin except BL	0	18	33	32	**83**	5.1	42.3	-	6.3	8.7	7.2	**6.9**	105	100.0	0.0
	c. Burkitt (BL)	0	3	7	6	**16**	1.0	8.2	-	1.1	1.8	1.4	**1.3**	20	100.0	0.0
	d. Lymphoreticular	3	0	0	0	**3**	0.2	1.5	4.2	-	-	-	**0.3**	4	66.7	0.0
	e. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
III	CNS NEOPLASMS †	17	109	123	114	**363**	22.3	100.0	23.8	38.4	32.5	25.7	**31.7**	468	91.2	0.0
	a. Ependymoma	1	12	7	13	**33**	2.0	9.1	1.4	4.2	1.8	2.9	**2.9**	42	100.0	0.0
	b. Astrocytoma	5	43	57	64	**169**	10.4	46.6	7.0	15.1	15.1	14.4	**14.3**	215	99.4	0.0
	c. CNS embryonal	7	31	25	15	**78**	4.8	21.5	9.8	10.9	6.6	3.4	**7.2**	103	100.0	0.0
	d. Other gliomas	1	8	8	9	**26**	1.6	7.2	1.4	2.8	2.1	2.0	**2.3**	33	96.2	0.0
	e. Other specified	1	8	7	8	**24**	1.5	6.6	1.4	2.8	1.8	1.8	**2.1**	31	100.0	0.0
	f. Unspecified CNS	2	7	19	5	**33**	2.0	9.1	2.8	2.5	5.0	1.1	**2.9**	43	9.1	0.0
IV	NEUROBLASTOMA	50	54	16	5	**125**	7.7	100.0	70.0	19.0	4.2	1.1	**13.0**	173	100.0	0.0
	a. (Ganglio)neuroblastoma	49	54	15	4	**122**	7.5	97.6	68.6	19.0	4.0	0.9	**12.8**	169	100.0	0.0
	b. Peripheral nervous	1	0	1	1	**3**	0.2	2.4	1.4	-	0.3	0.2	**0.3**	4	100.0	0.0
V	RETINOBLASTOMA	16	16	1	1	**34**	2.1	100.0	22.4	5.6	0.3	0.2	**3.6**	47	2.9	0.0
VI	RENAL TUMOURS	22	50	26	2	**100**	6.2	100.0	30.8	17.6	6.9	0.5	**10.2**	138	100.0	0.0
	a. Nephroblastoma	22	50	26	2	**100**	6.2	100.0	30.8	17.6	6.9	0.5	**10.2**	138	100.0	0.0
	b. Renal carcinoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VII	HEPATIC TUMOURS	9	9	5	8	**31**	1.9	100.0	12.6	3.2	1.3	1.8	**2.9**	41	100.0	0.0
	a. Hepatoblastoma	9	9	5	2	**25**	1.5	80.6	12.6	3.2	1.3	0.5	**2.5**	34	100.0	0.0
	b. Hepatic carcinoma	0	0	0	6	**6**	0.4	19.4	-	-	-	1.4	**0.4**	7	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VIII	BONE TUMOURS	0	4	16	79	**99**	6.1	100.0	-	1.4	4.2	17.8	**7.0**	116	100.0	0.0
	a. Osteosarcoma	0	1	7	45	**53**	3.3	53.5	-	0.4	1.8	10.1	**3.7**	61	100.0	0.0
	b. Chondrosarcoma	0	1	0	4	**5**	0.3	5.1	-	0.4	-	0.9	**0.4**	6	100.0	0.0
	c. Ewing & related	0	2	9	29	**40**	2.5	40.4	-	0.7	2.4	6.5	**2.9**	47	100.0	0.0
	d. Other specified	0	0	0	1	**1**	0.1	1.0	-	-	-	0.2	**0.1**	1	100.0	0.0
	e. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
IX	SOFT TISSUE SARCOMA	11	21	27	23	**82**	5.0	100.0	15.4	7.4	7.1	5.2	**7.3**	107	98.8	0.0
	a. Rhabdomyosarcoma	4	17	19	12	**52**	3.2	63.4	5.6	6.0	5.0	2.7	**4.7**	68	100.0	0.0
	b. Fibrosarcoma	5	1	1	2	**9**	0.6	11.0	7.0	0.4	0.3	0.5	**0.9**	12	88.9	0.0
	c. Kaposi sarcoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	d. Other specified	1	1	7	9	**18**	1.1	22.0	1.4	0.4	1.8	2.0	**1.4**	22	100.0	0.0
	e. Unspecified	1	2	0	0	**3**	0.2	3.7	1.4	0.7	-	-	**0.3**	4	100.0	0.0
X	GERM CELL TUMOURS	16	16	6	39	**77**	4.7	100.0	22.4	5.6	1.6	8.8	**6.5**	97	100.0	0.0
	a. CNS germ cell ‡	3	2	1	11	**17**	1.0	22.1	4.2	0.7	0.3	2.5	**1.3**	21	100.0	0.0
	b. Other extragonadal	2	3	1	3	**9**	0.6	11.7	2.8	1.1	0.3	0.7	**0.8**	12	100.0	0.0
	c. Gonadal germ cell	11	10	4	24	**49**	3.0	63.6	15.4	3.5	1.1	5.4	**4.2**	62	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	e. Unspecified gonadal	0	1	0	1	**2**	0.1	2.6	-	0.4	-	0.2	**0.2**	3	100.0	0.0
XI	CARCINOMA & MELANOMA	0	3	8	22	**33**	2.0	100.0	-	1.1	2.1	5.0	**2.4**	40	100.0	0.0
	a. Adrenocortical	0	1	0	0	**1**	0.1	3.0	-	0.4	-	-	**0.1**	1	100.0	0.0
	b. Thyroid	0	0	1	5	**6**	0.4	18.2	-	-	0.3	1.1	**0.4**	7	100.0	0.0
	c. Nasopharyngeal	0	0	2	3	**5**	0.3	15.2	-	-	0.5	0.7	**0.4**	6	100.0	0.0
	d. Melanoma	0	2	1	2	**5**	0.3	15.2	-	0.7	0.3	0.5	**0.4**	6	100.0	0.0
	e. Skin carcinoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	f. Other & unspecified	0	0	4	12	**16**	1.0	48.5	-	-	1.1	2.7	**1.1**	19	100.0	0.0
XII	OTHER & UNSPECIFIED	0	1	0	1	**2**	0.1	100.0	-	0.4	-	0.2	**0.2**	3	100.0	0.0
	a. Other specified	0	1	0	1	**2**	0.1	100.0	-	0.4	-	0.2	**0.2**	3	100.0	0.0
	b. Other unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	TOTAL	171	516	424	515	**1626**	100.0	100.0	239.3	181.6	112.0	116.1	**144.6**	2107	95.9	0.0

† includes 123 non-malignant ‡ includes 6 non-malignant

Please consult the quality indicators for this registry

Slovenia

Cancer Registry of Republic of Slovenia, 1991–2012

Maja Primic Zakelj, Vesna Zadnik, Tina Zagar, Fani Skrlec

Slovenia is bordered by Italy to the west, Austria to the north, Hungary to the north-east, Croatia to the south and south-east, and the Adriatic Sea to the south-west. It covers an area of 20 273 km^2. More than half of its mountainous territory is covered by forest, and the country has a mostly continental climate.

Slovenia became an independent country in 1991, after the introduction of multiparty representative democracy and a split from Serbia and Montenegro. The export-oriented developed economy is composed of services, industry (motor vehicles, electrical and electronic equipment, machinery, pharmaceuticals, and fuels), and construction. The country has a very high HDI. The population of 2.1 million is ageing because of a low birth rate (1.3 children per woman) and an increasing life expectancy (78 years in 2016); 19% of the population is younger than 20 years (Table A.6), and 18% is aged 65 years and older. Slovenians make up 83% of the population, and people of other nationalities are mainly from neighbouring countries.

Cancer care is completely covered by mandatory public health insurance. Primary care is provided by health-care centres and general practitioners in private practice within the public network. Secondary health care is provided by 11 general hospitals and two tertiary clinical centres, located in Ljubljana and Maribor. The Institute of Oncology Ljubljana, which was founded in 1938, is the only national comprehensive cancer centre and is involved in research and education. Common cancers are also treated in general hospitals, but the Institute of Oncology Ljubljana is the referral centre for rare cancers; radiotherapy is administered only at the institute. Since 2010, the National Cancer Control Programme (https://www.dpor.si/) has had the goal of improving all aspects of cancer prevention and care in Slovenia.

The Cancer Registry of Republic of Slovenia was founded in 1950 (Table A.10) at the Institute of Oncology Ljubljana; it covers the entire Slovenian population. Notification of cancer is mandated by law. The main sources of data are notifications from all hospitals and diagnostic centres; additional sources are death certificates and autopsy protocols. Trained registrars, supervised by a physician, perform data coding. Case identification is based on the personal identification number, which enables accurate follow-up for vital status by daily online linkage to the Slovenian Central Population Register; people are lost to follow-up only if they move to another country.

There have been no major changes in data processing in recent years. The high MV% and the low DCO% attest to the quality of the registry data. The completeness of registration has never been formally evaluated. Registration may be less complete for non-melanoma skin cancer and for other malignancies that are treated on an outpatient basis; both cancer types are uncommon in children.

Since 2010, annual reports of the registry (https://www.onko-i.si/crs) are published on the SLORA online portal (http://www.slora.si/), where analyses of registry data are available to the general public. Registry data are used for planning and evaluation of the National Cancer Control Programme and in national and international research.

POPULATION AT RISK

Population data are provided by the Statistical Office of the Republic of Slovenia (https://pxweb.stat.si/pxweb/dialog/statfile1.asp) and are based on the Central Population Register of the Republic of Slovenia. National censuses were conducted in 1991, 2002, and 2011 (Table A.7). Data were provided in the requested detail.

EDITORS' COMMENTS

The registry participated in both previous IICC volumes (Table A.1). The MV% was very high in the IICC-3 dataset (Table A.9); accordingly, the proportion of cases diagnosed clinically was small. Non-malignant CNS tumours are included, and pilocytic astrocytoma was coded with either uncertain behaviour or malignant behaviour throughout the reporting period, according to the ICD-O edition in use (Table A.10) and pathology reports. Laterality is complete. Skin carcinomas are systematically notified and registered.

SLOVENIA (1991-2012)

	Age group (years)	Males	Females
Person-years	0	218 308	206 418
	1-4	890 146	841 687
	5-9	1 180 114	1 117 600
	10-14	1 325 308	1 257 125
	15-19	1 477 004	1 399 617
	0-14	3 613 876	3 422 830
	0-19	5 090 880	4 822 447
Average annual population	0-14	164 267	155 583
	0-19	231 404	219 202

Please consult the quality indicators for this registry

SLOVENIA (1991-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	12	141	61	60	87	274	361	28.2	100.0	23.5	100.0	28.3	81.4	26.5	23.2	30.2	42.8	40.0	604	755	100.0	0.0
	a. Lymphoid	8	124	51	39	46	222	268	22.9	81.0	17.5	74.2	18.8	71.6	22.2	15.1	16.0	35.2	30.9	493	572	100.0	0.0
	b. Acute myeloid	3	16	9	17	27	45	72	4.6	16.4	4.7	19.9	7.1	9.2	3.9	6.6	9.4	6.6	7.2	97	143	100.0	0.0
	c. CMD	0	0	0	2	10	2	12	0.2	0.7	0.8	3.3	-	-	-	0.8	3.5	0.2	1.0	4	21	100.0	0.0
	d. MDS & other	1	1	0	2	2	4	6	0.4	1.5	0.4	1.7	2.4	0.6	-	0.8	0.7	0.6	0.6	9	12	100.0	0.0
	e. Unspecified	0	0	1	0	2	1	3	0.1	0.4	0.2	0.8	-	-	0.4	-	0.7	0.1	0.3	2	6	100.0	0.0
II	LYMPHOMA & RELATED	3	22	40	72	142	137	279	14.1	100.0	18.2	100.0	7.1	12.7	17.4	27.9	49.4	18.2	25.2	284	531	100.0	0.0
	a. Hodgkin	0	5	13	40	104	58	162	6.0	42.3	10.6	58.1	-	2.9	5.7	15.5	36.2	7.2	13.7	117	298	100.0	0.0
	b. Non-Hodgkin except BL	2	9	13	27	31	51	82	5.3	37.2	5.3	29.4	4.7	5.2	5.7	10.5	10.8	6.8	7.7	106	160	100.0	0.0
	c. Burkitt (BL)	0	7	13	5	6	25	31	2.6	18.2	2.0	11.1	-	4.0	5.7	1.9	2.1	3.6	3.3	54	65	100.0	0.0
	d. Lymphoreticular	1	0	1	0	0	2	2	0.2	1.5	0.1	0.7	2.4	-	0.4	-	-	0.3	0.2	4	4	100.0	0.0
	e. Unspecified	0	1	0	0	1	1	2	0.1	0.7	0.1	0.7	-	0.6	-	-	0.3	0.2	0.2	2	4	100.0	0.0
III	CNS NEOPLASMS †	19	55	60	59	56	193	249	19.9	100.0	16.2	100.0	44.7	31.8	26.1	22.8	19.5	28.3	26.3	416	514	93.2	0.0
	a. Ependymoma	8	13	5	3	2	29	31	3.0	15.0	2.0	12.4	18.8	7.5	2.2	1.2	0.7	4.8	3.9	65	69	100.0	0.0
	b. Astrocytoma	4	17	28	33	25	82	107	8.4	42.5	7.0	43.0	9.4	9.8	12.2	12.8	8.7	11.4	10.8	174	217	100.0	0.0
	c. CNS embryonal	5	17	14	7	8	43	51	4.4	22.3	3.3	20.5	11.8	9.8	6.1	2.7	2.8	6.7	5.8	95	109	100.0	0.0
	d. Other gliomas	1	1	5	6	9	13	22	1.3	6.7	1.4	8.8	2.4	0.6	2.2	2.3	3.1	1.7	2.0	27	43	100.0	0.0
	e. Other specified	0	3	2	7	7	12	19	1.2	6.2	1.2	7.6	-	1.7	0.9	2.7	2.4	1.6	1.8	25	37	100.0	0.0
	f. Unspecified CNS	1	4	6	3	5	14	19	1.4	7.3	1.2	7.6	2.4	2.3	2.6	1.2	1.7	2.1	2.0	30	39	10.5	0.0
IV	NEUROBLASTOMA	19	28	5	0	0	52	52	5.4	100.0	3.4	100.0	44.7	16.2	2.2	-	-	9.1	7.1	120	120	100.0	0.0
	a. (Ganglio)neuroblastoma	19	27	5	0	0	51	51	5.3	98.1	3.3	98.1	44.7	15.6	2.2	-	-	9.0	6.9	118	118	100.0	0.0
	b. Peripheral nervous	0	1	0	0	0	1	1	0.1	1.9	0.1	1.9	-	0.6	-	-	-	0.2	0.1	2	2	100.0	0.0
V	RETINOBLASTOMA	3	19	0	0	0	22	22	2.3	100.0	1.4	100.0	7.1	11.0	-	-	-	3.9	3.1	51	51	100.0	0.0
VI	RENAL TUMOURS	6	46	9	1	1	62	63	6.4	100.0	4.1	100.0	14.1	26.6	3.9	0.4	0.3	10.7	8.4	142	144	98.4	0.0
	a. Nephroblastoma	6	45	9	1	1	61	62	6.3	98.4	4.0	98.4	14.1	26.0	3.9	0.4	0.3	10.5	8.2	140	142	100.0	0.0
	b. Renal carcinoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	c. Unspecified	0	1	0	0	0	1	1	0.1	1.6	0.1	1.6	-	0.6	-	-	-	0.2	0.1	2	2	0.0	0.0
VII	HEPATIC TUMOURS	7	4	1	1	0	13	13	1.3	100.0	0.8	100.0	16.5	2.3	0.4	0.4	-	2.2	1.7	30	30	100.0	0.0
	a. Hepatoblastoma	7	4	0	1	0	12	12	1.2	92.3	0.8	92.3	16.5	2.3	-	0.4	-	2.1	1.6	27	27	100.0	0.0
	b. Hepatic carcinoma	0	0	1	0	0	1	1	0.1	7.7	0.1	7.7	-	-	0.4	-	-	0.1	0.1	2	2	100.0	0.0
	c. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VIII	BONE TUMOURS	0	0	10	26	46	36	82	3.7	100.0	5.3	100.0	-	-	4.4	10.1	16.0	4.3	7.0	72	152	100.0	0.0
	a. Osteosarcoma	0	0	8	15	24	23	47	2.4	63.9	3.1	57.3	-	-	3.5	5.8	8.3	2.8	4.1	46	88	100.0	0.0
	b. Chondrosarcoma	0	0	0	1	3	1	4	0.1	2.8	0.3	4.9	-	-	-	0.4	1.0	0.1	0.3	2	7	100.0	0.0
	c. Ewing & related	0	0	2	9	17	11	28	1.1	30.6	1.8	34.1	-	-	0.9	3.5	5.9	1.3	2.3	22	51	100.0	0.0
	d. Other specified	0	0	0	0	2	0	2	-	-	0.1	2.4	-	-	-	-	0.7	-	0.2	-	3	100.0	0.0
	e. Unspecified	0	0	0	1	0	1	1	0.1	2.8	0.1	1.2	-	-	-	0.4	-	0.1	0.1	2	2	100.0	0.0
IX	SOFT TISSUE SARCOMA	4	17	20	24	28	65	93	6.7	100.0	6.1	100.0	9.4	9.8	8.7	9.3	9.7	9.3	9.4	139	187	100.0	0.0
	a. Rhabdomyosarcoma	2	16	10	13	7	41	48	4.2	63.1	3.1	51.6	4.7	9.2	4.4	5.0	2.4	6.1	5.3	89	101	100.0	0.0
	b. Fibrosarcoma	1	1	2	0	4	4	8	0.4	6.2	0.5	8.6	2.4	0.6	0.9	-	1.4	0.6	0.8	9	16	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	d. Other specified	1	0	6	10	15	17	32	1.8	26.2	2.1	34.4	2.4	-	2.6	3.9	5.2	2.1	2.8	35	61	100.0	0.0
	e. Unspecified	0	0	2	1	2	3	5	0.3	4.6	0.3	5.4	-	-	0.9	0.4	0.7	0.4	0.5	6	10	100.0	0.0
X	GERM CELL TUMOURS	5	13	9	18	92	45	137	4.6	100.0	8.9	100.0	11.8	7.5	3.9	7.0	32.0	6.5	12.2	96	256	99.3	0.0
	a. CNS germ cell ‡	1	0	5	2	2	8	10	0.8	17.8	0.7	7.3	2.4	-	2.2	0.8	0.7	1.1	1.0	17	21	100.0	0.0
	b. Other extragonadal	4	9	1	0	2	14	16	1.4	31.1	1.0	11.7	9.4	5.2	0.4	-	0.7	2.5	2.1	32	36	100.0	0.0
	c. Gonadal germ cell	0	4	3	14	84	21	105	2.2	46.7	6.8	76.6	-	2.3	1.3	5.4	29.2	2.7	8.7	43	189	100.0	0.0
	d. Gonadal carcinoma	0	0	0	1	3	1	4	0.1	2.2	0.3	2.9	-	-	-	0.4	1.0	0.1	0.3	2	7	100.0	0.0
	e. Unspecified gonadal	0	0	0	1	1	1	2	0.1	2.2	0.1	1.5	-	-	-	0.4	0.3	0.1	0.2	2	4	50.0	0.0
XI	CARCINOMA & MELANOMA	1	2	9	56	110	68	178	7.0	100.0	11.6	100.0	2.4	1.2	3.9	21.7	38.2	8.1	14.9	135	326	100.0	0.0
	a. Adrenocortical	1	1	0	0	1	2	3	0.2	2.9	0.2	1.7	2.4	0.6	-	-	0.3	0.4	0.4	5	6	100.0	0.0
	b. Thyroid	0	1	1	27	43	29	72	3.0	42.6	4.7	40.4	-	0.6	0.4	10.5	14.9	3.4	6.0	57	132	100.0	0.0
	c. Nasopharyngeal	0	0	0	3	2	3	5	0.3	4.4	0.3	2.8	-	-	-	1.2	0.7	0.3	0.4	6	9	100.0	0.0
	d. Melanoma	0	0	6	9	29	15	44	1.5	22.1	2.9	24.7	-	-	2.6	3.5	10.1	1.9	3.7	30	81	100.0	0.0
	e. Skin carcinoma	0	0	1	7	12	8	20	0.8	11.8	1.3	11.2	-	-	0.4	2.7	4.2	0.9	1.7	16	37	100.0	0.0
	f. Other & unspecified	0	0	1	10	23	11	34	1.1	16.2	2.2	19.1	-	-	0.4	3.9	8.0	1.3	2.8	22	62	100.0	0.0
XII	OTHER & UNSPECIFIED	3	0	0	1	2	4	6	0.4	100.0	0.4	100.0	7.1	-	-	0.4	0.7	0.7	0.7	9	12	66.7	0.0
	a. Other specified	0	0	0	1	1	1	2	0.1	25.0	0.1	33.3	-	-	-	0.4	0.3	0.1	0.2	2	4	100.0	0.0
	b. Other unspecified	3	0	0	0	1	3	4	0.3	75.0	0.3	66.7	7.1	-	-	-	0.3	0.5	0.5	7	9	50.0	0.0
	TOTAL	82	347	224	318	564	971	1535	100.0	100.0	100.0	100.0	193.1	200.4	97.5	123.1	196.1	144.2	155.9	2098	3078	98.6	0.0

† includes 55 non-malignant ‡ includes 1 non-malignant

Please consult the quality indicators for this registry

Spain

Spain is in south-western Europe. It covers an area of 505 196 km^2, including the Balearic Islands in the Mediterranean Sea and the Canary Islands in the Atlantic Ocean. The mainland has coastlines on the Mediterranean Sea to the east and south and the Atlantic Ocean to the north, west, and south. Spain is bordered by France to the north and Portugal to the west. The climate is Mediterranean and Atlantic on the coast and continental in the interior.

Spain is divided into 17 autonomous regions (also known as autonomous communities), which are further subdivided into 50 provinces, and two autonomous cities (on the north coast of Africa). In 2010, the estimated total population was 46.6 million (Table A.7), and 19% of the population was younger than 20 years (Table A.6). In 2010, the average population density was 92 per km^2, with marked variations across the country. Native-born Spanish citizens comprise 88% of the population. The economy is based mainly on the tertiary sector (65%), industry (16%), building (9%), and agriculture (3%) (https://www.ine.es/). Spain is a high-income country with a very high HDI (http://hdr.undp.org/en).

The Spanish National Health System provides universal health-care coverage. Responsibility for the provision of health-care services is decentralized to the autonomous communities.

The cancer registration is managed and funded mostly locally. Cancer notification is not compulsory in Spain; therefore, the registries use a combination of active case finding and passive linkage with electronic databases, where they are available. In 2010, 15 population-based cancer registries in Spain established the cooperative Spanish Network of Cancer Registries (REDECAN; https://redecan.org/en). Use of a joint REDECAN database ensures improved quality and provision of data to the national health authorities and the scientific community, in support of the main goal of REDECAN.

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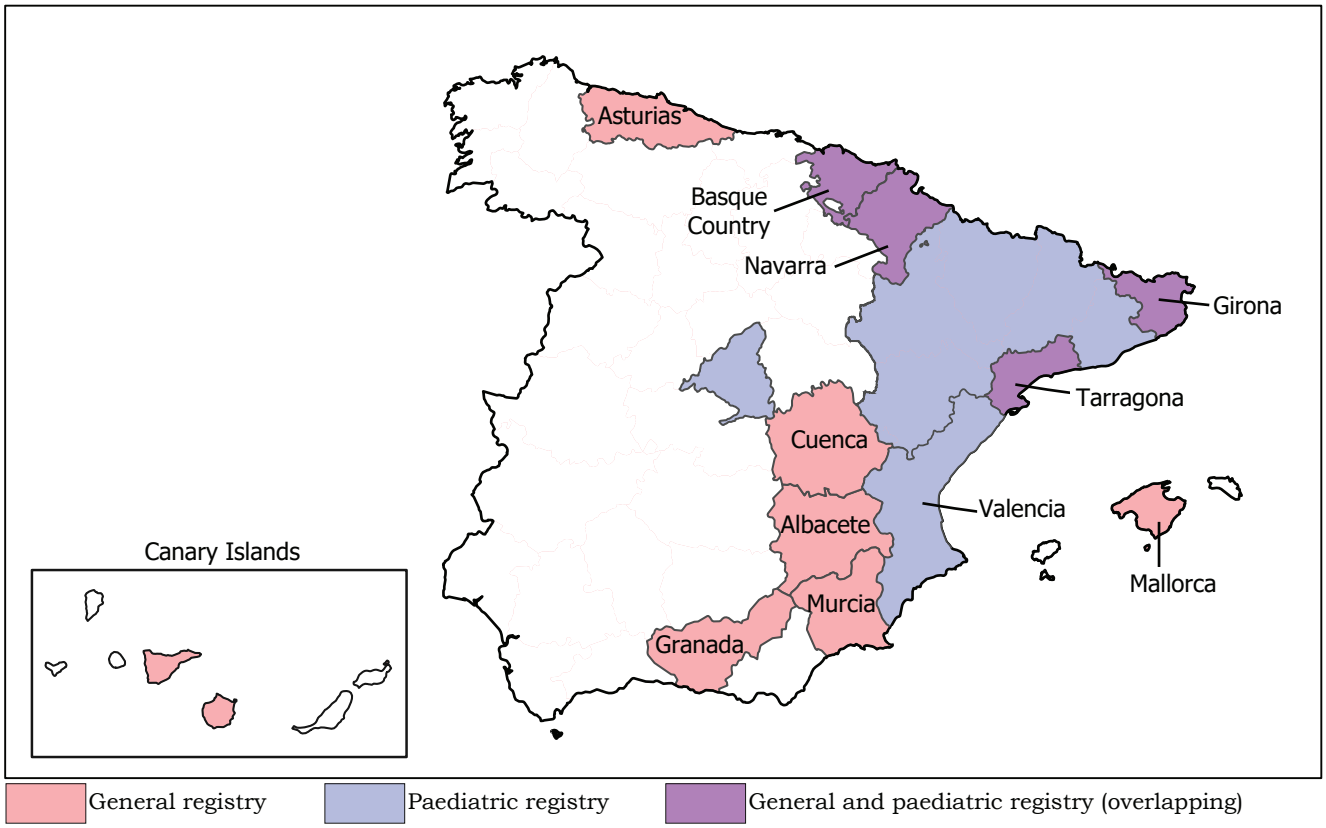

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POPULATION AT RISK

The population data are provided by the National Statistics Institute (INE) (https://www.ine.es/), which also conducts decennial national censuses (Table A.7). The census data are the basis for the intercensal estimates prepared by INE. The autonomous communities also generate population data for their areas, and these data were used by some registries.

EDITORS' COMMENTS

The cancer data for Spain are presented in the IICC-3 book in four tables, as shown in Table A.12: (i) data collected by the Spanish Registry of Childhood Tumours (RETI-SEHOP) in five selected regions (Aragon, the Basque Country, Catalonia, Navarra, and Madrid); (ii) data from the Childhood Cancer Registry of the Valencian Community; (iii) combined data from these two paediatric cancer registries; and (iv) data pooled from 11 subnational areas covered by general cancer registries (Albacete, Asturias, the Basque Country, Canary Islands, Cuenca, Girona, Granada, Mallorca, Murcia, Navarra, and Tarragona). Additional full incidence tables are available online for nine individual general cancer registries, and abbreviated tables for the Albacete and Cuenca registries are available online within the Spanish combined dataset (Table A.12). The two paediatric cancer registries cover about half of the national population aged 0–14 years, and the combined dataset of the general cancer registries covers about one quarter of the national population aged 0–19 years (Table A.6). The populations covered by the general cancer registries of the Basque Country, Girona, Navarra, and Tarragona are also covered by RETI-SEHOP.

The cancer registries of Asturias, the Basque Country, Granada, Murcia, Navarra, and Tarragona participated in IICC-2; the Childhood Cancer Registry of the Valencian Community participated in IICC-2 and contributed frequency data to IICC-1 (Table A.1).

With the exception of RETI-SEHOP, all registries have access to death certificates (Table A.9). Day of incidence was missing for 16% of cases in the combined dataset of the general cancer registries and for an even larger proportion in the paediatric registries. Therefore, the age of some patients may be imprecise (Table A.8). Non-malignant CNS tumours were recorded in all registries except that of Murcia, although in some registries their recording was restricted to part of the reporting period. Where these tumours were recorded, pilocytic astrocytoma was originally coded according to the ICD-O edition in use (Table A.10) and, if needed, was recoded with uncertain behaviour for submission to IICC-3, to comply with ICD-O-3. Skin carcinomas were registered in RETI-SEHOP and the registries of Mallorca, Girona, Granada, Navarra, and Tarragona but not in the other cancer registries. Laterality was available in the paediatric cancer registries; therefore, these data are included in the tables in the IICC-3 book for the larger diagnostic groups (retinoblastoma and Wilms tumour). Information on laterality was less available in the general cancer registries. No screening programmes were reported in any of the registration areas during the reporting periods.

SPAIN, 2 paediatric registries (1991-2013)

	Age group (years)	Males	Females
Person-years	0	1 740 730	1 636 057
	1-4	6 835 469	6 449 192
	5-9	8 073 862	7 645 238
	10-14	8 071 330	7 639 327
	0-14	24 721 391	23 369 814

Please consult the quality indicators for this pool and its constituent registries

Spanish Registry of Childhood Tumours (RETI-SEHOP), selected regions, 2000–2013

Rafael Peris Bonet, Tomás Acha García, José Sánchez de Toledo Codina, Ana Sastre Urgelles, Saray Felipe García, Salvador Valero Poveda, Elena Pardo Romaguera

The Spanish Registry of Childhood Tumours (RETI-SEHOP) is a joint venture of the Spanish Society of Paediatric Haematology and Oncology (SEHOP) and the University of Valencia. The main goal is to estimate childhood cancer survival. This central cancer registry coordinates a nationwide network of all the paediatric oncology units in Spain. These units provide notification of new cases and follow up the cases until the fifth anniversary of the incidence. All malignant tumours and CNS tumours of any behaviour are reportable. The residence status of the cases is determined using the address of residence on the date of incidence. Automatic and manual checks are performed to avoid duplicates. Data checks are routinely performed using the DEPedits software provided by IARC. The registry does not have access to death certificates.

The registry is considered population-based for children aged 0–14 years in five regions, where the ratios of the observed to the expected numbers of cases are about 100% (using the pool of regional population-based cancer registries of Spain as the reference). The combined covered population is 18.1 million, and 15% of the population is younger than 15 years (Table A.6). The contributing regions are Aragon (~7% of the combined childhood population of the five regions), the Basque Country (11%), Catalonia (42%), and Navarra (4%) since 1990, and Madrid (36%) since 2000. A total of 40% of the childhood population of Spain is covered (Table A.6). The location of the constituent regions is shown on the map.

The five covered regions are the wealthiest in Spain. The GDP per capita is up to 20% higher than the national average (https://www.ine.es/). All areas have hospitals that have paediatric oncology units, some of which are the largest in the country, and provide comprehensive diagnostic and treatment services.

RETI-SEHOP data are used to describe incidence and monitor survival of childhood cancer, for planning and evaluation of health services and for epidemiological research on the causes of childhood cancer. RETI-SEHOP collaborates on several national and international projects, such as EUROCARE, CONCORD, ACCIS, and the European Union Joint Action on Rare Cancers (JARC).

RETI-SEHOP is supported mainly by the Ministry of Health, Social Services and Equality of Spain, the University of Valencia, and the Enriqueta Villavecchia Private Foundation for Child Oncology in Barcelona.

POPULATION AT RISK

Data were provided in the requested detail, by sex and single year of age within the age range 0–14 years, and by region (Aragon, the Basque Country, Catalonia, Navarra, and Madrid) for each calendar year of the reporting period. The population denominators are the official intercensal and postcensal estimates provided by INE.

EDITORS' COMMENTS

In this paediatric cancer registry, registration focused on the age group 0–14 years during the reporting period. Therefore, data for age groups 15–19 years and 0–19 years are not shown in the tables. This dataset overlaps with those provided by the cancer registries of the Basque Country, Girona, Navarra, and Tarragona for the age group 0–14 years for 2000 onwards. Because the registry does not have access to identified death certificates (Table A.9), a proportion of new cases may be missed. Day of incidence is not recorded (Table A.8). The age is calculated from the month and year of the dates of birth and incidence and is then adjusted according to the medical records, if needed (Table A.8). Non-malignant CNS tumours were systematically registered. Laterality was complete for retinoblastoma and nephroblastoma. See also Spain, above.

SPAIN, selected regions, paediatric (2000-2013)

	Age group (years)	Males	Females
Person-years	0	1 320 485	1 242 150
	1-4	5 094 664	4 807 459
	5-9	5 809 608	5 503 571
	10-14	5 535 750	5 237 307
	0-14	17 760 507	16 790 487
Average annual population	0-14	1 268 608	1 199 321

Please consult the quality indicators for this registry

SPAIN, 2 paediatric registries (1991-2013)

Registry	Period	Cases	%	Person-years	%
Valencia, paediatric	1991-2010	2204	29.4	13 540 211	28.2
selected regions, paediatric	2000-2013	5293	70.6	34 550 994	71.8
SPAIN	**1991-2013**	**7497**	**100.0**	**48 091 205**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

Valencia, Childhood Cancer Registry of the Valencian Community, 1991–2010

C. Sabater Gregori, F. Almela Vich, N. Fuster Camarena, J. Peñalver Herrero, M.L. Vicente Raneda, A. Vizcaino Batllés, E. Banqueri Guerrero, P. Botella Rocamora, C. Alberich Martí

The Valencian Community is located on the east coast of Spain. Narrow and elongated, it is bordered by the Mediterranean Sea to the east, Catalonia to the north, Aragon and Castilla-La Mancha to the west, and Murcia to the south. It covers an area of 23 255 km^2 (4.6% of the total area of Spain). The climate is Mediterranean, with scarce rainfall. Administratively, the region has 355 municipalities and is subdivided into three provinces: Alicante, Castellón, and Valencia. The population is 5.0 million, and 15% of the population is younger than 15 years (Table A.6). The region is mostly urban, and the population density is 219 per km^2. The proportion of foreign-born residents (15%) is slightly higher than the national average (10%). The foreign-born residents are from other countries in Europe (59%), Latin America (25%), Africa (12%, mainly from the Maghreb), and Asia (3%).

The economy is based on a strong tourism sector and a large contribution from agriculture. The Valencian Community generates almost 10% of Spain's GDP and has the fourth largest GDP among regions in Spain.

Three hospitals – two in Valencia and one in Alicante – of the Spanish National Health System provide paediatric oncology, surgery, chemotherapy, and radiotherapy services. The region also has a private oncology hospital.

The population-based childhood cancer registry, the Childhood Cancer Registry of the Valencian Community, covers the whole Valencia region. It began operating in 1985 (Table A.10) and is integrated into the legal framework of the cancer information system of the regional health authority within the regional cancer control plan. The registry was founded by and is run by the regional government. Cancer in residents younger than 15 years has been registered

SPAIN, 2 paediatric registries (1991-2013)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	128	1010	634	461	**2233**	29.8	100.0	37.9	76.0	40.3	29.3	**48.0**	690	100.0	0.0
	a. Lymphoid	64	833	515	325	**1737**	23.2	77.8	19.0	62.7	32.8	20.7	**37.4**	536	100.0	0.0
	b. Acute myeloid	45	153	98	114	**410**	5.5	18.4	13.3	11.5	6.2	7.3	**8.7**	127	100.0	0.0
	c. CMD	4	5	12	12	**33**	0.4	1.5	1.2	0.4	0.8	0.8	**0.7**	10	100.0	0.0
	d. MDS & other	9	10	3	2	**24**	0.3	1.1	2.7	0.8	0.2	0.1	**0.5**	7	100.0	0.0
	e. Unspecified	6	9	6	8	**29**	0.4	1.3	1.8	0.7	0.4	0.5	**0.6**	9	96.6	3.4
II	LYMPHOMA & RELATED	16	173	319	429	**937**	12.5	100.0	4.7	13.0	20.3	27.3	**18.9**	295	100.0	0.0
	a. Hodgkin	1	18	84	222	**325**	4.3	34.7	0.3	1.4	5.3	14.1	**6.3**	103	100.0	0.0
	b. Non-Hodgkin except BL	4	67	114	135	**320**	4.3	34.2	1.2	5.0	7.3	8.6	**6.5**	101	100.0	0.0
	c. Burkitt (BL)	2	81	120	72	**275**	3.7	29.3	0.6	6.1	7.6	4.6	**5.7**	86	100.0	0.0
	d. Lymphoreticular	9	7	0	0	**16**	0.2	1.7	2.7	0.5	-	-	**0.4**	5	100.0	0.0
	e. Unspecified	0	0	1	0	**1**	0.0	0.1	-	-	0.1	-	**0.0**	0	100.0	0.0
III	CNS NEOPLASMS †	118	564	567	461	**1710**	22.8	100.0	34.9	42.5	36.1	29.3	**36.0**	532	79.4	0.0
	a. Ependymoma	23	89	42	43	**197**	2.6	11.5	6.8	6.7	2.7	2.7	**4.3**	61	98.0	0.0
	b. Astrocytoma	35	216	213	184	**648**	8.6	37.9	10.4	16.3	13.6	11.7	**13.6**	202	81.8	0.0
	c. CNS embryonal	33	144	132	73	**382**	5.1	22.3	9.8	10.8	8.4	4.6	**8.2**	118	98.4	0.0
	d. Other gliomas	6	62	87	53	**208**	2.8	12.2	1.8	4.7	5.5	3.4	**4.3**	65	32.7	0.0
	e. Other specified	17	39	62	82	**200**	2.7	11.7	5.0	2.9	3.9	5.2	**4.1**	63	88.5	0.0
	f. Unspecified CNS	4	14	31	26	**75**	1.0	4.4	1.2	1.1	2.0	1.7	**1.5**	24	17.3	0.0
IV	NEUROBLASTOMA	293	284	55	14	**646**	8.6	100.0	86.8	21.4	3.5	0.9	**14.8**	195	95.7	0.0
	a. (Ganglio)neuroblastoma	291	282	53	13	**639**	8.5	98.9	86.2	21.2	3.4	0.8	**14.6**	193	95.8	0.0
	b. Peripheral nervous	2	2	2	1	**7**	0.1	1.1	0.6	0.2	0.1	0.1	**0.2**	2	85.7	0.0
V	RETINOBLASTOMA	78	124	12	1	**215**	2.9	100.0	23.1	9.3	0.8	0.1	**5.0**	65	37.7	0.0
VI	RENAL TUMOURS	65	220	60	14	**359**	4.8	100.0	19.2	16.6	3.8	0.9	**8.1**	109	87.2	0.0
	a. Nephroblastoma	65	220	57	11	**353**	4.7	98.3	19.2	16.6	3.6	0.7	**8.0**	107	87.0	0.0
	b. Renal carcinoma	0	0	2	3	**5**	0.1	1.4	-	-	0.1	0.2	**0.1**	2	100.0	0.0
	c. Unspecified	0	0	1	0	**1**	0.0	0.3	-	-	0.1	-	**0.0**	0	100.0	0.0
VII	HEPATIC TUMOURS	28	49	12	10	**99**	1.3	100.0	8.3	3.7	0.8	0.6	**2.2**	30	96.0	0.0
	a. Hepatoblastoma	27	48	7	4	**86**	1.1	86.9	8.0	3.6	0.4	0.3	**2.0**	26	96.5	0.0
	b. Hepatic carcinoma	1	1	5	6	**13**	0.2	13.1	0.3	0.1	0.3	0.4	**0.3**	4	92.3	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VIII	BONE TUMOURS	3	34	128	264	**429**	5.7	100.0	0.9	2.6	8.1	16.8	**8.4**	136	99.8	0.0
	a. Osteosarcoma	0	7	44	124	**175**	2.3	40.8	-	0.5	2.8	7.9	**3.4**	56	100.0	0.0
	b. Chondrosarcoma	0	0	0	5	**5**	0.1	1.2	-	-	-	0.3	**0.1**	2	100.0	0.0
	c. Ewing & related	3	24	81	132	**240**	3.2	55.9	0.9	1.8	5.2	8.4	**4.7**	76	100.0	0.0
	d. Other specified	0	2	3	3	**8**	0.1	1.9	-	0.2	0.2	0.2	**0.2**	3	87.5	0.0
	e. Unspecified	0	1	0	0	**1**	0.0	0.2	-	0.1	-	-	**0.0**	0	100.0	0.0
IX	SOFT TISSUE SARCOMA	55	139	127	148	**469**	6.3	100.0	16.3	10.5	8.1	9.4	**9.8**	146	99.6	0.0
	a. Rhabdomyosarcoma	21	98	71	45	**235**	3.1	50.1	6.2	7.4	4.5	2.9	**5.1**	73	100.0	0.0
	b. Fibrosarcoma	17	7	11	17	**52**	0.7	11.1	5.0	0.5	0.7	1.1	**1.1**	16	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	d. Other specified	15	27	39	67	**148**	2.0	31.6	4.4	2.0	2.5	4.3	**3.0**	46	98.6	0.0
	e. Unspecified	2	7	6	19	**34**	0.5	7.2	0.6	0.5	0.4	1.2	**0.7**	11	100.0	0.0
X	GERM CELL TUMOURS	45	46	39	93	**223**	3.0	100.0	13.3	3.5	2.5	5.9	**4.6**	69	95.1	0.0
	a. CNS germ cell ‡	8	3	24	33	**68**	0.9	30.5	2.4	0.2	1.5	2.1	**1.4**	21	88.2	0.0
	b. Other extragonadal	24	26	2	5	**57**	0.8	25.6	7.1	2.0	0.1	0.3	**1.3**	17	94.7	0.0
	c. Gonadal germ cell	13	17	13	53	**96**	1.3	43.0	3.8	1.3	0.8	3.4	**1.9**	30	100.0	0.0
	d. Gonadal carcinoma	0	0	0	2	**2**	0.0	0.9	-	-	-	0.1	**0.0**	1	100.0	0.0
	e. Unspecified gonadal	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
XI	CARCINOMA & MELANOMA	7	14	39	106	**166**	2.2	100.0	2.1	1.1	2.5	6.7	**3.2**	52	99.4	0.0
	a. Adrenocortical	1	2	3	2	**8**	0.1	4.8	0.3	0.2	0.2	0.1	**0.2**	2	100.0	0.0
	b. Thyroid	2	5	12	48	**67**	0.9	40.4	0.6	0.4	0.8	3.1	**1.3**	21	98.5	0.0
	c. Nasopharyngeal	0	0	2	5	**7**	0.1	4.2	-	-	0.1	0.3	**0.1**	2	100.0	0.0
	d. Melanoma	3	6	12	17	**38**	0.5	22.9	0.9	0.5	0.8	1.1	**0.8**	12	100.0	0.0
	e. Skin carcinoma	1	0	1	3	**5**	0.1	3.0	0.3	-	0.1	0.2	**0.1**	2	100.0	0.0
	f. Other & unspecified	0	1	9	31	**41**	0.5	24.7	-	0.1	0.6	2.0	**0.8**	13	100.0	0.0
XII	OTHER & UNSPECIFIED	2	4	2	3	**11**	0.1	100.0	0.6	0.3	0.1	0.2	**0.2**	3	90.9	0.0
	a. Other specified	2	3	0	1	**6**	0.1	54.5	0.6	0.2	-	0.1	**0.1**	2	100.0	0.0
	b. Other unspecified	0	1	2	2	**5**	0.1	45.5	-	0.1	0.1	0.1	**0.1**	2	80.0	0.0
	TOTAL	838	2661	1994	2004	**7497**	100.0	100.0	248.2	200.3	126.9	127.6	**159.2**	2322	92.2	0.0

† includes 533 non-malignant ‡ includes 9 non-malignant

Please consult the quality indicators for this pool and its constituent registries

SPAIN, selected regions, paediatric (2000-2013)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	90	708	460	330	**1588**	30.0	100.0	35.1	71.5	40.7	30.6	**46.8**	677	100.0	0.0
	a. Lymphoid	45	588	374	234	**1241**	23.4	78.1	17.6	59.4	33.1	21.7	**36.6**	528	100.0	0.0
	b. Acute myeloid	32	105	71	77	**285**	5.4	17.9	12.5	10.6	6.3	7.1	**8.4**	122	100.0	0.0
	c. CMD	3	4	8	9	**24**	0.5	1.5	1.2	0.4	0.7	0.8	**0.7**	11	100.0	0.0
	d. MDS & other	7	7	3	2	**19**	0.4	1.2	2.7	0.7	0.3	0.2	**0.6**	8	100.0	0.0
	e. Unspecified	3	4	4	8	**19**	0.4	1.2	1.2	0.4	0.4	0.7	**0.5**	8	100.0	0.0
II	LYMPHOMA & RELATED	7	112	256	298	**673**	12.7	100.0	2.7	11.3	22.6	27.7	**19.0**	299	100.0	0.0
	a. Hodgkin	1	13	69	166	**249**	4.7	37.0	0.4	1.3	6.1	15.4	**6.9**	113	100.0	0.0
	b. Non-Hodgkin except BL	3	44	95	92	**234**	4.4	34.8	1.2	4.4	8.4	8.5	**6.6**	104	100.0	0.0
	c. Burkitt (BL)	1	52	92	40	**185**	3.5	27.5	0.4	5.3	8.1	3.7	**5.3**	80	100.0	0.0
	d. Lymphoreticular	2	3	0	0	**5**	0.1	0.7	0.8	0.3	-	-	**0.2**	2	100.0	0.0
	e. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
III	CNS NEOPLASMS †	84	407	388	296	**1175**	22.2	100.0	32.8	41.1	34.3	27.5	**34.3**	506	80.0	0.0
	a. Ependymoma	19	67	27	31	**144**	2.7	12.3	7.4	6.8	2.4	2.9	**4.3**	61	99.3	0.0
	b. Astrocytoma	21	149	144	112	**426**	8.0	36.3	8.2	15.0	12.7	10.4	**12.4**	184	82.2	0.0
	c. CNS embryonal	22	108	92	43	**265**	5.0	22.6	8.6	10.9	8.1	4.0	**7.8**	113	98.9	0.0
	d. Other gliomas	5	47	64	41	**157**	3.0	13.4	2.0	4.7	5.7	3.8	**4.5**	68	33.1	0.0
	e. Other specified	13	28	43	52	**136**	2.6	11.6	5.1	2.8	3.8	4.8	**3.9**	60	91.2	0.0
	f. Unspecified CNS	4	8	18	17	**47**	0.9	4.0	1.6	0.8	1.6	1.6	**1.3**	21	19.1	0.0
IV	NEUROBLASTOMA	208	192	44	11	**455**	8.6	100.0	81.2	19.4	3.9	1.0	**14.0**	185	94.5	0.0
	a. (Ganglio)neuroblastoma	207	190	43	10	**450**	8.5	98.9	80.8	19.2	3.8	0.9	**13.8**	183	94.7	0.0
	b. Peripheral nervous	1	2	1	1	**5**	0.1	1.1	0.4	0.2	0.1	0.1	**0.1**	2	80.0	0.0
V	RETINOBLASTOMA	67	87	6	1	**161**	3.0	100.0	26.1	8.8	0.5	0.1	**5.0**	65	20.5	0.0
VI	RENAL TUMOURS	46	168	39	10	**263**	5.0	100.0	18.0	17.0	3.4	0.9	**8.0**	108	83.3	0.0
	a. Nephroblastoma	46	168	38	8	**260**	4.9	98.9	18.0	17.0	3.4	0.7	**7.9**	106	83.1	0.0
	b. Renal carcinoma	0	0	1	2	**3**	0.1	1.1	-	-	0.1	0.2	**0.1**	1	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VII	HEPATIC TUMOURS	18	38	11	6	**73**	1.4	100.0	7.0	3.8	1.0	0.6	**2.2**	30	94.5	0.0
	a. Hepatoblastoma	17	37	7	3	**64**	1.2	87.7	6.6	3.7	0.6	0.3	**2.0**	26	95.3	0.0
	b. Hepatic carcinoma	1	1	4	3	**9**	0.2	12.3	0.4	0.1	0.4	0.3	**0.3**	4	88.9	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VIII	BONE TUMOURS	2	26	89	184	**301**	5.7	100.0	0.8	2.6	7.9	17.1	**8.4**	136	99.7	0.0
	a. Osteosarcoma	0	6	32	80	**118**	2.2	39.2	-	0.6	2.8	7.4	**3.3**	54	100.0	0.0
	b. Chondrosarcoma	0	0	0	4	**4**	0.1	1.3	-	-	-	0.4	**0.1**	2	100.0	0.0
	c. Ewing & related	2	19	57	98	**176**	3.3	58.5	0.8	1.9	5.0	9.1	**4.9**	79	100.0	0.0
	d. Other specified	0	1	0	2	**3**	0.1	1.0	-	0.1	-	0.2	**0.1**	1	66.7	0.0
	e. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
IX	SOFT TISSUE SARCOMA	36	95	87	104	**322**	6.1	100.0	14.0	9.6	7.7	9.7	**9.4**	139	99.4	0.0
	a. Rhabdomyosarcoma	14	62	46	28	**150**	2.8	46.6	5.5	6.3	4.1	2.6	**4.4**	64	100.0	0.0
	b. Fibrosarcoma	9	4	8	12	**33**	0.6	10.2	3.5	0.4	0.7	1.1	**1.0**	14	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	d. Other specified	12	23	27	51	**113**	2.1	35.1	4.7	2.3	2.4	4.7	**3.2**	50	98.2	0.0
	e. Unspecified	1	6	6	13	**26**	0.5	8.1	0.4	0.6	0.5	1.2	**0.7**	11	100.0	0.0
X	GERM CELL TUMOURS	38	39	36	63	**176**	3.3	100.0	14.8	3.9	3.2	5.8	**5.1**	76	93.8	0.0
	a. CNS germ cell ‡	7	1	23	27	**58**	1.1	33.0	2.7	0.1	2.0	2.5	**1.6**	26	86.2	0.0
	b. Other extragonadal	20	22	2	3	**47**	0.9	26.7	7.8	2.2	0.2	0.3	**1.4**	19	93.6	0.0
	c. Gonadal germ cell	11	16	11	33	**71**	1.3	40.3	4.3	1.6	1.0	3.1	**2.0**	31	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	e. Unspecified gonadal	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
XI	CARCINOMA & MELANOMA	3	12	28	57	**100**	1.9	100.0	1.2	1.2	2.5	5.3	**2.8**	45	99.0	0.0
	a. Adrenocortical	1	2	2	0	**5**	0.1	5.0	0.4	0.2	0.2	-	**0.2**	2	100.0	0.0
	b. Thyroid	0	4	10	22	**36**	0.7	36.0	-	0.4	0.9	2.0	**1.0**	16	97.2	0.0
	c. Nasopharyngeal	0	0	0	3	**3**	0.1	3.0	-	-	-	0.3	**0.1**	1	100.0	0.0
	d. Melanoma	1	5	8	11	**25**	0.5	25.0	0.4	0.5	0.7	1.0	**0.7**	11	100.0	0.0
	e. Skin carcinoma	1	0	1	3	**5**	0.1	5.0	0.4	-	0.1	0.3	**0.1**	2	100.0	0.0
	f. Other & unspecified	0	1	7	18	**26**	0.5	26.0	-	0.1	0.6	1.7	**0.7**	12	100.0	0.0
XII	OTHER & UNSPECIFIED	2	2	2	0	**6**	0.1	100.0	0.8	0.2	0.2	-	**0.2**	2	100.0	0.0
	a. Other specified	2	2	0	0	**4**	0.1	66.7	0.8	0.2	-	-	**0.1**	2	100.0	0.0
	b. Other unspecified	0	0	2	0	**2**	0.0	33.3	-	-	0.2	-	**0.1**	1	100.0	0.0
	TOTAL	601	1886	1446	1360	**5293**	100.0	100.0	234.5	190.5	127.8	126.2	**155.1**	2268	91.5	0.0

† includes 379 non-malignant ‡ includes 7 non-malignant

Please consult the quality indicators for this registry

SPAIN, Valencia, paediatric (1991-2010)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	38	302	174	131	**645**	29.3	100.0	46.7	89.3	39.5	26.5	**51.8**	735	99.8	0.2
	a. Lymphoid	19	245	141	91	**496**	22.5	76.9	23.3	72.4	32.0	18.4	**40.0**	567	100.0	0.0
	b. Acute myeloid	13	48	27	37	**125**	5.7	19.4	16.0	14.2	6.1	7.5	**9.8**	141	100.0	0.0
	c. CMD	1	1	4	3	**9**	0.4	1.4	1.2	0.3	0.9	0.6	**0.7**	10	100.0	0.0
	d. MDS & other	2	3	0	0	**5**	0.2	0.8	2.5	0.9	-	-	**0.5**	6	100.0	0.0
	e. Unspecified	3	5	2	0	**10**	0.5	1.6	3.7	1.5	0.5	-	**0.9**	12	90.0	10.0
II	LYMPHOMA & RELATED	9	61	63	131	**264**	12.0	100.0	11.1	18.0	14.3	26.5	**18.8**	288	100.0	0.0
	a. Hodgkin	0	5	15	56	**76**	3.4	28.8	-	1.5	3.4	11.3	**4.9**	80	100.0	0.0
	b. Non-Hodgkin except BL	1	23	19	43	**86**	3.9	32.6	1.2	6.8	4.3	8.7	**6.1**	94	100.0	0.0
	c. Burkitt (BL)	1	29	28	32	**90**	4.1	34.1	1.2	8.6	6.4	6.5	**6.7**	100	100.0	0.0
	d. Lymphoreticular	7	4	0	0	**11**	0.5	4.2	8.6	1.2	-	-	**1.0**	13	100.0	0.0
	e. Unspecified	0	0	1	0	**1**	0.0	0.4	-	-	0.2	-	**0.1**	1	100.0	0.0
III	CNS NEOPLASMS †	34	157	179	165	**535**	24.3	100.0	41.8	46.4	40.6	33.4	**40.4**	598	77.9	0.0
	a. Ependymoma	4	22	15	12	**53**	2.4	9.9	4.9	6.5	3.4	2.4	**4.2**	60	94.3	0.0
	b. Astrocytoma	14	67	69	72	**222**	10.1	41.5	17.2	19.8	15.7	14.6	**16.8**	248	81.1	0.0
	c. CNS embryonal	11	36	40	30	**117**	5.3	21.9	13.5	10.6	9.1	6.1	**9.0**	132	97.4	0.0
	d. Other gliomas	1	15	23	12	**51**	2.3	9.5	1.2	4.4	5.2	2.4	**3.9**	57	31.4	0.0
	e. Other specified	4	11	19	30	**64**	2.9	12.0	4.9	3.3	4.3	6.1	**4.5**	70	82.8	0.0
	f. Unspecified CNS	0	6	13	9	**28**	1.3	5.2	-	1.8	3.0	1.8	**2.0**	31	14.3	0.0
IV	NEUROBLASTOMA	85	92	11	3	**191**	8.7	100.0	104.4	27.2	2.5	0.6	**17.3**	226	98.4	0.0
	a. (Ganglio)neuroblastoma	84	92	10	3	**189**	8.6	99.0	103.2	27.2	2.3	0.6	**17.1**	224	98.4	0.0
	b. Peripheral nervous	1	0	1	0	**2**	0.1	1.0	1.2	-	0.2	-	**0.2**	2	100.0	0.0
V	RETINOBLASTOMA	11	37	6	0	**54**	2.5	100.0	13.5	10.9	1.4	-	**4.9**	64	88.9	0.0
VI	RENAL TUMOURS	19	52	21	4	**96**	4.4	100.0	23.3	15.4	4.8	0.8	**8.3**	112	97.9	0.0
	a. Nephroblastoma	19	52	19	3	**93**	4.2	96.9	23.3	15.4	4.3	0.6	**8.1**	109	97.8	0.0
	b. Renal carcinoma	0	0	1	1	**2**	0.1	2.1	-	-	0.2	0.2	**0.1**	2	100.0	0.0
	c. Unspecified	0	0	1	0	**1**	0.0	1.0	-	-	0.2	-	**0.1**	1	100.0	0.0
VII	HEPATIC TUMOURS	10	11	1	4	**26**	1.2	100.0	12.3	3.3	0.2	0.8	**2.2**	30	100.0	0.0
	a. Hepatoblastoma	10	11	0	1	**22**	1.0	84.6	12.3	3.3	-	0.2	**2.0**	26	100.0	0.0
	b. Hepatic carcinoma	0	0	1	3	**4**	0.2	15.4	-	-	0.2	0.6	**0.2**	4	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VIII	BONE TUMOURS	1	8	39	80	**128**	5.8	100.0	1.2	2.4	8.9	16.2	**8.4**	136	100.0	0.0
	a. Osteosarcoma	0	1	12	44	**57**	2.6	44.5	-	0.3	2.7	8.9	**3.6**	59	100.0	0.0
	b. Chondrosarcoma	0	0	0	1	**1**	0.0	0.8	-	-	-	0.2	**0.1**	1	100.0	0.0
	c. Ewing & related	1	5	24	34	**64**	2.9	50.0	1.2	1.5	5.4	6.9	**4.3**	69	100.0	0.0
	d. Other specified	0	1	3	1	**5**	0.2	3.9	-	0.3	0.7	0.2	**0.4**	6	100.0	0.0
	e. Unspecified	0	1	0	0	**1**	0.0	0.8	-	0.3	-	-	**0.1**	1	100.0	0.0
IX	SOFT TISSUE SARCOMA	19	44	40	44	**147**	6.7	100.0	23.3	13.0	9.1	8.9	**11.3**	165	100.0	0.0
	a. Rhabdomyosarcoma	7	36	25	17	**85**	3.9	57.8	8.6	10.6	5.7	3.4	**6.8**	97	100.0	0.0
	b. Fibrosarcoma	8	3	3	5	**19**	0.9	12.9	9.8	0.9	0.7	1.0	**1.5**	22	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	d. Other specified	3	4	12	16	**35**	1.6	23.8	3.7	1.2	2.7	3.2	**2.5**	38	100.0	0.0
	e. Unspecified	1	1	0	6	**8**	0.4	5.4	1.2	0.3	-	1.2	**0.5**	8	100.0	0.0
X	GERM CELL TUMOURS	7	7	3	30	**47**	2.1	100.0	8.6	2.1	0.7	6.1	**3.3**	50	100.0	0.0
	a. CNS germ cell ‡	1	2	1	6	**10**	0.5	21.3	1.2	0.6	0.2	1.2	**0.7**	11	100.0	0.0
	b. Other extragonadal	4	4	0	2	**10**	0.5	21.3	4.9	1.2	-	0.4	**0.9**	12	100.0	0.0
	c. Gonadal germ cell	2	1	2	20	**25**	1.1	53.2	2.5	0.3	0.5	4.1	**1.6**	26	100.0	0.0
	d. Gonadal carcinoma	0	0	0	2	**2**	0.1	4.3	-	-	-	0.4	**0.1**	2	100.0	0.0
	e. Unspecified gonadal	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
XI	CARCINOMA & MELANOMA	4	2	11	49	**66**	3.0	100.0	4.9	0.6	2.5	9.9	**4.2**	69	100.0	0.0
	a. Adrenocortical	0	0	1	2	**3**	0.1	4.5	-	-	0.2	0.4	**0.2**	3	100.0	0.0
	b. Thyroid	2	1	2	26	**31**	1.4	47.0	2.5	0.3	0.5	5.3	**2.0**	32	100.0	0.0
	c. Nasopharyngeal	0	0	2	2	**4**	0.2	6.1	-	-	0.5	0.4	**0.3**	4	100.0	0.0
	d. Melanoma	2	1	4	6	**13**	0.6	19.7	2.5	0.3	0.9	1.2	**0.9**	14	100.0	0.0
	e. Skin carcinoma	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
	f. Other & unspecified	0	0	2	13	**15**	0.7	22.7	-	-	0.5	2.6	**0.9**	15	100.0	0.0
XII	OTHER & UNSPECIFIED	0	2	0	3	**5**	0.2	100.0	-	0.6	-	0.6	**0.4**	5	80.0	0.0
	a. Other specified	0	1	0	1	**2**	0.1	40.0	-	0.3	-	0.2	**0.2**	2	100.0	0.0
	b. Other unspecified	0	1	0	2	**3**	0.1	60.0	-	0.3	-	0.4	**0.2**	3	66.7	0.0
	TOTAL	237	775	548	644	**2204**	100.0	100.0	291.1	229.1	124.4	130.4	**171.3**	2480	94.1	0.0

† includes 154 non-malignant ‡ includes 2 non-malignant

Please consult the quality indicators for this registry

since 1983; in 2007, registration was expanded to include residents younger than 20 years.

Cases are identified actively from all clinical and administrative sources of information. Follow-up of patients involves both active and passive methods. Death certificates of the regional mortality registry are reviewed annually and linked with the Spanish National Death Index and regional death files. The DEPedits program is used to verify the recorded data, in agreement with ENCR recommendations. Confidentiality guidelines are applied according to Spanish law (Personal Data Protection Act 15/1999). The database is registered with the Spanish Agency for Data Protection.

The registry data are used to monitor incidence and survival of childhood cancer, for planning and evaluation of health services, and for epidemiological research. The registry has conducted and participated in various epidemiological studies, such as EUROCARE.

POPULATION AT RISK

The population data are provided by the Regional Statistics Institute (http://pegv.gva.es/) from 1999. Data were provided in the requested detail.

EDITORS' COMMENTS

Day of incidence was missing for one quarter of the registrations (Table A.8). Non-malignant CNS tumours were systematically registered. Laterality was complete for retinoblastoma and nephroblastoma. See also Spain, above.

SPAIN, Valencia, paediatric (1991-2010)

	Age group (years)	Males	Females
Person-years	0	420 245	393 907
	1-4	1 740 805	1 641 733
	5-9	2 264 254	2 141 667
	10-14	2 535 580	2 402 020
	0-14	6 960 884	6 579 327
Average annual population	0-14	348 044	328 966

Please consult the quality indicators for this registry

SPAIN, 11 registries (1990-2013)

Registry	Period	Cases	%	Person-years	%
Albacete	1991-2010	286	3.6	1 752 522	3.9
Asturias	1992-2010	561	7.2	3 449 497	7.6
Basque Country	1990-2012	1728	22.0	9 400 582	20.8
Canary Islands	1993-2011	1064	13.6	6 772 909	15.0
Cuenca	1993-2012	155	2.0	818 192	1.8
Girona	1990-2013	594	7.6	3 185 311	7.1
Granada	1992-2013	753	9.6	4 612 851	10.2
Mallorca	1990-2012	621	7.9	3 653 444	8.1
Murcia	1991-2009	1033	13.2	5 924 458	13.1
Navarra	1990-2010	475	6.1	2 443 010	5.4
Tarragona	1990-2011	569	7.3	3 098 068	6.9
SPAIN	**1990-2013**	**7839**	**100.0**	**45 110 844**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

Albacete Cancer Registry, 1991–2010

I. de la Cruz, A. Mateos, C. Ramírez, M. Lillo, R. Vera

The province of Albacete is located on the central plateau of Spain. The province covers an area of 14 926 km^2 and is divided into 87 municipalities. The total population is 0.4 million, and 21% of the population is younger than 20 years (Table A.6). The population density is 27 per km^2, and one third of residents live in rural municipalities with fewer than 2000 inhabitants.

There are 36 public primary health-care centres, five public hospitals, and two private hospitals. There is only one paediatric oncology unit. Many patients must travel outside the province to receive diagnostic and treatment services.

The population-based Albacete Cancer Registry was established in 1991, within the Epidemiology Service of the Health Department of the autonomous community of Castilla-La Mancha, and covers the entire province of Albacete.

Data are collected actively by registry staff members through the review of clinical records in hospitals and primary health-care centres. Information sources include automated discharge files from public hospitals, electronic pathology reports, and other records from different information sources. Individualized information is also

received from general practitioners, from physicians who diagnose and treat patients with cancer in hospitals, from association of parents of children with cancer, and from other sources.

All malignant tumours are recorded, except basal and squamous cell skin carcinomas. Non-malignant CNS tumours are registered according to ICD-O-3. All cancers diagnosed in residents since 1 January 1991, including the DCO cases, are eligible for registration.

The registry follows IARC/IACR recommendations for classifying multiple primary tumours and for coding different variables. Access to the data is restricted to registry staff, and data security protocols guarantee confidentiality.

POPULATION AT RISK

Data were provided in the requested detail, by sex and single year of age for each calendar year of the reporting period, as generated by INE.

EDITORS' COMMENTS

The calculated age was inconsistent with the provided dates in 11% of cases (Table A.8). The proportion of cases aged 19 years in the age group 15–19 years was low (14.6%) (Table A.9); this can probably be explained by the small size of the dataset. Pilocytic astrocytoma was registered throughout the reporting period, but other non-malignant CNS tumours were registered only from 2008 onwards. Laterality was complete for retinoblastoma and nephroblastoma. See also Spain, above.

Asturias Cancer Registry, 1992–2010

V. Menéndez, M.V. Argüelles, C. Rodríguez Oleaga, J.R. Quirós

The Principality of Asturias, a Spanish autonomous community that covers an area of 10 565 km^2, is located in the north-western part of the Iberian Peninsula between the Cantabrian Mountains and the Bay of Biscay.

The population is 1.1 million (2.3% of the national population). Asturias has one of the lowest fertility rates in Europe (0.99 live births per woman), and only 14% of the population is younger than 20 years (Table A.6). About 80% of the population lives in urban areas, and the population density is 102 per km^2.

The iron and steel industry, metal processing, coal mining, a growing food industry, and ecotourism form the basis of the Asturian economy. In 2010, the GDP per capita was about 89% of the European Union average, and the unemployment rate was 16%.

General health care is provided mostly by public services through a well-developed network comprising eight district hospitals, 220 urban and local primary health-care centres, and a central hospital located in the capital, Oviedo. The hospital's comprehensive oncology centre provides surgery, radiotherapy, and chemotherapy services for children and adolescents with cancer. These facilities are supplemented by one private hospital, which offers some cancer treatments. Patients with suspected cancer are referred from primary care paediatricians to hospital services. All children with cancer in Asturias are referred to the central hospital in Oviedo. Although few patients need to travel outside Asturias for additional treatment, those who do mainly travel to Madrid.

The Asturias Cancer Registry covers the whole Principality of Asturias. The registry was established in 1978 and became population-based in 1982 (Table A.10). It is funded by the Asturian regional government and is overseen by the Public Health Directorate. The registry is staffed by one part-time epidemiologist and two full-time registrars.

Active case finding is performed using the records of all public and private hospitals, pathology and haematology laboratories, and death certificates. Passive follow-up is performed through record linkage with health insurance and mortality records. The paediatric cases are reported to RETI-SEHOP (located in Valencia). The registry uses the procedures and rules established by IARC and ENCR.

POPULATION AT RISK

The sources of the population data are the official censuses and annual updates of official population figures extracted from municipalities and published by INE and the Asturian Society of Economic and Industrial Studies (https://www.sadei.es/). Data were provided in the requested detail.

EDITORS' COMMENTS

In the IICC-3 dataset, the sex ratio is relatively high in the age group 15–19 years. Non-malignant CNS tumours were registered (Table A.9). Information on laterality was not provided. Non-melanoma skin cancers were not included. See also Spain, above.

Basque Country Cancer Registry, 1990–2012

Arantza Lopez de Munain, Nerea Larrañaga, Visitación de Castro, Marta De la Cruz, Leire Gil, Domingo Eizaguirre, Covadonga Audícana, M. Luisa Iruretagoyena

The Basque Country Cancer Registry covers the autonomous community of the Basque Country, which covers an area of 7261 km^2 and is located in northern Spain. It is administratively divided into three provinces: Araba, Bizkaia, and Gipuzkoa. The territory is quite mountainous. In most of the area the climate is oceanic; the average temperature is about 15 °C, and the average humidity is 70%.

The total population is 2.2 million, and 17% of the population is younger than 20 years (Table A.6). The economically active population is employed in the services sector (69%), industry (24%), construction (6%), and agriculture (1%).

Immigration plays an important role in the demographics of the Basque Country; 29% of the population was born outside the region. During the 20th century most of the immigrants were from other parts of Spain; the recent immigrants are from South America and Africa.

Universal health-care coverage is provided by the Basque Autonomous Government. Health care is provided

to 95% of the population by the Osakidetza (the public health-care system of the Basque Country). There are 40 hospitals (public and private). Most patients with cancer who are seen within the network of primary health-care centres are referred to general hospitals with oncology facilities. Although the upper age limit for paediatric primary care is 14 years, the age range for specialized paediatric services including oncology usually extends to include patients aged 18–20 years.

The registry was established in 1986 (Table A.10) by the region's health department, which coordinates three provincial teams. Beginning in 1995, large hospitals in the region established hospital-based cancer registries, and these were the main data sources for the Basque Country Cancer Registry. A system of active case finding from other sources has been established at the provincial level, enabling the registrars to match cancer records with data on residents treated outside the area and with death certificates.

Completeness of registration is excellent; multiple data sources are used to constitute a case record. Children and adolescents with cancer, who receive specialist care at referral hospitals, are particularly well covered.

The registry reports incidence and survival patterns and trends for the main cancer sites annually. Registry data are used for the planning and evaluation of health services, the cancer strategy for the Basque Country, and screening programmes. The registry collaborates on several national and international projects, such as EUROCARE, CONCORD, RARECARE, Cancer Prevalence in Europe (EUROPREVAL), ACCIS, and the European Prospective Investigation into Cancer and Nutrition (EPIC).

PUBLICATIONS

De Castro V, Tobalina MC, Larrañaga N, Bidaurrazaga J, De la Cruz M, Lopez de Munain A, et al. (2016). Cáncer infantil en la Comunidad Autónoma Vasca, 1990–2012. Gobierno Vasco. Available from: https://www.euskadi.eus/contenidos/informacion/registros_cancer/es_def/adjuntos/Cancer-infantil-CAV.pdf.

POPULATION AT RISK

Intercensal figures were estimated by the registry by linear interpolation until 2010 and by linear extrapolation for 2012, using the data from the 2006 census conducted specifically in the Basque Country and from the 2011 national census. Census data were provided by the Basque Statistical Institute (https://www.eustat.eus/). Data were provided in the requested detail.

EDITORS' COMMENTS

This dataset overlaps with that provided by RETI-SEHOP for the age group 0–14 years from 2000 onwards. The proportion of cancers diagnosed at age 19 years is high (Table A.9). Systematic registration of non-malignant CNS tumours started in 1995, although some were present in the dataset for earlier years. Skin carcinomas were not registered. Information on laterality was available for only 13% of the cases of interest. See also Spain, above.

Canary Islands Cancer Registry, 1993–2011

M.D. Rojas-Martín, A. Alemán-Herrera, E. De Miguel

The Canary Islands, an autonomous community of Spain, is located 100 km east of the coast of northern Africa and 1500 km from mainland Spain.

The Canary Islands Cancer Registry covers the two main islands, Gran Canaria and Tenerife, which are the administrative capitals of the two eponymous provinces and make up 83% of the population of the archipelago. The population of the two islands is 1.8 million, and 20% of the population is younger than 20 years (Table A.6). The residents are almost exclusively White, and a small minority is of Indian origin. The principal economic activities are services (mainly tourism, 77.9%), agriculture (7%), and industry (3.4%).

The Canary Health Service covers almost 100% of the population. The area has three hospitals with specialized paediatric oncology units.

The registry is located within the Public Health headquarters and is part of the Epidemiology and Health Prevention Service. It was created by law in 1993 (Table A.10) and is registered in the Spanish National Agency for Data Protection. On each island, a team of three people work in the registry.

The registry collects data actively from public and private data sources, including pathology, oncology, radiotherapy, and haematology departments, coded hospital discharge systems, hospital cancer registries, and death certificates with cancer as the underlying cause of death. In addition, the registry can access clinical histories from the four major hospitals online, and since 2014, the registry has also had access to primary health-care records. Registered cases are followed up by both active and passive methods.

Although most patients with cancer are diagnosed in the Canary Islands, some may travel to mainland Spain for diagnosis and treatment. The registry is working on data exchange with RETI-SEHOP.

The data produced by the registry are updated periodically (https://www3.gobiernodecanarias.org/sanidad/scs/organica.jsp?idCarpeta=b25ca6dc-a9a4-11dd-b574-dd4e320f085c) and are used by hospitals and the government to plan health programmes. The registry contributed to CI5 Volumes VII–XI.

POPULATION AT RISK

Data were provided by sex and 5-year age groups for 1993–1999 and by sex and single year of age for 2000–2011. INE did not publish separate data for the islands of Gran Canaria and Tenerife for 1993–1999; thus, these data were estimated at the Canary Islands Cancer Registry by geometric interpolation of the 1991 census data produced by INE and the data from the official municipality census of 1 May 1996, provided by the Canary Islands Statistics Institute. Since 1999, an official Municipality Continuous Census is conducted, and the data are published on 1 January of each year. The data for the remaining missing year–age–sex categories were estimated at IARC using the methods described in Chapter 2.

EDITORS' COMMENTS

Non-malignant CNS tumours became eligible for registration progressively: in 1993–2002, the registration was incomplete; in 2003–2004, it was systematic except for the sites C75.1–C75.3, and from 2005, it was complete. Information on laterality was available for 73% of the cases of interest. See also Spain, above.

Cuenca Cancer Registry, 1993–2012

Ana Isabel Marcos Navarro, Rosario Jiménez Chillarón, Amparo Chumillas Martínez, Gonzalo Gutiérrez Ávila

The Cuenca Cancer Registry covers the province of Cuenca, which covers an area of 17 140 km^2 and is located on the central plateau of Spain. The covered population is 0.2 million; 18% of the population is younger than 20 years (Table A.6) and 25% is 65 years and older. The province has 238 municipalities. The population density is 11.7 per km^2, and 40% of the population lives in rural municipalities with fewer than 2000 inhabitants. The economic activity consists of services (45%), industry and construction (30%), and agriculture (25%).

The province has 37 public primary health-care centres, one public hospital, and one private hospital. Most beds (90%) are in the public sector, which provides chemotherapy and surgical services. Patients are referred to highly specialized centres that provide radiotherapy and neuro-oncology therapy. Most children with cancer are treated in specialized hospitals.

The population-based Cuenca Cancer Registry was established in 1993 (Table A.10), within the Epidemiology Service of the Health Department of the autonomous community of Castilla-La Mancha. The registry personnel actively review clinical records from hospitals and primary health-care centres. Case finding is based on automated discharge files provided by the public hospital and electronic pathology reports. Additional data sources are individualized information from general practitioners, from attending physicians in hospitals, and from death certificates.

All malignant tumours are registered, with the exception of basal and squamous cell skin carcinomas. Non-malignant CNS tumours are also registered, according to ICD-O-3 rules. IARC recommendations are followed to classify multiple primary tumours and to code the different variables. Access to the data is restricted to registry staff, and data security protocols guarantee confidentiality.

POPULATION AT RISK

Data were provided in the requested detail, as generated by INE.

EDITORS' COMMENTS

The registry staff was unable to access the files of specialized paediatric hospitals; this may affect the data accuracy. The date of birth or date of incidence was imprecise in more than 10% of cases (Table A.8). The proportion of cases with unspecified morphology is rather high (11%) (Table A.9). Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. The high proportion of cases aged 19 years in the age group 15–19 years and the low sex ratio (Table A.9) may result from random variation due to the small number of cases in the dataset. Non-malignant CNS tumours are systematically recorded. Skin carcinomas are not registered. Laterality information was complete for retinoblastoma and gonadal tumours. See also Spain, above.

Girona Cancer Registry, 1990–2013

Rafael Marcos-Gragera, Loreto Vilardell, Montse Puigdemont, Angel Izquierdo, Josepa Ribes, Jordi Galvez, Anna Vidal, Laura Esteban, Josep Maria Borràs

The province of Girona is located in north-eastern Spain; it is the northernmost of the four provinces of the Catalonia region. The total population is 0.7 million, and 21% of the population is younger than 20 years (Table A.6). In recent years, there has been a large increase in immigration from Africa and South America.

Health care is provided predominantly by the Spanish National Health System, through district hospitals and a network of primary health-care centres. Radiotherapy, cancer surgery, and chemotherapy are coordinated by the cancer centre in the city of Girona and provided at various general hospitals.

The Girona Cancer Registry was formed in 1994 as an extension of the specialized registry of breast cancer and female genital cancer, which had been operating since 1980. Population-based data have been produced since 1994. Information on malignant, uncertain, and benign tumours in children and adolescents was collected retrospectively. Thus, incidence, mortality, and survival data are available from 1980.

The registry is part of the Oncology Coordination Plan within the Department of Health of the Autonomous Government of Catalonia, at the Catalan Institute of Oncology. The registry staff consists of a director, two epidemiologists, a computer scientist, two health documentarians, a statistician, and a clerk. Data are assembled from automated notifications by most sources and from active case finding in other sources. Most data sources are located in the province of Girona, although childhood cancers are mostly ascertained from the two referral hospitals in Barcelona, in which they are usually treated. The registry obtains mortality data from the Mortality Registry of Catalonia and the Spanish National Death Index and analyses all death certificates for residents of the province of Girona annually. Several types of checks are used systematically to detect and remove errors and inconsistencies in the collected data.

The registry data are published in annual incidence reports and serve as a basis for health planning. Studies are also conducted on the survival and the treatment of patients with specific tumour types.

POPULATION AT RISK

The source of the data is the Statistical Institute of Catalonia (https://www.idescat.cat/). Data were provided in the requested detail.

EDITORS' COMMENTS

This dataset overlaps with that provided by RETI-SEHOP for ages 0–14 years from 2000 onwards. Day of incidence is missing for one quarter of the cases (Table A.8), because this information was not available in the data sources. All non-malignant CNS tumours were registered. Skin carcinomas were registered, although data on outpatients may be missing. Information on laterality was provided for 74% of the cases of interest. See also Spain, above.

Granada Cancer Registry, 1992–2013

Maria-José Sánchez-Pérez, Miguel Rodriguez-Barranco, Yoe-Ling Chang-Chan, Daniel Redondo Sánchez, David López López, Carmen Ruiz-Baena, Carmen Estévez-Estévez, Victoria Barragán-Sánchez, Maribel Antoniles-Moreno

The province of Granada covers an area of 12 531 km^2. It is part of the Andalusian region, located in southern Spain.

The population is 0.9 million, and 22% of the population is younger than 20 years (Table A.6). The province is divided into 170 municipalities. The one urban area, Granada, has a population of about 0.2 million; 18 other areas have a population of more than 10 000, and the rest of the population lives in smaller municipalities. The population is ethnically homogeneous. The province of Granada has one of the lowest per capita incomes in Spain.

The area has five public hospitals (1880 beds) and three private hospitals (338 beds). Private hospitals serve a small part of the population. Childhood cancer diagnostic and treatment services are available within the province, and only a few cancer cases are diagnosed or treated outside the province.

The Granada Cancer Registry was established in 1985 (Table A.10) at the Andalusian School of Public Health, with the main objective of providing cancer epidemiology information for the province of Granada. In 2007, the Andalusia Cancer Registry was created and regulated by Decree 297/2007. It was made up of newly established population-based cancer registries in all eight Andalusian provinces and affiliated with the General Secretariat for Public Health and Participation of the Regional Ministry of Health of the Andalusian Government.

The Granada Cancer Registry is directed by a medical epidemiologist; other staff members include one physician, two statisticians, and four clerks. All staff members are involved in case finding, data collection, cancer coding, and data processing. Cancer notification is voluntary. Basic information sources include automated discharge files and reports from pathology, radiotherapy, haematology, and paediatric oncology departments from all public and private hospitals. Data collection is mixed (active and passive).

The registry uses the specialized software provided by IARC (IARCcrgTools, DEPedits) and other programs developed in the registry for quality control purposes. The IARC/IACR rules are used for multiple primary tumours. Passive and active follow-up of registered cases for vital status is conducted through linkage to the Spanish National Death Index and the regional mortality registry, and by reviewing medical records.

Underregistration of cancer cases is unlikely, because information on cancer diagnosis and treatment is always available to the registry.

In addition to estimating incidence, trends, and survival, the registry participates in international studies on cancer care and survival, including EUROCARE, EUROCHIP, and CONCORD, and other national studies on childhood cancer in collaboration with RETI-SEHOP.

POPULATION AT RISK

Intercensal population estimates were provided by the Institute of Statistics of Andalusia for 1981–2002 and by INE for the more recent years. Data were provided in the requested detail.

EDITORS' COMMENTS

Non-malignant CNS tumours other than pilocytic astrocytoma were not systematically registered before 2003. Therefore, the reported incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. Skin carcinomas are registered and are believed to be complete. Information on laterality was complete for the cases of interest. See also Spain, above.

Mallorca Cancer Registry, 1990–2012

Paula Franch, Lynn Fieraert, Maria Ramos

The Mallorca Cancer Registry covers the population of Mallorca Island, the largest of the Balearic Islands. The estimated population is 0.9 million, and 22% of the population is younger than 20 years (Table A.10). The Balearic Islands are located in the Mediterranean Sea, to the east of the Iberian Peninsula.

The Balearic Health Service is part of the Spanish National Health System and covers 95% of the population through a network of 40 primary health-care centres and three hospitals, which comprise the public health sector. The private sector includes four hospitals. About 29% of the population has private health insurance. All public hospitals have an oncology department, and one has a specialized paediatric oncology department.

The Mallorca Cancer Registry was established by a non-profit organization, the Colorectal Cancer Study Group, and was funded by the regional government until January 2008, when it became part of the Balearic Public Health Department. Population-based data were provided from 1988 (Table A.10).

In Mallorca, notification of cancer is voluntary. Data are collected through passive notification from most data

sources, and active case finding is performed from some sources. Since 2008, access to death certificates has been unrestricted. The registry also has electronic access to the clinical records of primary health-care and public hospitals.

POPULATION AT RISK

Population data for Mallorca were calculated from Balearic intercensal estimates (censuses of 1981 and 1991) until 2000. Estimates based on later censuses were provided by INE. Data were provided in the requested detail.

EDITORS' COMMENTS

Day of incidence was missing for a large proportion of cases (Table A.8). All intracranial and intraspinal CNS tumours were included from 2000. Laterality information was complete for retinoblastoma. Skin carcinomas may be underrepresented because of variable registration practices during the reporting period. See also Spain, above.

Murcia Cancer Registry, 1991–2009

Carmen Navarro, María Dolores Chirlaque, Jacinta Tortosa, Isabel Valera, Encarnación Párraga, Diego Salmerón

The Murcia Cancer Registry covers the whole population of the Murcia region, one of the 17 autonomous communities of Spain. The region is a Mediterranean area located in south-eastern Spain. The weather is warm, with a median annual temperature of 19 °C and a semi-arid climate. The Murcia region is one of Europe's main producers of fruits and vegetables. The economy is based on tourism, the food industry (fresh and canned food), and the energy sector (petrochemicals and renewable energy). About 62% of the working population is employed in services, 27% are employed in industry and construction, and 11% in agriculture. The population is 1.5 million, and 23% of the population is younger than 20 years. Resident children and adolescents constitute 3.8% of the national population younger than 20 years (Table A.6).

The Murcia Ministry of Healthcare is a public health system that is funded by social security insurance and provides primary care and hospital-based care free of charge.

The Murcia Cancer Registry began collecting data in 1982 (Table A.10). The data presented in IICC-3 are from 1991–2009, continuing from the period of this registry's contribution to IICC-2.

The main data sources are hospital discharge records, pathology reports, and information from haematology, medical oncology, radiotherapy, and day-hospital services. The data collection process is systematic, active, and continuous. Staff members regularly visit health centres to verify and complete records. The registry recently received online access to clinical records. To ascertain patients with cancer who are treated outside the region, the registry receives notifications from RETI-SEHOP and the social security service. Follow-up of registered patients is performed mainly using the Spanish National Death Index. Other sources, such as the social security database (which belongs to the Spanish National Health System), hospital records, primary care records, and municipal censuses, were used to complete vital status.

The proportion of cases notified from death certificates and the DCO% are used to monitor quality control. Registry data are used to estimate regional cancer incidence, trends, and survival, and to plan and evaluate cancer control programmes. The registry has participated in multicentre case–control studies and cohort studies (e.g. EPIC) in both Spain and Europe, and participates in EUROCARE. The Murcia Cancer Registry is a member of the Iberoamerican Network of Epidemiology and Information Systems on Cancer (REDEPICAN).

POPULATION AT RISK

The source of the population data was INE. Data were provided in the requested detail.

EDITORS' COMMENTS

Day of incidence was unknown in one quarter of the cases (Table A.8) and was coded to 1; this may have affected the age-specific rates. The sex ratio is rather high in adolescents aged 15–19 years (Table A.9). Non-malignant CNS tumours were not registered, and there were no cases of pilocytic astrocytoma in the dataset. Therefore, the reported incidence rates are likely to be underestimated for the diagnostic categories III and Xa and the total. Skin carcinomas were not registered. Information on laterality was provided for 92% of the cases of interest. See also Spain, above.

Navarra Cancer Registry, 1990–2010

Eva Ardanaz, Marcela Guevara, Rosana Burgui, María Aldereguía, Marta Ibarra, Maria Isabel Eciolaza

Navarra is one of the 17 autonomous communities of Spain and is located in the northern part of the Iberian Peninsula. It is bordered by France and the Pyrenees Mountains to the north, by the autonomous community of Aragon to the east, by the autonomous community of Rioja to the south, and by the autonomous community of the Basque Country to the west. Navarra covers an area of 10 421 km^2 and has three geographically distinct zones: the northern zone, which is characterized by the Pyrenees Mountains; the central zone, which is dominated by the region's capital city, Pamplona; and the southern zone, which borders the Ebro River.

The population is 0.6 million, half of whom live in Pamplona and the surrounding area; 20% of the population is younger than 20 years (Table A.6), and 17% is aged 65 years and older.

The Navarra Cancer Registry, which is a population-based registry, was established in 1970 (Table A.10) in an agreement between the Spanish Association Against

Cancer and the Navarra Public Health Institute. The principal goal is to study cancer epidemiology in Navarra. Data on all cancer cases in residents of the region are systematically collected by active methods.

The principal data sources include pathology, radiotherapy, and oncology departments and the medical records of all the hospitals in the region (public and private). The registry data are linked to the regional mortality registry, to identify patients whose cause of death was cancer. Data are collected and stored as individual electronic records. Each case is verified to avoid duplicate registration and errors in the records. About 3200 new malignant tumours (other than non-melanoma skin cancer) are registered per year. The registry produces incidence reports by 5-year periods and has participated in various epidemiological studies.

POPULATION AT RISK

The population data are the official intercensal estimates provided by the Navarra Institute of Statistics (https://nastat.navarra.es/es/). Data were provided in the requested detail.

EDITORS' COMMENTS

This dataset overlaps with that provided by RETI-SEHOP for the age group 0–14 years from 2000 onwards. Non-malignant CNS tumours were systematically registered from 1995, although some non-malignant cases were present in the dataset for earlier years. Nevertheless, the incidence rates for CNS tumours and overall may be lower than those in the registries with complete registration of these neoplasms. Information on laterality was provided for all cases of interest. Skin carcinomas were systematically recorded and are believed to be complete. See also Spain, above.

Tarragona Cancer Registry, 1990–2011

Jaume Galceran, Marià Carulla, Alberto Ameijide, Xavier Cardó, Laia Llauradó, Araceli Jiménez, Joan Borràs

The province of Tarragona is located in north-eastern Spain; it is the southernmost of the four provinces of the Catalonia region. The total population is 0.8 million, and 21% of the population is younger than 20 years (Table A.6). In 2000, about 3% of the population younger than 20 years consisted of foreign-born residents from Africa, other European countries, the Americas, and Asia. The influx of immigrants led to 17% of children and adolescents being foreign-born by 2007. The working population is employed in agriculture (6%), industry (20%), construction (16%), and services (58%).

Almost all residents are covered by the Spanish National Health System, and most use its services. In 2005, the province had about 2900 physicians, seven public hospitals with 1250 beds, and three private hospitals with 100 beds. One of the public hospitals has an oncology department, with 32 beds, that comprises medical oncology, radiotherapy, oncology, and palliative care units. Paediatric cancer care is provided in two referral hospitals in Barcelona, outside the province of Tarragona.

The Tarragona Cancer Registry was established in 1979 and achieved complete coverage of the population in 1980 (Table A.10). The registry is part of the Foundation League for Cancer Research and Prevention, which has a provincial scope. The registry staff consists of a director, an epidemiologist, a computer scientist, two nurses, a statistician, a technician, and a clerk. Data are collected through passive automated notification from most sources and by active case finding in the remaining sources. Registered cases are ascertained mostly in the province of Tarragona; however, most childhood cancer cases are ascertained from the two referral hospitals in Barcelona. The registry systematically obtains mortality data from the Mortality Registry of Catalonia and the Spanish National Death Index and has access to all death certificates for residents of the province of Tarragona. Cases notified from death certificates are systematically traced, and if no further information is obtained, they are registered as DCO cases. Several types of checks are used regularly to detect and remove errors and inconsistencies in the collected data. Completeness of the registry exceeds 95%. Since the registry was established, the availability of diagnostic and treatment services has increased, but it is difficult to estimate the influence on incidence trends.

The registry produces several sets of cancer statistics and describes their epidemiological characteristics and evolution (https://epicancer.cat/inici). It also promotes epidemiological research, helps policy-makers identify needs for cancer care services, and collaborates in evaluating screening programmes and other cancer control activities.

POPULATION AT RISK

A demographic survey conducted in 2007 by the Statistical Institute of Catalonia (https://www.idescat.cat/) is the source of the population data. For 1990–2000, intercensal estimates at 1 July were used; for 2001–2007, postcensal estimates at 1 July were used. Data were provided in the requested detail.

EDITORS' COMMENTS

This dataset overlaps with that provided by RETI-SEHOP for the age group 0–14 years from 2000 onwards. Day of incidence is missing for almost two thirds of the cases (Table A.8), because this information was not available in the data sources, mostly during the 1990s. Non-malignant CNS tumours were not systematically registered; however, some cases were included in the dataset throughout the reporting period. Skin carcinomas were systematically recorded and are believed to be complete from 1980. Information on laterality was provided for 90% of the cases of interest. See also Spain, above.

SPAIN, 11 registries (1990-2013)

	Age group (years)	Males	Females
Person-years	0	1 014 238	959 949
	1-4	4 163 015	3 968 098
	5-9	5 342 608	5 100 841
	10-14	5 850 542	5 589 807
	15-19	6 712 940	6 408 806
	0-14	16 370 403	15 618 695
	0-19	23 083 343	22 027 501

Please consult the quality indicators for this pool and its constituent registries

SPAIN, 11 registries (1990-2013)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	**LEUKAEMIA**	88	655	423	345	356	**1511**	**1867**	29.7	100.0	23.8	100.0	44.6	80.6	40.5	30.2	27.1	**50.3**	**45.1**	721	857	98.8	0.8
	a. Lymphoid	40	558	333	215	193	**1146**	**1339**	22.6	75.8	17.1	71.7	20.3	68.6	31.9	18.8	14.7	**38.6**	**33.3**	549	623	99.8	0.1
	b. Acute myeloid	30	63	60	85	103	**238**	**341**	4.7	15.8	4.4	18.3	15.2	7.7	5.7	7.4	7.8	**7.6**	**7.6**	112	151	99.4	0.3
	c. CMD	1	6	9	17	41	**33**	**74**	0.6	2.2	0.9	4.0	0.5	0.7	0.9	1.5	3.1	**1.0**	**1.5**	15	31	100.0	0.0
	d. MDS & other	7	12	7	5	7	**31**	**38**	0.6	2.1	0.5	2.0	3.5	1.5	0.7	0.4	0.5	**1.1**	**0.9**	15	18	100.0	0.0
	e. Unspecified	10	16	14	23	12	**63**	**75**	1.2	4.2	1.0	4.0	5.1	2.0	1.3	2.0	0.9	**2.0**	**1.8**	30	34	76.0	16.0
II	**LYMPHOMA & RELATED**	22	119	207	346	785	**694**	**1479**	13.7	100.0	18.9	100.0	11.1	14.6	19.8	30.2	59.8	**20.6**	**29.4**	320	619	98.9	0.4
	a. Hodgkin	0	9	54	181	531	**244**	**775**	4.8	35.2	9.9	52.4	-	1.1	5.2	15.8	40.5	**6.6**	**14.2**	109	312	99.9	0.0
	b. Non-Hodgkin except BL	3	34	70	90	194	**197**	**391**	3.9	28.4	5.0	26.4	1.5	4.2	6.7	7.9	14.8	**5.9**	**7.9**	91	165	99.0	0.5
	c. Burkitt (BL)	0	49	66	56	39	**171**	**210**	3.4	24.6	2.7	14.2	-	6.0	6.3	4.9	3.0	**5.3**	**4.8**	80	95	100.0	0.0
	d. Lymphoreticular	18	24	11	9	10	**62**	**72**	1.2	8.9	0.9	4.9	9.1	3.0	1.1	0.8	0.8	**2.2**	**1.9**	30	34	100.0	0.0
	e. Unspecified	1	3	6	10	11	**20**	**31**	0.4	2.9	0.4	2.1	0.5	0.4	0.6	0.9	0.8	**0.6**	**0.6**	9	13	64.5	12.9
III	**CNS NEOPLASMS** †	57	333	353	318	371	**1061**	**1432**	20.9	100.0	18.3	100.0	28.9	41.0	33.8	27.8	28.3	**33.9**	**32.6**	501	642	82.5	0.5
	a. Ependymoma	20	47	22	21	30	**110**	**140**	2.2	10.4	1.8	9.8	10.1	5.8	2.1	1.8	2.3	**3.8**	**3.4**	53	64	98.6	0.0
	b. Astrocytoma	14	129	137	140	160	**420**	**580**	8.3	39.6	7.4	40.5	7.1	15.9	13.1	12.2	12.2	**13.3**	**13.0**	198	259	95.9	0.0
	c. CNS embryonal	10	80	86	41	37	**217**	**254**	4.3	20.5	3.2	17.7	5.1	9.8	8.2	3.6	2.8	**7.1**	**6.2**	104	118	100.0	0.0
	d. Other gliomas	3	33	42	33	32	**111**	**143**	2.2	10.5	1.8	10.0	1.5	4.1	4.0	2.9	2.4	**3.5**	**3.3**	52	65	55.9	0.0
	e. Other specified	3	16	32	45	59	**96**	**155**	1.9	9.0	2.0	10.8	1.5	2.0	3.1	3.9	4.5	**2.9**	**3.2**	44	67	90.3	0.0
	f. Unspecified CNS	7	28	34	38	53	**107**	**160**	2.1	10.1	2.0	11.2	3.5	3.4	3.3	3.3	4.0	**3.4**	**3.5**	50	70	8.1	4.4
IV	**NEUROBLASTOMA**	164	164	41	10	20	**379**	**399**	7.5	100.0	5.1	100.0	83.1	20.2	3.9	0.9	1.5	**14.1**	**11.3**	186	194	97.0	0.0
	a. (Ganglio)neuroblastoma	162	162	38	10	9	**372**	**381**	7.3	98.2	4.9	95.5	82.1	19.9	3.6	0.9	0.7	**13.8**	**10.9**	183	186	96.9	0.0
	b. Peripheral nervous	2	2	3	0	11	**7**	**18**	0.1	1.8	0.2	4.5	1.0	0.2	0.3	-	0.8	**0.2**	**0.4**	3	8	100.0	0.0
V	**RETINOBLASTOMA**	35	67	4	1	0	**107**	**107**	2.1	100.0	1.4	100.0	17.7	8.2	0.4	0.1	-	**4.1**	**3.1**	53	53	74.8	0.0
VI	**RENAL TUMOURS**	52	137	37	11	20	**237**	**257**	4.7	100.0	3.3	100.0	26.3	16.8	3.5	1.0	1.5	**8.7**	**7.1**	116	124	95.3	0.4
	a. Nephroblastoma	50	136	37	6	6	**229**	**235**	4.5	96.6	3.0	91.4	25.3	16.7	3.5	0.5	0.5	**8.4**	**6.6**	112	115	95.7	0.0
	b. Renal carcinoma	0	1	0	5	14	**6**	**20**	0.1	2.5	0.3	7.8	-	0.1	-	0.4	1.1	**0.2**	**0.4**	3	8	100.0	0.0
	c. Unspecified	2	0	0	0	0	**2**	**2**	0.0	0.8	0.0	0.8	1.0	-	-	-	-	**0.1**	**0.1**	1	1	0.0	50.0
VII	**HEPATIC TUMOURS**	18	25	8	9	19	**60**	**79**	1.2	100.0	1.0	100.0	9.1	3.1	0.8	0.8	1.4	**2.1**	**2.0**	29	36	93.7	0.0
	a. Hepatoblastoma	18	22	2	3	0	**45**	**45**	0.9	75.0	0.6	57.0	9.1	2.7	0.2	0.3	-	**1.7**	**1.3**	22	22	97.8	0.0
	b. Hepatic carcinoma	0	3	5	6	18	**14**	**32**	0.3	23.3	0.4	40.5	-	0.4	0.5	0.5	1.4	**0.4**	**0.6**	7	13	93.8	0.0
	c. Unspecified	0	0	1	0	1	**1**	**2**	0.0	1.7	0.0	2.5	-	-	0.1	-	0.1	**0.0**	**0.0**	0	1	0.0	0.0
VIII	**BONE TUMOURS**	2	22	78	227	205	**329**	**534**	6.5	100.0	6.8	100.0	1.0	2.7	7.5	19.8	15.6	**9.1**	**10.6**	148	227	99.1	0.2
	a. Osteosarcoma	0	6	35	112	101	**153**	**254**	3.0	46.5	3.2	47.6	-	0.7	3.4	9.8	7.7	**4.2**	**5.0**	69	107	99.6	0.0
	b. Chondrosarcoma	0	0	2	1	13	**3**	**16**	0.1	0.9	0.2	3.0	-	-	0.2	0.1	1.0	**0.1**	**0.3**	1	6	100.0	0.0
	c. Ewing & related	1	13	37	105	78	**156**	**234**	3.1	47.4	3.0	43.8	0.5	1.6	3.5	9.2	5.9	**4.3**	**4.7**	71	100	100.0	0.0
	d. Other specified	1	3	1	4	8	**9**	**17**	0.2	2.7	0.2	3.2	0.5	0.4	0.1	0.3	0.6	**0.3**	**0.4**	4	7	100.0	0.0
	e. Unspecified	0	0	3	5	5	**8**	**13**	0.2	2.4	0.2	2.4	-	-	0.3	0.4	0.4	**0.2**	**0.3**	4	6	69.2	7.7
IX	**SOFT TISSUE SARCOMA**	21	102	90	105	238	**318**	**556**	6.3	100.0	7.1	100.0	10.6	12.5	8.6	9.2	18.1	**10.2**	**12.0**	150	241	100.0	0.0
	a. Rhabdomyosarcoma	10	81	57	33	53	**181**	**234**	3.6	56.9	3.0	42.1	5.1	10.0	5.5	2.9	4.0	**6.1**	**5.6**	87	107	100.0	0.0
	b. Fibrosarcoma	3	2	5	10	20	**20**	**40**	0.4	6.3	0.5	7.2	1.5	0.2	0.5	0.9	1.5	**0.6**	**0.8**	9	17	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	3	**0**	**3**	-	-	0.0	0.5	-	-	-	-	0.2	**-**	**0.1**	-	1	100.0	0.0
	d. Other specified	7	14	23	50	147	**94**	**241**	1.9	29.6	3.1	43.3	3.5	1.7	2.2	4.4	11.2	**2.8**	**4.7**	43	99	100.0	0.0
	e. Unspecified	1	5	5	12	15	**23**	**38**	0.5	7.2	0.5	6.8	0.5	0.6	0.5	1.0	1.1	**0.7**	**0.8**	11	16	100.0	0.0
X	**GERM CELL TUMOURS**	29	27	36	58	261	**150**	**411**	3.0	100.0	5.2	100.0	14.7	3.3	3.4	5.1	19.9	**4.7**	**8.1**	70	170	99.3	0.0
	a. CNS germ cell ‡	6	1	17	14	19	**38**	**57**	0.7	25.3	0.7	13.9	3.0	0.1	1.6	1.2	1.4	**1.1**	**1.2**	18	25	100.0	0.0
	b. Other extragonadal	15	10	4	2	14	**31**	**45**	0.6	20.7	0.6	10.9	7.6	1.2	0.4	0.2	1.1	**1.1**	**1.1**	15	20	100.0	0.0
	c. Gonadal germ cell	6	16	15	39	199	**76**	**275**	1.5	50.7	3.5	66.9	3.0	2.0	1.4	3.4	15.2	**2.3**	**5.2**	35	111	100.0	0.0
	d. Gonadal carcinoma	0	0	0	3	21	**3**	**24**	0.1	2.0	0.3	5.8	-	-	-	0.3	1.6	**0.1**	**0.4**	1	9	100.0	0.0
	e. Unspecified gonadal	2	0	0	0	8	**2**	**10**	0.0	1.3	0.1	2.4	1.0	-	-	-	0.6	**0.1**	**0.2**	1	4	70.0	0.0
XI	**CARCINOMA & MELANOMA**	5	22	47	148	474	**222**	**696**	4.4	100.0	8.9	100.0	2.5	2.7	4.5	12.9	36.1	**6.2**	**13.0**	101	281	100.0	0.0
	a. Adrenocortical	2	5	2	1	4	**10**	**14**	0.2	4.5	0.2	2.0	1.0	0.6	0.2	0.1	0.3	**0.4**	**0.3**	5	6	100.0	0.0
	b. Thyroid	0	4	20	65	183	**89**	**272**	1.8	40.1	3.5	39.1	-	0.5	1.9	5.7	13.9	**2.4**	**5.0**	40	110	100.0	0.0
	c. Nasopharyngeal	0	0	0	5	24	**5**	**29**	0.1	2.3	0.4	4.2	-	-	-	0.4	1.8	**0.1**	**0.5**	2	11	100.0	0.0
	d. Melanoma	2	10	14	29	115	**55**	**170**	1.1	24.8	2.2	24.4	1.0	1.2	1.3	2.5	8.8	**1.6**	**3.2**	25	69	100.0	0.0
	e. Skin carcinoma	0	1	2	18	49	**21**	**70**	0.4	9.5	0.9	10.1	-	0.1	0.2	1.6	3.7	**0.6**	**1.3**	9	28	100.0	0.0
	f. Other & unspecified	1	2	9	30	99	**42**	**141**	0.8	18.9	1.8	20.3	0.5	0.2	0.9	2.6	7.5	**1.2**	**2.6**	19	57	100.0	0.0
XII	**OTHER & UNSPECIFIED**	3	2	2	6	9	**13**	**22**	0.3	100.0	0.3	100.0	1.5	0.2	0.2	0.5	0.7	**0.4**	**0.5**	6	9	68.2	9.1
	a. Other specified	1	2	0	4	2	**7**	**9**	0.1	53.8	0.1	40.9	0.5	0.2	-	0.3	0.2	**0.2**	**0.2**	3	4	100.0	0.0
	b. Other unspecified	2	0	2	2	7	**6**	**13**	0.1	46.2	0.2	59.1	1.0	-	0.2	0.2	0.5	**0.2**	**0.3**	3	5	46.2	15.4
	TOTAL	496	1675	1326	1584	2758	**5081**	**7839**	100.0	100.0	100.0	100.0	251.2	206.0	127.0	138.5	210.2	**164.3**	**174.6**	2401	3452	95.4	0.4

† includes 460 non-malignant ‡ includes 7 non-malignant

Please consult the quality indicators for this pool and its constituent registries

Sweden

Swedish Cancer Registry, 1990–2011

Staffan Khan, Niklas Toorell

Sweden is one of the Nordic countries of Europe. The country's climate is relatively mild considering the northerly latitudes, because of the significant maritime influence. Sweden covers an area of 450 295 km^2 and is sparsely populated; most of the population lives in the southern part of the country. In 2010, the population was 9.4 million (Table A.7), and 23% of the population was younger than 20 years (Table A.6). Almost 25% of the residents are foreign-born. Sweden ranks high in per capita income and has a social welfare system with universal health care and a high education level.

The general health-care system includes all medical specialties (including paediatric and adolescent oncology, pathology, and neuro-oncology). Children and adolescents with a cancer diagnosis are referred to one of six regional paediatric oncology centres, which coordinate both the medical and the psychosocial aspects of cancer care. Treatment is provided either at the paediatric cancer centre or at a local hospital, closer to the child's home, depending on the diagnosis and the services required. Children are followed up until age 18 years, for surveillance of late effects of the cancer or its treatment. The availability of specialists (both physicians and nurses) in paediatric oncology is evenly distributed within the population, but more specialists are needed.

The Swedish Cancer Registry has had national coverage since it was established in 1958 (Table A.10). The registry is managed by the Swedish National Board of Health and Welfare. Reporting of all malignant and certain non-malignant tumours is mandatory. The six regional paediatric cancer centres continuously register cases in coordination with reporting to certain clinical cancer registries. The Swedish Cancer Registry receives and consolidates regional data annually into a national database. Records are checked for duplicate entries, and patients are followed up annually through linkage to the population register for vital status and emigration. All residents of Sweden have a unique personal identification number, which enables linkage between data sources. Most incident cases are reported from at least two sources (a clinical report and a pathology report). Neoplasms have been coded according to ICD-O-3 since 2005 (Table A.10). All cancer diagnoses are also converted into earlier coding systems, to enable adequate analysis of time trends. Overall completeness of cancer registration is estimated to be 96%, with results varying between sites and ages. DCO cases are not included in the Swedish Cancer Registry, but this has negligible relevance for childhood cancer.

In addition to producing routine statistics (a statistical database and annual incidence reports are available at https://www.socialstyrelsen.se/), the registry shares data for use in quality assurance of public health services, including cancer prevention and cancer survival. Data are also used for clinical and epidemiological research.

PUBLICATIONS

Barlow L, Westergren K, Holmberg L, Talbäck M (2009). The completeness of the Swedish Cancer Register: a sample survey for year 1998. Acta Oncol. 48(1):27–33. https://doi.org/10.1080/02841860802247664 PMID:18767000

POPULATION AT RISK

The annual population data were provided by Statistics Sweden (https://www.scb.se/en) using data from censuses conducted in 1990 and 2005 and from a survey conducted in 2012 (Table A.7). Data were provided in the requested detail.

EDITORS' COMMENTS

The registry contributed to all three IICC volumes (Table A.1). Day of birth and day of incidence were not supplied (Table A.8), for confidentiality reasons, but they are recorded and are used by the registry to calculate age. Death certificates were not available for ascertainment of cancer cases (Table A.9). Thus, a proportion of new cases may be missed, although this proportion is believed to be small. Non-malignant CNS tumours are registered, and pilocytic astrocytoma is coded with uncertain behaviour. Basal cell skin carcinomas are not registered. Data on laterality are not presented, because the provided data did not include a code for bilateral tumours.

SWEDEN (1990-2011)

	Age group (years)	Males	Females
Person-years	0	1 187 181	1 123 916
	1-4	4 792 998	4 548 189
	5-9	5 994 295	5 688 932
	10-14	6 091 356	5 779 375
	15-19	6 275 277	5 951 121
	0-14	18 065 830	17 140 412
	0-19	24 341 107	23 091 533
Average annual population	0-14	821 174	779 110
	0-19	1 106 414	1 049 615

Please consult the quality indicators for this registry

SWEDEN (1990-2011)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	109	845	442	333	272	**1729**	**2001**	32.7	100.0	26.5	100.0	47.2	90.5	37.8	28.1	22.2	**52.0**	**45.3**	739	850	98.7	0.0
	a. Lymphoid	53	702	376	237	151	**1368**	**1519**	25.9	79.1	20.1	75.9	22.9	75.2	32.2	20.0	12.4	**41.3**	**34.8**	585	646	98.6	0.0
	b. Acute myeloid	41	99	51	72	87	**263**	**350**	5.0	15.2	4.6	17.5	17.7	10.6	4.4	6.1	7.1	**7.8**	**7.7**	112	148	99.4	0.0
	c. CMD	1	5	7	11	30	**24**	**54**	0.5	1.4	0.7	2.7	0.4	0.5	0.6	0.9	2.5	**0.7**	**1.1**	10	22	96.3	0.0
	d. MDS & other	2	12	0	1	0	**15**	**15**	0.3	0.9	0.2	0.7	0.9	1.3	-	0.1	-	**0.5**	**0.4**	6	6	93.3	0.0
	e. Unspecified	12	27	8	12	4	**59**	**63**	1.1	3.4	0.8	3.1	5.2	2.9	0.7	1.0	0.3	**1.8**	**1.5**	25	27	100.0	0.0
II	LYMPHOMA & RELATED	11	80	161	233	514	**485**	**999**	9.2	100.0	13.2	100.0	4.8	8.6	13.8	19.6	42.0	**13.2**	**19.7**	206	416	100.0	0.0
	a. Hodgkin	0	7	36	127	363	**170**	**533**	3.2	35.1	7.1	53.4	-	0.7	3.1	10.7	29.7	**4.3**	**10.0**	72	220	100.0	0.0
	b. Non-Hodgkin except BL	6	42	70	68	112	**186**	**298**	3.5	38.4	3.9	29.8	2.6	4.5	6.0	5.7	9.2	**5.2**	**6.1**	79	125	100.0	0.0
	c. Burkitt (BL)	0	9	28	18	17	**55**	**72**	1.0	11.3	1.0	7.2	-	1.0	2.4	1.5	1.4	**1.5**	**1.5**	23	30	100.0	0.0
	d. Lymphoreticular	4	10	5	0	0	**19**	**19**	0.4	3.9	0.3	1.9	1.7	1.1	0.4	-	-	**0.6**	**0.5**	8	8	100.0	0.0
	e. Unspecified	1	12	22	20	22	**55**	**77**	1.0	11.3	1.0	7.7	0.4	1.3	1.9	1.7	1.8	**1.5**	**1.6**	23	32	100.0	0.0
III	CNS NEOPLASMS †	78	429	441	420	361	**1368**	**1729**	25.9	100.0	22.9	100.0	33.8	45.9	37.7	35.4	29.5	**39.3**	**37.1**	583	731	89.5	0.0
	a. Ependymoma	19	58	40	30	35	**147**	**182**	2.8	10.7	2.4	10.5	8.2	6.2	3.4	2.5	2.9	**4.4**	**4.1**	63	77	100.0	0.0
	b. Astrocytoma	20	167	181	189	146	**557**	**703**	10.5	40.7	9.3	40.7	8.7	17.9	15.5	15.9	11.9	**15.8**	**15.0**	237	297	99.9	0.0
	c. CNS embryonal	13	94	108	63	42	**278**	**320**	5.3	20.3	4.2	18.5	5.6	10.1	9.2	5.3	3.4	**8.1**	**7.0**	119	136	100.0	0.0
	d. Other gliomas	9	12	25	34	44	**80**	**124**	1.5	5.8	1.6	7.2	3.9	1.3	2.1	2.9	3.6	**2.2**	**2.5**	34	52	99.2	0.0
	e. Other specified	8	24	30	48	56	**110**	**166**	2.1	8.0	2.2	9.6	3.5	2.6	2.6	4.0	4.6	**3.1**	**3.4**	47	70	100.0	0.0
	f. Unspecified CNS	9	74	57	56	38	**196**	**234**	3.7	14.3	3.1	13.5	3.9	7.9	4.9	4.7	3.1	**5.7**	**5.1**	84	99	23.1	0.0
IV	NEUROBLASTOMA	109	138	34	12	8	**293**	**301**	5.5	100.0	4.0	100.0	47.2	14.8	2.9	1.0	0.7	**9.4**	**7.5**	126	129	99.7	0.0
	a. (Ganglio)neuroblastoma	109	138	34	10	5	**291**	**296**	5.5	99.3	3.9	98.3	47.2	14.8	2.9	0.8	0.4	**9.4**	**7.4**	125	127	99.7	0.0
	b. Peripheral nervous	0	0	0	2	3	**2**	**5**	0.0	0.7	0.1	1.7	-	-	-	0.2	0.2	**0.0**	**0.1**	1	2	100.0	0.0
V	RETINOBLASTOMA	56	85	6	1	0	**148**	**148**	2.8	100.0	2.0	100.0	24.2	9.1	0.5	0.1	-	**4.9**	**3.8**	63	63	78.4	0.0
VI	RENAL TUMOURS	47	174	49	12	15	**282**	**297**	5.3	100.0	3.9	100.0	20.3	18.6	4.2	1.0	1.2	**9.0**	**7.2**	121	127	99.0	0.0
	a. Nephroblastoma	47	170	44	9	11	**270**	**281**	5.1	95.7	3.7	94.6	20.3	18.2	3.8	0.8	0.9	**8.6**	**6.9**	116	120	99.6	0.0
	b. Renal carcinoma	0	3	2	3	4	**8**	**12**	0.2	2.8	0.2	4.0	-	0.3	0.2	0.3	0.3	**0.2**	**0.3**	3	5	100.0	0.0
	c. Unspecified	0	1	3	0	0	**4**	**4**	0.1	1.4	0.1	1.3	-	0.1	0.3	-	-	**0.1**	**0.1**	2	2	50.0	0.0
VII	HEPATIC TUMOURS	29	35	8	7	10	**79**	**89**	1.5	100.0	1.2	100.0	12.5	3.7	0.7	0.6	0.8	**2.5**	**2.1**	34	38	100.0	0.0
	a. Hepatoblastoma	29	31	5	2	1	**67**	**68**	1.3	84.8	0.9	76.4	12.5	3.3	0.4	0.2	0.1	**2.2**	**1.7**	29	29	100.0	0.0
	b. Hepatic carcinoma	0	4	3	5	9	**12**	**21**	0.2	15.2	0.3	23.6	-	0.4	0.3	0.4	0.7	**0.3**	**0.4**	5	9	100.0	0.0
	c. Unspecified	0	0	0	0	0	**0**	**0**	-	-	-	-	-	-	-	-	-	**-**	**-**	-	-	-	-
VIII	BONE TUMOURS	1	13	61	121	191	**196**	**387**	3.7	100.0	5.1	100.0	0.4	1.4	5.2	10.2	15.6	**5.1**	**7.5**	83	161	100.0	0.0
	a. Osteosarcoma	0	4	30	75	115	**109**	**224**	2.1	55.6	3.0	57.9	-	0.4	2.6	6.3	9.4	**2.8**	**4.3**	46	93	100.0	0.0
	b. Chondrosarcoma	0	1	1	7	15	**9**	**24**	0.2	4.6	0.3	6.2	-	0.1	0.1	0.6	1.2	**0.2**	**0.5**	4	10	100.0	0.0
	c. Ewing & related	0	8	30	34	53	**72**	**125**	1.4	36.7	1.7	32.3	-	0.9	2.6	2.9	4.3	**1.9**	**2.5**	31	52	100.0	0.0
	d. Other specified	0	0	0	4	6	**4**	**10**	0.1	2.0	0.1	2.6	-	-	-	0.3	0.5	**0.1**	**0.2**	2	4	100.0	0.0
	e. Unspecified	1	0	0	1	2	**2**	**4**	0.0	1.0	0.1	1.0	0.4	-	-	0.1	0.2	**0.1**	**0.1**	1	2	100.0	0.0
IX	SOFT TISSUE SARCOMA	48	100	86	112	152	**346**	**498**	6.5	100.0	6.6	100.0	20.8	10.7	7.4	9.4	12.4	**10.0**	**10.6**	147	210	100.0	0.0
	a. Rhabdomyosarcoma	16	63	52	18	29	**149**	**178**	2.8	43.1	2.4	35.7	6.9	6.7	4.5	1.5	2.4	**4.5**	**4.0**	64	76	100.0	0.0
	b. Fibrosarcoma	11	7	13	14	25	**45**	**70**	0.9	13.0	0.9	14.1	4.8	0.7	1.1	1.2	2.0	**1.3**	**1.5**	19	29	100.0	0.0
	c. Kaposi sarcoma	0	0	0	1	0	**1**	**1**	0.0	0.3	0.0	0.2	-	-	-	0.1	-	**0.0**	**0.0**	0	0	100.0	0.0
	d. Other specified	12	24	14	51	69	**101**	**170**	1.9	29.2	2.2	34.1	5.2	2.6	1.2	4.3	5.6	**2.8**	**3.5**	43	71	100.0	0.0
	e. Unspecified	9	6	7	28	29	**50**	**79**	0.9	14.5	1.0	15.9	3.9	0.6	0.6	2.4	2.4	**1.4**	**1.6**	21	33	100.0	0.0
X	GERM CELL TUMOURS	35	37	25	58	295	**155**	**450**	2.9	100.0	6.0	100.0	15.1	4.0	2.1	4.9	24.1	**4.5**	**8.9**	66	187	100.0	0.0
	a. CNS germ cell ‡	12	9	9	15	26	**45**	**71**	0.9	29.0	0.9	15.8	5.2	1.0	0.8	1.3	2.1	**1.3**	**1.5**	19	30	100.0	0.0
	b. Other extragonadal	18	8	0	2	12	**28**	**40**	0.5	18.1	0.5	8.9	7.8	0.9	-	0.2	1.0	**0.9**	**0.9**	12	17	100.0	0.0
	c. Gonadal germ cell	5	17	10	35	228	**67**	**295**	1.3	43.2	3.9	65.6	2.2	1.8	0.9	2.9	18.6	**1.9**	**5.6**	28	122	100.0	0.0
	d. Gonadal carcinoma	0	0	0	2	15	**2**	**17**	0.0	1.3	0.2	3.8	-	-	-	0.2	1.2	**0.0**	**0.3**	1	7	100.0	0.0
	e. Unspecified gonadal	0	3	6	4	14	**13**	**27**	0.2	8.4	0.4	6.0	-	0.3	0.5	0.3	1.1	**0.4**	**0.5**	6	11	100.0	0.0
XI	CARCINOMA & MELANOMA	4	7	28	127	435	**166**	**601**	3.1	100.0	8.0	100.0	1.7	0.7	2.4	10.7	35.6	**4.2**	**11.3**	70	248	99.8	0.0
	a. Adrenocortical	1	6	1	1	1	**9**	**10**	0.2	5.4	0.1	1.7	0.4	0.6	0.1	0.1	0.1	**0.3**	**0.2**	4	4	100.0	0.0
	b. Thyroid	0	1	19	45	138	**65**	**203**	1.2	39.2	2.7	33.8	-	0.1	1.6	3.8	11.3	**1.7**	**3.8**	28	84	100.0	0.0
	c. Nasopharyngeal	0	0	0	11	11	**11**	**22**	0.2	6.6	0.3	3.7	-	-	-	0.9	0.9	**0.3**	**0.4**	5	9	100.0	0.0
	d. Melanoma	2	0	1	24	178	**27**	**205**	0.5	16.3	2.7	34.1	0.9	-	0.1	2.0	14.6	**0.7**	**3.8**	11	84	99.5	0.0
	e. Skin carcinoma	0	0	0	2	7	**2**	**9**	0.0	1.2	0.1	1.5	-	-	-	0.2	0.6	**0.0**	**0.2**	1	4	100.0	0.0
	f. Other & unspecified	1	0	7	44	100	**52**	**152**	1.0	31.3	2.0	25.3	0.4	-	0.6	3.7	8.2	**1.3**	**2.8**	22	63	100.0	0.0
XII	OTHER & UNSPECIFIED	13	13	5	6	20	**37**	**57**	0.7	100.0	0.8	100.0	5.6	1.4	0.4	0.5	1.6	**1.1**	**1.3**	16	24	73.7	0.0
	a. Other specified	0	2	0	1	0	**3**	**3**	0.1	8.1	0.0	5.3	-	0.2	-	0.1	-	**0.1**	**0.1**	1	1	100.0	0.0
	b. Other unspecified	13	11	5	5	20	**34**	**54**	0.6	91.9	0.7	94.7	5.6	1.2	0.4	0.4	1.6	**1.1**	**1.2**	15	23	72.2	0.0
	TOTAL	540	1956	1346	1442	2273	**5284**	**7557**	100.0	100.0	100.0	100.0	233.7	209.4	115.2	121.5	185.9	**155.3**	**162.2**	2254	3184	96.6	0.0

† includes 653 non-malignant ‡ includes 21 non-malignant

Please consult the quality indicators for this registry

Switzerland

Switzerland is a landlocked country located in western Europe. It covers an area of 41 285 km^2, which lies between the Alps, the central plateau of Switzerland, and the Jura Mountains. The climate is generally temperate.

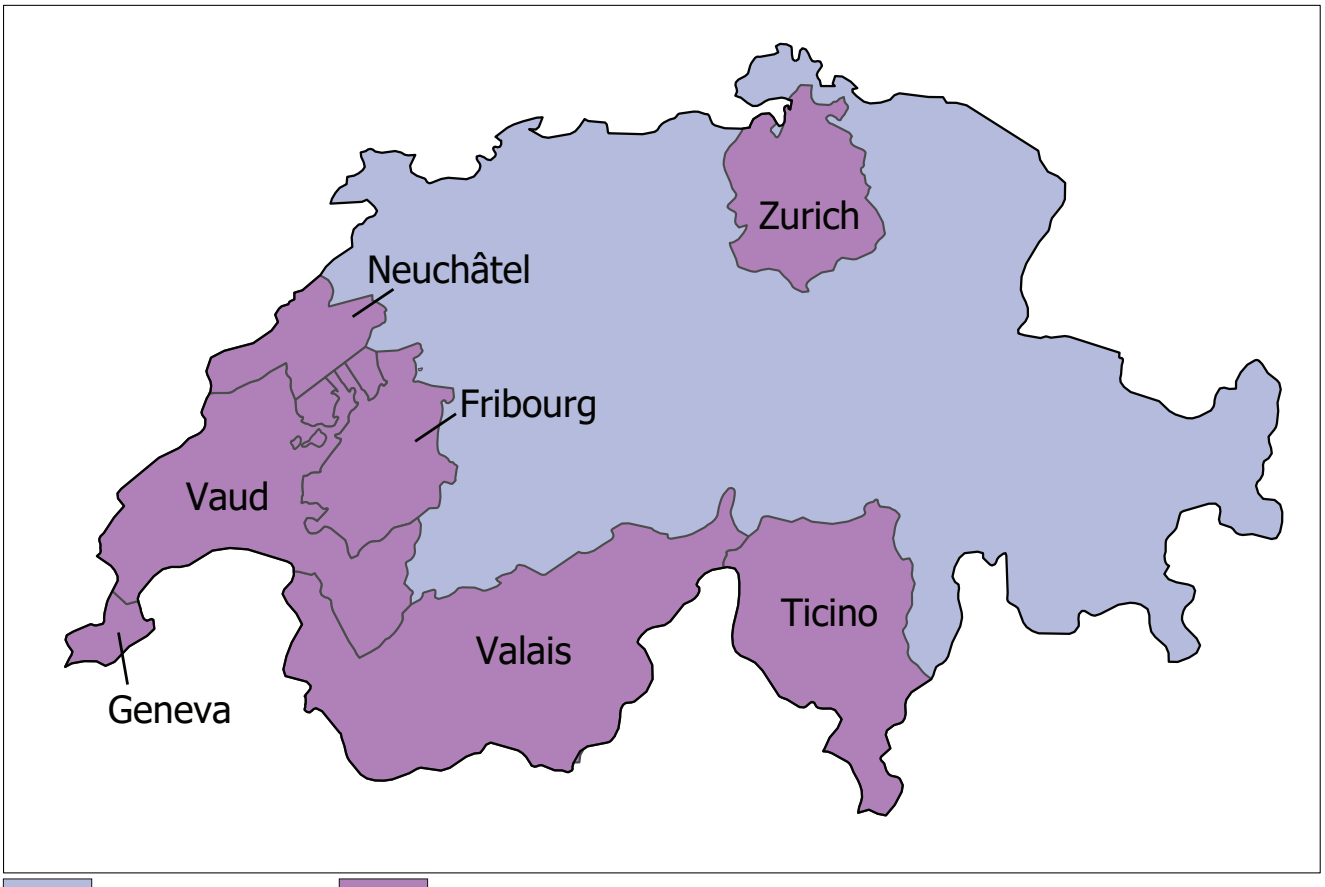
Switzerland (officially the Swiss Confederation, with the capital city of Bern) is divided into 26 cantons. In 2010, the population was 7.8 million (Table A.7); 15% of the population was younger than 15 years, and 21% was younger than 20 years (Table A.6). People speak one or several of the four official languages: German, French, Italian, and Romansh. Foreign-born residents (people without Swiss citizenship) comprise one quarter of the total population; most of them are from other European countries. Switzerland is a developed country. It ranks high in terms of government transparency, civil liberties, standard of living, economic competitiveness, and human development, and it has a stable modern economy.

Swiss citizens are required to purchase universal health insurance from private insurance companies, which are required to accept all applicants regardless of their medical condition or age. The insurance covers access to preventive and therapeutic care, including paediatric haematology and oncology and pharmaceuticals. The main supplementary health insurance policies, known as private and semi-private policies, cover additional benefits not covered by the compulsory health insurance (i.e. choice of hospital-based physician and superior levels of hospital accommodation). The cancer registries have no access to medical or social insurance data. All patients younger than 16 years diagnosed with cancer and a variable proportion of those diagnosed at ages 16–20 years are treated in one of the nine paediatric haematology and oncology units. Most children are monitored from birth by a paediatrician; the remainder are followed up by general practitioners.

Three Swiss cantons (Geneva, Neuchâtel, and Vaud) provided data on childhood cancer incidence to all three IICC volumes. Since 2007, the National Institute for Cancer Epidemiology and Registration (NICER) (https://www.nicer.org/en) foundation has promoted and supported population-based cancer registration and epidemiological cancer research in Switzerland. NICER is supported mainly by federal funds. The foundation compiles and aggregates data collected by all the cantonal and regional general cancer registries, of which there were 15 in October 2018, and cooperates with the Swiss Childhood Cancer Registry. The cantonal cancer registries exchange data on patients if the cases are ascertained outside the canton of residence. During the reporting period, notification of cancer was voluntary. A federal law of 2020 mandates cancer registration.

POPULATION AT RISK

The source of the population data is the Swiss Federal Statistical Office, which also conducts decennial national censuses (Table A.7). In 2010, the censuses were replaced by surveys provided by Population and Households Statistics (https://www.bfs.admin.ch/). These surveys are based on official registries (harmonized registers of people of the confederation, the cantons, and the communities, and the federal registry of dwellings). Population and Households Statistics presents the status of the population on 31 December of each year. Data were provided in the requested detail, by sex and single year of age.



EDITORS' COMMENTS

In the IICC-3 book, the Swiss data are presented in one table showing data for the Swiss Childhood Cancer Registry for the age group 0–14 years and in another table showing data combined from seven general cancer registries for the age group 0–19 years. The tables for the individual registries that constitute the combined dataset are available online; these are the full incidence tables for Geneva, Vaud, and Zurich and the abbreviated tables for Neuchâtel, Ticino, and Valais, which contribute to the Swiss pool table. No table is available for Fribourg, because of the small dataset, but the data from this registry are included in the pooled dataset (Table A.12). The Zurich Cancer Registry also contributed to IICC-2, and the registries of Geneva, Neuchâtel, and Vaud contributed to all three IICC volumes (Table A.1).

All registries can ascertain cancer cases from mortality records. The dates of birth and incidence are incomplete in most of the contributing registries (Table A.8); this may affect the age-specific incidence rates. All registries registered all or almost all non-malignant CNS tumours. The behaviour of pilocytic astrocytoma was originally coded according to the ICD-O edition in use (Table A.10), although most registries recoded pilocytic astrocytoma with uncertain behaviour according to ICD-O-3. There are few cases of pilocytic astrocytoma coded with malignant behaviour in the pooled dataset of general registries; the most recent such case is from 2000. The MV% for retinoblastoma differs between the Swiss Childhood Cancer Registry and the pooled dataset because of differences in the registration methods. Retinoblastoma is detected mostly by imaging and is treated non-invasively using laser surgery (enucleation); thus, pathology reports or samples are rarely provided. Although the Swiss Childhood Cancer Registry routinely collects imaging reports, cantonal cancer registries rely mainly on pathology reports. Laterality was complete in almost all registries; however, because the completeness was lower for retinoblastoma and ovarian tumours in the pooled dataset, the data for these two tumour types were not included in the laterality tables.

Swiss Childhood Cancer Registry, 1990–2013

Verena Pfeiffer, Shelagh Redmond, Gisela Michel, Nicolas Xavier von der Weid, Claudia Elisabeth Kuehni

In 1976, the Swiss Paediatric Oncology Group established the Swiss Childhood Cancer Registry, a nationwide cancer registry for children and adolescents. Since 2004, the registry has been located at the Institute of Social and Preventive Medicine of the University of Bern. Detailed characteristics of the registry and its research are presented online (https://www.childhoodcancerregistry.ch/). All children and adolescents with cancer diagnosed or treated in one of the nine paediatric haematology and oncology units in Switzerland are reported to the Swiss Childhood Cancer Registry. The registry collects data on patients aged 0–20 years at diagnosis. Population-based data are available for the age range 0–14 years from 1990. A clinical research assistant in each clinic notifies new cases to the registry, using a standard notification form that includes patient identification data (name, date of birth, diagnosis, sex, address) and diagnostic details (exact diagnosis, localization, morphology, behaviour, staging, and metastases). Regular linkages with cantonal cancer registries, pathology laboratories, and mortality statistics enable the identification of patients who were not treated in paediatric cancer centres. Case ascertainment is excellent for children aged 0–15 years at diagnosis. Currently, coverage of adolescents aged 16–20 years is less satisfactory; however, it is expected to improve as a result of the 2020 federal law mandating cancer registration.

For children treated and followed up in paediatric cancer centres (for 5–10 years from the time of diagnosis), follow-up information on remissions, relapses, late effects, second tumours, changes in treatments, and clinical study participation is extracted annually from patient records by local data managers. Afterwards, information on vital status is regularly updated through community registries, mortality statistics, and linkage with cantonal registries. Information on morbidity, health behaviours, quality of life, and social and psychological outcomes is collected from the patients using questionnaires. Linkage with the Swiss National Cohort (https://www.swissnationalcohort.ch/) enables assessment of whether environmental and socioeconomic factors are associated with incidence and prognosis.

The Swiss Childhood Cancer Registry is authorized to collect non-anonymized data, by permission of the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research. After the implementation in 2014 of the new act on human research, the new authorization issued by the Ethics Committee of the Canton of Bern was granted to the registry in July 2014.

PUBLICATIONS

Swiss Childhood Cancer Registry (2016). Annual report of the Swiss Childhood Cancer Registry 2014–2015. Available from: https://www.kinderkrebsregister.ch/zahlen-und-berichte/jahresberichte/.

Schindler M, Belle FN, Grotzer MA, von der Weid NX, Kuehni CE; Swiss Paediatric Oncology Group (SPOG) (2017). Childhood cancer survival in Switzerland (1976–2013): time-trends and predictors. Int J Cancer. 140(1):62–74. https://doi.org/10.1002/ijc.30434 PMID:27632765

POPULATION AT RISK

See Switzerland, above.

EDITORS' COMMENTS

In this paediatric cancer registry, registration focused on the age range 0–14 years during the reporting period. Therefore, data for the age groups 15–19 years and 0–19 years are not shown in the tables. The accuracy of the calculated age could not be verified at IARC; only year of birth and year of diagnosis were submitted (Table A.8), because of the data protection requirement, although complete dates are recorded by the registry. The reported proportion of non-malignant CNS tumours is high, because of strong links with neurology clinics throughout the country and systematic registration of all types of CNS tumours. Pilocytic astrocytoma was coded with uncertain behaviour. Laterality was complete for 99% of the cases of interest. Skin carcinomas are recorded, but notification is not complete, especially when the excision is performed by a practicing dermatologist. See also Switzerland, above.

SWITZERLAND, paediatric (1990-2013)

	Age group (years)	Males	Females
Person-years	0	964 658	913 554
	1-4	3 899 160	3 692 213
	5-9	4 964 121	4 699 848
	10-14	5 102 561	4 830 782
	0-14	14 930 500	14 136 397
Average annual population	0-14	622 104	589 017

Please consult the quality indicators for this registry

SWITZERLAND, paediatric (1990-2013)

		Number of cases					Percentage		Incidence rates per million person-years						MV	DCO
		Age group (years)					0-14		Age-specific				ASR	Cumulative	%	%
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	0-14	0-14	0-14	0-14
I	LEUKAEMIA	63	701	404	296	**1464**	32.7	100.0	33.5	92.3	41.8	29.8	**53.4**	761	99.5	0.1
	a. Lymphoid	25	605	327	208	**1165**	26.0	79.6	13.3	79.7	33.8	20.9	**42.7**	607	99.8	0.1
	b. Acute myeloid	26	76	52	57	**211**	4.7	14.4	13.8	10.0	5.4	5.7	**7.6**	109	97.6	0.0
	c. CMD	0	2	5	11	**18**	0.4	1.2	-	0.3	0.5	1.1	**0.6**	9	100.0	0.0
	d. MDS & other	7	15	16	18	**56**	1.2	3.8	3.7	2.0	1.7	1.8	**2.0**	29	100.0	0.0
	e. Unspecified	5	3	4	2	**14**	0.3	1.0	2.7	0.4	0.4	0.2	**0.5**	7	100.0	0.0
II	LYMPHOMA & RELATED	14	93	158	285	**550**	12.3	100.0	7.5	12.3	16.3	28.7	**18.0**	282	98.9	0.2
	a. Hodgkin	0	11	37	157	**205**	4.6	37.3	-	1.4	3.8	15.8	**6.3**	104	99.5	0.0
	b. Non-Hodgkin except BL	5	30	63	81	**179**	4.0	32.5	2.7	4.0	6.5	8.2	**5.9**	92	99.4	0.6
	c. Burkitt (BL)	1	29	49	39	**118**	2.6	21.5	0.5	3.8	5.1	3.9	**4.0**	61	99.2	0.0
	d. Lymphoreticular	8	22	8	8	**46**	1.0	8.4	4.3	2.9	0.8	0.8	**1.7**	24	93.5	0.0
	e. Unspecified	0	1	1	0	**2**	0.0	0.4	-	0.1	0.1	-	**0.1**	1	100.0	0.0
III	CNS NEOPLASMS †	61	279	368	276	**984**	22.0	100.0	32.5	36.8	38.1	27.8	**34.2**	509	86.3	0.1
	a. Ependymoma	22	44	21	11	**98**	2.2	10.0	11.7	5.8	2.2	1.1	**3.7**	51	100.0	0.0
	b. Astrocytoma	7	113	146	123	**389**	8.7	39.5	3.7	14.9	15.1	12.4	**13.4**	201	91.5	0.0
	c. CNS embryonal	22	67	97	34	**220**	4.9	22.4	11.7	8.8	10.0	3.4	**7.9**	114	97.7	0.5
	d. Other gliomas	1	27	53	24	**105**	2.3	10.7	0.5	3.6	5.5	2.4	**3.6**	54	27.6	0.0
	e. Other specified	5	25	48	75	**153**	3.4	15.5	2.7	3.3	5.0	7.6	**5.0**	78	94.8	0.0
	f. Unspecified CNS	4	3	3	9	**19**	0.4	1.9	2.1	0.4	0.3	0.9	**0.6**	10	31.6	0.0
IV	NEUROBLASTOMA	134	128	17	14	**293**	6.5	100.0	71.3	16.9	1.8	1.4	**11.7**	154	90.8	1.0
	a. (Ganglio)neuroblastoma	134	128	17	13	**292**	6.5	99.7	71.3	16.9	1.8	1.3	**11.7**	154	90.8	1.0
	b. Peripheral nervous	0	0	0	1	**1**	0.0	0.3	-	-	-	0.1	**0.0**	1	100.0	0.0
V	RETINOBLASTOMA	59	57	7	1	**124**	2.8	100.0	31.4	7.5	0.7	0.1	**5.0**	65	29.8	0.0
VI	RENAL TUMOURS	28	134	59	11	**232**	5.2	100.0	14.9	17.7	6.1	1.1	**8.9**	122	97.0	0.0
	a. Nephroblastoma	28	134	57	7	**226**	5.0	97.4	14.9	17.7	5.9	0.7	**8.7**	119	96.9	0.0
	b. Renal carcinoma	0	0	2	4	**6**	0.1	2.6	-	-	0.2	0.4	**0.2**	3	100.0	0.0
	c. Unspecified	0	0	0	0	**0**	-	-	-	-	-	-	**-**	-	-	-
VII	HEPATIC TUMOURS	17	19	7	11	**54**	1.2	100.0	9.1	2.5	0.7	1.1	**2.0**	28	96.3	1.9
	a. Hepatoblastoma	15	19	6	5	**45**	1.0	83.3	8.0	2.5	0.6	0.5	**1.7**	24	97.8	0.0
	b. Hepatic carcinoma	1	0	1	6	**8**	0.2	14.8	0.5	-	0.1	0.6	**0.2**	4	100.0	0.0
	c. Unspecified	1	0	0	0	**1**	0.0	1.9	0.5	-	-	-	**0.0**	1	0.0	100.0
VIII	BONE TUMOURS	0	12	65	127	**204**	4.6	100.0	-	1.6	6.7	12.8	**6.4**	104	100.0	0.0
	a. Osteosarcoma	0	5	33	66	**104**	2.3	51.0	-	0.7	3.4	6.6	**3.2**	53	100.0	0.0
	b. Chondrosarcoma	0	0	0	3	**3**	0.1	1.5	-	-	-	0.3	**0.1**	2	100.0	0.0
	c. Ewing & related	0	7	31	56	**94**	2.1	46.1	-	0.9	3.2	5.6	**3.0**	48	100.0	0.0
	d. Other specified	0	0	1	1	**2**	0.0	1.0	-	-	0.1	0.1	**0.1**	1	100.0	0.0
	e. Unspecified	0	0	0	1	**1**	0.0	0.5	-	-	-	0.1	**0.0**	1	100.0	0.0
IX	SOFT TISSUE SARCOMA	34	89	71	109	**303**	6.8	100.0	18.1	11.7	7.3	11.0	**10.6**	157	99.7	0.0
	a. Rhabdomyosarcoma	18	67	42	42	**169**	3.8	55.8	9.6	8.8	4.3	4.2	**6.1**	88	100.0	0.0
	b. Fibrosarcoma	4	4	2	10	**20**	0.4	6.6	2.1	0.5	0.2	1.0	**0.7**	10	100.0	0.0
	c. Kaposi sarcoma	0	1	0	1	**2**	0.0	0.7	-	0.1	-	0.1	**0.1**	1	100.0	0.0
	d. Other specified	4	11	26	46	**87**	1.9	28.7	2.1	1.4	2.7	4.6	**2.8**	45	100.0	0.0
	e. Unspecified	8	6	1	10	**25**	0.6	8.3	4.3	0.8	0.1	1.0	**0.9**	13	96.0	0.0
X	GERM CELL TUMOURS	25	31	18	59	**133**	3.0	100.0	13.3	4.1	1.9	5.9	**4.6**	69	97.0	0.0
	a. CNS germ cell ‡	1	2	11	19	**33**	0.7	24.8	0.5	0.3	1.1	1.9	**1.0**	17	87.9	0.0
	b. Other extragonadal	19	12	0	3	**34**	0.8	25.6	10.1	1.6	-	0.3	**1.4**	18	100.0	0.0
	c. Gonadal germ cell	4	17	7	36	**64**	1.4	48.1	2.1	2.2	0.7	3.6	**2.1**	33	100.0	0.0
	d. Gonadal carcinoma	0	0	0	1	**1**	0.0	0.8	-	-	-	0.1	**0.0**	1	100.0	0.0
	e. Unspecified gonadal	1	0	0	0	**1**	0.0	0.8	0.5	-	-	-	**0.0**	1	100.0	0.0
XI	CARCINOMA & MELANOMA	3	6	24	95	**128**	2.9	100.0	1.6	0.8	2.5	9.6	**3.9**	65	94.5	0.8
	a. Adrenocortical	1	1	1	3	**6**	0.1	4.7	0.5	0.1	0.1	0.3	**0.2**	3	100.0	0.0
	b. Thyroid	0	0	4	25	**29**	0.6	22.7	-	-	0.4	2.5	**0.9**	15	100.0	0.0
	c. Nasopharyngeal	0	0	0	1	**1**	0.0	0.8	-	-	-	0.1	**0.0**	1	100.0	0.0
	d. Melanoma	2	3	11	32	**48**	1.1	37.5	1.1	0.4	1.1	3.2	**1.5**	24	91.7	0.0
	e. Skin carcinoma	0	2	3	9	**14**	0.3	10.9	-	0.3	0.3	0.9	**0.4**	7	100.0	0.0
	f. Other & unspecified	0	0	5	25	**30**	0.7	23.4	-	-	0.5	2.5	**0.9**	15	90.0	3.3
XII	OTHER & UNSPECIFIED	2	3	1	6	**12**	0.3	100.0	1.1	0.4	0.1	0.6	**0.4**	6	58.3	0.0
	a. Other specified	1	3	0	1	**5**	0.1	41.7	0.5	0.4	-	0.1	**0.2**	3	100.0	0.0
	b. Other unspecified	1	0	1	5	**7**	0.2	58.3	0.5	-	0.1	0.5	**0.2**	4	28.6	0.0
	TOTAL	440	1552	1199	1290	**4481**	100.0	100.0	234.3	204.4	124.1	129.9	**159.2**	2321	93.6	0.2

† includes 404 non-malignant ‡ includes 6 non-malignant

Please consult the quality indicators for this registry

SWITZERLAND, 7 registries (1990-2013)

Registry	Period	Cases	%	Person-years	%
Fribourg	2006-2013	120	4.5	534 716	3.7
Geneva	1993-2013	345	12.9	1 954 486	13.7
Neuchâtel	1993-2013	163	6.1	802 020	5.6
Ticino	1996-2012	201	7.5	1 053 292	7.4
Valais	1990-2012	270	10.1	1 531 149	10.7
Vaud	1993-2012	520	19.5	2 971 432	20.8
Zurich	1993-2013	1046	39.2	5 420 147	38.0
SWITZERLAND	**1990-2013**	**2665**	**100.0**	**14 267 242**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

Fribourg Cancer Registry, 2006–2013

Bertrand Camey

The cancer registry of the canton of Fribourg started operating on 1 January 2006 (https://fribourg.liguecancer.ch/registre-des-tumeurs/). It covers the whole population of the canton. The cantonal population of 0.3 million is slightly younger than the national average (Table A.6), with slow but constant growth and rejuvenation.

The Fribourg Cancer Registry receives information from all data sources in the canton, including pathology laboratories, hospitals, oncologists, and the compulsory medical statistics hospital reports. All malignant tumours (invasive and in situ) of any topography and non-malignant tumours of the CNS are registered. Anonymized data are transferred annually to NICER, which produces cantonal and national statistics.

POPULATION AT RISK

See Switzerland, above.

EDITORS' COMMENTS

The number of incident cases during the reporting period was not sufficiently large for presentation of the data in a full table, but the registry contributed to the national pool (Table A.12). More than half of the CNS tumours were non-malignant (many of them meningioma); pilocytic astrocytoma was coded with uncertain behaviour. Laterality was complete for the cases of interest. See also Switzerland, above.

Geneva Cancer Registry, 1993–2013

Isabelle Neyroud-Caspar, Elisabetta Rapiti

The canton of Geneva in western Switzerland accounts for 5.8% of the total Swiss population. Geneva is surrounded by the Jura Mountains and the Alps. The canton covers an area of 282 km^2. The population is 0.5 million, and 22% of the population is younger than 20 years (Table A.6); 80% of the population lives in urban areas. The population structure is the result of a low fertility rate, a high life expectancy, and fairly heavy immigration of economically active people. The proportion of foreign-born residents is about 40%. Economic activity is concentrated in the administrative and service sectors. There is one paediatric unit in the public Cantonal University Hospital, which provides outpatient consultation and a day hospital, and paediatric emergency consultation services in a private clinic. Almost all cases of cancer in patients younger than 20 years are treated in this unit.

The Geneva Cancer Registry was established in 1970 and has been affiliated with the University of Geneva since 1999. The registry covers the entire population of the canton of Geneva. The registry staff consists of 12 employees, including three physicians and two statisticians. The Cantonal University Hospital, the five private clinics, all the pathology laboratories, and private practitioners in the canton are requested to report all cancer cases. An annual list of hospitalizations with any tumour diagnosis code enables the recording of tumours without histology information. The adult and paediatric oncology services provide annual listings, which enable the registry to record new cases and treatments. Trained tumour registrars systematically abstract data from medical and laboratory records. Tumours are coded according to IARC rules. Tumour staging is coded according to TNM-7. Passive and active follow-up is performed annually using the Cantonal Population Office records; this office is responsible for the registration of the resident population. Cause of death is ascertained from clinical files and from death certificates

from the Swiss Federal Statistical Office. The DCO% is very low (< 1% in 2008–2012). The low proportion of cases found at autopsy (0.3% in 2008–2012) compared with the total number of histologically confirmed cases suggests that most cases are identified during the lifetime of the patient.

The registry routinely publishes incidence and survival data. It conducts studies and collaborates on epidemiological studies at the local, national, and international levels. The registry transmits data annually to the Swiss Childhood Cancer Registry.

POPULATION AT RISK

Population data were provided by the Geneva Cancer Registry in the requested detail for 1993–2012. The population data for 2013 were estimated at IARC using the methods described in Chapter 2. See also Switzerland, above.

EDITORS' COMMENTS

The registry has access to death certificates, but no DCO cases were identified among the patients diagnosed before age 20 years (Table A.9). The reported proportion of non-malignant CNS tumours is high (Table A.9), although only intracranial tumours are eligible for registration, because of strong links with the neurology clinic in the registration area. Pilocytic astrocytoma was coded with malignant behaviour until 2002 and was recoded with uncertain behaviour according to ICD-O-3 for submission to IICC-3. Laterality was complete for the cases of interest. Malignant carcinoid tumours of the appendix made up 2.3% of the cases (Table A.11). See also Switzerland, above.

Neuchâtel Cancer Registry, 1993–2013

Manuela Maspoli-Conconi, Roland Choffat, Lalao Randimbison, Fabio Levi

The French-speaking canton of Neuchâtel is located in western Switzerland and shares half of its border with France. It covers an area of 803 km^2. The population is 0.2 million, and 22% of the population is younger than 20 years (Table A.6). The canton is a mainly rural region, with only two cities with about 35 000 inhabitants. In the absence of heavy industry, watchmaking and the microtechnology industry are the main economic activities. Almost all the population is White; 23% are Protestant, 24% are Catholic, and 40% are non-religious. Foreign-born residents (predominantly of Mediterranean origin) make up about 25% of residents. In 2012, the main occupational sectors in the canton of Neuchâtel were industry (35%), agriculture (2%), and services (63%).

In 2012, the region had about 4 hospital beds available for diagnosis and treatment per 1000 residents, and 337 practicing physicians (including 27 paediatricians). Radiotherapy and oncology services for adults are integrated into a unique coordinated multisite public organization that covers the whole area. Paediatric oncology services (diagnosis and treatment) are provided in university medical centres in the neighbouring cantons (e.g. Bern and Vaud).

The Neuchâtel Cancer Registry was established in 1972, and population-based data are available from 1974 (Table A.10). Until 2012, the registry received 60% of its funding from the local League Against Cancer and 40% from the cantonal public health department. Since 2013, the registry has been fully funded by the cantonal public health department. Additional support is also provided by the Swiss government through NICER.

Information is provided mainly by the Neuchâtel Institute of Pathology through biopsy, cytology, and autopsy reports. The paediatric cases are provided by neighbouring cancer registries or identified by periodic linkage with the database of the Swiss Childhood Cancer Registry. Notification is voluntary for medical institutions. Additional information is abstracted by the registry staff from electronic hospital charts. The registry routinely integrates abstracts of medical records into its database and performs periodic electronic linkage between the registry database and the centralized cantonal administrative population database (active follow-up). All death certificates established within the region are checked against the registry files annually. The registry follows IARC/IACR rules for the definition of incidence and multiple primary tumours.

The registry publishes routine annual incidence and mortality data by sex, age, and primary site, provides data for local planning purposes, and contributes anonymized annual incidence data to NICER. The registry also conducts epidemiological studies in collaboration with the Vaud Cancer Registry.

PUBLICATIONS

Levi F, Siegenthaler P, Méan AM, Baumann RP, Erler G, Haefliger JM (1997). Neuchâtel Tumor Registry: evaluation and results of 25 years of activity. [in French] Rev Med Suisse Romande. 117(7):537–86. PMID:9289808

Levi F, Moeckli R, Randimbison L, Te VC, Maspoli M, La Vecchia C (2006). Skin cancer in survivors of childhood and adolescent cancer. Eur J Cancer. 42(5):656–9. https://doi.org/10.1016/j.ejca.2005.08.042 PMID:16442793

POPULATION AT RISK

See Switzerland, above.

EDITORS' COMMENTS

The small number of cases may have contributed to some of the observed extreme values described below. The MV% is very high (Table A.9); however, given the high overall incidence rates (Table A.9), it is unlikely that any cases diagnosed clinically were missed. The date of birth and date of incidence were considered incomplete for a proportion of cases, because of the high proportion of certain days or months. This resulted in inconsistency between the reported age and the dates for 4% of cases (Table A.8). The proportion of cases aged 19 years in the age group 15–19 years was 33.3% (Table A.9), but the age was queried in only one such case. The reported proportion of non-malignant CNS tumours is high because of systematic registration of all types of CNS tumours. Pilocytic astrocytoma was coded with malignant behaviour until 2005 and recoded with uncertain behaviour according to the ICD-O edition in use (Table A.10). Laterality was complete for the cases of interest. See also Switzerland, above.

Ticino Cancer Registry, 1996–2012

Laura Ortelli, Paola Mazzola, Simona Peverelli, Alessandra Spitale, Andrea Bordoni

The canton of Ticino is located in the southernmost part of Switzerland. It covers an area of 2812 km^2 and is bordered by the canton of Uri to the north, by the canton of Graubünden and by Italy to the east, and by Italy to the south and west. The highest point is 3402 m above sea level, and the lowest is 194 m above sea level. The population is 0.3 million, and 19% of the population is younger than 20 years (Table A.6). The foreign-born population makes up 27% of the total and originates mainly in Italy, Portugal, Serbia, and Montenegro. Most of the population is Christian (76% are Catholic). The official language is Italian. The economy is based mainly on the services sector. The areas of trade, gastronomy, finances, insurance and real estate activities, health and social care, education, transportation, communication, and public administration employ about 81% of the population, followed by industry and manufacturing (17%) and farming and forestry (2%).

During the reporting period, the canton of Ticino had four public hospitals (two with a specific paediatric and adolescent oncology department), six private health-care facilities, and one radiotherapy department (located at the hospital in Bellinzona).

The Ticino Cancer Registry (https://www4.ti.ch/dss/dsp/rct/home) was established in 1995 by the local government through a cantonal law, based on a popular initiative; the registry began its activities in 1996 (Table A.10). The registry is mostly government-funded, with additional funding from the Federal Ministry of Health, through NICER. The registry is located within the Cantonal Institute of Pathology and Cytology and is staffed by a full-time physician, two data managers, and two full-time statisticians. About 80% of cases are notified by the Cantonal Institute of Pathology and Cytology. Additional cases come from the main public and private hospitals, radiotherapy and oncology centres, haematology laboratories, oncologists, general practitioners, and other Swiss cancer registries.

The registry database includes all children and adolescents with a malignant tumour at any site or with a non-malignant CNS tumour, diagnosed at age 0–19 years. Data are actively collected, checked, and coded manually by registry staff members before being entered into the database. Initial plausibility tests are automatically performed during the data entry phase. In addition, the registry staff members periodically apply IARC checks and rules for multiple primary tumours and several other plausibility, validity, and consistency checks (e.g. logical sequence of dates, validity of codes, and morphology by topography, sex, and age). Active follow-up for vital status of all patients with tumours is performed annually, by consulting the electronic records of the cantonal population office, accessible online.

Policy-makers frequently use registry data to plan and evaluate health services. The registry also conducts epidemiological research at the local, national, and international levels, including analysis of prognostic factors, incidence, and survival (e.g. EUROCARE, Cancer Registry-Based Project on Haematologic Malignancies [HAEMACARE], RARECARE, CONCORD, EUROCIM, and the Swiss HIV Cohort Study).

POPULATION AT RISK

See Switzerland, above.

EDITORS' COMMENTS

Although the registry collects complete dates of birth and incidence, the days were not provided in the submitted datasets (Table A.8); thus, the accuracy of the calculated age could not be verified at IARC. The MV% is very high; this suggests that some cases diagnosed clinically may be missed by the registry, and this may affect the resulting incidence rates. The registry has access to death certificates, but no DCO cases were identified among the patients diagnosed before age 20 years (Table A.9). Non-malignant CNS tumours were registered, but their low proportion suggests that some may have been missed. Pilocytic astrocytoma was coded with uncertain behaviour. Laterality was complete for 88% of the cases of interest. See also Switzerland, above.

Valais Cancer Registry, 1990–2012

Isabelle Konzelmann

The canton of Valais covers an area of 5225 km^2 and is located in southern Switzerland. The economy is supported mainly by production of wine and fruit brandies, cattle breeding, and tourism. Industries include hydroelectric power plants, agricultural factories, an oil refinery, a large aluminium processing plant, and other metal and chemical production. The population is 0.3 million (4% of the national population), and 21% of the population is younger than 20 years (Table A.6). About 25% of the population lives in the German-speaking area (Upper Valais), and 75% lives in the French-speaking area (Central Valais and Lower Valais). Foreign-born residents (mainly from Italy, Portugal, Serbia, and Montenegro) make up 24% of the population.

General health care in the region is provided predominantly by one public hospital and a few private clinics. This is supplemented by more than 800 private practitioners (25 physicians per 10 000 residents in 2013). Children suspected to have cancer are admitted to the hospital in Sion (the capital of the canton of Valais) to receive care in the department of paediatrics. Patients who require more complex treatment are referred to university centres in Lausanne or Geneva (for French-speaking people) and in Bern or Zürich (for German-speaking people).

The registry was established in 1989 (Table A.10); it is located in Sion and has been administered by the Valais Health Observatory (https://www.ovs.ch/) since 2001. The registry is funded primarily by the canton of Valais, and NICER provides a portion of the funding. The registry uses passive and active case finding from

numerous sources (pathology laboratories, hospitals, oncology and radiotherapy departments, other Swiss cantons, and death certificates). All malignant invasive and in situ tumours and brain tumours of any behaviour in all residents of the canton are registered. The registry follows IARC and ENCR coding rules. Active follow-up of registered patients is conducted by inquiring about the vital status or migration of the patients in the communes of their registered residence. The incidence data are used to inform public health planners, health professionals, and the general population about cancer in the population. Anonymized data are transferred to NICER for incidence, prevalence, mortality, and survival analysis.

POPULATION AT RISK

See Switzerland, above.

EDITORS' COMMENTS

Dates of birth and incidence were incomplete for a proportion of cases, and because the originally provided age was queried in almost half of the cases, the age recalculated at IARC was used in analyses (Table A.8). Pilocytic astrocytoma was coded with malignant behaviour until 2002 and with uncertain behaviour thereafter, according to the ICD-O edition in use (Table A.10). Laterality was complete for the cases of interest. See also Switzerland, above.

Vaud Cancer Registry, 1993–2012

Rafael Blanc Moya, Lalao Randimbison, Fabio Levi

The French-speaking canton of Vaud covers an area of 3212 km^2 and has a population of 0.7 million; 23% of the population is younger than 20 years (Table A.6).The canton is divided into 318 communes (16 with more than 5000 residents), which are grouped into 10 administrative and political districts. The canton's capital, Lausanne, hosts about 30% of the canton's total population. The population density is slightly higher than the national average. Foreign-born residents, predominantly of Mediterranean origin, make up about 32% of the population. The economy is based heavily on services that offer high added value (health care, finance, insurance, consulting, education, and research); almost 80% of workers are employed in these services. The canton also has state-of-the-art industrial activities, notably in the fields of micromechanics, electronics, watchmaking, medical engineering, information technology, and biotechnology.

The canton of Vaud has advanced hospital facilities and medical infrastructures; the Vaud University Hospital Centre is a hub of medicine and medical research in Europe. In 2011, the canton had about 3750 hospital beds available for cancer diagnosis and treatment (~5 per 1000 residents) and about 5860 hospital medical residents and private practitioners (4.1 per 1000 residents). Cancer care is provided by one major, multidisciplinary, public university oncology and radiotherapy centre, by four private radiotherapy units available to all residents, and by several peripheral (mostly hospital-based) medical and surgical oncology facilities and specialists.

The Vaud Cancer Registry, which covers the entire canton of Vaud, is part of the Cancer Epidemiology Unit of the Institute of Social and Preventive Medicine within the Faculty of Biology and Medicine of the University of Lausanne. Notification is voluntary. The main sources of information are the University Institute of Pathology of the University of Lausanne and three major private pathology laboratories. Registered patients are followed up passively and actively. Data on all deaths in the canton are available for review by the registry. All non-melanoma skin cancers are registered and linked to reports of selected preneoplastic conditions to the registry database for study of subsequent cancer risk. The registry also analyses the risk of second neoplasm and trends in survival.

POPULATION AT RISK

See Switzerland, above.

EDITORS' COMMENTS

The calculated age was inconsistent with the provided dates in 2.7% of cases (Table A.8). The MV% is very high overall (Table A.9), especially for CNS tumours; this suggests that some cases diagnosed clinically may be missed by the registry, and this may affect the resulting incidence rates. The reported proportion of non-malignant CNS tumours was high (Table A.9) because of the systematic registration of all types of CNS tumours. Pilocytic astrocytoma was recorded with malignant behaviour until 2005, but all cases were recoded with uncertain behaviour for submission to IICC-3, according to the ICD-O in use. Laterality was provided for 94% of the cases of interest, and it was complete for nephroblastoma. See also Switzerland, above.

Zurich Cancer Registry, 1993–2013

Sabine Rohrmann, Dimitri Korol, Manuela Limam, Katarina Matthes, Miriam Wanner

The predominantly urban, German-speaking canton of Zurich is located in north-eastern Switzerland and covers an area of 1729 km^2. Although most of the land is cultivated, manufacturing predominates in all parts of the canton. There is a large paper industry, and many small and medium-sized companies are active in construction and electronics. The service sector employs 84% of the population, and the city of Zurich is a major financial centre.

The population is 1.4 million, and 20% of the population is younger than 20 years (Table A.6). Foreign-born residents (mainly from eastern and southern Europe and Germany) make up about 25% of the population. There are more than 40 cantonal, public, or private hospitals and clinics, some of which have oncology departments providing specialized services (e.g. radiotherapy). The children's hospital in Zurich, which has an oncology department, is the referral centre for children with cancer.

The Zurich Cancer Registry, which was established in 1980 (Table A.10), covers the entire canton. It is affiliated with the Institute of Pathology and Molecular Pathology at the University Hospital Zurich, and with the Epidemiology, Biostatistics and Prevention Institute at the University of Zurich. The main information sources are reports from public and private pathology and haematology institutes. Additional sources are patient lists with cancer-specific ICD-10 codes from hospital statistics and medical records. Most of these files are actively abstracted by the registry staff. Treating physicians are asked for further information when needed. Date of death is supplied by official population registries and by the Swiss Federal Statistical Office. Death certificates are used for additional case finding. All information is manually checked and coded. Plausibility checks are performed regularly and before data submission or analysis. The data sources and procedures are the same for children and adults. Completeness of registration is estimated to be high and stable. Patients are followed up for vital status actively in 1-year and 5-year follow-up procedures and passively. Because the canton of Zurich lacks a centralized population register, individual requests are sent to the respective residents' registration offices.

Registry data are used to produce annual cantonal cancer incidence and mortality statistics and national statistics to help policy-makers plan and evaluate health services. The registry also participates in national and international studies.

POPULATION AT RISK

See Switzerland, above.

EDITORS' COMMENTS

Although the registry collects complete dates of birth and incidence, the days were not provided in the submitted datasets (Table A.8); thus, the accuracy of the calculated age could not be verified at IARC. The reported proportion of non-malignant CNS tumours was high because of systematic registration of all types of CNS tumours (Table A.9). Pilocytic astrocytoma was coded with uncertain behaviour. Laterality was complete for nephroblastoma and gonadal tumours. See also Switzerland, above.

SWITZERLAND, 7 registries (1990-2013)

	Age group (years)	Males	Females
Person-years	0	354 034	334 713
	1-4	1 462 730	1 383 369
	5-9	1 814 987	1 718 332
	10-14	1 824 395	1 730 537
	15-19	1 859 584	1 784 561
	0-14	5 456 146	5 166 951
	0-19	7 315 730	6 951 512

Please consult the quality indicators for this pool and its constituent registries

SWITZERLAND, 7 registries (1990-2013)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	29	274	138	110	77	551	628	30.6	100.0	23.6	100.0	42.1	96.3	39.1	30.9	21.1	54.8	47.2	779	884	99.4	0.6
	a. Lymphoid	11	222	113	77	38	423	461	23.5	76.8	17.3	73.4	16.0	78.0	32.0	21.7	10.4	42.1	35.0	598	650	99.3	0.7
	b. Acute myeloid	13	33	11	23	21	80	101	4.4	14.5	3.8	16.1	18.9	11.6	3.1	6.5	5.8	7.9	7.4	113	142	100.0	0.0
	c. CMD	0	1	4	5	14	10	24	0.6	1.8	0.9	3.8	-	0.4	1.1	1.4	3.8	0.9	1.5	14	33	100.0	0.0
	d. MDS & other	3	5	2	3	4	13	17	0.7	2.4	0.6	2.7	4.4	1.8	0.6	0.8	1.1	1.3	1.3	18	24	100.0	0.0
	e. Unspecified	2	13	8	2	0	25	25	1.4	4.5	0.9	4.0	2.9	4.6	2.3	0.6	-	2.5	2.0	35	35	96.0	4.0
II	LYMPHOMA & RELATED	6	46	71	107	236	230	466	12.8	100.0	17.5	100.0	8.7	16.2	20.1	30.1	64.8	20.9	30.8	325	648	100.0	0.0
	a. Hodgkin	0	7	14	58	162	79	241	4.4	34.3	9.0	51.7	-	2.5	4.0	16.3	44.5	6.8	15.3	111	334	100.0	0.0
	b. Non-Hodgkin except BL	4	14	32	36	64	86	150	4.8	37.4	5.6	32.2	5.8	4.9	9.1	10.1	17.6	7.8	10.0	121	209	100.0	0.0
	c. Burkitt (BL)	0	15	21	10	8	46	54	2.6	20.0	2.0	11.6	-	5.3	5.9	2.8	2.2	4.4	3.9	65	76	100.0	0.0
	d. Lymphoreticular	2	8	4	3	1	17	18	0.9	7.4	0.7	3.9	2.9	2.8	1.1	0.8	0.3	1.7	1.4	24	25	100.0	0.0
	e. Unspecified	0	2	0	0	1	2	3	0.1	0.9	0.1	0.6	-	0.7	-	-	0.3	0.2	0.2	3	4	100.0	0.0
III	CNS NEOPLASMS †	23	105	144	124	106	396	502	22.0	100.0	18.8	100.0	33.4	36.9	40.8	34.9	29.1	37.3	35.4	559	705	86.7	0.2
	a. Ependymoma	9	17	14	7	12	47	59	2.6	11.9	2.2	11.8	13.1	6.0	4.0	2.0	3.3	4.7	4.4	66	83	84.7	0.0
	b. Astrocytoma	3	40	50	59	46	152	198	8.5	38.4	7.4	39.4	4.4	14.1	14.2	16.6	12.6	14.1	13.8	215	278	96.5	0.0
	c. CNS embryonal	8	29	39	16	15	92	107	5.1	23.2	4.0	21.3	11.6	10.2	11.0	4.5	4.1	8.9	7.8	130	151	99.1	0.0
	d. Other gliomas	1	6	12	5	6	24	30	1.3	6.1	1.1	6.0	1.5	2.1	3.4	1.4	1.6	2.3	2.1	34	42	40.0	0.0
	e. Other specified	0	9	19	31	21	59	80	3.3	14.9	3.0	15.9	-	3.2	5.4	8.7	5.8	5.3	5.4	83	112	90.0	0.0
	f. Unspecified CNS	2	4	10	6	6	22	28	1.2	5.6	1.1	5.6	2.9	1.4	2.8	1.7	1.6	2.1	2.0	31	39	14.3	3.6
IV	NEUROBLASTOMA	49	58	8	4	2	119	121	6.6	100.0	4.5	100.0	71.1	20.4	2.3	1.1	0.5	12.8	10.0	168	171	100.0	0.0
	a. (Ganglio)neuroblastoma	49	58	8	3	1	118	119	6.6	99.2	4.5	98.3	71.1	20.4	2.3	0.8	0.3	12.7	9.9	167	168	100.0	0.0
	b. Peripheral nervous	0	0	0	1	1	1	2	0.1	0.8	0.1	1.7	-	-	-	0.3	0.3	0.1	0.1	1	3	100.0	0.0
V	RETINOBLASTOMA	22	17	2	0	0	41	41	2.3	100.0	1.5	100.0	31.9	6.0	0.6	-	-	4.5	3.5	58	58	78.0	0.0
VI	RENAL TUMOURS	11	39	25	5	9	80	89	4.4	100.0	3.3	100.0	16.0	13.7	7.1	1.4	2.5	8.2	6.9	113	125	100.0	0.0
	a. Nephroblastoma	11	39	25	2	2	77	79	4.3	96.3	3.0	88.8	16.0	13.7	7.1	0.6	0.5	7.9	6.3	109	112	100.0	0.0
	b. Renal carcinoma	0	0	0	3	7	3	10	0.2	3.8	0.4	11.2	-	-	-	0.8	1.9	0.2	0.6	4	14	100.0	0.0
	c. Unspecified	0	0	0	0	0	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
VII	HEPATIC TUMOURS	10	8	3	5	9	26	35	1.4	100.0	1.3	100.0	14.5	2.8	0.8	1.4	2.5	2.7	2.6	37	49	97.1	2.9
	a. Hepatoblastoma	7	8	2	3	1	20	21	1.1	76.9	0.8	60.0	10.2	2.8	0.6	0.8	0.3	2.1	1.7	28	30	100.0	0.0
	b. Hepatic carcinoma	2	0	1	2	8	5	13	0.3	19.2	0.5	37.1	2.9	-	0.3	0.6	2.2	0.5	0.9	7	18	100.0	0.0
	c. Unspecified	1	0	0	0	0	1	1	0.1	3.8	0.0	2.9	1.5	-	-	-	-	0.1	0.1	1	1	0.0	100.0
VIII	BONE TUMOURS	0	8	29	55	62	92	154	5.1	100.0	5.8	100.0	-	2.8	8.2	15.5	17.0	8.0	10.0	130	215	99.4	0.0
	a. Osteosarcoma	0	3	12	29	36	44	80	2.4	47.8	3.0	51.9	-	1.1	3.4	8.2	9.9	3.8	5.2	62	111	100.0	0.0
	b. Chondrosarcoma	0	0	0	3	4	3	7	0.2	3.3	0.3	4.5	-	-	-	0.8	1.1	0.2	0.4	4	10	100.0	0.0
	c. Ewing & related	0	4	17	22	19	43	62	2.4	46.7	2.3	40.3	-	1.4	4.8	6.2	5.2	3.8	4.1	61	87	100.0	0.0
	d. Other specified	0	0	0	1	3	1	4	0.1	1.1	0.2	2.6	-	-	-	0.3	0.8	0.1	0.2	1	6	100.0	0.0
	e. Unspecified	0	1	0	0	0	1	1	0.1	1.1	0.0	0.6	-	0.4	-	-	-	0.1	0.1	1	1	0.0	0.0
IX	SOFT TISSUE SARCOMA	9	37	29	47	52	122	174	6.8	100.0	6.5	100.0	13.1	13.0	8.2	13.2	14.3	11.5	12.1	172	244	100.0	0.0
	a. Rhabdomyosarcoma	6	27	15	18	12	66	78	3.7	54.1	2.9	44.8	8.7	9.5	4.2	5.1	3.3	6.5	5.7	93	110	100.0	0.0
	b. Fibrosarcoma	1	2	4	6	5	13	18	0.7	10.7	0.7	10.3	1.5	0.7	1.1	1.7	1.4	1.2	1.2	18	25	100.0	0.0
	c. Kaposi sarcoma	0	1	0	1	0	2	2	0.1	1.6	0.1	1.1	-	0.4	-	0.3	-	0.2	0.1	3	3	100.0	0.0
	d. Other specified	0	3	9	20	29	32	61	1.8	26.2	2.3	35.1	-	1.1	2.5	5.6	8.0	2.8	3.9	45	85	100.0	0.0
	e. Unspecified	2	4	1	2	6	9	15	0.5	7.4	0.6	8.6	2.9	1.4	0.3	0.6	1.6	0.9	1.1	13	21	100.0	0.0
X	GERM CELL TUMOURS	14	10	3	26	102	53	155	2.9	100.0	5.8	100.0	20.3	3.5	0.8	7.3	28.0	5.0	10.2	75	215	100.0	0.0
	a. CNS germ cell	0	0	2	7	5	9	14	0.5	17.0	0.5	9.0	-	-	0.6	2.0	1.4	0.8	0.9	13	20	100.0	0.0
	b. Other extragonadal	9	3	0	1	3	13	16	0.7	24.5	0.6	10.3	13.1	1.1	-	0.3	0.8	1.4	1.3	18	22	100.0	0.0
	c. Gonadal germ cell	4	7	1	18	89	30	119	1.7	56.6	4.5	76.8	5.8	2.5	0.3	5.1	24.4	2.8	7.6	42	164	100.0	0.0
	d. Gonadal carcinoma	0	0	0	0	4	0	4	-	-	0.2	2.6	-	-	-	-	1.1	-	0.2	-	5	100.0	0.0
	e. Unspecified gonadal	1	0	0	0	1	1	2	0.1	1.9	0.1	1.3	1.5	-	-	-	0.3	0.1	0.1	1	3	100.0	0.0
XI	CARCINOMA & MELANOMA	1	3	18	61	210	83	293	4.6	100.0	11.0	100.0	1.5	1.1	5.1	17.2	57.6	7.1	18.4	117	405	100.0	0.0
	a. Adrenocortical	0	1	1	1	2	3	5	0.2	3.6	0.2	1.7	-	0.4	0.3	0.3	0.5	0.3	0.3	4	7	100.0	0.0
	b. Thyroid	0	0	2	10	41	12	53	0.7	14.5	2.0	18.1	-	-	0.6	2.8	11.3	1.0	3.3	17	73	100.0	0.0
	c. Nasopharyngeal	0	0	0	0	7	0	7	-	-	0.3	2.4	-	-	-	-	1.9	-	0.4	-	10	100.0	0.0
	d. Melanoma	1	2	7	25	98	35	133	1.9	42.2	5.0	45.4	1.5	0.7	2.0	7.0	26.9	3.0	8.4	49	184	100.0	0.0
	e. Skin carcinoma	0	0	2	8	16	10	26	0.6	12.0	1.0	8.9	-	-	0.6	2.3	4.4	0.8	1.6	14	36	100.0	0.0
	f. Other & unspecified	0	0	6	17	46	23	69	1.3	27.7	2.6	23.5	-	-	1.7	4.8	12.6	1.9	4.3	32	96	100.0	0.0
XII	OTHER & UNSPECIFIED	1	1	1	2	2	5	7	0.3	100.0	0.3	100.0	1.5	0.4	0.3	0.6	0.5	0.5	0.5	7	10	71.4	14.3
	a. Other specified	0	1	0	1	2	2	4	0.1	40.0	0.2	57.1	-	0.4	-	0.3	0.5	0.2	0.3	3	6	100.0	0.0
	b. Other unspecified	1	0	1	1	0	3	3	0.2	60.0	0.1	42.9	1.5	-	0.3	0.3	-	0.3	0.2	4	4	33.3	33.3
	TOTAL	175	606	471	546	867	1798	2665	100.0	100.0	100.0	100.0	254.1	212.9	133.3	153.6	237.9	173.1	187.7	2539	3729	96.8	0.3

† includes 232 non-malignant

Please consult the quality indicators for this pool and its constituent registries

Ukraine

National Cancer Registry of Ukraine, 2002–2012

Anton Ryzhov, Olena Soumkina, Liudmyla Goulak, Yevgeniy Gorokh, Lyubov Koutsenko, Zoya Fedorenko

Ukraine is a large country in eastern Europe; it was one of the republics of the former Soviet Union. It covers an area of 603 000 km^2. In 2010, the estimated population was 45.6 million (Table A.7), and 20% of the population was younger than 20 years (Table A.6). The capital and largest city is Kyiv. The extensive fertile farmlands make the country one of the largest grain exporters in the world. Ukraine is classified as a lower-middle-income country, which has to deal with poverty and corruption. The population is 78% Ukrainians, with Russians and other nationalities comprising the reminder. Ukraine is a unitary republic with a semi-presidential system and separation of powers into legislative, executive, and judicial branches. Medical services are provided free of charge, but a transition to an insurance-based health-care system is under way.

Cancer registration was mandatory throughout the former Soviet Union in the beginning of the 1950s. In 1996, 5 years after Ukraine gained its independence, the National Cancer Registry of Ukraine was established. It took 6 years, until 2002, to cover the whole country with a network of regional cancer registries.

The registry collects data on incident cases via notification forms provided by all medical institutions that are likely to identify or treat a new patient with cancer. Registered patients are followed up by regional cancer registry personnel, who link the registry data with the departments of vital statistics, and by regional oncologists, who have direct contact with patients or their relatives. The delay in registering the follow-up status of patients may be more than 1.5 years, especially in the young population, who are highly mobile.

The registry collects data on all malignant cases in all age groups within the country. An estimated 93.4% of new cancer cases and 90.7% of deaths from cancer are registered within the first year of diagnosis. The completeness of ascertainment of new cases is estimated to be 87.0% in the age group 0–17 years, and the completeness of mortality data is estimated to be 77.9% in the age group 0–19 years. The database records more than 100 data items on each patient, grouped into four categories: personal information, diagnosis, treatment, and follow-up.

Local systems for coding topography and morphology of neoplasms were developed and are used by regional registrars. Automated conversion from local codes to ICD-O-3 and ICD-10 enables the registry to participate in international projects. Procedures for data quality and completeness are developed in accordance with international recommendations and guidelines.

Registry data are included in international databases and publications, including CI5 Volumes X and XI, estimates of cancer incidence, mortality, and prevalence (EUCAN), and database and software presenting data from European Cancer Registries (EUREG).

PUBLICATIONS

Karalexi MA, Papathoma P, Thomopoulos TP, Ryzhov A, Zborovskaya A, Dimitrova N, et al. (2015). Childhood central nervous system tumour mortality and survival in Southern and Eastern Europe (1983–2014): gaps persist across 14 cancer registries. Eur J Cancer. 51(17):2665–77. https://doi.org/10.1016/j.ejca.2015.08.018 PMID:26343313

Ryzhov A, Bray F, Ferlay J, Fedorenko Z, Goulak L, Gorokh Y, et al. (2018). Evaluation of data quality at the National Cancer Registry of Ukraine. Cancer Epidemiol. 53:156–65. https://doi.org/10.1016/j.canep.2018.02.002 PMID:29459256

POPULATION AT RISK

The source of the data is the State Statistics Service of Ukraine (http://database.ukrcensus.gov.ua/MULT/Database/Population/databasetree_en.asp). The annual data are based on the national census conducted in 2001 (Table A.7). Data were provided in the requested detail, by sex and single year of age for each calendar year of the reporting period.

EDITORS' COMMENTS

The proportion of cases with unspecified morphology is rather high (11%) (Table A.9), because of poor or no reporting of morphology in pathology reports from specialized paediatric hospitals that diagnose and treat childhood cancers. Thus, the resulting rates may be lower for specific and higher for unspecified cancer types. The registry does not collect exact dates of diagnosis (Table A.8), and age is calculated using only the month and year of the date of incidence. As a result, age-specific rates may be slightly affected. Non-malignant CNS tumours (including pilocytic astrocytoma) were not registered during the reporting period. Therefore, the reported incidence rates are lower for the diagnostic categories III and Xa and the total. Information on laterality was not collected during the reporting period.

UKRAINE (2002-2012)

	Age group (years)	Males	Females
Person-years	0	2 537 938	2 392 345
	1-4	9 603 336	9 074 690
	5-9	11 989 170	11 373 677
	10-14	14 677 880	13 965 888
	15-19	18 729 741	17 870 468
	0-14	38 808 324	36 806 600
	0-19	57 538 065	54 677 068
Average annual population	0-14	3 528 029	3 346 055
	0-19	5 230 733	4 970 643

Please consult the quality indicators for this registry

UKRAINE (2002-2012)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)							0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19	0-14	0-19	All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	209	1445	979	721	974	**3354**	**4328**	33.3	100.0	26.5	100.0	42.4	77.4	41.9	25.2	26.6	**47.9**	**43.1**	686	819	99.7	0.1
	a. Lymphoid	85	1158	771	461	499	**2475**	**2974**	24.6	73.8	18.2	68.7	17.2	62.0	33.0	16.1	13.6	**35.7**	**30.7**	509	577	99.9	0.0
	b. Acute myeloid	54	150	112	153	236	**469**	**705**	4.7	14.0	4.3	16.3	11.0	8.0	4.8	5.3	6.4	**6.4**	**6.4**	94	126	100.0	0.0
	c. CMD	24	32	29	39	98	**124**	**222**	1.2	3.7	1.4	5.1	4.9	1.7	1.2	1.4	2.7	**1.7**	**1.9**	25	38	100.0	0.0
	d. MDS & other	4	9	10	10	17	**33**	**50**	0.3	1.0	0.3	1.2	0.8	0.5	0.4	0.3	0.5	**0.5**	**0.5**	7	9	100.0	0.0
	e. Unspecified	42	96	57	58	124	**253**	**377**	2.5	7.5	2.3	8.7	8.5	5.1	2.4	2.0	3.4	**3.6**	**3.6**	52	68	97.9	0.8
II	LYMPHOMA & RELATED	43	278	312	597	1638	**1230**	**2868**	12.2	100.0	17.5	100.0	8.7	14.9	13.4	20.8	44.8	**15.6**	**22.2**	239	463	99.5	0.0
	a. Hodgkin	1	95	125	350	1269	**571**	**1840**	5.7	46.4	11.2	64.2	0.2	5.1	5.4	12.2	34.7	**6.8**	**13.1**	108	282	99.7	0.0
	b. Non-Hodgkin except BL	8	70	91	145	297	**314**	**611**	3.1	25.5	3.7	21.3	1.6	3.7	3.9	5.1	8.1	**4.0**	**4.9**	61	102	99.3	0.2
	c. Burkitt (BL)	1	44	68	69	31	**182**	**213**	1.8	14.8	1.3	7.4	0.2	2.4	2.9	2.4	0.8	**2.4**	**2.0**	36	40	100.0	0.0
	d. Lymphoreticular	32	60	13	13	13	**118**	**131**	1.2	9.6	0.8	4.6	6.5	3.2	0.6	0.5	0.4	**1.8**	**1.5**	25	26	98.5	0.0
	e. Unspecified	1	9	15	20	28	**45**	**73**	0.4	3.7	0.4	2.5	0.2	0.5	0.6	0.7	0.8	**0.6**	**0.6**	9	13	98.6	0.0
III	CNS NEOPLASMS	113	478	586	572	631	**1749**	**2380**	17.4	100.0	14.5	100.0	22.9	25.6	25.1	20.0	17.2	**23.6**	**22.2**	350	437	76.9	0.7
	a. Ependymoma	14	55	54	35	36	**158**	**194**	1.6	9.0	1.2	8.2	2.8	2.9	2.3	1.2	1.0	**2.2**	**2.0**	32	37	100.0	0.0
	b. Astrocytoma	32	142	179	243	281	**596**	**877**	5.9	34.1	5.4	36.8	6.5	7.6	7.7	8.5	7.7	**7.8**	**7.8**	118	156	99.2	0.0
	c. CNS embryonal	15	123	156	102	64	**396**	**460**	3.9	22.6	2.8	19.3	3.0	6.6	6.7	3.6	1.7	**5.5**	**4.6**	80	89	99.8	0.2
	d. Other gliomas	6	18	34	36	43	**94**	**137**	0.9	5.4	0.8	5.8	1.2	1.0	1.5	1.3	1.2	**1.2**	**1.2**	19	25	80.3	0.0
	e. Other specified	1	3	7	16	34	**27**	**61**	0.3	1.5	0.4	2.6	0.2	0.2	0.3	0.6	0.9	**0.3**	**0.5**	5	10	98.4	0.0
	f. Unspecified CNS	45	137	156	140	173	**478**	**651**	4.7	27.3	4.0	27.4	9.1	7.3	6.7	4.9	4.7	**6.6**	**6.1**	96	120	21.2	2.3
IV	NEUROBLASTOMA	169	280	101	49	59	**599**	**658**	5.9	100.0	4.0	100.0	34.3	15.0	4.3	1.7	1.6	**9.3**	**7.5**	125	133	96.7	0.0
	a. (Ganglio)neuroblastoma	163	269	87	33	28	**552**	**580**	5.5	92.2	3.5	88.1	33.1	14.4	3.7	1.2	0.8	**8.6**	**6.9**	116	120	96.2	0.0
	b. Peripheral nervous	6	11	14	16	31	**47**	**78**	0.5	7.8	0.5	11.9	1.2	0.6	0.6	0.6	0.8	**0.6**	**0.7**	9	14	100.0	0.0
V	RETINOBLASTOMA	84	135	16	4	3	**239**	**242**	2.4	100.0	1.5	100.0	17.0	7.2	0.7	0.1	0.1	**3.9**	**3.0**	51	51	89.7	0.0
VI	RENAL TUMOURS	125	408	125	37	59	**695**	**754**	6.9	100.0	4.6	100.0	25.4	21.8	5.4	1.3	1.6	**10.8**	**8.8**	146	154	92.8	0.3
	a. Nephroblastoma	113	381	114	20	10	**628**	**638**	6.2	90.4	3.9	84.6	22.9	20.4	4.9	0.7	0.3	**9.9**	**7.7**	133	134	95.3	0.2
	b. Renal carcinoma	6	16	5	16	41	**43**	**84**	0.4	6.2	0.5	11.1	1.2	0.9	0.2	0.6	1.1	**0.6**	**0.7**	9	14	100.0	0.0
	c. Unspecified	6	11	6	1	8	**24**	**32**	0.2	3.5	0.2	4.2	1.2	0.6	0.3	0.0	0.2	**0.4**	**0.3**	5	6	25.0	3.1
VII	HEPATIC TUMOURS	54	73	14	18	39	**159**	**198**	1.6	100.0	1.2	100.0	11.0	3.9	0.6	0.6	1.1	**2.5**	**2.1**	33	38	90.9	0.0
	a. Hepatoblastoma	40	55	4	7	1	**106**	**107**	1.1	66.7	0.7	54.0	8.1	2.9	0.2	0.2	0.0	**1.7**	**1.3**	22	22	100.0	0.0
	b. Hepatic carcinoma	8	14	9	10	30	**41**	**71**	0.4	25.8	0.4	35.9	1.6	0.7	0.4	0.3	0.8	**0.6**	**0.6**	8	12	98.6	0.0
	c. Unspecified	6	4	1	1	8	**12**	**20**	0.1	7.5	0.1	10.1	1.2	0.2	0.0	0.0	0.2	**0.2**	**0.2**	3	4	15.0	0.0
VIII	BONE TUMOURS	2	28	111	331	467	**472**	**939**	4.7	100.0	5.7	100.0	0.4	1.5	4.8	11.6	12.8	**5.4**	**7.0**	88	152	97.3	0.1
	a. Osteosarcoma	0	5	42	148	208	**195**	**403**	1.9	41.3	2.5	42.9	-	0.3	1.8	5.2	5.7	**2.2**	**3.0**	36	64	99.8	0.0
	b. Chondrosarcoma	1	1	6	21	52	**29**	**81**	0.3	6.1	0.5	8.6	0.2	0.1	0.3	0.7	1.4	**0.3**	**0.6**	5	12	100.0	0.0
	c. Ewing & related	1	10	42	81	94	**134**	**228**	1.3	28.4	1.4	24.3	0.2	0.5	1.8	2.8	2.6	**1.6**	**1.8**	25	38	100.0	0.0
	d. Other specified	0	3	11	47	68	**61**	**129**	0.6	12.9	0.8	13.7	-	0.2	0.5	1.6	1.9	**0.7**	**0.9**	11	20	99.2	0.0
	e. Unspecified	0	9	10	34	45	**53**	**98**	0.5	11.2	0.6	10.4	-	0.5	0.4	1.2	1.2	**0.6**	**0.8**	10	16	76.5	1.0
IX	SOFT TISSUE SARCOMA	84	194	142	221	446	**641**	**1087**	6.4	100.0	6.6	100.0	17.0	10.4	6.1	7.7	12.2	**8.8**	**9.5**	128	189	99.6	0.0
	a. Rhabdomyosarcoma	23	102	55	47	54	**227**	**281**	2.3	35.4	1.7	25.9	4.7	5.5	2.4	1.6	1.5	**3.3**	**2.9**	46	54	100.0	0.0
	b. Fibrosarcoma	19	24	19	44	106	**106**	**212**	1.1	16.5	1.3	19.5	3.9	1.3	0.8	1.5	2.9	**1.4**	**1.7**	21	35	100.0	0.0
	c. Kaposi sarcoma	0	0	0	0	1	**0**	**1**	-	-	0.0	0.1	-	-	-	-	0.0	**-**	**0.0**	-	0	100.0	0.0
	d. Other specified	37	57	50	108	218	**252**	**470**	2.5	39.3	2.9	43.2	7.5	3.1	2.1	3.8	6.0	**3.3**	**3.9**	49	79	99.8	0.0
	e. Unspecified	5	11	18	22	67	**56**	**123**	0.6	8.7	0.8	11.3	1.0	0.6	0.8	0.8	1.8	**0.7**	**1.0**	11	20	97.6	0.0
X	GERM CELL TUMOURS	66	85	59	144	514	**354**	**868**	3.5	100.0	5.3	100.0	13.4	4.6	2.5	5.0	14.0	**4.8**	**6.8**	70	140	98.2	0.0
	a. CNS germ cell	4	5	10	20	18	**39**	**57**	0.4	11.0	0.3	6.6	0.8	0.3	0.4	0.7	0.5	**0.5**	**0.5**	8	10	98.2	0.0
	b. Other extragonadal	34	51	4	12	49	**101**	**150**	1.0	28.5	0.9	17.3	6.9	2.7	0.2	0.4	1.3	**1.6**	**1.5**	21	28	99.3	0.0
	c. Gonadal germ cell	26	23	36	77	273	**162**	**435**	1.6	45.8	2.7	50.1	5.3	1.2	1.5	2.7	7.5	**2.1**	**3.3**	32	69	100.0	0.0
	d. Gonadal carcinoma	1	2	5	20	117	**28**	**145**	0.3	7.9	0.9	16.7	0.2	0.1	0.2	0.7	3.2	**0.3**	**1.0**	5	21	100.0	0.0
	e. Unspecified gonadal	1	4	4	15	57	**24**	**81**	0.2	6.8	0.5	9.3	0.2	0.2	0.2	0.5	1.6	**0.3**	**0.6**	5	12	82.7	0.0
XI	CARCINOMA & MELANOMA	7	42	71	323	1294	**443**	**1737**	4.4	100.0	10.6	100.0	1.4	2.2	3.0	11.3	35.4	**5.1**	**11.9**	82	259	99.6	0.0
	a. Adrenocortical	1	6	3	5	10	**15**	**25**	0.1	3.4	0.2	1.4	0.2	0.3	0.1	0.2	0.3	**0.2**	**0.2**	3	4	100.0	0.0
	b. Thyroid	0	0	16	146	491	**162**	**653**	1.6	36.6	4.0	37.6	-	-	0.7	5.1	13.4	**1.7**	**4.3**	29	96	100.0	0.0
	c. Nasopharyngeal	0	0	3	25	38	**28**	**66**	0.3	6.3	0.4	3.8	-	-	0.1	0.9	1.0	**0.3**	**0.5**	5	10	100.0	0.0
	d. Melanoma	2	5	16	48	202	**71**	**273**	0.7	16.0	1.7	15.7	0.4	0.3	0.7	1.7	5.5	**0.8**	**1.9**	13	41	97.8	0.0
	e. Skin carcinoma	0	1	3	18	129	**22**	**151**	0.2	5.0	0.9	8.7	-	0.1	0.1	0.6	3.5	**0.2**	**1.0**	4	22	100.0	0.0
	f. Other & unspecified	4	30	30	81	424	**145**	**569**	1.4	32.7	3.5	32.8	0.8	1.6	1.3	2.8	11.6	**1.8**	**4.0**	28	86	99.8	0.0
XII	OTHER & UNSPECIFIED	27	51	35	31	155	**144**	**299**	1.4	100.0	1.8	100.0	5.5	2.7	1.5	1.1	4.2	**2.1**	**2.6**	29	51	46.8	3.3
	a. Other specified	1	4	2	2	25	**9**	**34**	0.1	6.3	0.2	11.4	0.2	0.2	0.1	0.1	0.7	**0.1**	**0.3**	2	5	97.1	0.0
	b. Other unspecified	26	47	33	29	130	**135**	**265**	1.3	93.8	1.6	88.6	5.3	2.5	1.4	1.0	3.6	**1.9**	**2.3**	28	45	40.4	3.8
	TOTAL	983	3497	2551	3048	6279	**10079**	**16358**	100.0	100.0	100.0	100.0	199.4	187.2	109.2	106.4	171.6	**139.6**	**146.8**	2027	2885	94.5	0.2

Please consult the quality indicators for this registry

United Kingdom

The United Kingdom of Great Britain and Northern Ireland includes the island of Great Britain, the north-eastern part of the island of Ireland, and many smaller islands located off the north-western coast of the European mainland. Except for the land border with the Republic of Ireland, the United Kingdom is surrounded by seas: the Atlantic Ocean and the Irish Sea to the west, the North Sea to the east, the English Channel to the south, and the Celtic Sea to the south-west. The natural resources include petroleum, natural gas, tin, limestone, iron ore, salt, clay, chalk, gypsum, lead, silica, and an abundance of arable land. Intensive agriculture practices result in the production of 60% of the population's food needs by less than 1.6% of the labour force. The service sector comprises about 79% of the GDP. Important industries include manufacturing, automotive, aerospace, pharmaceutical, tourism, and creative industries. The capital and the largest city is London, a global financial centre with a population of 10.3 million. The United Kingdom has a partially regulated market economy, one of the largest in the world. The unemployment rate is low, and residents are generally satisfied with their living conditions. The United Kingdom is a developed high-income country and has a very high HDI. Since the 1980s, economic inequality has increased, and in 2011 an estimated 5% of the population experienced severe material deprivation.

In 2010, the population of the United Kingdom was 62.7 million (Table A.7), and 24% of the population was younger than 20 years (Table A.6). During the reporting period, almost 80% of the population lived in urban areas. In 2012, the average total fertility rate was 1.92 children per woman, which is below the replacement rate of 2.1, and 47.3% of births were to unmarried women.

Public health care is provided to all permanent residents of the United Kingdom and is mostly free of charge at the point of use; health care is funded through general taxation. by Each of the four constituent countries (England, Northern Ireland, Scotland, and Wales) independently administers its own health care system, education system, and environmental initiatives. Each National Health Service has distinct policies and priorities.

Cancer registration in the United Kingdom dates back to 1945, when population-based data were first collected in the south-western region. The United Kingdom also hosted the first-ever National Registry of Childhood Tumours (NRCT). Cancer registration has since evolved into national coverage of all ages nationwide; the four independent registries, for England, Northern Ireland, Scotland, and Wales, formed the United Kingdom and Ireland Association of Cancer Registries. Registration is not mandatory and patients have the right to refuse to have their data registered, although this right is seldom exercised.

POPULATION AT RISK

In the United Kingdom, the censuses pertinent to IICC-3 were conducted in 1991, 2001, and 2011 (Table A.7). The censuses were organized separately in England and Wales, Northern Ireland, and Scotland, during coinciding dates. The collected data are published and used by the Office for National Statistics (https://www.ons.gov.uk). The annual mid-year estimates incorporate information on births, deaths, and migration. The details on the submitted data and the sources are specified separately for each registry below.

EDITORS' COMMENTS

The United Kingdom data are presented in six full tables in the IICC-3 book (Table A.12). The first table presents the pooled data for the four United Kingdom general cancer registries over the common period of registration. The second table shows data for England and Wales for the age group 0–14 years provided by NRCT. The four other tables present the data from the general cancer registries of England, Northern Ireland, Scotland, and Wales, respectively. Two of the included registries – NRCT and the Scottish Cancer Registry – participated in both previous IICC volumes (Table A.1). Each of the four United Kingdom registries has a different history and distinct registration practices.

England and Wales, National Registry of Childhood Tumours, paediatric, 1991–2010

Charles A. Stiller, Anita Bayne, Nicole Diggens, Janette King, Tim Vincent, Michael Murphy

The National Registry of Childhood Tumours (NRCT) was established on the recommendation of the Department of Health Standing Medical Advisory Committee in 1974 and was maintained by the Childhood Cancer Research Group of the Department of Paediatrics at the University of Oxford. The registry was population-based for Great Britain (England, Scotland, and Wales) from 1962 onwards and for Northern Ireland (and therefore for the whole of the United Kingdom) from 1993 onwards. From 2013, the national cancer registries of the four countries of the United Kingdom took sole responsibility for childhood cancer registration.

In IICC-3, data submitted by NRCT are for England and Wales, which cover a combined area of 15 207 km^2. England is predominantly lowland, with upland regions in the north and south-west. Wales is hilly and mountainous, with extensive tracts of high plateau. The annual mean temperature is about 10 °C, and the average annual rainfall is about 90 cm.

In 2010, the population of England and Wales was 55.7 million, and 18% of the population was younger than 15 years (Table A.6). Ethnic minority groups made up 14% of the population; of these, 54% were Asian and 24% were Black. Conurbations centred on the English cities of London, Birmingham, Leeds, Liverpool, Manchester, Newcastle-upon-Tyne, and Sheffield are home to 35% of the population; 5.5% of the population lives in Wales. Service industries account for 83% of employment, manufacturing for 8%, construction for 6%, and agriculture for 1%.

Medical treatment is available free of charge at the point of use under the National Health Service (NHS). More than 90% of children with cancer in England and Wales are treated within a network of 14 paediatric oncology principal treatment centres. There are two national treatment centres for treatment of retinoblastoma.

Children who received care at principal treatment centres were notified directly to the registry. Cases were also ascertained by regular data exchange with regional and national general (all ages) cancer registries throughout the United Kingdom and with specialized childhood cancer registries in several regions of England. The registry received copies of all death certificates for deaths occurring before age 20 years with a neoplasm as the underlying cause of death in Great Britain. Diagnoses were coded according to ICD-O-3, supplemented by codes for new entities as recommended in the WHO Classification of Tumours. Completeness of ascertainment is estimated to be at least 99% overall and for nearly all diagnostic groups; however, registration of skin carcinomas is likely to be less complete because of varying registration practices in general cancer registries. Passive follow-up of children who were not already known to have died was performed through the NHS Central Registers. Less than 1% of children diagnosed since 1991 were lost to follow-up.

Registry data have been presented in a book that offers a comprehensive account of the descriptive epidemiology of childhood cancer in Britain. The data have been used for a wide range of epidemiological studies within the United Kingdom. The registry has contributed to numerous international collaborations. The cohort for the British Childhood Cancer Survivor Study is derived from the registry.

PUBLICATIONS

Stiller C, editor (2007). Childhood cancer in Britain: incidence, survival, mortality. Oxford, UK: Oxford University Press. https://doi.org/10.1093/acprof:oso/9780198520702.001.0001

Kroll ME, Murphy MF, Carpenter LM, Stiller CA (2011). Childhood cancer registration in Britain: capture-recapture estimates of completeness of ascertainment. Br J Cancer. 104(7):1227–33. https://doi.org/10.1038/bjc.2011.70 PMID:21407221

POPULATION AT RISK

The source of the data is the Office for National Statistics (https://www.ons.gov.uk). Data were provided in the requested detail. See also United Kingdom, above.

EDITORS' COMMENTS

In this paediatric cancer registry, registration focused on the age range 0–14 years during the reporting period. Therefore, data for the age groups 15–19 years and 0–19 years are not shown in the tables. The proportion of cases with unknown basis of diagnosis was 2.3% (Table A.9). Non-malignant CNS tumours were included. Pilocytic astrocytoma was coded with uncertain behaviour throughout the reporting period. Laterality information was complete for retinoblastoma, nephroblastoma, and testicular tumours. Laterality was 93% complete for ovarian tumours. See also United Kingdom, above.

UNITED KINGDOM, England and Wales, paediatric (1991-2010)

	Age group (years)	Males	Females
Person-years	0	6 668 942	6 350 082
	1-4	26 567 519	25 335 362
	5-9	33 436 698	31 896 132
	10-14	33 829 738	32 265 945
	0-14	100 502 897	95 847 521
Average annual population	0-14	5 025 145	4 792 376

Please consult the quality indicators for this registry

UNITED KINGDOM, England and Wales, paediatric (1991-2010)

		Number of cases Age group (years)					Percentage 0-14		Incidence rates per million person-years Age-specific						MV %	DCO %
		0	1-4	5-9	10-14	0-14	All	Group	0	1-4	5-9	10-14	ASR 0-14	Cumulative 0-14	0-14	0-14
I	**LEUKAEMIA**	514	4142	2331	1731	**8718**	31.4	100.0	39.5	79.8	35.7	26.2	**46.9**	668	98.3	0.4
	a. Lymphoid	240	3509	1889	1173	**6811**	24.5	78.1	18.4	67.6	28.9	17.7	**36.8**	522	99.3	0.1
	b. Acute myeloid	184	447	319	397	**1347**	4.8	15.5	14.1	8.6	4.9	6.0	**7.1**	103	97.9	0.9
	c. CMD	9	25	36	97	**167**	0.6	1.9	0.7	0.5	0.6	1.5	**0.8**	13	85.6	0.6
	d. MDS & other	66	136	69	46	**317**	1.1	3.6	5.1	2.6	1.1	0.7	**1.7**	24	92.1	0.6
	e. Unspecified	15	25	18	18	**76**	0.3	0.9	1.2	0.5	0.3	0.3	**0.4**	6	73.7	13.2
II	**LYMPHOMA & RELATED**	18	427	873	1464	**2782**	10.0	100.0	1.4	8.2	13.4	22.1	**13.4**	212	96.5	0.3
	a. Hodgkin	0	79	286	827	**1192**	4.3	42.8	-	1.5	4.4	12.5	**5.5**	91	97.7	0.0
	b. Non-Hodgkin except BL	11	207	385	467	**1070**	3.8	38.5	0.8	4.0	5.9	7.1	**5.3**	82	95.9	0.3
	c. Burkitt (BL)	0	118	181	154	**453**	1.6	16.3	-	2.3	2.8	2.3	**2.3**	35	99.3	0.0
	d. Lymphoreticular	7	17	7	2	**33**	0.1	1.2	0.5	0.3	0.1	0.0	**0.2**	3	78.8	3.0
	e. Unspecified	0	6	14	14	**34**	0.1	1.2	-	0.1	0.2	0.2	**0.2**	3	58.8	11.8
III	**CNS NEOPLASMS** †	485	2077	2383	2104	**7049**	25.4	100.0	37.3	40.0	36.5	31.8	**36.3**	539	78.9	0.7
	a. Ependymoma	102	295	163	136	**696**	2.5	9.9	7.8	5.7	2.5	2.1	**3.8**	53	97.0	0.1
	b. Astrocytoma	142	898	1055	917	**3012**	10.8	42.7	10.9	17.3	16.1	13.9	**15.4**	230	83.0	0.2
	c. CNS embryonal	120	452	462	280	**1314**	4.7	18.6	9.2	8.7	7.1	4.2	**6.9**	101	97.0	0.4
	d. Other gliomas	22	185	305	214	**726**	2.6	10.3	1.7	3.6	4.7	3.2	**3.7**	55	31.4	1.1
	e. Other specified	54	166	302	440	**962**	3.5	13.6	4.1	3.2	4.6	6.7	**4.7**	73	86.2	0.1
	f. Unspecified CNS	45	81	96	117	**339**	1.2	4.8	3.5	1.6	1.5	1.8	**1.7**	26	16.8	8.8
IV	**NEUROBLASTOMA**	525	889	188	49	**1651**	5.9	100.0	40.3	17.1	2.9	0.7	**9.6**	127	96.4	0.0
	a. (Ganglio)neuroblastoma	524	883	183	41	**1631**	5.9	98.8	40.2	17.0	2.8	0.6	**9.5**	125	96.4	0.0
	b. Peripheral nervous	1	6	5	8	**20**	0.1	1.2	0.1	0.1	0.1	0.1	**0.1**	2	95.0	0.0
V	**RETINOBLASTOMA**	333	422	31	7	**793**	2.9	100.0	25.6	8.1	0.5	0.1	**4.7**	61	71.5	0.0
VI	**RENAL TUMOURS**	197	958	277	82	**1514**	5.4	100.0	15.1	18.5	4.2	1.2	**8.6**	116	97.8	0.3
	a. Nephroblastoma	196	956	270	51	**1473**	5.3	97.3	15.1	18.4	4.1	0.8	**8.4**	113	98.0	0.3
	b. Renal carcinoma	1	2	4	30	**37**	0.1	2.4	0.1	0.0	0.1	0.5	**0.2**	3	97.3	2.7
	c. Unspecified	0	0	3	1	**4**	0.0	0.3	-	-	0.0	0.0	**0.0**	0	0.0	0.0
VII	**HEPATIC TUMOURS**	102	143	29	45	**319**	1.1	100.0	7.8	2.8	0.4	0.7	**1.8**	24	94.4	0.3
	a. Hepatoblastoma	97	135	17	15	**264**	0.9	82.8	7.5	2.6	0.3	0.2	**1.5**	20	95.8	0.0
	b. Hepatic carcinoma	1	7	12	30	**50**	0.2	15.7	0.1	0.1	0.2	0.5	**0.2**	4	94.0	0.0
	c. Unspecified	4	1	0	0	**5**	0.0	1.6	0.3	0.0	-	-	**0.0**	0	20.0	20.0
VIII	**BONE TUMOURS**	8	47	306	768	**1129**	4.1	100.0	0.6	0.9	4.7	11.6	**5.2**	86	97.3	0.2
	a. Osteosarcoma	0	14	165	450	**629**	2.3	55.7	-	0.3	2.5	6.8	**2.9**	48	98.4	0.3
	b. Chondrosarcoma	1	0	3	22	**26**	0.1	2.3	0.1	-	0.0	0.3	**0.1**	2	88.5	0.0
	c. Ewing & related	1	31	125	264	**421**	1.5	37.3	0.1	0.6	1.9	4.0	**2.0**	32	99.0	0.0
	d. Other specified	3	1	6	20	**30**	0.1	2.7	0.2	0.0	0.1	0.3	**0.1**	2	96.7	0.0
	e. Unspecified	3	1	7	12	**23**	0.1	2.0	0.2	0.0	0.1	0.2	**0.1**	2	47.8	0.0
IX	**SOFT TISSUE SARCOMA**	161	564	504	601	**1830**	6.6	100.0	12.4	10.9	7.7	9.1	**9.5**	140	97.0	0.2
	a. Rhabdomyosarcoma	69	417	282	154	**922**	3.3	50.4	5.3	8.0	4.3	2.3	**5.0**	71	98.8	0.0
	b. Fibrosarcoma	36	18	25	82	**161**	0.6	8.8	2.8	0.3	0.4	1.2	**0.8**	12	92.5	1.2
	c. Kaposi sarcoma	0	1	4	4	**9**	0.0	0.5	-	0.0	0.1	0.1	**0.0**	1	66.7	0.0
	d. Other specified	42	110	165	318	**635**	2.3	34.7	3.2	2.1	2.5	4.8	**3.1**	48	96.4	0.0
	e. Unspecified	14	18	28	43	**103**	0.4	5.6	1.1	0.3	0.4	0.7	**0.5**	8	94.2	1.0
X	**GERM CELL TUMOURS**	183	217	145	397	**942**	3.4	100.0	14.1	4.2	2.2	6.0	**4.8**	72	91.5	0.3
	a. CNS germ cell ‡	27	36	75	171	**309**	1.1	32.8	2.1	0.7	1.1	2.6	**1.5**	24	79.9	0.6
	b. Other extragonadal	116	94	11	18	**239**	0.9	25.4	8.9	1.8	0.2	0.3	**1.4**	18	96.7	0.4
	c. Gonadal germ cell	39	87	54	195	**375**	1.3	39.8	3.0	1.7	0.8	3.0	**1.9**	29	98.1	0.0
	d. Gonadal carcinoma	0	0	2	8	**10**	0.0	1.1	-	-	0.0	0.1	**0.0**	1	100.0	0.0
	e. Unspecified gonadal	1	0	3	5	**9**	0.0	1.0	0.1	-	0.0	0.1	**0.0**	1	66.7	0.0
XI	**CARCINOMA & MELANOMA**	13	82	203	649	**947**	3.4	100.0	1.0	1.6	3.1	9.8	**4.4**	72	87.4	0.2
	a. Adrenocortical	4	22	9	6	**41**	0.1	4.3	0.3	0.4	0.1	0.1	**0.2**	3	97.6	0.0
	b. Thyroid	1	15	39	128	**183**	0.7	19.3	0.1	0.3	0.6	1.9	**0.9**	14	97.8	0.0
	c. Nasopharyngeal	0	0	4	46	**50**	0.2	5.3	-	-	0.1	0.7	**0.2**	4	100.0	0.0
	d. Melanoma	7	29	54	143	**233**	0.8	24.6	0.5	0.6	0.8	2.2	**1.1**	18	88.8	0.4
	e. Skin carcinoma	1	10	54	137	**202**	0.7	21.3	0.1	0.2	0.8	2.1	**0.9**	15	78.7	0.0
	f. Other & unspecified	0	6	43	189	**238**	0.9	25.1	-	0.1	0.7	2.9	**1.1**	18	81.1	0.4
XII	**OTHER & UNSPECIFIED**	20	50	20	35	**125**	0.4	100.0	1.5	1.0	0.3	0.5	**0.7**	10	44.8	1.6
	a. Other specified	6	17	3	11	**37**	0.1	29.6	0.5	0.3	0.0	0.2	**0.2**	3	100.0	0.0
	b. Other unspecified	14	33	17	24	**88**	0.3	70.4	1.1	0.6	0.3	0.4	**0.5**	7	21.6	2.3
	TOTAL	2559	10018	7290	7932	**27799**	100.0	100.0	196.6	193.0	111.6	120.0	**145.8**	2127	91.3	0.4

† includes 2767 non-malignant ‡ includes 62 non-malignant

Please consult the quality indicators for this registry

UNITED KINGDOM (2000-2011)

Registry	Period	Cases	%	Person-years	%
England	2000-2011	21626	82.1	149 635 076	83.8
Northern Ireland	2000-2011	939	3.6	5 858 928	3.3
Scotland	2000-2011	2366	9.0	14 382 939	8.1
Wales	2000-2011	1415	5.4	8 711 888	4.9
UNITED KINGDOM	**2000-2011**	**26346**	**100.0**	**178 588 831**	**100.0**

Please consult the quality indicators for this pool and its constituent registries

England, National Cancer Registration and Analysis Service (NCRAS), 1990–2013

Jem Rashbass, Charles A. Stiller

In 2010, the population of England was 52.6 million, and 24% of the population was younger than 20 years (Table A.6). Most residents live in metropolitan or smaller urban areas, and the rest live in mixed urban–rural areas. At the 2001 census, 91% of residents described themselves as White, 4.6% as Asian, 2.3% as Black, and 2.1% as mixed, Chinese, or other ethnic groups.

Patients with cancer are treated within the NHS, which is free of charge at the point of use. A minority of patients receive care within the private sector. Cancer services were restructured in 1995; cancer specialists now work in multidisciplinary teams, with services concentrated in specialized centres. Targets have been set to achieve reasonable waiting time for treatment, and cancer audits were established. These initiatives were reinforced by the NHS Cancer Plan published in 2000.

Cancer is not a reportable disease in England. The collection of personally identifiable information is permitted by a special provision within the NHS Act 2006. Cancers were registered by eight population-based registries, which collectively covered all of England until 2013, and subsequently by the national cancer registry maintained by the National Cancer Registration and Analysis Service (NCRAS). The data included in IICC-3 were submitted by the National Cancer Data Repository, which provides annual aggregate information for England. Data are collected from sources including hospital records, pathology reports, and waiting-time datasets, but the registries' methods varied during the reporting period. The national registry (and formerly the regional registries) is notified by the national death registration system of all deaths in their covered area, if a death certificate mentions cancer.

NCRAS performs a variety of public health surveillance and health protection functions and provides information to health organizations and researchers. The registry is the only source of reliable population-based cancer incidence, prevalence, and survival data, which are essential for implementing and monitoring key national initiatives, such as the Cancer Reform Strategy (2007).

POPULATION AT RISK

The population data are based on mid-year population estimates provided by the Office for National Statistics in Titchfield, England. Estimates for 1991–2000 are based on 2001 Census Area Statistical ward estimates adjusted to Lower Layer Super Output Areas (LSOAs) boundaries. Estimates for 2001–2007 are provided at LSOA level by the Office for National Statistics Small Area Population Estimates under Microdata Release Panel Data Access Agreement No. 0826 2007. In October 2010, the Office for National Statistics provided revised LSOA population estimates for 2002–2007 that use more specific methods of adjustment for international migrants, students, and internal migrants. Population data were provided by sex and 5-year age groups for 1991–1994, and by sex and single year of age for all the following years of the reporting period. The data provided for 1991 were applied to 1990, and the data for the missing year–age–sex categories were estimated at IARC using the methods described in Chapter 2. See also United Kingdom, above.

EDITORS' COMMENTS

Day of birth and day of incidence are collected, but they were not provided because of data protection rules (Table A.8). Basis of diagnosis was unknown for 2.7% of cases (Table A.9). Non-malignant CNS tumours were systematically recorded, although their proportion is relatively low (Table A.9). Pilocytic astrocytoma was coded with uncertain behaviour. Only the first occurrence of a non-melanoma skin cancer in a patient is registered. Laterality was not provided. See also United Kingdom, above.

Northern Ireland Cancer Registry, 1993–2013

Anna T. Gavin, Deirdre A. Fitzpatrick

Northern Ireland covers the north-eastern part of the island of Ireland and has a temperate maritime climate. The traditionally industrial economy has been replaced by services, which employ 70% of the workforce, complemented by high-tech industry and tourism. The capital city is Belfast.

In 2010, the population was about 1.8 million, and 27% of the population was younger than 20 years (Table A.6). The population is ethnically homogeneous, although there has been a recent influx of immigrants, mainly from eastern Europe.

Most patients with cancer are treated within the NHS, and even patients treated privately receive some of their treatment in the NHS hospitals. The Royal Belfast Hospital for Sick Children is the only hospital in Northern Ireland dedicated specifically to the care of children and provides most of the paediatric regional specialities for children throughout Northern Ireland.

The Northern Ireland Cancer Registry covers the entire population of Northern Ireland. The registry is part of the Centre for Public Health in the School of Medicine, Dentistry and Biomedical Sciences at Queen's University Belfast. In May 1994, the registry was re-established under an agreement between the Public Health Agency and Queen's University Belfast, with a remit to collect all cancers diagnosed in the population of Northern Ireland from 1993 onwards. It replaced an older, incomplete, paper-based registry, which was established in 1959.

The Northern Ireland Cancer Registry collects information on all malignant neoplasms, all carcinoma in situ, all neoplasms of uncertain behaviour, a subset of benign neoplasms, and some pre-malignant conditions.

Cases are registered using an automated computer system with multiple sources of information, primarily the Patient Administration System, histopathology reports, and death notifications. From the Patient Administration System, the registry obtains patient demographic information, tumour site (ICD-10), and treatment information. More detailed tumour information is matched electronically against the records of histopathology and cytopathology laboratories, coded to Systematized Nomenclature of Medicine, third edition (SNOMED-3). Registry staff members have access to the Cancer Patient Pathways System, which is used to record patient treatment plans and care from hospital multidisciplinary team meetings. Staff members also have access to practitioner notes for patients who have died from cancer. For other patients whose only source of information is from the Patient Administration System, registry staff members examine patient hospital records. The registered patients are followed up for vital status using information extracted from death certificates as provided by the General Registrar Office. Residence status is confirmed regularly by the Business Services Organisation, unless a registered patient has migrated.

The registry is the provider of official cancer incidence, prevalence, and survival statistics for Northern Ireland. It aims to provide accurate, timely information on cancers occurring in the population of Northern Ireland, for research, planning, and education, to help reduce the burden of disease and improve patient experience and outcomes.

POPULATION AT RISK

The annual mid-year resident population was estimated using the cohort component method, and the data were provided by the Northern Ireland Statistics and Research Agency (https://www.nisra.gov.uk/). Data were provided in the requested detail. See also United Kingdom, above.

EDITORS' COMMENTS

The proportion of cases with unspecified morphology is high (Table A.9). Non-malignant CNS tumours were registered. Pilocytic astrocytoma was coded with malignant behaviour until 2007 and with uncertain behaviour thereafter. Laterality is complete for 79% of the cases of interest. See also United Kingdom, above.

Scottish Cancer Registry, 1991–2013

Lesley A. Bhatti, Joannes J. Kerssens, Paula L. McClements, Andrew J. Deas, David H. Brewster

Scotland covers the northern third of the island of Great Britain, which has a temperate and oceanic climate. A mixed economy is open to the rest of the United Kingdom and internationally. Historically, the Scottish economy has been dominated by shipbuilding, coal mining, and steel industries. Petroleum-related industries associated with the extraction of North Sea oil have also been important employers since the 1970s. Services and tourism increasingly contribute to the economy. Exports include whisky, electronics, and financial services. The capital city is Edinburgh, and the largest city is Glasgow.

In 2010, the population was 5.3 million, and 23% of the population was younger than 20 years (Table A.6). Most of the population lives in an industrialized belt across the centre of the country; the remainder reside in more sparsely populated areas to the north and south. At the 2011 census, only 4% of people assigned themselves to minority ethnic groups.

The NHS is funded mainly through taxation and is mostly free at the point of use. The private health-care sector in Scotland is relatively small, and it is largely irrelevant to paediatric oncology. Access to hospital care is controlled by primary care physicians. Scotland has a nationally Managed Service Network for Children and Young People with Cancer (https://www.youngcancer.scot.nhs.uk). Small numbers of children with very rare cancers (e.g. retinoblastoma) are referred to specialized centres in England, but most children with cancer in Scotland are managed by paediatric haematology and oncology centres in the cities of Glasgow, Edinburgh, and Aberdeen.

The Scottish Cancer Registry covers the whole of Scotland. The registry forms part of the Information

Services Division within the Public Health and Intelligence unit of NHS National Services Scotland. It is funded by the Scottish government. Cancer is not a notifiable disease in Scotland. Potential registrations are identified from multiple electronic sources, including hospital discharge records, oncology records, pathology records, and death records. Information from these and other sources is linked to create provisional registrations, which are made available to out-posted cancer registration staff. By referring to medical records, the out-posted staff members validate provisional registrations and abstract additional information that cannot currently be collected electronically. In addition, childhood cancers are notified actively by paediatric haematology and oncology centres to the cancer registry (formerly to NRCT based in Oxford, England, but since 2013, directly to the Scottish Cancer Registry).

Registration data are believed to be of comparatively high quality, in terms of both accuracy and completeness of ascertainment.

Follow-up for vital status is achieved by regular linkage to mortality records; it is also believed to be relatively complete. In addition, emigrations of patients registered with cancer from Scotland to other United Kingdom countries are notified to the cancer registry by the NHS Central Register, thereby enabling censoring of data for these individuals.

After the publication of a dedicated report on childhood cancer in Scotland, the registry has maintained separate webpages for childhood cancer information (https://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Childhood). The registry data are used to support a wide range of activities, including research.

PUBLICATIONS

Campbell J, Wallace WHB, Bhatti LA, Stockton DL, Rapson T, Brewster DH (2004). Childhood cancer in Scotland. Trends in incidence, mortality and survival 1975–1999. Edinburgh, UK: NHS Scotland. Informatics and Statistics Division.

POPULATION AT RISK

The annual mid-year population estimates provided by National Records of Scotland (https://www.nrscotland.gov.uk/) are based on a decennial census, supplemented by information on births, deaths, and estimated migration. Data were provided in the requested detail. See also United Kingdom, above.

EDITORS' COMMENTS

Day of birth and day of incidence were not provided by the registry, because of data protection requirements (Table A.8); thus, the accuracy of the calculated age could not be verified at IARC. CNS tumours with uncertain or unknown behaviour have been reported since 1975, and benign CNS tumours have been systematically registered since 2000. Pilocytic astrocytoma was coded with malignant behaviour until 2005 and with uncertain behaviour thereafter, but all cases were recoded with uncertain behaviour for submission to IICC-3. Laterality is known for two thirds of the cases of interest. Skin carcinomas are registered and are believed to be complete. See also United Kingdom, above.

Wales Cancer Registry, 2000–2011

Dyfed Wyn Huws, Ceri White, Janet Warlow

Wales covers an area of 20 779 km^2 in the western part of the island of Great Britain. The land is largely mountainous and has a changeable, maritime climate. The traditional extractive and heavy industries have been largely replaced by the public sector, light and service industries, and tourism. Two thirds of the population lives in southern Wales, concentrated around Cardiff, the capital. In 2010, the resident population was 3.0 million, and 24% of the population was younger than 20 years (Table A.6).

The Welsh government is responsible for the NHS in Wales. The seven health boards are responsible for delivering all NHS health-care services within a geographical area. In addition, NHS Trusts operate nationwide agencies and services, including ambulance, blood service, and health education. The health boards and trusts are funded by the Welsh government.

There are specialized cancer centres in Cardiff, in the north, and in the south-west. There is a network of cancer site-specific multidisciplinary teams across the country. Many young adults and children (depending on the type of cancer) are diagnosed and treated at specialized units in Wales, and a small proportion require specialized treatment that is available at centres in England.

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) covers the entire population of Wales. It was established in 1997 to provide information on cancer in Wales and hold the population-based cancer registry. It is part of the Health Intelligence Division of Public Health Wales, which is the NHS national public health agency. WCISU produces official statistics on cancer incidence and survival in Wales and has a statutory duty to publish cancer mortality information. WCISU is staffed by 25 employees trained in public health, who perform registration, coding, informatics, analysis, administration, and management.

The main sources of information for cancer registration are electronic submission of multidisciplinary team clinical data, hospital inpatient records, radiology and pathology reports, cancer screening data, death certificates, and registrations from other cancer registries (for resident cases diagnosed and/or treated outside Wales). A new informatics registration system, developed in partnership with Public Health England, forms part of a broader cancer data warehouse for linkage of radiotherapy, chemotherapy, general practitioner data, prescribing data, laboratory data, genetic and molecular data, and other relevant information.

The registry also provides a data request and analysis service to organizations and individuals who require cancer information and provides information to support genetic counselling services. WCISU has also participated in more health service-level analyses with the health-care service, and it produces several annual reports on various topics.

There is an increasing emphasis on collaboration with universities, cancer charities, clinicians, and epidemiologists within Wales, the United Kingdom, and internationally.

POPULATION AT RISK

The source of the data is the Office for National Statistics of the Welsh government (https://www.gov.wales/census-population). Data were provided in the requested detail. See also United Kingdom, above.

EDITORS' COMMENTS

The MV% is low (83%), and for an additional 11% of cases the basis of diagnosis is unknown (Table A.9). The unknown basis of diagnosis is inconsistent with the precise morphology codes in 11% of cases (Table A.11). The sex ratio is rather high in adolescents (Table A.9); the excess of males is seen especially for bone and soft tissue sarcomas and germ cell tumours. Non-malignant CNS tumours were registered. Pilocytic astrocytoma was originally coded with malignant behaviour, but all cases were recoded with uncertain behaviour for submission to IICC-3. Skin carcinomas are registered, but ascertainment may be incomplete. Laterality was available for only about half of the cases of interest. See also United Kingdom, above.

UNITED KINGDOM (2000-2011)

	Age group (years)	Males	Females
Person-years	0	4 487 770	4 275 142
	1-4	17 590 228	16 765 052
	5-9	22 107 939	21 062 950
	10-14	23 412 365	22 308 888
	15-19	23 754 735	22 823 762
	0-14	67 598 302	64 412 032
	0-19	91 353 037	87 235 794

Please consult the quality indicators for this pool and its constituent registries

UNITED KINGDOM (2000-2011)

		Number of cases							Percentage				Incidence rates per million person-years									MV	DCO
		Age group (years)					0-14	0-19	0-14		0-19		Age-specific					ASR		Cumulative		%	%
		0	1-4	5-9	10-14	15-19			All	Group	All	Group	0	1-4	5-9	10-14	15-19	0-14	0-19	0-14	0-19	0-19	0-19
I	LEUKAEMIA	351	2711	1504	1187	1128	**5753**	**6881**	32.1	100.0	26.1	100.0	40.1	78.9	34.8	26.0	24.2	**46.3**	**41.3**	659	780	96.5	0.2
	a. Lymphoid	175	2323	1246	823	626	**4567**	**5193**	25.5	79.4	19.7	75.5	20.0	67.6	28.9	18.0	13.4	**37.0**	**31.7**	524	591	97.1	0.1
	b. Acute myeloid	125	318	213	282	345	**938**	**1283**	5.2	16.3	4.9	18.6	14.3	9.3	4.9	6.2	7.4	**7.4**	**7.4**	107	144	96.1	0.2
	c. CMD	5	12	19	63	111	**99**	**210**	0.6	1.7	0.8	3.1	0.6	0.3	0.4	1.4	2.4	**0.7**	**1.1**	11	23	94.3	0.0
	d. MDS & other	30	35	11	4	10	**80**	**90**	0.4	1.4	0.3	1.3	3.4	1.0	0.3	0.1	0.2	**0.7**	**0.6**	9	10	93.3	1.1
	e. Unspecified	16	23	15	15	36	**69**	**105**	0.4	1.2	0.4	1.5	1.8	0.7	0.3	0.3	0.8	**0.6**	**0.6**	8	12	82.9	5.7
II	LYMPHOMA & RELATED	24	287	585	1076	2121	**1972**	**4093**	11.0	100.0	15.5	100.0	2.7	8.4	13.6	23.5	45.5	**14.0**	**21.1**	221	449	97.5	0.1
	a. Hodgkin	0	52	203	618	1479	**873**	**2352**	4.9	44.3	8.9	57.5	-	1.5	4.7	13.5	31.8	**5.9**	**11.7**	97	256	98.7	0.0
	b. Non-Hodgkin except BL	8	128	225	310	494	**671**	**1165**	3.7	34.0	4.4	28.5	0.9	3.7	5.2	6.8	10.6	**4.9**	**6.2**	76	129	96.3	0.2
	c. Burkitt (BL)	0	86	132	126	75	**344**	**419**	1.9	17.4	1.6	10.2	-	2.5	3.1	2.8	1.6	**2.6**	**2.3**	39	47	98.8	0.0
	d. Lymphoreticular	13	12	8	1	10	**34**	**44**	0.2	1.7	0.2	1.1	1.5	0.3	0.2	0.0	0.2	**0.3**	**0.3**	4	5	88.6	0.0
	e. Unspecified	3	9	17	21	63	**50**	**113**	0.3	2.5	0.4	2.8	0.3	0.3	0.4	0.5	1.4	**0.4**	**0.6**	6	12	83.2	0.9
III	CNS NEOPLASMS †	234	1249	1369	1136	920	**3988**	**4908**	22.2	100.0	18.6	100.0	26.7	36.4	31.7	24.8	19.8	**30.8**	**28.3**	455	554	81.6	0.1
	a. Ependymoma	46	176	97	60	53	**379**	**432**	2.1	9.5	1.6	8.8	5.2	5.1	2.2	1.3	1.1	**3.1**	**2.7**	44	49	96.1	0.0
	b. Astrocytoma	86	593	687	614	436	**1980**	**2416**	11.0	49.6	9.2	49.2	9.8	17.3	15.9	13.4	9.4	**15.1**	**13.8**	225	272	87.9	0.1
	c. CNS embryonal	55	267	297	201	122	**820**	**942**	4.6	20.6	3.6	19.2	6.3	7.8	6.9	4.4	2.6	**6.4**	**5.5**	94	107	98.2	0.1
	d. Other gliomas	12	139	192	159	133	**502**	**635**	2.8	12.6	2.4	12.9	1.4	4.0	4.4	3.5	2.9	**3.8**	**3.6**	57	71	47.7	0.0
	e. Other specified	13	31	51	55	81	**150**	**231**	0.8	3.8	0.9	4.7	1.5	0.9	1.2	1.2	1.7	**1.1**	**1.3**	17	26	84.0	0.0
	f. Unspecified CNS	22	43	45	47	95	**157**	**252**	0.9	3.9	1.0	5.1	2.5	1.3	1.0	1.0	2.0	**1.2**	**1.4**	18	28	17.5	1.2
IV	NEUROBLASTOMA	362	576	134	44	44	**1116**	**1160**	6.2	100.0	4.4	100.0	41.3	16.8	3.1	1.0	0.9	**9.7**	**7.7**	129	134	96.7	0.1
	a. (Ganglio)neuroblastoma	361	572	131	35	26	**1099**	**1125**	6.1	98.5	4.3	97.0	41.2	16.6	3.0	0.8	0.6	**9.6**	**7.5**	127	130	96.7	0.0
	b. Peripheral nervous	1	4	3	9	18	**17**	**35**	0.1	1.5	0.1	3.0	0.1	0.1	0.1	0.2	0.4	**0.1**	**0.2**	2	4	97.1	2.9
V	RETINOBLASTOMA	218	268	20	4	2	**510**	**512**	2.8	100.0	1.9	100.0	24.9	7.8	0.5	0.1	0.0	**4.5**	**3.5**	59	59	72.9	0.0
VI	RENAL TUMOURS	151	662	190	54	50	**1057**	**1107**	5.9	100.0	4.2	100.0	17.2	19.3	4.4	1.2	1.1	**9.1**	**7.3**	122	128	97.9	0.0
	a. Nephroblastoma	149	656	187	37	6	**1029**	**1035**	5.7	97.4	3.9	93.5	17.0	19.1	4.3	0.8	0.1	**8.9**	**6.9**	119	120	98.3	0.0
	b. Renal carcinoma	1	2	3	16	42	**22**	**64**	0.1	2.1	0.2	5.8	0.1	0.1	0.1	0.3	0.9	**0.2**	**0.3**	2	7	96.9	0.0
	c. Unspecified	1	4	0	1	2	**6**	**8**	0.0	0.6	0.0	0.7	0.1	0.1	-	0.0	0.0	**0.1**	**0.0**	1	1	62.5	0.0
VII	HEPATIC TUMOURS	82	123	22	35	59	**262**	**321**	1.5	100.0	1.2	100.0	9.4	3.6	0.5	0.8	1.3	**2.2**	**2.0**	30	36	95.6	0.0
	a. Hepatoblastoma	79	110	16	15	2	**220**	**222**	1.2	84.0	0.8	69.2	9.0	3.2	0.4	0.3	0.0	**1.9**	**1.5**	25	26	97.7	0.0
	b. Hepatic carcinoma	1	7	5	18	56	**31**	**87**	0.2	11.8	0.3	27.1	0.1	0.2	0.1	0.4	1.2	**0.2**	**0.4**	3	9	94.3	0.0
	c. Unspecified	2	6	1	2	1	**11**	**12**	0.1	4.2	0.0	3.7	0.2	0.2	0.0	0.0	0.0	**0.1**	**0.1**	1	1	66.7	0.0
VIII	BONE TUMOURS	6	42	226	562	641	**836**	**1477**	4.7	100.0	5.6	100.0	0.7	1.2	5.2	12.3	13.8	**5.7**	**7.5**	93	162	96.5	0.0
	a. Osteosarcoma	0	12	105	324	344	**441**	**785**	2.5	52.8	3.0	53.1	-	0.3	2.4	7.1	7.4	**2.9**	**3.9**	49	86	97.8	0.0
	b. Chondrosarcoma	0	0	5	18	40	**23**	**63**	0.1	2.8	0.2	4.3	-	-	0.1	0.4	0.9	**0.2**	**0.3**	3	7	98.4	0.0
	c. Ewing & related	4	24	103	201	209	**332**	**541**	1.9	39.7	2.1	36.6	0.5	0.7	2.4	4.4	4.5	**2.3**	**2.8**	37	60	97.8	0.0
	d. Other specified	1	3	8	9	28	**21**	**49**	0.1	2.5	0.2	3.3	0.1	0.1	0.2	0.2	0.6	**0.2**	**0.3**	2	5	98.0	0.0
	e. Unspecified	1	3	5	10	20	**19**	**39**	0.1	2.3	0.1	2.6	0.1	0.1	0.1	0.2	0.4	**0.1**	**0.2**	2	4	46.2	0.0
IX	SOFT TISSUE SARCOMA	114	374	294	401	497	**1183**	**1680**	6.6	100.0	6.4	100.0	13.0	10.9	6.8	8.8	10.7	**9.1**	**9.5**	134	188	98.0	0.0
	a. Rhabdomyosarcoma	44	276	189	119	134	**628**	**762**	3.5	53.1	2.9	45.4	5.0	8.0	4.4	2.6	2.9	**5.0**	**4.6**	72	86	98.3	0.0
	b. Fibrosarcoma	31	13	17	54	54	**115**	**169**	0.6	9.7	0.6	10.1	3.5	0.4	0.4	1.2	1.2	**0.9**	**0.9**	13	19	96.4	0.0
	c. Kaposi sarcoma	0	1	1	3	5	**5**	**10**	0.0	0.4	0.0	0.6	-	0.0	0.0	0.1	0.1	**0.0**	**0.1**	1	1	80.0	0.0
	d. Other specified	24	57	63	180	225	**324**	**549**	1.8	27.4	2.1	32.7	2.7	1.7	1.5	3.9	4.8	**2.3**	**2.9**	36	61	98.5	0.0
	e. Unspecified	15	27	24	45	79	**111**	**190**	0.6	9.4	0.7	11.3	1.7	0.8	0.6	1.0	1.7	**0.8**	**1.0**	13	21	97.4	0.0
X	GERM CELL TUMOURS	124	108	81	268	1142	**581**	**1723**	3.2	100.0	6.5	100.0	14.2	3.1	1.9	5.9	24.5	**4.4**	**8.9**	66	188	94.2	0.1
	a. CNS germ cell ‡	8	5	37	112	98	**162**	**260**	0.9	27.9	1.0	15.1	0.9	0.1	0.9	2.4	2.1	**1.1**	**1.3**	18	29	88.5	0.0
	b. Other extragonadal	79	47	9	14	32	**149**	**181**	0.8	25.6	0.7	10.5	9.0	1.4	0.2	0.3	0.7	**1.3**	**1.2**	17	21	93.9	0.6
	c. Gonadal germ cell	32	54	31	130	898	**247**	**1145**	1.4	42.5	4.3	66.5	3.7	1.6	0.7	2.8	19.3	**1.8**	**5.8**	28	124	97.0	0.0
	d. Gonadal carcinoma	1	0	2	5	76	**8**	**84**	0.0	1.4	0.3	4.9	0.1	-	0.0	0.1	1.6	**0.1**	**0.4**	1	9	90.5	0.0
	e. Unspecified gonadal	4	2	2	7	38	**15**	**53**	0.1	2.6	0.2	3.1	0.5	0.1	0.0	0.2	0.8	**0.1**	**0.3**	2	6	67.9	0.0
XI	CARCINOMA & MELANOMA	11	49	95	416	1685	**571**	**2256**	3.2	100.0	8.6	100.0	1.3	1.4	2.2	9.1	36.2	**3.9**	**11.2**	63	244	98.2	0.0
	a. Adrenocortical	4	15	4	3	7	**26**	**33**	0.1	4.6	0.1	1.5	0.5	0.4	0.1	0.1	0.2	**0.2**	**0.2**	3	4	100.0	0.0
	b. Thyroid	1	13	28	106	381	**148**	**529**	0.8	25.9	2.0	23.4	0.1	0.4	0.6	2.3	8.2	**1.0**	**2.6**	16	57	99.4	0.0
	c. Nasopharyngeal	0	0	1	29	68	**30**	**98**	0.2	5.3	0.4	4.3	-	-	0.0	0.6	1.5	**0.2**	**0.5**	3	11	100.0	0.0
	d. Melanoma	3	15	25	90	665	**133**	**798**	0.7	23.3	3.0	35.4	0.3	0.4	0.6	2.0	14.3	**0.9**	**3.9**	15	86	98.0	0.0
	e. Skin carcinoma	0	1	4	12	55	**17**	**72**	0.1	3.0	0.3	3.2	-	0.0	0.1	0.3	1.2	**0.1**	**0.4**	2	8	98.6	0.0
	f. Other & unspecified	3	5	33	176	509	**217**	**726**	1.2	38.0	2.8	32.2	0.3	0.1	0.8	3.8	10.9	**1.4**	**3.6**	24	79	97.1	0.0
XII	OTHER & UNSPECIFIED	23	35	23	32	115	**113**	**228**	0.6	100.0	0.9	100.0	2.6	1.0	0.5	0.7	2.5	**0.9**	**1.2**	13	25	41.7	0.9
	a. Other specified	6	12	4	4	10	**26**	**36**	0.1	23.0	0.1	15.8	0.7	0.3	0.1	0.1	0.2	**0.2**	**0.2**	3	4	100.0	0.0
	b. Other unspecified	17	23	19	28	105	**87**	**192**	0.5	77.0	0.7	84.2	1.9	0.7	0.4	0.6	2.3	**0.7**	**1.0**	10	21	30.7	1.0
	TOTAL	1700	6484	4543	5215	8404	**17942**	**26346**	100.0	100.0	100.0	100.0	194.0	188.7	105.2	114.1	180.4	**140.5**	**149.5**	2045	2948	93.1	0.1

† includes 1539 non-malignant ‡ includes 3 non-malignant

Please consult the quality indicators for this pool and its constituent registries